

# Evidence-based Assessment of Health-related Quality of Life and Functional Impairment in Pediatric Psychology

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**Objective** To provide an evidence-based review of measures of health-related quality of life (HRQOL) and functional impairment, with a specific focus on their use in the field of pediatric psychology. **Methods** As part of a larger survey of pediatric psychologists from the Society of Pediatric Psychology e-mail listserv (American Psychological Association, APA, Division 54), 16 measures were selected for this psychometric review. Measures that qualified for the review fell into one of the following three categories: (a) generic HRQOL scales, (b) disease-specific quality of life scales, and (c) functional impairment rating scales. **Results** Psychometric characteristics (i.e., three types of reliability, two types of validity) were strong for the majority of measures reviewed, with 12 of the 16 measures meeting "well-established" evidence-based assessment criteria. Strengths and weaknesses of existing measures were noted. **Conclusions** Recommendations for future work in this area of assessment are presented, including suggestions that further validation and exploration of measure properties such as factor analysis and changes in HRQOL over time be conducted.

**Key words** children; chronic illness; psychosocial functioning; quality of life; systematic review.

## Introduction

Measurement of health-related quality of life (HRQOL) and functional impairment in pediatric psychology populations has increased significantly in recent decades (Drotar, 2004a; Eiser & Jenney, 2007; Quittner, Davis, & Modi, 2003). HRQOL measures are now frequently included as outcomes in clinical trials and in response, there has been a major rise in the development of measures, both generic and disease-specific, to assess HRQOL (Drotar, 2004a). Recently, the Food and Drug Administration (FDA) has created a set of guidelines for the development and utilization of patient-reported outcomes (PROs) in trials evaluating new medications, with HRQOL measures designated as one type of PRO that is recommended for use (Goss & Quittner, 2007).

The construct of HRQOL incorporates assessment of an individual's perception of the impact a disease or condition has on his or her physical health status,

psychological and social functioning, and emotional well-being (Eiser & Morse, 2001b; Naughton & Shumaker, 2003). HRQOL describes an individual's perceived ability to participate in physical and social activities in their environment and their level of enjoyment or satisfaction in that involvement given their disease or health status (Eiser & Morse, 2001b). Functional impairment or disability, on the other hand, is a concept that is related to HRQOL but has a distinct definition. Functional disability has been defined as limitations in a person's ability to perform activities relevant to daily life including physical, social, and personal activities (Stein & Jessop, 1990). Compared to HRQOL, fewer measures of functional impairment have been developed. As a result, there is less research on functional impairment assessment tools, which is reflected in this review.

HRQOL and functional impairment data have many potential applications in research and clinical care.

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Most commonly in the pediatric psychology literature, HRQOL assessment has been used to estimate the burden of specific diseases and compare the impact of different diseases on functioning and well-being. This concurrent assessment of multiple domains of functioning can provide a broader evaluation of a child's functioning than assessing a single domain in isolation. Data on HRQOL can also be used to compare the benefits of two different medical or psychological interventions (Eiser, 2004; Olson, Lara, & Pat Frintner, 2004), to establish the efficacy of new medications for registration, and to inform social policies that allocate health care resources. Clinical applications include: assessment of functioning in children and adolescents with chronic medical conditions, responsiveness of patients to psychological interventions, and evaluation of significant changes in health status, such as disease-specific complications (Goss & Quittner, 2007).

In extending the significant body of work on adult HRQOL measures downward to children, unique issues have emerged (Quittner et al., 2003). First, 10 years ago there was a relative lack of well-developed measures available for pediatric populations in comparison to those available for adult populations. Second, new dimensions of functioning that are relevant for children and adolescents were identified (e.g., social and academic functioning at school) (Modi & Quittner, 2003). Third, because of critical developmental changes that occur in children, HRQOL measures needed to consider age, reading ability, and emotional maturity in the instrument development process (Turner, Quittner, Parasuraman, & Cleeland, 2007). Factors impacting children's HRQOL are often associated with physical, social, and cognitive development. For example, an adolescent's HRQOL may include a greater focus on social roles and independence, whereas assessment of a younger child may be more focused on physical abilities (Drotar, 2004b).

An additional consideration in assessing HRQOL in the pediatric population centers on the question of whose perspective should be assessed. While pediatric patient self-report has been considered the standard for measuring perceptions of HRQOL (Riley, 2004), there may be circumstances in which children are too young, too ill or too fatigued to complete an HRQOL instrument. In these cases, reliable and valid parent-proxy report instruments have been used (Modi & Quittner, 2003; Quittner et al., 2003). Further, it may be important to assess HRQOL and functional impairment from both the parent and child perspectives because of potential differences in their observations of functioning (Eiser & Morse, 2001a). Research has been conducted in this area, and some

studies have shown that children report greater emotional distress (Modi & Quittner, 2003; Verrips, Vogels, den Ouden, Paneth, & Verloove-Vanhorick, 2000), as well as more physical complaints and problems with motor functioning (Theunissen et al., 1998) compared to parents. Conversely, within certain populations adolescents report better HRQOL in many domains compared to healthy populations (e.g., cystic fibrosis; Britto et al., 2004). Research has also shown that children with chronic conditions and their parents have higher agreement on HRQOL than is the case in healthy populations (Eiser & Morse, 2001a). Parents' reports of HRQOL and functional impairment may also be critical because of their influence on healthcare utilization and management of the chronic illness (Eiser & Jenney, 2007).

