Arthritis Care & Research
Vol. 63, No. S11, November 2011, pp S420–S430
DOI 10.1002/acr.20637

Measures of General Pediatric Quality of Life

Child Health Questionnaire (CHQ), DISABKIDS Chronic Generic Measure (DCGM), KINDL-R, Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales, and Quality of My Life Questionnaire (QoML)

STEPHANIE E. HULLMANN, JAMIE L. RYAN, RACHELLE R. RAMSEY, JOHN M. CHANEY, AND LARRY L. MULLINS

CHILD HEALTH QUESTIONNAIRE (CHQ)

Description

Purpose. To measure health-related quality of life (HRQOL) in children and adolescents ages 5–18 years. This measure consists of child report (ages 10–18 years) and 2 versions of parent-proxy report (ages 5–18 years) of the child's HRQOL. It can be used with healthy children and those with both acute and chronic health conditions.

Content. Assesses for 14 physical and psychosocial domains: general health perceptions, physical functioning, role/social physical functioning, bodily pain, role/social emotional functioning, role/social behavioral functioning, parent impact-time, parent impact-emotional, self-esteem, mental health, behavior, family activities, family cohesion, and change in health.

Number of items. The child-report questionnaire (CHQ-CF87) consists of 87 items. The long parent-report questionnaire (CHQ-PF50) consists of 50 items, and the short parent-report questionnaire (CHQ-PF28) consists of 28 items.

Response options/scale. The response options for the CHQ are ordinal scales that vary by the item. Each item consists of 4–6 response options. Additionally, each scale consists of varying numbers of items.

Recall period for items. Varies by subscale. Most scales have a recall period of 4 weeks. The change in health subscale has a recall period of 1 year, and the global health, general health perception, and family cohesion subscales ask about the child's health "in general."

Stephanie E. Hullmann, MS, Jamie L. Ryan, MS, Rachelle R. Ramsey, MS, John M. Chaney, PhD, and Larry L. Mullins, PhD: Oklahoma State University, Stillwater.

Address correspondence to Stephanie E. Hullmann, MS, Oklahoma State University, 116 North Murray Hall, Stillwater, OK 74078. E-mail: stephanie.hullmann@okstate.edu.

Submitted for publication January 23, 2011; accepted in revised form May 10, 2011.

Endorsements. No information.

Examples of use.

Apaz MT, Saad-Magalhaes C, Pistorio A, Ravelli A, de Oliveira Sato J, Marcantoni MB, et al, for the Paediatric Rheumatology International Trials Organisation. Health-related quality of life of patients with juvenile dermatomyositis: results from the Paediatric Rheumatology International Trials Organisation multinational quality of life cohort study. Arthritis Rheum 2009; 61:509–17.

Brunner HI, Higgins GC, Wiers K, Lapidus SK, Olson JC, Onel K, et al. Health-related quality of life and its relationship to patient disease course in childhood-onset systemic lupus erythematosus. J Rheumatol 2009;36: 1536–45 (1).

Gutierrez-Suarez R, Pistorio A, Cespedes Cruz A, Norambuena X, Flato B, Rumba I, et al. Health-related quality of life of patients with juvenile idiopathic arthritis coming from 3 different geographic areas: the PRINTO multinational quality of life cohort study. Rheumatology (Oxford) 2007;46:314–20 (2).

Oliveira S, Ravelli A, Pistorio A, Castell E, Malattia C, Prieur AM, et al, for the Pediatric Rheumatology International Trials Organization (PRINTO). Proxy-reported health-related quality of life of patients with juvenile idiopathic arthritis: the Pediatric Rheumatology International Trials Organization multinational quality of life cohort study. Arthritis Rheum 2007;57:35–43 (3).

Ruperto N, Buratti S, Duarte-Salazar C, Pistorio A, Reiff A, Bernstein B, et al. Health-related quality of life in juvenile-onset systemic lupus erythematosus and its relationship to disease activity and damage. Arthritis Rheum 2004; 51:458–64.

Selvaag AM, Flato B, Lien G, Sorskaar D, Vinje O, Forre O. Measuring health status in early juvenile idiopathic arthritis: determinants and responsiveness of the Child Health Questionnaire. J Rheumatol 2003;30:1602–10 (4).

Takken T, Elst E, Spermon N, Helders PJ, Prakken AB, van der Net J. The physiological and physical determinants of functional ability measures in children with juvenile dermatomyositis. J Rheumatol 2002;42:591–5.

Practical Application

How to obtain. The CHQ scales can be obtained from the authors at www.healthact.com. The licensing fee is based upon the proposed use of the questionnaires, funding source, sample size, number of administrations, number of sites, start and end dates of the project, and the language.

Method of administration. Parents and children (ages 10–18 years) may self-administer the CHQ after instructions from the administrator.

Scoring. Overall means for the individual CHQ scales and items can be derived using a simple summated rating approach. This method yields a profile for each of the 14 health concepts. In addition, the individual scale scores can be aggregated to derive 2 summary component scores: the physical functioning and psychosocial health summary scores. Scores are transformed to a 0–100 scale, with a mean ± SD of 50 ± 10. The CHQ Scoring and Interpretation Manual is available on CD and is required for scoring and interpretation.

Score interpretation. Range on subscales and the overall scale is 0–100, where 0 = worst possible health state and 100 = best possible health state. Individual or population means of parent-reported quality of life can be easily compared to a normative sample via the computer scoring system. This allows for interpretation of the quality of life score and comparison to a sample of healthy children. A normative sample is not available for comparison of pediatric patient-reported quality of life. Poor HRQOL has been defined as 2 SDs below the mean of the normative sample or a physical functioning or psychosocial health summary score <30 (2,3).

Respondent burden. Minimal burden; respondents generally answer 6 items per minute.

Administrative burden. Minimal burden; the administrator provides a brief introduction to the questionnaire, and then the authors indicate that completion takes ~1 minute for each of 6 items. Therefore, administration time varies from 5–25 minutes, depending on the number of items in the version being administered (i.e., 28, 50, or 87 items). No training is necessary for administration.

Translations/adaptations. The CHQ-PF50 and CHQ-PF28 have each been translated into 72 different languages, and the CHQ-CF87 has been translated into 25 different languages. A complete list of translations is available online at http://www.healthact.com/translation-chq.php.

Psychometric Information

Method of development. The CHQ was developed for children to assess HRQOL in a similar structure and methodology as that used by the Short Form 36 Health Survey (SF-36) (5). The scale was developed with parents of children ages 5–18 years with and without chronic health conditions using traditional item scaling analysis (6).

Acceptability. An examination of schoolchildren conducted by Raat and colleagues (7) indicated that <2% of data were missing on the CHQ-PF50 and up to 4% of items had nonunique answers. In another examination, Raat et al (5) examined the utility of the CHQ-PF28; results indicated that up to 1.7% of data were missing and up to 0.8% had nonunique answers. The authors have also compared the acceptability of the pencil and paper version of the CHQ-CF87 with an internet version. The internet version was found to yield fewer missing answers than the paper and pencil CHQ-CF87 (8).

