

# A review of measures of quality of life for children with chronic illness

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## Abstract

**Aims**—To identify currently available generic and disease specific measures of quality of life (QoL) for work with children; and make recommendations about the future development and application of QoL measures.

**Methods**—Systematic searches were conducted to identify measures of QoL. Primary research papers were coded by the authors on the basis of predefined inclusion and exclusion criteria.

**Results**—Of the 137 papers included in the review, 43 involved the development of a new measure. These included 19 generic and 24 disease specific measures. Almost half the measures were developed in the USA. Measures were identified which were appropriate for children across a broad age range, and included provision for completion by different respondents (child only, parent only, or both). There were no clear distinctions between measures of QoL, health, or functional status.

**Conclusions**—We have identified a small number of measures which fulfil basic requirements and could be used to assess QoL in clinical trials or following interventions. However, there remain a number of problems in measuring QoL in children. These include limited availability of disease specific measures; discrepancies between child and parent ratings; limited availability of measures for self completion by children; lack of precision regarding the content of domains of QoL; and the cultural appropriateness of measures developed elsewhere for children in the UK.

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Advances in medical care have changed the emphasis in paediatric medicine from the diagnosis and management of infectious disease to prevention and control of chronic conditions. Mortality is no longer viewed as the only end point when considering the efficacy of medical intervention. Issues of quality of life (QoL) are also important. As a consequence, there has been a call for new outcome measures that reflect a more holistic approach to management. Such an emphasis reflects contemporary views about the relation between mind and body, and acknowledges the critical link between physical and psychological health. QoL measures may be of potential value in comparing outcomes in clinical trials, evaluat-

ing interventions, commissioning programmes of care, assessing the outcomes of new treatments, and in audit work.

As in adult work, issues about the definition and measurement of QoL have been a matter of considerable debate.<sup>1,2</sup> Several key ideas define the concept of QoL. First is the idea that individuals have their own unique perspective on QoL, which depends on present lifestyle, past experience, hopes for the future, dreams, and ambition. Second, when used in a medical context, QoL is generally conceptualised as a multidimensional construct encompassing several domains.<sup>3</sup> This follows from the widely accepted definition of health put forward by the World Health Organisation as the state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity.<sup>4</sup> The Group goes on to describe QoL as “the individual’s perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns”.<sup>5</sup> Third, QoL can include both objective and subjective perspectives in each domain.<sup>6</sup> The objective assessment of QoL focuses on what the individual can do, and is important in defining the degree of health. The subjective assessment of QoL includes the meaning to the individual; essentially it involves the translation or appraisal of the more objective measurement of health status into the experience of QoL. Differences in appraisal account for the fact that individuals with the same objective health status can report very different subjective QoL: “The patient’s perceptions of, and attributions about the dysfunction are as important as their existence”.<sup>5</sup>

Children are often regarded as unreliable respondents, and for this reason, early attempts to rate children’s QoL were based on data provided by mothers. However, children and parents do not necessarily share similar views about the impact of illness,<sup>7</sup> and therefore there are calls to involve children more directly in decisions about their own care and treatment.<sup>8</sup> As a consequence, any evaluation of current approaches to measuring children’s QoL needs to consider the provision made for children to rate their own QoL.

However, assessment of QoL in children poses unique problems.<sup>9</sup> Children do not share adult views about the cause, aetiology, and treatment of illness. They may interpret questions differently, and adopt a different time perspective regarding the course of a disease. In addition, their abilities to use rating scales, understand the language, and generally complete lengthy questionnaires of the type

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used in adult work, may be compromised by age and cognitive development.

Given the state of the art in terms of assessing QoL in children, we report a methodological review of QoL measures which could be used to assess children with chronic illness. There are currently no formal guidelines for the conduct of methodological (as opposed to systematic reviews of randomised controlled trials) reviews. The papers included here have not been reviewed systematically in the conventional sense of applying an established methodology as used by the Cochrane groups. This was a result of the heterogeneity of the studies identified, and the lack of consistency in the information reported across studies. Nevertheless, given the interest in this topic and the need for measures of QoL in paediatric research and practice, this review was conducted in order to:

- Identify currently available generic and disease specific measures
- Determine how far measures allow for child self completion
- Make recommendations about the availability of measures for research purposes
- Make recommendations for the future development and application of QoL measures.