Two types of HRQOL measures have been developed, generic and condition-specific instruments. Generic or noncategorical instruments typically include global or summary ratings of multiple domains or health profile approaches. Advantages of generic instruments include the ability to compare across different groups of patients (e.g., asthma vs. diabetes), although the disadvantages include lack of precision and sensitivity in detecting changes over time (Quittner et al., 2003). In contrast, condition-specific measures of HRQOL address the challenges associated with a particular illness, such as cancer. Advantages include their greater clinical relevance to patients and families, their ability to detect small, but clinically meaningful changes, and their recognition by the FDA as potential primary or secondary endpoints in clinical trials. Their primary disadvantage is the inability to compare across disease groups (Matza, Swensen, Flood, Secnik, & Leidy, 2004). These two categories of HRQOL assessment, generic and condition-specific, are both summarized in this review.

Assessment of functional impairment or disability is utilized for reasons that are similar to HRQOL assessment, namely, to measure the extent of restriction in a child's ability to perform important daily life activities including physical, social, and personal activities due to their health condition or to specific symptoms. These assessments can be done at a single point in time to understand the impact of health conditions or symptoms on a child's level of impairment and to measure change in functional impairment as a result of psychological or health-related interventions. Functional impairment or disability is measured in response to specific symptoms related to a health condition such as pain. Because children's daily activities are different from those of adults, functional impairment measures should assess areas that are salient

to children's lives, such as ability to attend school and play with friends. Although many multidimensional HRQOL measures subsume the concept of functional impairment and have items (typically on multiple subscales) concerning impairment in social roles and physical functioning, there are clinically relevant situations in which a separate assessment of functional impairment may be desired. For example, if a specific symptom, such as pain, is thought to impact children's daily activities, the child's perception of difficulty in performing his or her usual activities both before and after treatment may be desirable. Both HRQOL and functional impairment assessments are subjective, in that they rely on the respondent's perception of health-related functioning. Thus, assessment tools may demonstrate lower levels of reliability, particularly test-retest and cross-informant, than tools assessing more stable constructs (e.g., psychopathology, cognitive functioning).

Both HRQOL and functional impairment measures have been widely used in pediatric psychology studies. Available cross-sectional studies in the pediatric literature have assessed HRQOL in a variety of populations including oncology (e.g., Varni, Limbers, & Burwinkle, 2007), arthritis (Tennant et al., 2001), cystic fibrosis (Modi & Quittner, 2003; Quittner, Buu, Messer, Modi, & Watrous, 2005), and chronic pain (Hunfeld et al., 2001). HRQOL has also been assessed prospectively in treatment studies and clinical trials. For example, HRQOL was assessed in the context of a medication trial in children with juvenile idiopathic arthritis, and showed improvement following medication treatment (Cespedes-Cruz et al., 2008). Recently, the FDA recommended using an HRQOL measure for cystic fibrosis (Cystic Fibrosis Questionnaire-Revised, CFQ-R; Quittner et al., 2005) as the primary endpoint in the Phase III trial of an inhaled antibiotic. Respiratory symptoms improved significantly, with concomitant increases in pulmonary function. FDA approval of the new antibiotic is imminent, with efficacy established by change in the Respiratory Domain of the CFQ-R (Retsch-Bogart et al., 2007). Functional disability has been examined in treatment studies for recurrent abdominal pain (Robins, Smith, Glutting, & Bishop, 2005). As the use of HRQOL and functional disability measures increases in the field of pediatric psychology, critical evaluation of and development of these assessment tools will continue to play an important role in research.

Numerous articles, chapters, and edited books have been written regarding the assessment of HRQOL in children and adolescents (Drotar, 1998; Koot & Wallander, 2001; Quittner et al., 2003; Rodrigue, Geffken, & Streisand, 1999). These resources have

provided important information on the methodological considerations in HRQOL assessment, including conceptual issues, instrument development, response format, and item specificity (Drotar, 2004b; Eiser & Jenney, 2007; Matza et al., 2004). Less attention has been devoted in previous reviews and texts concerning empirical validation and a critical review of the evidence base of specific HRQOL and functional impairment instruments. Published reviews of HRQOL instruments in oncology (Varni et al., 2007) and generic HRQOL assessment tools (Ravens-Sieberer et al., 2006) fill this gap. However, they have not focused on the measures most commonly used in pediatric psychology. This evidence-based review of HRQOL and functional impairment assessment summarizes 16 of the measures that pediatric psychologists most frequently use in research or clinical work. An online survey of pediatric psychologists was used to determine, which measures were selected for review. The purpose of the present review was to provide an evidence-based assessment (EBA) of the most frequently used HRQOL and functional impairment measures to guide researchers and clinicians in their use. Specifically, the goals were to review psychometric characteristics and to categorize the level of evidence for each measure, to offer perspectives on the strengths and weaknesses of specific measures, and their utility for different purposes. Finally, we suggest areas for future refinement and development of pediatric HRQOL and functional impairment measures.