Reliability. Studies have indicated that internal consistency for the CHQ-PF50 is good, with Cronbach's α for Dutch schoolchildren ranging from 0.39–0.96 for an average of 0.72 for the subscales (7). Additionally, Cronbach's α has been computed for US schoolchildren (0.66–0.94), children with asthma (0.67–-0.91), and children with attention deficit hyperactivity disorder (0.56–0.92) (9). The CHQ-PF28 has been found to demonstrate adequate internal consistency for the 2 summary scales, but the individual subscales demonstrate low internal consistency (5). Internal consistency for the CHQ-CF87 has been found to be adequate for the pencil and paper version and internet version, with Cronbach's α ranging from 0.69–0.92 (8).

Examination of test–retest reliability on the CHQ-PF50 indicated that intraclass correlations were significant for all but 2 scales, and test–retest means were not significantly different (7). Test–retest reliability for the CHQ-PF28 psychosocial summary scale was found to be excellent, but the individual scales were found to have low test–retest reliability (5).

Validity. *Construct validity.* The CHQ-CF87 has demonstrated good construct validity, with scores being lower for children with no chronic health conditions and higher for those with an increasing number of chronic conditions (8). These results were unaffected by mode of questionnaire administration (i.e., paper and pencil versus the internet). Further, exploratory and confirmatory factor analyses of the CHQ-PF50 with a sample of children and adolescents with various chronic illnesses, including juvenile idiopathic arthritis (JIA), have been conducted. These analyses suggest that the CHQ-PF50 demonstrates good construct validity for physical and psychosocial health constructs; however, the factor structure was observed to be different for children with chronic illnesses than for medically healthy children (10). Additionally, in a sample of children with systemic lupus erythematosus (SLE), the CHQ-PF50 has demonstrated good construct validity (1).

Convergent validity. Convergent validity for the CHQ-PF50 was examined using the Health Utilities Index in a sample of schoolchildren. Convergent validity was found to be acceptable, with correlations ranging from 0.21–0.49 for parallel domains on the questionnaires (7). Further, the CHQ-P50 has demonstrated good convergent validity with the Pediatric Quality of Life Inventory in a sample of children with SLE (1). The CHQ-PF28 was compared with a visual analog scale (VAS) to determine convergent validity. Convergent validity was found to be acceptable (0.15–0.50), and the VAS was found to correlate best with the general health perceptions subscale (0.50) (5).

Discriminant validity. Discriminant validity for the CHQ-PF50 was found to be moderate to strong when comparing children without a chronic medical condition to those with ≥2 chronic conditions, and when comparing

those who had not attended a physician's appointment in the last year and those who had attended at least 3 times in the last year (7). The CHQ-PF28 demonstrated adequate discriminant validity, differentiating those children with a chronic health condition from those without (5).

Ability to detect change. In a sample of children with SLE, change in CHQ-PF50 physical health summary scores was observed to be consistent with changes in disease activity (1). However, the CHQ-PF50 psychosocial summary score and the CHQ-PF50 total score were observed to be less responsive to changes in health. Responsiveness of the CHQ-PF50 was also examined in a sample of Italian children with JIA (10). Similar to the pattern observed in children with SLE, the CHQ demonstrated good responsiveness to change in disease activity, with the physical health summary score evidencing better responsiveness than the total score or the psychosocial summary score. The responsiveness of the physical health summary score has also been examined independently in children with JIA. The CHQ was found to be sensitive to clinical change with a large standardized response mean for those who improved (0.96), small for those whose health was unchanged (0.16), and moderate for those whose health worsened (−0.60) (4).

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths. The CHQ has demonstrated adequate to good psychometric properties in a number of chronic illness populations. It also has both child and parent-proxy report versions, which allow for comparison of parent and child perceptions of child HRQOL. The CHQ is also available in a wide range of languages for cross-cultural comparison. The CHQ is easy to administer, and there is minimal respondent burden.

Caveats and cautions. Although the CHQ-PF50 has demonstrated good psychometric properties, the authors recommend using and interpreting summary scales on the CHQ-PF28 rather than individual scales, the latter of which have been found to have poor psychometrics. The CHQ may be confusing for some respondents because the item response options and recall periods vary by item. Further, the CHQ may only be used with parents and children ages 5–18 years and has not been validated for use with children ages <5 years.

Clinical usability. The CHQ requires minimal training for administration and scoring. It provides information on many discrete aspects of child HRQOL as well as overall scores; therefore, it may provide more detailed information for clinicians than other measures of HRQOL. Further, the CHQ can be mapped onto the SF-36, allowing for longitudinal measurement of HRQOL as patients transition from pediatric to adult care. However, the CHQ has several features that may limit use in a clinical setting. First, the completion time for the CHQ may inhibit clinic flow. Additionally, the CHQ may be expensive for regular use in a clinic. As the CHQ requires computer scoring, it does not allow clinicians to quickly review a patient's response and determine their level of HRQOL.

Research usability. The CHQ provides information regarding discrete aspects of child HRQOL. It is also very easy to administer and score. The internet version, which has shown similar psychometric properties to the traditional pencil and paper version, may be beneficial for research use because data entry will not be required. Additionally, a large normative sample is available for comparison across illness groups and with healthy children. Unfortunately, the varying item response options and recall periods may be confusing to children and their parents, so researchers should be available for clarification of items and verify that items were completed appropriately.

DISABKIDS CHRONIC GENERIC MEASURE (DCGM)

Description

Purpose. To assess health-related quality of life (HRQOL) in children and adolescents (ages 8–16 years) diagnosed with different chronic health conditions. The DISABKIDS, which was developed by the European DISABKIDS Group in 2002, is a modular measure and consists of both a generic form and 7 illness-specific forms. The following review will focus on the generic measures of HRQOL (refer to DISABKIDS Condition-Specific Measures for HRQOL, as it pertains to 7 different chronic illnesses).

Content. The DCGM consists of 3 domains of HRQOL: mental, social, and physical. Within each domain are 2 dimensions: independence (e.g., autonomy or living without impairments caused by the chronic health condition) and emotion (e.g., worries, concerns, or anger problems), social inclusion (e.g., acceptance of others, positive social relationships) and social exclusion (e.g., stigmatized, feeling left out), and limitation (e.g., functional limitations, perceived health status) and treatment (e.g., emotional impact of taking medication, receiving injections, taking insulin, etc.), respectively.

Number of items. The DCGM has 2 versions (long and short). The long version consists of 37 items (DCGM-37): mental (independence: 6 items, emotion: 7 items), social (social inclusion: 6 items, social exclusion: 6 items), and physical (limitation: 6 items, treatment: 6 items). The short version consists of 12 items and was derived from the DCGM-37.

Response options/scale. The DCGM-37 consists of ordinal scale items ranging from 1 (never) to 5 (always).

Recall period for items. Respondents are asked to refer back to the last 4 weeks.

Endorsements. The DISABKIDS Group.