## Method

### LITERATURE SEARCH AND INCLUSION CRITERIA

As measures of functional status, health status, and QoL have been used interchangeably,<sup>2,3</sup> we included all three terms in our searches to ensure a comprehensive recall across a range of measures. For the same reason, we specified individual chronic conditions in addition to general terms such as “chronic disease” and “illness”. Reliability and validity are the most frequently cited requirements of an acceptable measure of QoL. In the most simple terms, it is important to know that a measure is reliable (children will respond similarly on different occasions) and valid (we are measuring QoL rather than some other concept). In addition, a measure needs to be responsive—that is, to detect change in QoL associated with illness or treatment. The criteria for inclusion in this review were that attempts were made to establish some of these properties of reliability, validity, and responsiveness. Search strategies were devised using the appropriate keywords and combination of keywords. These were applied in combination using the logical operators specified by each database.

Adoption of these very broad concepts resulted in good sensitivity but poor specificity. The searches included both text words and medical subject headings and were restricted to the English language. The following databases were searched (between 1980 and July 1999): Medline, BIDS ISI Science Citation Index, BIDS ISI Social Science Citation Index, PsycLIT, the Cochrane Controlled Trials Register (CTR), and meta Register of Controlled Trials (mRCT). These were supplemented by hand searching relevant journals and cross referencing with reference lists in identified

articles. Table 1 summarises inclusion and exclusion criteria adopted.

As a result of the initial screening, 255 abstracts were identified; these were downloaded into Reference Manager. An additional 24 references were obtained from other sources (for example, requests for articles in press). Research papers were coded by two independent researchers who later cross checked for errors and omissions. Application of the inclusion criteria resulted in 137 papers being retained for the review.

## Results

### IDENTIFICATION OF MEASURES OF QOL

Of the 137 papers included in the review, 43 involved the development of a new measure, and 79 reported their further development and application. Fifteen adopted a battery approach to assessment of QoL (they used a number of measures related to different domains of QoL). However, the quality of the studies reporting battery approaches was invariably poor, and therefore these studies are not reported here.

The measures were described by their authors as QoL (n = 30), health status (n = 8), functional status (n = 2), perception of illness (n = 1), life satisfaction (n = 1), and quality of wellbeing (n = 1). Descriptive characteristics of the 19 generic measures are shown in table 2 and of the 24 disease specific measures in table 3. Multiple measures were identified for some chronic conditions: asthma (n = 4), cancer (n = 5), and epilepsy (n = 4). Measures were also identified for arthritis, Crohn's disease, diabetes, headache, neuromuscular disorders, otitis media, rhinoconjunctivitis, skin disorders, spina bifida, short stature, and spine deformities.

### RESPONDENT

Among generic measures, nine included provision for child and parent assessment, two for parents only, and eight for children only. Among disease specific measures, seven included provision for child and parent assessment, five for parents only, and 12 for children only.

Table 1 Inclusion and exclusion criteria adopted in the review

<i>Inclusion criteria</i>	
Measures of quality of life, health status, or wellbeing	
The presence of an ICD-10 diagnosis of a chronic disease or condition	
Children aged 18 years or under	
Measures that include minimum psychometric properties (some reliability or validity data)	
Measures that include facility for completion by child or proxy or both	
Single (generic or disease specific) or proxy measures (batteries)	
<i>Exclusion criteria</i>	
Quality of life measured only by clinical indicators (for example, haemoglobin level)	
Quality of life restricted to demographic or environmental factors	
Review articles or comments about the measurement of quality of life in children	