## Method

### Measure Selection

Selection of measures was conducted in several phases. First, in 2002, a list of assessment measures was generated by workgroups of the Society of Pediatric Psychology (SPP) Assessment Task Force in broad domains of interest, one of which was quality of life and functional impairment. Our workgroup generated a list of 58 measures of HRQL and functional impairment from a review of recent textbooks and review articles (Drotar et al., 1998; Eiser & Morse, 2001b; Harding, 2001; Rodrigue et al., 1999; Wallander & Schmitt, 2001) on assessment of HRQOL and functional impairment. Second, a survey was distributed via the Internet to the SPP listserv asking members to indicate whether they had used or considered using each of the 58 measures in research or clinical practice. Respondents were also asked to identify any additional HRQOL or functional impairment measures that they found useful, but that were not included on the original list. Eighty-seven listserv respondents completed the survey. Measures were included in the current review if

they were identified by five or more survey respondents. Sixteen of the original 58 measures met this criterion. Respondents identified four additional measures not included in the original survey and these measures were also included for review. Of these 20 measures, four were eventually dropped from consideration because they were alternate versions of scales already being included. Thus, a total of 16 HRQOL and functional impairment measures were reviewed by members of our workgroup.

Based on the aforementioned criteria, we divided the 16 measures identified for inclusion into three specific categories: generic HRQOL measures, condition-specific HRQOL measures, and functional impairment measures. Instruments represented a range within these three categories and were most frequently used in the pediatric psychology literature. In 2007, another literature search was conducted specifically on the 16 measures selected for inclusion in this review to identify additional studies and update psychometric data. This review was not intended to be exhaustive or systematic. There are a number of measures that are not included in this review due to lack of familiarity by the survey respondents. For example, measures that were specifically developed to assess HRQOL in children with cognitive, motor, and other neurological impairments were not identified for review. In addition, many condition-specific HRQOL measures (e.g., hemophilia, Manco-Johnson, Morrissey-Harding, Edelman-Lewis, Oster, & Larson, 2004; systemic lupus, Moorthy, Peterson, Harrison, Onel, & Lehman, 2007) were not identified. The final list of 16 measures consisted of four generic measures, nine condition-specific measures, and three functional impairment measures (Table I).

### **Framework and Assessment Criteria**

There are many instruments available to assess HRQOL and functional impairment in children and adolescents, enhancing the importance of providing an evidence-based review of these assessment tools. The current evaluation focuses on the HRQOL and functional impairment measures being used in pediatric populations, describing the reliability and validity of these assessment tools and the evidence for their use. The criteria used for evidence-based categorization of the HRQOL measures are identical to those used by the other SPP Assessment Task Force groups (Cohen et al., 2007). The three categories are (a) Well-established assessment, (b) Approaching well-established assessment, and (c) Promising assessment. Categories are based on features of reliability and validity, as well as on published usage of each measure. In addition to meeting

criteria for good psychometric properties, receiving a “well-established” categorization required that the HRQOL or functional impairment measure had been used in studies published by more than one investigator or investigative team. An “approaching” categorization required that the measure be utilized in at least two peer-reviewed articles and had moderate or vague psychometrics presented. For a “promising assessment” categorization, publication in at least one peer-reviewed article and moderate or vague psychometrics were required.

### **Methodology of Workgroup and Review Process**

Following identification and selection of the 16 measures for review, updated literature was obtained on each measure and these data were evaluated. Three types of reliability data and two types of validity data were sought and evaluated for each measure consistent with the other SPP Assessment Task Force workgroups. Reliability data included internal consistency (Cronbach's  $\alpha$ ), test-retest reliability, and cross-informant reliability. Validity data included concurrent or predictive (reported correlations between a measure and outcomes the measure was expected to predict) and convergent or discriminant (reported correlations between the target measure and other measures purported to assess similar constructs). Brief summaries of each measure were written by the workgroup. We then contacted original authors of each measure and asked for their review of the summary, in order to identify missing literature or inaccuracies in our information. Tables were then constructed to summarize the reliability and validity data. Three independent raters reviewed the tables to judge each measure using the EBA criteria. Raters showed 100% agreement on categorization for 14 of the 16 measures (i.e., 3 of 3 raters chose the same category). Agreement was in the substantial range, with a  $\kappa$ -coefficient of .78. In the case of the two measures with discrepant ratings, T.M.P. adjudicated the final categorization.

### **Review and Description of Measures**

The data from this review are summarized in Table I by measure (applicable age range, response formats, psychometric information, EBA categorization) and in Appendix A of the supplementary material (primary references and purpose of the measure, language and cultural adaptations, address for obtaining the measure and manual; available at [www.societyofpediatricpsychology.org](http://www.societyofpediatricpsychology.org)). The measures are grouped by category (generic, condition specific, functional impairment) and listed alphabetically.