Examples of use. Bullinger M, Schmidt S, Petersen C, and the DISABKIDS Group. Assessing quality of life of children with chronic health conditions and disabilities: a European approach. Int J Rehabil Res 2002;25:197–206.

Chaplin JE, Hanas R, Lind A, Tollig H, Wramner N, Lindblad B. Assessment of childhood diabetes-related quality-of-life in West Sweden. Acta Paediatrica 2008;98: 361–6.

Petersen C, Schmidt S, Bullinger M, and the DISABKIDS Group. Coping with a chronic pediatric health condition

and health-related quality of life. Eur Psychol 2006;11: 50–6.

Sandberg M, Johannson E, Bjork J, Wettergren L. Health-related quality of life related to school attendance in children on treatment for cancer. J Pediatr Oncol Nurs 2008; 25:265–74.

Practical Application

How to obtain. Interested parties are to complete a collaboration form (found online at http://www.disabkids.de/cms/licensing) and return it to the DISABKIDS Group. Following registration, the interested party will receive practical information (e.g., cost, versions) and login information to access questionnaires.

Method of administration. Two versions of the DCGM-37 are available: a child/adolescent self-report and a parent-proxy report. Both are paper and pencil questionnaires. A computer-assisted version is available.

Scoring. Hand scoring. Within each of the 6 subscales, item raw scores are summed and transformed into a scaled score ranging from 0 (poor HRQOL) to 100 (excellent HRQOL). Reference scores necessary for transformations are found in the DCGM manual. The subscales can also be combined to produce a general score of HRQOL (DCGM-37 total score). Missing values are to be substituted, if all but 1 item of each subscale is completed, by person-specific means based on his/her existing answers.

Score interpretation. The possible range for the DCGM total score is 37–185. Higher summed scores indicate better HRQOL.

Respondent burden. Minimal time to complete.

Administrative burden. Minimal training is necessary.

Translations/adaptations. Validated for use in the following languages: Dutch, English, French, German, Greek, and Swedish (12). Validation studies in Brazil and Mexico are currently being conducted.

Psychometric Information

Method of development. Development included focus groups of children and adolescents across Europe, in addition to parents and medical professionals, to identify aspects of HRQOL themes. Groups were classified by age, type of disease, and severity of disease. Results were used to derive items for the generic as well as the disease-specific modules (not discussed in this review).Three centers examined 3,027 statements for redundancy through a card-sort procedure. A total of 119 chronic generic items were selected to form the questionnaire for pilot testing.

Pilot studies were conducted to examine acceptability of the DCGM and its initial psychometric properties. The item-selection process following the pilot study resulted in a 56-item chronic generic questionnaire. Field tests were done to analyze the DCGM in a sample of 1,606 children and adolescents with a chronic condition. Participants were recruited from pediatric hospitals. There was equal representation across age ranges (4–7, 8–12, and 13–16 years), and the sample was primarily in the mild to moderate range of disease severity (38.7–50.7% of valid cases), although it also included more severe cases (10.6% of valid cases). Results from the field study provide the reference data reported in the manual.

Acceptability. No information.

Reliability. Internal consistency on the subscales (Cronbach's $\alpha = 0.70–0.87$) and test–retest reliability (intraclass correlation coefficient 0.71–0.83) is satisfactory across various chronic health conditions (12). In a sample of 117 Swedish children with cancer, internal consistency for the 6 subscales ranged from 0.71–0.87 (13).

Validity. *Content validity.* Items on the DCGM-37 were generated by focus groups, including children and adolescents with a chronic health condition, parents, and professionals (e.g., psychologists, physicians, and statisticians) (14). Analyses during pilot and field testing verified the grouping of items according to theoretical dimensions. Items with >5% of missing data, ceiling or floor effects of >60%, or absolute value of skewness of >2.0 were removed. When correlation coefficients between items were >0.8, redundant items were also discarded (12). A panel of experts classified all items according to age, type, and severity of disease.

Construct validity. In a sample of 1,153 children and adolescents (ages 8–16 years) with a chronic health condition (i.e., asthma, arthritis, epilepsy, cerebral palsy, diabetes mellitus, atopic dermatitis, cystic fibrosis), confirmatory factor analysis (root mean square of error approximation = 0.04, non-normed fit index = 0.95, comparative fit index = 0.95) supported a 6-factor structure for the final 37 items (12). Construct validity was further supported by satisfactory internal consistency on each of the 6 subscales.

Convergent validity. Simeoni and colleagues (12) found that the DCGM-37 was moderately associated with other already validated measures of HRQOL: Children's General Health Perceptions-Child Report (0.24–0.41), Functional Status-II (general health: 0.22–0.36), and Pediatric Quality of Life Inventory (physical: 0.23–0.70, emotional: 0.39–0.67, social: 0.19–0.64, and school: 0.35–0.59).

Discriminant validity. In the article by Simeoni et al (12), this was confirmed with girls and older adolescents reporting lower HRQOL compared to boys and younger children. Children from families with lower socioeconomic status and those with more severe diseases reported significantly lower HRQOL.

Ability to detect change. No information.

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths. The DCGM is a reliable and valid measure of HRQOL and 6 specific dimensions across a variety of chronic health conditions. As one of the chronic health conditions included in development of the measure as well as pilot and field testing, it is well suited to assess HRQOL in children and adolescents with juvenile idiopathic arthritis (JIA). It has been validated in 6 languages thus far and has been utilized in different national and cultural contexts. The DCGM is easy to administer and score, with little training necessary.

Caveats and cautions. Research on the DCGM has largely focused on children and adolescents in European

countries. As such, more studies are needed in the US to determine whether previous findings are generalizable to other children with chronic health conditions (e.g., JIA). The DCGM has examined HRQOL in JIA, but little is known about its applicability in other juvenile rheumatic diseases (e.g., lupus, dermatomyositis, spondylarthropathy). Furthermore, the DCGM does not provide information on how to interpret scores; therefore, it is difficult to know whether significant changes occur in child responses. The DCGM is also not useful for younger children (i.e., ages ≤8 years) with JIA.

Clinical usability. It is quick and easy to administer and score, limiting the burden to both respondents and clinicians. The psychometric properties and reference points of the DCGM indicate that it is a sound measure of HRQOL in JIA.

Research usability. Similarly, the DCGM is supported for its use in research with JIA, given that its development included this population. The measure is self-explanatory, allowing research participants to complete it with ease and without much assistance from researchers.

KINDL-R

Description

Purpose. To measure health-related quality of life (HRQOL) in healthy and ill children and adolescents (ages 4–16 years).

Content. The KINDL-R (15) consists of 24 items associated with 6 dimensions: physical well-being (e.g., illness, pain, fatigue), emotional well-being (e.g., boredom, loneliness, scared), self-esteem (e.g., pride, feeling on top of the world), family (e.g., relationship with parents, conflict at home), friends (e.g., getting along, feeling different from others), and everyday functioning in school (e.g., enjoying class, worrying about the future). Disease is an optional subscale (e.g., illness uncertainty, parent overprotection, missing school) that can be added in the case of prolonged illness or hospitalization. Disease-specific modules are available for children with obesity, bronchial asthma, atopic dermatitis, and diabetes mellitus.