Table 2 Generic measures of quality of life identified

Measure	Report	Child age (y)	No. of domains	No. of items	Reliability	Validity	Origin
Child Health and Illness Profile <sup>10</sup>	Self	11–17	6	153	Test–retest Internal	Criterion Construct	USA
Child Health Questionnaire <sup>11</sup>	Parent	4–19	12	98, 50, 28	Internal	Concurrent	USA
	Self	10–19	12				
Child Quality of Life Questionnaire <sup>12</sup>	Parent	9–15	15	15	Test–retest	Construct	UK
	Self	9–15	15				
Dartmouth Coop Functional Health Assessment Charts <sup>13</sup>	Self	Teen	6	6	Test–retest	Construct	USA
Exeter Quality of Life Measure <sup>14</sup>	Self	7–12	—	16	Internal	Clinical	UK
	Parent	0–16	8	43			
Functional Status (II) R <sup>15</sup>	Parent	0–16	8	43	Internal	Concurrent	USA
	Self	6–16	5	25			
Generic Health Questionnaire <sup>16</sup>	Parent	7–13	5	80	Test–retest Internal	Construct	Holland
	Self	7–13	5	80			
KINDL <sup>18</sup>	Parent	7–13	5	80	Internal Test–retest	Construct Clinical	Germany
	Self	8–16	4	40			
Nordic Quality of Life Questionnaire for Children <sup>19</sup>	Parent	2–18	4	74	Under evaluation	Under evaluation	Sweden
	Self	12–18	4	74			
Pediatric Quality of Life Questionnaire <sup>20</sup>	Parent	2–18	5	30	Internal	Construct Clinical	USA
	Self	5–18	5	30			
Perceived Illness Experience <sup>21</sup>	Parent	11–18	8	34	Test–retest Internal	Construct	UK
	Self	11–18	8	34			
Quality of Life Profile—Adolescent Version <sup>22</sup>	Self	14–20	3	54	Internal	Construct	Canada
Sickness Impact Profile (adapted from the adult version) <sup>23</sup>	Parent	3–14	12	135	Available for adults, not children		USA
TACQOL <sup>24,25</sup>	Parent	8–11	7	108	Internal	Construct Clinical	Holland
	Self	8–11	7	108			
The Warwick Child Health and Morbidity Profile <sup>26</sup>	Parent	0–5	10	16	Test–retest Inter-rater	Construct	UK
Health Utilities Index Mark 2 <sup>27</sup>	Parent	6–18	7	7	Test–retest	Clinical	Canada
Health utilities Index Mark 3 <sup>28</sup>	Parent	6–18	15	15	Internal		
16D <sup>29</sup>	Self	12–15	16	16	Test–retest	Clinical	Finland
17D <sup>30</sup>	Self	8–11	17	17			
Quality of Well Being <sup>31</sup>	Parent	0–18	3	3	Test–retest Internal	Clinical	USA

## AGE RANGE

Measures were categorised according to the chronological age of the child targeted. Among generic measures, one was targeted at children aged 0–5 years, seven at children across a broad age range, two at children in middle childhood (roughly 6–11 years), four at adolescents, and four at children from 8 years to late adolescence; one was aimed at adults. Comparable figures for disease specific measures were zero, eight, one, six, and eight; and one adult measure.

## DOMAINS ASSESSED

The number of domains assessed ranged between one<sup>40,41</sup> and 17.<sup>10</sup> The total number of items ranged between one<sup>40,41</sup> and 153.<sup>10</sup> Although most measures include a cross section of domains to measure the key components of QoL identified by the WHO, there was considerable heterogeneity in number and content of domains (see tables 2 and 3).

## RELIABILITY AND VALIDITY

As shown in tables 2 and 3, reliability was reported in terms of internal consistency (n = 25), test–retest reliability (n = 21), and inter-rater reliability (n = 4). In addition, construct (n = 18), clinical (n = 14), concurrent (n = 7), and criterion validity (n = 1) were reported for different measures.

## ORIGIN

Measures were identified which were developed in the United States (n = 18), the UK (n = 8), Canada (n = 8), and Holland (n = 2). Single measures were developed in Germany, Israel, Spain, Sweden, Norway, and Finland.

## Discussion

The measurement of any psychological concept such as QoL is inherently different from measuring a physical concept such as height, and it may therefore be inevitable that we must live with some limitation in any measure. However, this is not to say that we should give up on measuring QoL. For children, QoL is too important to be disregarded. Further development of measures depends crucially on experience gained in using the measures that are now available. This is relevant not only for refinement of currently available measures, but also to enable the development of more sophisticated measures in the future. For these reasons, it is important to recognise the limitations of currently available measures, while also acknowledging that improvements can only be made when we understand how current measures perform in practice.

Given the current state of the art, we draw on information about the performance characteristics of available measures summarised in tables 2 and 3. Based on these data, we conclude that only three<sup>11,20,27</sup> generic measures and two disease specific measures<sup>35,38</sup> fulfil very basic psychometric criteria. Our own recommendations would be based on these measures and might involve the following.

For work evaluating clinical trials, whether in the context of high technology medicine such as childhood cancer, or in a community setting, there is a need for a brief measure of QoL that can be completed during a regular clinic visit. In order to recruit a large sample of patients, a measure is needed that is simple to administer with minimal training or expertise. The measure needs to include those aspects of functioning