**Table I.** Reliability and Validity of Generic, Condition-specific, and Functional Disability Measures Reviewed

Measures	Ages	Respondents and response formats	Psychometrics: reliability	Psychometrics: validity	EBA classification
<b>Generic HRQOL</b>					
Child Health and Illness Profile (CHIP) (Starfield, Riley, & Green, 1999)	6–17	Child-report (CHIP-CE): 45 items + 4 demographic Adolescent-report (CHIP-AE): 108 items Parent-report on adolescents (CHIP-PRF): 45 items + 7 demographic Parent-report on children (CHIP-CPRF): 45 items + 31 health items	$\alpha = .70-.82$ (CE); $.42-.93$ (AE); .79–.88 (PRF) Test–retest: $.63-.76$ (CE), $.53-.95$ (AE); $.71-.85$ (PRF) Cross-informant: $-.11-.45$ Intraclass correlation coefficient (parent and adolescent)	Achievement subscale correlated with school grades (AE); Emotional discomfort correlated with depression and anxiety questionnaires Subscales correlate with CHQ ( $.41-.61$ ) (CE and PRF) Distinguishes between ill and healthy populations Factor analyses conducted	Well-established
Child Health Questionnaire (CHQ) (Landgraf, Abetz & Ware, 1996)	5–18	Child-report (HQ-CF): 87 items Parent-report (CHQ-PF): 98, 50 and 28 items (3 versions)	$\alpha = .63-.97$ (CF); $.62-.98$ (PF-50) No test–retest or cross-informant reported	Distinguishes between ill and healthy populations Associated with illness severity Factor analysis conducted for CHQ-PF	Well-established
Pediatric Quality of Life Inventory (PedsQL) (note: disease-specific modules also available, see Appendix A) (Varni, Seid, & Rode, 1999)	2–18	Child-report: 23 items; young child (5–7), child (8–12), adolescent (13–18) Parent-report: 23 items; Toddler (2–4) young child (5–7), child (8–12), adolescent (13–18) PedsQL short form: 15 items, same ages and reporters	$\alpha = .68-.90$ Cross-informant: $.36-.50$ (parent and child) No test–retest reported	Correlated with other HRQOL measures Relates to number of days ill, missed school days, parent missed work days, disease severity Distinguishes between chronic conditions and healthy children; children hospitalized in previous year and children not Factor analysis conducted for child and parent report	Well-established
Youth Quality of Life (YQOL) (Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards, & Topolski, 2002)	12–18	Child-report Surveillance (YQOL-S): 13 items Child-report Research & Program Evaluation (YQOL-R): 41 items	$\alpha > .80$ Test–retest: $.74-.85$ (1 week)	Correlates with a German HRQOL measure (KINDL) Sensitive to current symptom status Distinguishes between chronic conditions and healthy populations Factor analysis conducted	Well-established

(continued)

Table I. Continued

Measures	Ages	Respondents and response formats	Psychometrics: reliability	Psychometrics: validity	EBA classification
<b>Condition-specific HRQOL</b>					
Child Health Assessment Questionnaire (CHAQ) (Arthritis) (Singh, Athreya, Fries & Goldsmith, 1994)	8–19	Parent-report: 30 items Child-report: 30 items CHAQ-38 (revised to include challenge items; Lam, Young, Marwaha et al., 2004)	$\alpha = .94$ Test–retest: .80 Cross-informant: .84 (parent and child)	Associated with number of joints involved, morning stiffness and physician rating of illness severity Correlates with JAFAS	Well-established
Cystic Fibrosis Questionnaire Revised (CFQ-R) (Quittner et al., 2005; Modi & Quittner, 2003)	6–adult	Child-report: 35 items Teen/adult self-report: 50 items Parent-report: 43 items	$\alpha = .60-.76$ for all subscales except Treatment Burden (low) (child report); $.67-.94$ for all subscales except Treatment Burden (low) (teen/adult report) Test–retest: $.45-.92$ , except treatment burden $.25$ (parent and teen); physical $.16$ , digestion $.36$ , body image $.03$ (child version) Cross-informant: Parent and child agreement on 5 of 8 subscales	Correlates with SF-36 (a short health survey), PedsQL subscales, and pulmonary function tests Discriminates between disease severity based on lung function Minimal clinically important difference (MCID) has been established Responsiveness in three clinical trials documented	Well-established
Diabetes Quality of Life for Youth (DQOLY) (Ingersoll & Marrero, 1991)	10–21	Child-report: 51 items	$\alpha = .82-.85$ (subscales) No test–retest reported	Subscales correlate with self-report health status	Approaching
Juvenile Arthritis Functional Assessment Report (JAFAR) (Howe, Levinson, Shear, Hartner, McGirr, et al., 1991)	7–18	Child-report (JAFAR-C): 23 items Parent-report (JAFAR-P): 23 items	$\alpha = .85$ (child), $.93$ (parent) No test–retest or cross-informant reported	Correlates with indices of functional ability: JAFAS (clinician observational version of JAFAR), Steinbrocker functional class, pain reports, level of disease activity	Well-established
Miami Pediatric Quality of Life Questionnaire (MPQLQ) (Armstrong, et al., 1999)	1–18	Child-report: 39 items Parent-report: 39 items	$\alpha = .76-.89$ (parent) Test–retest: $.38-.94$ (1 month, parent) No cross-informant reported	Distinguishes between children with brain tumors and children with other cancers Promising as a general HRQOL measure, as has only been used with oncology populations Factor analysis conducted for parent report	Promising
Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (Juniper, Guyatt, Feeny, Ferrie, Griffith & Townsend, 1996)	7–17	Child-report: 23 items	$\alpha = .54-.89$ No test–retest reported	Responsive to changes in asthma symptoms and clinical asthma control Associated with physician ratings of asthma severity Correlates with feeling thermometer	Well-established
Pediatric Oncology Quality of Life Scale (POQOLS) (Goodwin, Boggs, & Graham-Pole, 1994)	2–19	Parent-report: 21 items	$\alpha = .68-.87$ Cross-informant: $.75-.91$ (mother and father) No test–retest reported	Factors correlate with PPSC, CBCL (internalizing and externalizing), Eyberg Child Behavior Inventory, Physical Symptom Checklist Discriminates between children with active vs. past treatment Factor analysis conducted	Well-established
Play Performance Scale for Children (PPSC) (Lansky, List, Lansky, Cohen, & Sinks, 1985)	6 months–16 years	Parent-report: observational domains vary by age	Cross-informant: $.71$ (mother and father) No internal consistency or test–retest reported	Differentiates between inpatient, outpatient, and healthy children	Promising
Quality of Life Headache in Youth (QLH-Y) (Langeveld, Koot, Loonen, Hazebroek-Kampschreur, & Passchier, 1996)	12–18	Adolescent-report: 71 items; short form 44 items	$\alpha = .66-.87$ (subscales) Test–retest: $.44-.66$ (2 week), $.31-.60$ (4 week) Cross-informant: Correlates moderately to parent report	Subscales relate to satisfaction with life and health Correlates with headache status	Well-established