Number of items. The KINDL-R consists of 24 items, with each subscale containing 4 items.

Response options/scale. Responses are on a 5-point ordinal scale from 1 (never) to 5 (all of the time).

Recall period for items. Respondents are asked to refer to the past week.

Endorsements. No information.

Examples of use. Ertan P, Yilmaz O, Caglayan M, Sogut A, Aslan S, Yuksel H. Relationship of sleep quality and quality of life in children with monosymptomatic enuresis. Child Care Health Dev 2008;35:469–74.

Milde-Busch A, Heinrich S, Thomas S, Kuhnlein A, Radon K, Straube A, et al. Quality of life in adolescents with headache: results from a population-based survey. Cephalagia 2010;30:713–21.

Muller-Godeffroy E, Lehmann H, Kuster RM, Thyen U. Quality of life and psychosocial adaptation in children and adolescents with juvenile idiopathic arthritis and reactive arthritis. J Rheumatol 2005;64:177–87.

Ravens-Sieberer U, Bullinger M. Assessing the health related quality of life in chronically ill children with the German KINDL: first psychometric and content-analytical results. Qual Life Res 1998;7:399–407 (15).

Ravens-Sieberer U, Erhart M, Wille N, Bullinger M. Health-related quality of life in children and adolescents in Germany: results of the BELLA study. Eur Child Adolesc Psychiatry 2008;17 Suppl:148–56.

Wille N, Erhart M, Petersen C, Ravens-Sieberer U. The impact of overweight and obesity on health-related quality of life in childhood: results from an intervention study. BMC Public Health 2008;8:421–9.

Practical Application

How to obtain. The KINDL-R may be used with permission from the developers (www.kindl.org). The manual, computer software, and questionnaires are free for all nonprofit or research institutions only, under the condition that a user form is completed. No other cost information is provided.

Method of administration. Three versions of the KINDL-R are available as self-report measures for different age groups: Kiddy-KINDL-R (ages 4–7 years; interview format), Kid-KINDL-R (ages 8–12 years), and Kiddo-KINDL-R (ages 13–16 years). It is also available in 2 parent-proxy versions (ages 4–7 years and 8–16 years). A shorter, 12-item version of the KINDL-R and a computer-assisted, touch screen version (CAT-Screen) are also available.

Scoring. The KINDL-R is scored with computer scoring software. Briefly, 10 items are reversed before being summed to reach 6 subscale scores (physical well-being, emotional well-being, self-esteem, family, friends, and school). If necessary, an additional subscale score for disease can be added. Subscales can be combined for a total score, or they can be transformed to values between 0 and 100. Scoring the parent version follows the same general steps. Instructions for common coding problems include: if 2 responses are marked for a single question and these responses are adjacent to one another, then 1 response is chosen according to a random procedure and entered; if 2 responses are marked for a single question and these responses are not adjacent to one another, then the item is coded as a missing value; and if 3 or more responses are marked for a single question, the item is coded as a missing value. The algorithm on the computer software replaces any missing values by an estimate made specifically for that person, provided that the respondent answered at least 70% of the items on the subscale.

Score interpretation. Higher scores on the KINDL-R indicate better HRQOL.

Respondent burden. Minimal; <15 minutes to complete, and the KINDL-R is self-explanatory.

Administrative burden. Minimal training is necessary for administration. Scoring requires training in SPSS software.

Translations/adaptations. The original KINDL was developed in German and is also available in English,

Dutch, French, Greek, Italian, Norwegian, Russian, Spanish, Swedish, and Turkish. The Turkish, English, and Spanish KINDL have been validated (16–18).

Psychometric Information

Method of development. No information.

Acceptability. Floor and ceiling effects are <10%.

Reliability. In a sample of 1,050 children and adolescents (mean age 12.6 years) with bronchial asthma, atopic dermatitis, or obesity who were recruited from 7 German rehabilitation clinics, internal consistency for the KINDL-R subscales was satisfactory (0.63–0.76) and good for the total score (0.84) (19). For the parent version, internal consistency was satisfactory for the subscales (0.62–0.81) and excellent for the total score (0.89) (16).

In a study by Erhart and colleagues (20), HRQOL using the KINDL-R and KINDL proxy version was examined among 6,813 German children and adolescents (ages 11–17 years; 17.5% classified as having a chronic health condition) and their parents. Internal consistency for the total score was slightly higher for the parent report than the child report (0.86 versus 0.82) (20).

Validity. *Content validity.* No information.

Construct validity. Using confirmatory factor analysis, the KINDL-R had an acceptable fit to the 6-dimensional model for the parent (root mean square of error approximation [RMSEA] = 0.07, comparative fit index [CFI] = 0.95) and the child (RMSEA = 0.06, CFI = 0.93) (20). Construct validity was further supported by satisfactory internal consistency on each of the 6 dimensions (child range 0.53–0.72, parent range 0.62–0.72).

Convergent validity. Ravens-Sieberer and colleagues (19) found the KINDL-R to be associated with other measures of HRQOL, including the Children's Health Questionnaire (general well-being: r = 0.7), Short Form 36 Health Survey (SF-36; vitality: 0.64, emotional well-being: 0.64), and Life Satisfaction Questionnaire adapted for children (life satisfaction: 0.69). Erhart and colleagues (20) reported similar findings with associations between the child and parent KINDL-R and the Strength and Difficulties Questionnaire (SDQ; child range 0.33–0.49, parent range 0.44–0.53).

Discriminant validity. In the same study by Erhart and colleagues (20), discriminant validity was indicated by low correlations between the KINDL-R and opposing dimensions of the SDQ. Regarding the ability to discriminate between healthy children and those with a chronic health condition, the child-report form exhibited small effect sizes (0.04–0.27) and the parent-report form had medium effect sizes (0.20–0.56) (20). Parent- and child-report total scores and physical well-being scores had small effect sizes (parent: 0.31 and 0.26, respectively, and child: 0.25 and 0.18, respectively), whereas the child report yielded large effect sizes for the impact of obesity on the dimensions of self-esteem (0.19), friends (0.28), and school-related well-being (0.23) (20).

Ability to detect change. No information.

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths. The KINDL-R is a flexible, modular, and psychometrically sound measure of HRQOL for children and adolescents with and without a chronic health condition. A few primary advantages of this measure are its self- and parent-report measures, which may be used to assess concordance rates, as well as age-specific versions to account for the changes that take place over the course of the child's development.

Caveats and cautions. Although this measure has been studied in various chronic health conditions (e.g., diabetes mellitus and cerebral palsy), less information is available on juvenile rheumatic diseases (JRDs). This limitation warrants future studies examining the generalizability to other chronic illnesses. Furthermore, the KINDL-R does not allow use throughout the entire pediatric age range, and is not appropriate for children ages <4 years with a JRD. Although the psychometric properties have been examined in some of the translated versions of the KINDL, the reliability and validity for several versions have not been investigated. Lastly, how to interpret scores on the KINDL-R is unknown, making it difficult to assess changes in HRQOL in children with JRDs.