Table 3 Disease specific measures of quality of life identified

Measure	Report	Child age (y)	No. of domains	No. of items	Reliability	Validity	Origin
<i>Asthma</i>							
About my Asthma <sup>32</sup>	Self	6–12	—	44	Internal	Concurrent	USA
Asthma Quality of Life <sup>33</sup>	Self	Adolescent	4	30	Adult based		Australia
Childhood Asthma Questionnaires <sup>34</sup>	Self	4–7	1	14	Internal		UK
		8–11	2	22	Test–retest		
		12–16	3	31			
Pediatric Asthma Quality of Life Questionnaire <sup>35</sup>	Self	7–17	3	23	Test–retest	Construct	Canada
<i>Cancer</i>							
Behavioral Affective and Somatic Experiences Scale <sup>36</sup>	Parent	5–17	5	38	Internal	Clinical	USA
	Self	5–17	5	14	Inter-rater		
	Nurse	5–17	5	38			
The Miami Pediatric Quality of Life Questionnaire <sup>37</sup>	Parent	1–18	3	56	Internal	Clinical	USA
					Test–retest		
The Pediatric Cancer Quality of Life Inventory <sup>38</sup>	Parent	8–18	5	32	Internal	Construct	USA
	Self	8–18	5	32		Clinical	
The Pediatric Oncology Quality of Life Questionnaire <sup>39</sup>	Parent	0–18	3	21	Internal	Concurrent	USA
					Inter-rater	Clinical	
Play Performance Scale for Children <sup>40–41</sup>	Parent	0.5–16	1	1	Inter-rater	Construct	USA
						Clinical	
<i>Epilepsy</i>							
Impact of Child Illness Scales <sup>42</sup>	Parent	6–17	5	30		Face	UK
Quality of Life in Epilepsy-31 <sup>43</sup>	Parent/self	Not clear	7	31	Adult measure		Canada
Quality of Life in Epilepsy (adapted from QOLIE-89) <sup>44</sup>	Self	8–18	5	25	Adult measure		USA
Quality of Life in Epilepsy—AD-48 <sup>45</sup>	Self	11–17	7	48	Internal	Construct	USA
					Test–retest		
<i>Other</i>							
Children's Dermatology Life Quality Index <sup>46</sup>	Self	3–16	6	10	Test–retest		UK
Diabetes Quality of Life <sup>47</sup>	Self	11–18	3	52	Internal		USA
					Test–retest		
Juvenile Arthritis Quality of Life Questionnaire <sup>48</sup>	Parent	2–18	4	74		Construct	Canada
	Self	9–18	4	74		Clinical	
	Self	12–18	5	35	Internal	Construct	Canada
Life Satisfaction Index for Adolescents (with neuromuscular disorders) <sup>49</sup>	Self	6–12	5	23	Internal	Concurrent	Canada
Pediatric Rhinoconjunctivitis Quality of Life <sup>50</sup>	Self	12–17	6	25	Test–retest		
Quality of Life in Children with Crohn's Disease <sup>51</sup>	Self	8–17	6	88		Concurrent	USA
Quality of Life Headache in Youth <sup>52</sup>	Parent	12–18	14	71	Internal	Clinical	Norway
	Self	12–18	14	71	Test–retest		
Quality of Life for Children with Otitis Media <sup>53</sup>	Parent	0.5–12	6	6	Internal	Construct	USA
					Test–retest	Sensitivity	
Quality of Life and Short Stature <sup>54</sup>	Self	8–18	5	45			Israel
Quality of Life in Spina Bifida Questionnaire <sup>55</sup>	Parent	5–12	10	44	Internal	Construct	Canada
	Self	13–20	10	47	Test–retest		
Quality of Life Profile for Spine Deformities <sup>56</sup>	Self	10–20	5	21	Test–retest		Spain
					Internal		

that are most likely to be compromised by the treatment protocol. Thus there is a need for measures that focus on physical symptoms and emotional wellbeing. Assessment of school or learning needs to be included especially for children (compared with adults), and if there is any concern about cognitive side effects of the protocol. Given the concern with physical symptoms, it is likely that disease specific measures might be more useful than generic. The Pediatric Quality of Life (PedsQL) and its associated modules for work in oncology, asthma, or diabetes<sup>20</sup> is one of the more thoroughly developed measures currently available. In asthma, the measure by Juniper and colleagues<sup>35</sup> also has much to recommend it.

The inclusion of QoL data in clinical trials creates new questions about statistical analyses which have not been resolved. The analysis of

multivariate QoL data (and the inevitable missing data) poses a very different problem compared with analyses based on univariate outcomes such as survival. Strategies to manage missing data are important, as is the need for hypothesis driven trials.

The choice of measures for evaluation of psychosocial interventions is relatively similar. If the need is for a brief assessment, generic measures such as the PedsQL<sup>20</sup> or HUI2 and HUI3<sup>27</sup> have some merit. However, it is unlikely that either of these will address the full range of functioning that might need to be assessed (and indeed they were not designed to do so). Additional measures will therefore need to be included, depending on the specific purpose of the intervention. Where the goal is to achieve greater school integration or improve family functioning, the Child Health Question-

naire<sup>11</sup> may be more appropriate. However, advantages of this need to be set against the length of the currently available measure (though shorter forms are in the process of development).