Functional disability	Age	Parent-report: 21 items Child-report: 21 items	$\alpha = .88-.95$ Test-retest: .33 (1 month, child report) Cross-informant: .32-.43 (child and parent)	Correlates with FDI Associated with pain ratings and with physician ratings of illness severity	Well-established
Child Activity Limitations Interview (CALI) (Palermo, Witherspoon, Valenzuela & Drotar, 2004)	8-16	Parent-report: 21 items Child-report: 21 items	$\alpha = .86-.91$ (child-report); .90-.94 (parent-report) Test-retest: .74 (2 weeks, child report); .48 (3 months, child-report); .64 (2 weeks, parent report); .39 (3 months, child report) Cross-informant: .26-.55 (mother and child)	Correlates with somatic complaints, depression, anxiety, bed days, medication use Predicts pain and school-related disability 2 weeks later; Predicts depressive symptoms 3 months later Distinguishes between children with abdominal pain and healthy children	Well-established
Functional Disability Inventory (FDI) (Walker & Greene, 1991; Claar & Walker, 2006)	8-17	Child-report: 15 items Parent-report: 15 items	$\alpha = .83-.94$ No test-retest reported	Correlates with days in bed, hospitalizations, and morbidity status (long version) Distinguishes between children with and without chronic conditions (long version) Less support for validity of short version	Approaching
Functional Status (II) R (Stein & Jessop, 1990)	0-16	Parent-report: 43 item long version; 14 item short version			

### Generic HRQOL Measures

Four measures were evaluated in the Generic HRQOL category (Table I). The purpose of these generic HRQOL measures is to provide global ratings of multiple domains or provide a health profile. These four measures were normed and validated on healthy children, and all have been used in children with chronic health conditions, such as epilepsy, arthritis, and headaches. All four measures in this category received “well-established” EBA classifications, specifically the Child Health Questionnaire (CHQ; Landgraf et al., 1996), Child Health and Illness Profile (CHIP; Starfield et al., 1999), Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999), and the Youth Quality of Life (YQOL; Edwards et al., 2002; Patrick et al., 2002).

The generic measures are all multidimensional and provide subscale scores in different domains such as physical and emotional functioning. Several measures assess unique areas of HRQOL. For example, the PedsQL includes a social functioning subscale that assess peer relations, whereas the CHQ parent report form includes assessment of family and parental impact of the child’s health; specific subscales include parental impact-time (PT), parental impact-emotional (PE), family cohesion (FC), and family limitations in activities (FA). In addition to subscale scores, both the PedsQL and the CHQ also provide physical and psychosocial summary scores.

The PedsQL measurement system is the only instrument that includes a generic core component that can be used alone or together with additional condition-specific modules. The condition-specific modules (e.g., cancer, asthma, diabetes, rheumatology, and cardiac conditions) are designed to supplement the generic core scales and include specific items associated with different clinical conditions. These condition-specific modules are useful because they increase measurement sensitivity and allow for more accurate HRQOL assessment in these populations. Another unique feature of the PedsQL is that multiple versions have been created across a 2- to 18-year old age span, including interviewer administered and parent report versions for young children.

As previous reviews of HRQOL measures have noted (Schmidt, Garratt, & Fitzpatrick, 2002), the generic HRQOL measures reviewed have acceptable reliability as measured by internal consistency. There are some cases, where lower  $\alpha$ ’s (below .60) are reported but these are generally associated with subscales rather than composites (Table I). For those measures that did report test-retest data (Edwards et al., 2002; Starfield et al., 1999), lower correlations tended to be associated with longer time lags between tests or were for particular subscales.