Clinical usability. The KINDL-R requires little time and effort on the part of the respondent, whether a child or parent. It has wide applicability in various settings such as community or clinical mental health and medical settings. Scoring, however, requires that the clinician have some knowledge of SPSS software. Therefore, the KINDL-R may not be the quickest measure of HRQOL in a clinical setting. Additionally, little research has been done on the appropriateness of using the KINDL-R in pediatric rheumatology clinics.

Research usability. This measure can be completed by several research participants in a short amount of time and offers a great deal of information regarding overall HRQOL, in addition to 6 specific domains. Again, scoring may be time consuming.

PEDIATRIC QUALIFY OF LIFE INVENTORY (PEDSQL) 4.0 GENERIC CORE SCALES

Description

Purpose. To measure health-related quality of life (HRQOL) in children and adolescents ages 2–18 years. This measure consists of child report (ages 5–18 years) and parent report (ages 2–18 years) of the child's HRQOL, and can be used with healthy children and those with acute and chronic health conditions. PedsQL 4.0 is the fourth and current version. The PedsQL 4.0 Generic Core Scales were specifically designed to measure the core health dimensions outlined by the World Health Organization.

Content. Physical, emotional, social, and school functioning. Specifically, questions inquire about problems related to child health, activities, feelings, getting along with others, and school.

Number of items. 23 items for the total scale score: 8 items for physical health summary score and 15 items for psychosocial health summary.

Response options/scale. For children ages 8–18 years and parent-proxy report formats, items are rated on a 5-point ordinal scale to indicate how much the child has problems with various areas of functioning, ranging from 0 (never) to 4 (almost always). For younger children, the ordinal scale is reworded and simplified to a 3-point scale: 0 (not at all a problem), 2 (sometimes a problem), and 4 (a lot of a problem).

Four subscales, including physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items), contribute to 3 summary scores: total scale score (all subscales), physical health summary score (physical functioning scale only), and psychosocial health summary (emotional, social, and school functioning scales combined).

Recall period for items. 1 month.

Endorsements. No information.

Examples of use. Brunner HI, Taylor J, Britto MT, Corcoran MS, Kramer SL, Melson PG, et al. Differences in disease outcomes between Medicaid and privately insured children: possible health disparities in juvenile rheumatoid arthritis. Arthritis Rheum 2006;55:378–84.

Brunner HI, Higgins GC, Wiers K, Lapidus SK, Olson JC, Onel K, et al. Health-related quality of life and its relationship to patient disease course in childhood-onset systemic lupus erythematosus. J Rheumatol 2009;36:1536–45 (1).

Moorthy LN, Harrison MJ, Peterson M, Onel KB, Lehman TJ. Relationship of quality of life and physical function measures with disease activity in children with systematic lupus erythematosus. Lupus 2005;14:280–7.

Ringold S, Wallace CA, Rivara FP. Health-related quality of life, physical function, fatigue, and disease activity in children with established polyarticular juvenile idiopathic arthritis. J Rheumatol 2009;36:1330–6.

Robinson RF, Nahata MC, Hayes JR, Rennebohm R, Higgins G. Quality of life measurements in juvenile rheumatoid arthritis patients treated with Etanercept. Clin Drug Investig 2003;23:511–8.

Sandstrom MJ, Schanberg LE. Peer rejection, social behavior, and psychological adjustment in children with juvenile rheumatic disease. J Pediatr Psychol 2004;29: 29–34.

Sawyer MG, Whitham JN, Roberton DM, Taplin JE, Varni JW, Baghurst PA. The relationship between health-related quality of life, pain, and coping strategies in juvenile idiopathic arthritis. J Rheumatol 2004;43:325–30.

Trapanotto M, Giorgino D, Zulian F, Benini F, Varni JW. The Italian version of the PedsQL in children with rheumatic diseases. Clin Exp Rheumatol 2009;27:373–80.

Practical Application

How to obtain. The PedsQL scales, modules, and translations are protected by copyright. Upon accepting the user agreement, a single copy of the measure can be obtained online at http://pedsql.org/pedsql12.html. Individuals, organizations, or institutions wishing to order the PedsQL should contact: Christelle Berne, Mapi Research Institute, 27, rue de la Villette, 69003 Lyon, France; e-mail: cberne@mapi.fr; telephone: +33 (0) 472 13 66 67.

The PedsQL is free to individuals conducting nonfunded academic research; however, the cost for funded academic research and large noncommercial organization research and evaluations (e.g., states, nations, hospitals, health care systems) and commercial studies can vary widely ($1,000–$20,000). Fee calculators can be found online at http://www.pedsql.org/conditions.html.

Method of administration. Parents, children (ages 8–12 years), and adolescents (ages 13–18 years) may self-administer the PedsQL after instructions from the administrator. For younger children (ages 5–7 years) or if the child or adolescent is unable to self-administer the PedsQL (e.g., due to illness, fatigue, reading difficulties), the measure should be read aloud. General protocol and administration guidelines (including a script) are available online at http://www.pedsql.org/pedsqladmin.html.

Scoring. Items are reverse scored and linearly transformed to a 0–100 scale, so that higher scores indicate better HRQOL. To reverse score, transform the scale items to 0–100 as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. To create scale scores, the mean is computed by totaling the item scores and dividing by the number of items answered (this accounts for missing data). If >50% of the items in the scale are missing, it is recommended that the scale score not be computed. Imputing the mean of the completed items in a scale when 50% or more are completed is generally the most unbiased method. To create the psychosocial health summary score, the mean is computed as the sum of the items over the number of items answered in the emotional, social, and school functioning subscales. The physical health summary score is the same as the physical functioning subscale score. To create the total scale score, the mean is computed as the sum of all of the items over the number of items answered on all of the scales. Computer scoring is not necessary.

Score interpretation. The range on subscales and the overall scale is 0–100, with lower scores indicating poorer HRQOL and higher scores indicating better HRQOL. When examining the total scale, scores of 4.4 and 4.5 are considered to be minimal clinically meaningful differences on the child self-report and parent-proxy report, respectively (21).

Respondent burden. Minimal; questions are written at a third- to sixth-grade reading level, and the entire questionnaire takes <4 minutes to complete.

Administrative burden. Minimal; the administrator provides a brief introduction to the questionnaire and then administration of the PedsQL takes <4 minutes, even when reading of the questionnaire is required. Scoring also takes a minimal amount of time (several minutes) and effort. No training necessary for administration.

Translations/adaptations. The PedsQL Generic Core questionnaire has been linguistically validated for children and adolescents (ages 2–18 years) and parents in the following languages: Belgium Dutch, Belgium French, Portuguese for Brazil, French for Canada, Croatian, Czech, Danish, French, German, Hungarian, Hebrew, Italian, Latvian, Lithuanian, Spanish for Mexico, Norwegian, Urdu for Pakistan, Spanish for Peru, Polish, Portuguese,

Russian, Slovakian, Slovenian, Spanish, and Swedish. It has also been translated, but not formally validated, into a variety of other languages. A complete list of translations is available online at http://pedsql.org/translations.html.

Psychometric Information

Method of development. The original PedsQL 1.0 was empirically derived from data collected from 291 pediatric patients with cancer and their parents at various stages of treatment. It was designed as a generic HRQOL instrument to be utilized across diverse pediatric populations. The PedsQL 2.0 and 3.0 included additional constructs and items, a more sensitive scaling range, and a broader age range for child self-report and parent-proxy report (22). The PedsQL 4.0 Generic Core Scales have resulted from this process and were specifically designed to measure the core health dimension outlined by the World Health Organization.

In the initial field trail, the PedsQL 4.0 Generic Core Scales were administered to 963 children and 1,629 parents (23). Later, the psychometric properties of the PedsQL 4.0 were tested in a group of children (n = 231) with rheumatoid arthritis (e.g., juvenile idiopathic arthritis [JIA; pauciarticular, polyarticular, and systemic subtypes], systemic lupus erythematosus, juvenile fibromyalgia, spondylarthritis, other rheumatic diseases) and their parents (22). Psychometric statistics provided below are from the investigation of children with juvenile rheumatic diseases.

Acceptability. Recent studies suggest that 0.7% of child report and 3% of parent report data were missing. Items about school were most frequently skipped, suggesting that these were not completed when children did not attend school during the previous month (when given in the summer) (22).

Reliability. Internal consistencies for the total scale score were as follows: child self-report Cronbach's α = 0.91, parent-proxy report Cronbach's α = 0.93; physical health summary scale score: child self-report Cronbach's α = 0.87, parent-proxy report Cronbach's α = 0.89; and psychosocial health summary scale score: child self-report Cronbach's α = 0.86, parent-proxy report Cronbach's α = 0.90.

Validity. Construct validity was determined by comparing scale scores across children with juvenile rheumatic diseases (JRDs) and healthy children, because these groups are known to differ in HRQOL. For every comparison (i.e., self- and parent-report of total score, physical health summary score, psychosocial health summary score, emotional functioning, social functioning, and school functioning), a statistically significant difference existed when comparing healthy children to children with JRDs (22). In other words, healthy children had higher PedsQL 4.0 scores (suggesting better HRQOL) than children with rheumatic diseases.

Ability to detect change. The responsiveness of the PedsQL was demonstrated through a longitudinal analysis of change within participants with JRDs for whom change was expected as a result of an intervention (22). For both child self-report and parent-proxy report, the PedsQL 4.0 Generic Core Total and summary scale scores increased progressively from visit 1 through visit 3. Effect sizes for the difference between visit 1 and 2 for child self-report (d = 0.34) and parent proxy (d = 0.27) were in the small range, while the effect sizes for the difference between visit 1 and 3 for child self-report (d = 0.92) and parent-proxy report (d = 0.71) were in the medium to large effect size range.

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths. The PedsQL Generic Core Scales are widely used in a variety of pediatric patient populations (i.e., JIA, systemic lupus erythematosus) and with healthy children. The measure is brief, developmentally appropriate for a broad range of ages, reliable, valid, responsive, and translated into many languages. Additionally, disease-specific modules (not discussed in this review) can also be added to the Generic Core Scales to provide both disease-specific and general measures of quality of life.

Caveats and cautions. Because the PedsQL asks children and parents to remember information from the past month, children and parents may have difficulty completing school-related questions if the child has not recently been in school.

Clinical usability. The PedsQL 4.0 Generic Core Scales are a practical measure for clinicians. In a short amount of time (~4 minutes), physicians and clinicians can gather general information about the child's physical, emotional, social, and school functioning.

Research usability. Overall, the PedsQL 4.0 Generic Core Scales can be used as an excellent measure of general HRQOL. Additionally, the measure can be self-administered and understood by most adults and children.

QUALITY OF MY LIFE QUESTIONNAIRE (QOML)

Description

Purpose. To assess quality of life (QOL) and health-related quality of life (HRQOL) as 2 separate constructs in children and adolescents.

Content. Two visual analog scales (VAS) and a categorical measure of change in QOL.

Number of items. 3 items: the QOL and HRQOL VAS and a categorical item assessing change in QOL since the previous visit.

Response options/scale. Children and parent-proxy reporters each complete 2 VAS. The QOL VAS asks "Overall, my life is . . . ," and the HRQOL VAS asks "Considering my health, my life is. . . ." Respondents are asked to record their responses on a 100-mm VAS for each question stem, which ranges from 0 (the worst) to 100 (the best). Respondents also provide a categorical response to the question, "Since the last time I was here, my life is. . . ." The item is rated on a 5-point ordinal scale ranging from much worse to much better.

Recall period for items. Current.

Endorsements. No information.

Examples of use. Dempster H, Porepa M, Young N, Feldman BM. The clinical meaning of functional outcome scores in children with juvenile arthritis. Arthritis Rheum 2001;44:1768–74.

Gong GW, Young NL, Dempster H, Porepa M, Feldman BM. The Quality of My Life questionnaire: the minimal clinically important difference for pediatric rheumatology patients. J Rheumatol 2007;34:581–7 (24).

Oen K, Tucker L, Huber AM, Miettunen P, Scuccimarri R, Campillo S, et al. Predictors of early inactive disease in a juvenile idiopathic arthritis cohort: results of a Canadian multicenter, prospective inception cohort study. Arthritis Rheum 2009;61:1077–86.

Singh-Grewal D, Schneiderman-Walker J, Wright V, Bar-Or O, Beyene J, Selvadurai H, et al. The effects of vigorous exercise training on physical function in children with arthritis: a randomized, controlled, single-blinded trial. Arthritis Rheum 2007;57:1202–10.

Stephens S, Feldman BM, Bradley N, Schneiderman J, Wright V, Singh-Grewal D, et al. Feasibility and effectiveness of an aerobic exercise program in children with fibromyalgia: results of a randomized controlled pilot trial. Arthritis Rheum 2008;59:1399–406.

Practical Application

How to obtain. The QoML is available in the appendices of the articles by Gong et al (24) and Feldman et al (25).

Method of administration. Parents and children (ages 8–12 years) may self-administer the QoML after instructions from the administrator.

Scoring. The VAS are scored by measuring the length (in mm) of the line between the left anchor and the respondent's mark on the line.

Score interpretation. The response range is from 0–100, with higher scores suggesting better QOL.

Respondent burden. Minimal burden; respondents complete 3 items, and the questionnaire takes <5 minutes to complete.

Administrative burden. Minimal burden; the administrator provides a brief introduction to the questionnaire, and then administration takes <5 minutes, even when reading of the questionnaire is required. Scoring also takes minimal time and effort. No training is necessary for administration.

Translations/adaptations. None.