Cross-informant (parent and child) correlations, which were only available for the CHIP and PedsQL were low to moderate. In terms of validity, the measures were found to be associated with child functioning and health status. They also tend to be strongly correlated with other measures assessing similar constructs, including other HRQOL measures. For additional details regarding specific reliability and validity data see Table I.

Strengths of the measures in this category are the development of multiple response formats (e.g. parent and child versions of the CHQ and PedsQL) and the development of different forms for children and adolescents (e.g., CHIP-CE and CHIP-AE). Having parent and child versions allows for cross-informant comparisons, making the CHQ, the CHIP, and the PedsQL good choices if multiple informant ratings are desired. These “well-established” generic measures have demonstrated reliability and validity for use with multiple chronic illness populations (e.g., CHQ, CHIP, PedsQL, and YQOL) and in youth with attention-deficit hyperactivity disorder (e.g., CHQ, YQOL). These measures are all low in administration burden, but vary in response and scoring burden. The CHIP is the lengthiest measure in this group with 87 self-report items. The CHQ has some additional scoring burden due to a complex scoring algorithm based on factor loadings, and summary scoring available only for parent-report (i.e., summary scoring for Physical and Psychosocial Health cannot be computed for the child self-report version). The YQOL is unique because it has both research and clinical versions (with 13 and 56 items respectively) making it a valuable research instrument when time is constrained. The PedsQL also has both long and short forms. Finally, several of these well-established measures have been translated into multiple languages and used internationally (see Appendix A, available at [www.societyofpediatricpsychology.org](http://www.societyofpediatricpsychology.org)).

### **Condition-specific HRQOL Measures**

Nine measures were evaluated in the condition-specific category. These measures were specific to one particular chronic health condition including: cancer, juvenile idiopathic arthritis, cystic fibrosis, headaches, asthma, and diabetes. Six of the measures received “well-established” EBA classifications, one was classified as “approaching well-established” and two were labeled as “promising.” The six measures that met “well-established” criteria are the: CFQ-R (Quittner et al., 2005), Pediatric Asthma Quality of Life Questionnaire (PAQLQ; Juniper et al., 1996), Pediatric Oncology Quality of Life Scale (POQOLS; Goodwin et al., 1994), Juvenile Arthritis

Functional Assessment Report (JAFAR; Howe et al., 1991), Child Health Assessment Questionnaire (CHAQ; Singh et al., 1994), and the Quality of Life Headache in Youth (QLH-Y; Langeveld et al., 1996). The Diabetes Quality of Life for Youth (DQOLY; Ingersoll & Marrero, 1991) was the one condition-specific HRQOL measure that received the “approaching well-established” classification. This classification was given because limited reliability and validity information has been published on this measure. Two measures in pediatric oncology received “promising” classifications, the Miami Pediatric Quality of Life Questionnaire (MPQOLQ; Armstrong et al., 1999) and the Play Performance Scale for Children (PPSC; Lansky et al., 1985). The measures listed in this category have some information about reliability and validity data available and have been published in a single peer-reviewed article or in multiple articles by a single research group.

With respect to psychometric properties, the condition-specific measures evidenced moderate to high internal consistency. Test-retest data were not available for all measures, but for the three measures that reported this information, correlations ranged from very low to high (Table I) with subscales generally demonstrating lower reliability estimates than summary scale scores. Cross-informant correlations were only available for five of the nine measures, with three reporting moderate to high parent-child agreement and two reporting high mother-father agreement. Validation studies conducted on most of the measures have demonstrated significant correlations with health status and disease symptoms (Table I).

Additional strengths of condition-specific measures include the availability of multiple informant versions, such as parent and youth report, or child and adolescent versions (e.g., CFQ-R, CHAQ, JAFAR), with the JAFAR and CHAQ having parallel forms for easy cross-informant comparisons. In addition, one measure, the CFQ-R, has been used in a Phase III clinical trial (Quittner, McCoy, & Montgomery, 2007). All of the condition-specific measures reviewed are low in administration and response burden, with the majority being less than 50 items. One weakness of these measures is that most fail to assess condition-specific HRQOL in children under 7-years old, the exceptions being the CFQ-R, which has a 3- to 6-year-old version, disease-specific modules of the PedsQL appropriate for children aged 5–7, as well as the MPQOLQ and the POQOL, which are appropriate for children as young as 1 and 2 years, respectively. Another limitation is that for most conditions, there are only a few choices of HRQOL instruments, with most having only one other measure available for that particular condition.



### **Functional Impairment Measures**

Three measures of functional impairment were evaluated. These measures are utilized to assess the impact of physical symptoms associated with a health condition on children's ability to perform age appropriate daily physical and psychosocial activities. All three measures include items assessing limitations in both physical and psychosocial domains. Of the three measures in this category, two received "well-established" EBA classification—the Functional Disability Inventory (FDI; Claar & Walker, 2006; Walker & Greene, 1991) and the Child Activity Limitations Interview, which assesses the impact of pain symptoms (CALI; Palermo, Witherspoon et al., 2004). The Functional Status II (R) (Stein & Jessop, 1990) has fewer reported psychometric data and received EBA classification of "approaching well-established".