Psychometric Information

Method of development. The QoML was developed in a pediatric rheumatology sample as a measure of both QOL and HRQOL. The scale is based upon other VAS that have been widely used to assess for QOL in adult cancer samples. The QoML was pretested on 10 children ages 4–12 years; 6 of the children were rheumatology clinic patients and 4 were healthy children. Face validity was assessed by 11 pediatric rheumatology professionals and found to be good to strong. The questionnaire was piloted on 122 pediatric rheumatology patients of various diagnoses, including pauciarticular juvenile arthritis, spondylarthropathy, fibromyalgia, and osteomyelitis, ranging in age from 10 months to 18 years. The patients and their parents independently determined at what age the child was able to complete the questionnaire for himself/herself or at what age a parent would need to provide proxy report. Results indicated that QOL and HRQOL were viewed by respondents as related yet discrete constructs.

Acceptability. No information.

Reliability. No information.

Validity. Convergent construct validity was determined by Feldman and colleagues (25) and Gong and colleagues (24) in pediatric rheumatology samples by comparing respondents' scores on the QOL and HRQOL VAS and the Childhood Health Assessment Questionnaire, a traditional measure of health status. For both examinations, results indicated that convergent construct validity was good, as the relationships between the scales and disease variables (i.e., disease severity, disability, morning stiffness, pain) were as expected. Criterion validity was not assessed.

Ability to detect change. With regard to the responsiveness of the QoML, or ability to detect change over time, Gong and colleagues (24) conducted an examination to determine the minimum clinically important difference (MCID) in QOL and HRQOL for pediatric rheumatology patients and their parents. MCID was determined by asking patients and their parents to provide VAS responses for their current QOL and HRQOL and 2 hypothetical situations. One situation suggests that the child's health had improved "just enough to make a difference," and the other suggests that the child's health had gotten worse "just enough to make a difference" in his/her QOL and HRQOL. The authors were able to provide numerical values of responsiveness for the QoML in the pediatric rheumatology population. MCID for improvement was 7 mm and 11 mm for QOL and HRQOL, respectively, and MCID for deterioration was −33 mm and −38 mm for QOL and HRQOL, respectively (24).

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths. The QoML was developed in a pediatric rheumatology sample, making it appropriate for other pediatric rheumatology populations. The questionnaire is quick and easy to administer and requires minimal reading on the part of the child or parent. Unlike most measures of QOL, the QoML provides an assessment of both the child's QOL and HRQOL.

Caveats and cautions. The QoML has limited psychometric data and is still in the process of being validated. Currently, age limitations do not allow the QoML to be used throughout the entire pediatric age range, with parents able to report on children as young as 10 months and children able to report on their own QOL as young as 4 years. Additionally, unlike measures of QOL with more items and subscales, the QoML does not provide domain-specific information about what factors (e.g., physical, emotional, social, behavioral, academic) are contributing to a child's change in QOL or HRQOL.

Clinical usability. The QoML is an easy measure to administer and score. Clinicians can quickly determine a child's QOL or HRQOL by viewing their completed VAS

and their report of qualitative change since the subsequent visit. It may be very useful for a clinician who is interested in a quick estimate of a child's QOL and change since the previous visit.

Research usability. The QoML can be completed quickly and easily by both child and parent research participants. The measure is available for free in the appendices of the authors' studies. Unlike most measures of pediatric QOL, the QoML provides a report of both QOL and HRQOL.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be published.

REFERENCES

1. Brunner HI, Higgins GC, Wiers K, Lapidus SK, Olson JC, Onel K, et al. Health-related quality of life and its relationship to patient disease course in childhood-onset systemic lupus erythematosus. J Rheumatol 2009;36:1536–45.
2. Gutierrez-Suarez R, Pistorio A, Cespedes Cruz A, Norambuena X, Flato B, Rumba I, et al. Health-related quality of life of patients with juvenile idiopathic arthritis coming from 3 different geographic areas: the PRINTO multinational quality of life cohort study. Rheumatology (Oxford) 2007;46:314–20.
3. Oliveira S, Ravelli A, Pistorio A, Castell E, Malattia C, Prieur AM, et al. for the Pediatric Rheumatology International Trials Organization. Proxy-reported health-related quality of life of patients with juvenile idiopathic arthritis: the Pediatric Rheumatology International Trials Organization multinational quality of life cohort study. Arthritis Rheum 2007;57:35–43.
4. Selvaag AM, Flato B, Lien G, Sorskaar D, Vinje O, Forre O. Measuring health status in early juvenile idiopathic arthritis: determinants and responsiveness of the Child Health Questionnaire. J Rheumatol 2003; 30:1602–10.
5. Raat H, Botterweck AM, Landgraf JM, Hoogeveen WC, Essink-Bot M. Reliability and validity of the short form of the Child Health Questionnaire for parents (CHQ-PF28) in large random school based and general population samples. J Epidemiol Community Health 2005;59:75–82.
6. Asmussen L, Olson LM, Grant EN, Landgraf JM, Fagan J, Weiss KB. Use of the Child Health Questionnaire in a sample of moderate and low-income inner-city children with asthma. Am J Respir Crit Care Med 2000;162:1215–21.
7. Raat H, Bonsel GJ, Essink-Bot M, Landgraf JM, Gemke RJ. Reliability and validity of comprehensive health status measures in children: the Child Health Questionnaire in relation to the Health Utilities Index. J Clin Epidemiol 2002;55:67–76.
8. Raat H, Mangunkusumo RT, Landgraf JM, Kloek G, Brug J. Feasibility, reliability, and validity of adolescent health status measurement by the Child Health Questionnaire Child Form (CHQ-CF): internet administration compared with standard administration. Qual Life Res 2007;16: 675–85.
9. Landgraf JL, Abetz L, Ware JE. The CHQ user's manual. Boston: The Health Institute, New England Medical Center; 1996.
10. Drotar D, Schwartz L, Palermo TM, Burant C. Factor structure of the Child Health Questionnaire-Parent Form in pediatric populations. J Ped Psychol 2006;31:127–38.
11. Moretti C, Viola S, Pistorio A, Magni-Manzoni S, Ruperto N, Martini A, et al. Relative responsiveness of condition specific and generic health status measures in juvenile idiopathic arthritis. Ann Rheum Dis 2005; 64:257–61.
12. Simeoni MC, Schmidt S, Muehlan H, Debensason D, Bullinger M, and the DISABKIDS Group. Field testing of a European quality of life instrument for children and adolescents with chronic conditions: the 37-item DISABKIDS Chronic Generic Module. Qual Life Res 2007;16: 881–93.
13. Sandeberg MA, Johansson EM, Hagell P, Wettergren L. Psychometric properties of the DISABKIDS Chronic Generic Module (DCGM-37) when used in children undergoing treatment for cancer. Health Qual Life Outcomes 2010;8:109–26.
14. Petersen C, Schmidt S, Power M, Bullinger M, and the DISABKIDS Group. Development and pilot-testing of a health-related quality of life chronic generic module for children and adolescents with chronic health conditions: a European perspective. Qual Life Res 2005;14: 1065–77.
15. Ravens-Sieberer U, Bullinger M. Assessing the health related quality of life in chronically ill children with the German KINDL: first psychometric and content-analytical results. Qual Life Res 1998;7:399–407.
16. Eser E, Yuksel H, Baydur H, Erhart M, Saatli G, Cengiz-Ozyurt B, et al. The psychometric properties of the new Turkish generic health-related quality of life questionnaire for children (Kid-KINDL). Turkish J Psychiatry 2008;19:409–17.
17. Fernandez-Lopez J, Fernandez Fidalgo M, Cieza A, Ravens-Sieberer U. Measuring health-related quality of life in children and adolescents: preliminary validation and reliability of the Spanish version of the KINDL questionnaire. Aten Primaria 2004;33:434–42.
18. Wee H, Lee W, Ravens-Sieberer U, Erhart M, Li S. Validation of the English version of the KINDL generic children's health-related quality of life instrument for an Asian population: results from a pilot test. Qual Life Res 2005;14:1193–200.
19. Ravens-Sieberer U, Redegeld M, Bullinger M. Lebensqualitat chronisch kranker KINDER im verlauf der statioaren rehabilitation. In: Neuser J, de Bruin JT, editors. Verbindung und veränderung im fokus der medizinischen psychologie. Lengerich (Germany): Pabst Science Publishers; 2000. p. 89–91.
20. Erhart M, Ellert U, Kurth B, Ravens-Sieberer U. Measuring adolescents' HRQOL via self reports and parent proxy reports: an evaluation of the psychometric properties of both versions of the KINDL-R instrument. Health Qual Life Outcomes 2009;7:77–88.
21. Varni JW, Burwinkle TM, Seid M, Skarr D. PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr 2003;3:329–41.
22. Varni JW, Seid M, Knight TS, Burwinkle TM, Brown J, Szer IS. The PedsQL in pediatric rheumatology: reliability, validity, and responsiveness of the Pediatric Quality of Life Inventory Generic Core Scales and Rheumatology Module. Arthritis Rheum 2002;46:714–25.
23. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care 2001;39:800–12.
24. Gong GW, Young NL, Dempster H, Porepa M, Feldman BM. The Quality of My Life questionnaire: the minimal clinically important difference for pediatric rheumatology patients. J Rheumatol 2007;34:581–7.
25. Feldman BM, Grundland B, McCullough L, Wright V. Distinction of quality of life, health-related quality of life, and health status in children referred for rheumatologic care. J Rheumatol 2003;27:226–33.