In terms of psychometric properties, these measures of functional disability had high internal consistency and test-retest reliability ranging from low to high (Table I). Cross-informant correlations between parent and child reports on these measures were moderate. In terms of validity, these measures were correlated with health status and internalizing symptoms. In addition, these measures were associated with school absences, medication use, and somatic complaints and distinguished between healthy children and those with chronic health conditions.

Strengths of the measures in this category are the low administration and scoring burden with all three measures having 21 items or less. The FDI, which has minimal response, administration, and scoring burden, is the most widely used of the measures and has been used in a range of populations in many published studies including chronic pain, sickle cell disease, headache, irritable bowel syndrome, and sarcoma. The CALI is a newer measure that assesses limitations associated with pain and can be used not only as a retrospective measure, but also in prospective diaries to obtain daily ratings of functional impairment (Palermo, Valenzuela, & Stork, 2004). Researchers have adapted the CALI for a self-report version (Hainsworth, Davies, Khan, & Weisman, 2007), and additional research regarding properties of the measure, including a factor analysis, is forthcoming. The Functional Status II (R) is the only measure of functional impairment that is available in a number of translations and has been used in international medication studies. Strengths of this measure include applicability to infants and preschoolers, and the availability of an empirically derived short version derived from factor analysis of the long version. Limitations include lack of a child-report version.

### **Strengths of Measures Reviewed**

Of the 16 measures included in the current review, 12 met criteria for a "well-established" classification, indicating that many HRQOL assessment tools have a strong evidence base in pediatric psychology. Across measures, many have produced good reliability and validity data that are readily available for researchers and clinicians to evaluate. In terms of psychometric strengths, a factor analysis has been conducted on at least one version (parent or child report) of six of the measures reviewed, with each of the generic measures having undergone factor analysis. Moreover, all of the generic and functional disability measures included in this review have been used in a range of pediatric populations making them useful tools for studies comparing illness groups. Additionally, many of these measures present normative data in healthy and chronic illness populations (e.g., CHQ, PedsQL).

In terms of strengths in reliability, nine of the measures have both caregiver and child versions making cross-informant comparisons of HRQOL or functional impairment possible. Moreover, seven of these measures have published cross-informant reliability data, the two exceptions being the CHQ and the MPQLQ. The majority of measures reviewed (11) have been translated for use in different languages. Notably, all four of the generic measures have multiple translations; whereas fewer of the disease-specific and functional impairment measures reviewed have been translated into other languages.

In addition, nine of the measures were able to differentiate between healthy children and children with health challenges (e.g., CHIP, CHQ, PedsQL, YQL), among illness subtypes (MPQLQ), or among children receiving active versus past treatment (POQLS). Nine of the assessment tools were condition-specific, with an emphasis on the physical and psychological issues specific to that illness group. These condition-specific measures are important because they are often considered more clinically relevant to a given population and more sensitive to condition-related symptoms and changes in health status (Goss & Quittner, 2007). The PedsQL was the only measure that contains both generic and condition-specific modules. This measurement system allows one to compare a child's abilities across illness groups, while retaining the sensitivity of a condition-specific measure. Importantly, many of the measures have been developed in a manner that is sensitive to the varying social contexts in which children function, including home, peer, and school domains. Thus they recognize that children's HRQOL occurs in different contexts, and may be more dependent on context than the HRQOL of adults (Matza et al., 2004).

### **Limitations of Measures Reviewed**

Many of the measures reviewed provided limited psychometric data, particularly test–retest reliability and lack of information on validity. Specifically, only half of the measures reported test–retest reliability, data that are necessary to ensure consistency of responses over time. Statistical information on the measure’s ability to assess change in symptoms or illness severity is also lacking. Of the 16 measures reviewed, only the PAQLQ, the CFQ-R, and the FDI reported psychometric data on the measure’s ability to assess changes in symptom severity or control over time. Moreover, although many measures presented some information on convergent validity (e.g., association with other measures, associations with condition severity) only one measure, the FDI, clearly reported predictive validity, with scores on the measure associated with school absences 3 months later. While the majority of the HRQOL measures demonstrated validity in assessing current health status, instruments that predict future social and functional outcomes are also necessary for the development of interventions and long-term treatment planning with patients and families.

The length and response burden associated with many of the measures are also a limitation, particularly when used in research or clinic settings. Measures such as the CHIP, the CHQ, and the DQLY are lengthy, especially for completion by children or adolescents in a short time frame. In terms of format, the majority of measures (with the exception of the CHIP-CE) reviewed use very similar types of self-report rating scales, specifically numerical Likert scales. Graphic and facial expression scales, which have demonstrated good reliability and reproducibility (Cremeens, Eiser, & Blades, 2007) and are recommended for HRQOL assessment in younger children (Matza et al., 2004) have rarely been used.