Summary Table for General Pediatric Measures of Quality of Life*

Scale	Purpose/ content	Method of administration	Respondent burden	Administrative burden	Score interpretation	Reliability evidence	Validity evidence	Ability to detect change	Strengths	Cautions
CHQ	To measure HRQOL in children (ages 5–18)	Parents and children (ages 10–18) may self-administer after a brief introduction	Minimal; 5–25 minutes (depending on version administered)	Minimal; no training necessary	0 (worst possible health status) to 100 (best possible health status) Normative sample available for comparison	CHQ-PF50: α = 0.66–0.92; test–retest means not significantly different CHQ-PF28: test–retest reliability was excellent CHQ-CF87: α = 0.69–0.92	CHQ-PF50: construct good, convergent acceptable with HUI and good with PedsQL, discriminant moderate to strong CHQ-PF28: discriminant adequate, convergent acceptable with VAS CHQ-CF87: construct good	CHQ-PF50: good responsiveness in samples of children with JIA and SLE; physical health summary score is most responsive to change in disease activity	Good psychometric properties in many chronic illness populations Child and parent-proxy versions Available in a wide variety of languages Normative sample available for comparison	CHQ-PF28: individual scales have poor psychometrics May be confusing because the item response options and recall periods vary by item Only validated in children ages 5–18 years
DCGM	To assess HRQOL in children (ages 8–16 years)	Child self-report and parent-proxy report Paper and pencil and computer-assisted versions	Minimal	Minimal training is necessary	37–185, with higher summed scores indicating better HRQOL	α = 0.70–0.87; test–retest is satisfactory	Construct: supported by satisfactory internal consistency on each of 6 subscales	No information	Reliable and valid Developed on populations of children with JIA Validated in 6 languages	Little research has been conducted on children and adolescents in the US Little research on its use with other JRDs
KINDL-R	To measure HRQOL in children (ages 4–16 years)	Self-report interview (ages 4–7 years) Self-report (ages 8–12 and 8–16 years) Parent proxy Paper and pencil and computer-assisted versions available	Minimal; <15 minutes to complete Self-explanatory	Minimal training is necessary Scoring requires training in SPSS software	0–100, with higher scores indicating better HRQOL	α = 0.84–0.89 for overall score α = 0.63–0.76 for subscales child report α = 0.62–0.81 for parent subscales	Construct: acceptable fit for the 6-dimensional model for parent and child	No information	Flexible, modular, psychometrically sound measure Concordance rates can be calculated Several age-specific versions are available	Little information available on using this measure in populations of children with JRDs
PedsQL 4.0 Generic Core Scales	To measure HRQOL in children (ages 2–18 years)	Child self-report and parent-proxy report are self-administered Paper and pencil questionnaire	Minimal; <4 minutes 3rd–6th-grade reading level	Minimal No training necessary Administrator provides a brief introduction Scoring takes minimal time and effort	0–100, with higher scores indicating better HRQOL; ~4.5 indicates minimum clinically important difference	Total scale score child self-report (α = 0.91), parent proxy (α = 0.93); scales (α = 0.86–0.90)	Construct: children with JRDs had lower scores (worse HRQOL) than healthy children	Longitudinal analysis demonstrated an increase in scores following an intervention	Brief, valid, reliable, and developmentally appropriate measure Translated into many languages Disease-specific modules are available	Children and parents may have difficulty completing school-related questions if the child has not been in school in the past month
QoML	To assess QOL and HRQOL as 2 separate constructs in children (ages 10 months to 18 years)	Child self-report and parent-proxy report are self-administered Paper and pencil questionnaire	Minimal; only 3 items, takes <5 minutes to complete	Minimal No training necessary Administrator provides a brief introduction Scoring takes minimal time and effort	VAS are scored by measuring the length between anchor and mark 0–100, with higher scores indicating better QOL	No information	Construct validity is good; relationship between scales and disease variables were as expected	Responses to hypothetical situations using "just enough change to make a difference" suggest that change can be observed on the VAS	Developed with a pediatric rheumatology sample Quick and easy questionnaire Requires minimal reading Assesses both QOL and HRQOL	Limited psychometric data available Does not provide information about factors contributing to a child's QOL or HRQOL

* CHQ = Child Health Questionnaire; HRQOL = health-related quality of life; CHQ-PF50 = CHQ long parent-report questionnaire; CHQ-PF28 = CHQ short parent-report questionnaire; CHQ-CF87 = CHQ child-report questionnaire; HUI = Health Utilities Index; PedsQL = Pediatric Quality of Life Inventory; VAS = visual analog scale; JIA = juvenile idiopathic arthritis; SLE = systemic lupus erythematosus; DCGM = DISABKIDS Chronic Generic Measure; JRDs = juvenile rheumatic diseases; QoML = Quality of My Life Questionnaire.