Finally, the majority of the measures reviewed failed to take into account the need for different types of items and response formats for different ages or developmental levels. Many of the measures reviewed, particularly the condition-specific instruments (e.g., MPQLQ, CHAQ, DQLY, JAFAR, PAQLQ), contain identical items for children and adolescents. Using the same items to assess physical and socio-emotional functioning for these disparate ages fails to consider the potential developmental differences in activity limitations, social relationships, and emotional functioning.

### **Recommendations**

This review indicates that future research regarding the assessment of HRQOL and functional impairment in

children and adolescents is warranted. Specifically, additional research is needed on the psychometric properties and clinical utility of these measures. Further development of HRQOL and functional impairment assessment tools in the areas listed below are considered current research priorities.

1. As mentioned in the section on limitations, a variety of measures have incomplete psychometric data available. Additional data on test–retest reliability, predictive validity, and cross-informant reliability are needed for many available generic, condition-specific, and functional impairment measures.
2. The research and clinical utility of measures of HRQOL and functional impairment is an area that needs specific research attention. Some consideration of expanding the populations that have completed these measures, such as minorities, those with developmental delays, etc. is important. Further, clinical applications are needed for all of the measures, including studies of predictive validity and evaluation of the responsiveness of the measures to psychological interventions.
3. Issues related to proxy versus self reporting have been studied in regard to several HRQOL and functional impairment measures, but a number of important research questions remain. Discrepancies between reporters need to be examined further in specific disease populations because initial research in this area has shown variability in parent–child agreement among children with various chronic health conditions. Additionally, other factors that potentially predict parent–child discrepancies need to be examined, including age, gender, length of illness, and healthcare utilization.
4. Future research should seek to establish the minimal clinically important difference scores (MCID) for HRQOL and functional impairment measures. This process identifies the smallest change that can be perceived by respondents (either positive or negative) and provides an empirical basis for interpreting the magnitude of change that is observed. Anchor-based and statistically based methods are available for calculating the MCID, with the FDA Guidance stating a preference for anchor-based methods that are derived directly from respondents (Guyatt, 2000; Jaeschke, Singer, & Guyatt, 1989; Terwee, Dekker, Wiersinga, Prummel, & Bossuyt, 2003). Identifying thresholds for meaningful change will expand the clinical

utility of these measures for both clinical trials and clinical practice.

5. Additional emphasis on longitudinal data is needed to assess how HRQOL changes over time and with maturation of the child. Different items should be developed for different age groups, and normative data, even within an illness group, should be collected and published by age. Few pediatric studies have tracked naturalistic changes in HRQOL as a function of disease status or other variables. Two exceptions are the PAQLQ, a condition-specific HRQOL measure, which demonstrated sensitivity to changes in health status due to natural symptom fluctuations or better symptom control due to treatment (Juniper et al., 1996) and research with the FDI, demonstrating that baseline levels of anxiety and depression predicted trajectories of functional impairment during the subsequent 5 years (Mulvaney, Lambert, Garber, & Walker, 2006).
6. Application of HRQOL and functional impairment measures in clinical trials is an important future direction. As more clinical trials include HRQOL and other types of PRO instruments, research on response shift and the relationship between HRQOL and other health outcomes will increase. For the majority of measures, it is not known whether they are sensitive to change following intervention. Consideration of using the reliable change index (RCI; Jacobson & Truax, 1991) would be an avenue for future research.
7. Factor analysis has been performed for a few of the reviewed measures but is still needed for most of the measures. For example, separate exploratory and confirmatory factor analyses were recently performed of the CHQ-PF-50 in children with chronic health conditions and healthy children (Drotar, Schwartz, Palermo, & Burant, 2006). Findings of this study suggested somewhat different factor solutions for each group. This study raised important questions about the clinical utility of the CHQ-PF-50, including how to interpret the domain scores for children with chronic health conditions and for healthy children. Factor analysis is an additional form of construct validity that is needed for the majority of HRQOL and functional impairment measures.
8. There are opportunities for questionnaire design and administration that are relevant to HRQOL and functional impairment measures. Expansion of the

response options (e.g., graphic rating scales) may extend the validity of child-report measures down to younger ages and improve the psychometric properties of child-report instruments. The use of technology (such as web and computer administration) is a key future direction for HRQOL tools, to provide greater access, decrease scoring burden, and increase measure accuracy.

## Conclusions

The purpose of this review was to provide an evidence-based evaluation of the most commonly used measures of HRQOL and functional impairment in pediatric psychology. Clinicians and researchers have a number of measures to choose from when assessing HRQOL and functional impairment in pediatric populations. Seventy-five percent of the measures reviewed received a “well-established” rating, indicating there are many potentially useful tools for research and clinical assessment. Pediatric psychologists should consider the purpose of the tool, as well as other desired features (e.g., low burden, cost, psychometric properties) when selecting a measure for research or clinical work. Even the “well-established” measures had shortcomings and may not meet a particular need. Research on HRQOL and functional impairment in pediatric populations will be improved by refinement of psychometric data, research on the clinical utility and applicability of measures in various clinic and hospital settings, and by longitudinal studies that seek to understand how HRQOL and functional impairment change in response to maturation, new treatment options, and changes in disease severity.

## Supplementary Data

Supplementary data are available at <http://jpepsy.oxfordjournals.org/>.

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