There are also measures developed for specific purposes, such as the BASES<sup>36</sup> for work involving children undergoing bone marrow transplantation. This does fulfil the basic criteria we identified, and has potential use in evaluating interventions involving children undergoing bone marrow transplantation. It is clear that there are many other specific contexts in paediatrics where QoL measures may be desirable (for example, palliative care), but no measure is currently available.

Our review highlights many inconsistencies and problems associated with measurement of QoL in children. These include the following.

(1) *Confusion about the definition and measurement of QoL*—This is reflected in the overlap between measures of QoL and health or functional status, and the variability in definition and number of domains assessed. This variability means that there may be little relation between QoL as assessed by different measures. There is an urgent need to determine how far currently available measures of QoL really assess the same underlying construct.

(2) *Limited availability of disease specific measures*—To the extent that generic measures are suitable to assess QoL regardless of the child's specific condition, such measures are assumed to be preferable when decisions need to be made regarding allocation of resources from public health perspectives. In contrast, disease specific measures are assumed to have merit when assessing the impact of a change in treatment, or when assessing outcomes in clinical trials. Among disease specific measures, asthma, cancer, and epilepsy have received most attention. For children with many other conditions it is only possible to rate QoL using a generic measure.

In practice, decisions about generic or disease specific measures may be less simple, given the limited number of measures available. Disease specific measures are inappropriate where a child has more than one condition. Furthermore, the low incidence of some conditions will preclude development of disease specific measures. There is also a need to understand the relation between generic and disease specific QoL. Development of a core generic instrument supplemented by disease specific modules may be one solution. This allows for direct comparison between illness samples, and additional information to be obtained concerning specific disease. Such an approach is central to the generic and module approach advocated by Varni and colleagues.<sup>20</sup>

(3) *Discrepancies between child and parent ratings*—We need to accept that both child and proxy ratings have value. The question is to clarify how differences in perception of QoL arise between child and proxy and the implications for the child's QoL. This applies as much to clinicians as parents, teachers, and other proxies. Parents may be influenced by the development of other children they know (their

own or those of friends), their expectations and hopes for their child, additional life stresses, and their own mental health. It is important to clarify how parent mental health and their perceptions of the disease influence the child's QoL over time. This is relevant to issues concerning how parenting practices and family organisation can subsequently effect the child's QoL.

(4) *Limited availability of measures for self completion by children*—Measures are typically targeted at children across a broad age range, with very few measures available for those below 8 years. Based on findings that children and parents differ in their understanding of illness and treatment,<sup>7</sup> there is a widely endorsed view that children should rate their own QoL wherever possible.<sup>38</sup> They have different views about illness. Furthermore, parents' views about their child's QoL may be influenced by their own mental health and concerns about the child's illness. Despite this, many measures rely exclusively on parent report. A limited number of measures provide parallel forms for completion by both child and parent. These may be the measures of choice in situations where children are well and able to rate their own QoL.

Techniques need to be developed to enable self ratings to be obtained routinely from children, especially those below 8 years of age. In addition, given differences between children and parents, basic research is needed to identify situations where parents are able to respond for their children.

(5) *Lack of precision regarding the content of domains of QoL*—Most developers of scales define QoL as a multidimensional construct, and attempt to assess domains including physical, social, and emotional QoL. Other domains (for example, cognitive or spiritual) are less often assessed. In addition, the precise content of these domains varies considerably in emphasis and generality. In measuring physical QoL, the emphasis may be on physical symptoms, self care, participation in physical activities, or distress caused by limitations in physical activities. There is even greater variability in content of social domains.

(6) *Cultural appropriateness of measures for use in the UK*—Many measures have been developed outside the UK, which may prove unacceptable to British children, given cultural differences in the meaning of illness, relationships between parents and children, and organisation of health care services. Consideration also needs to be given to the language used. (Questions about "difficulties walking one block" mean little to children in the UK.)

Other issues may be even more critical. In the cancer specific QoL measure described by Varni and colleagues<sup>38</sup> for example, a number of questions ask children to report their concerns about relapse. Inclusion of such direct questions (or even use of the term "cancer") may be unacceptable to some paediatricians and families in the UK. Translating a QoL instrument for use in different countries may appear a cheap and satisfactory option,

### Key messages

- Different measures have value depending on the purpose for which they are required
- Basic research is needed to understand the relation between child and parent ratings of QoL
- Many measures have been developed outside the UK and need to be assessed for cultural appropriateness
- Children must routinely be involved in development of new measures

but in fact requires extensive work to establish true comparability.<sup>57</sup>

There is no doubt that much needs to be done to improve the quality of QoL measures, and hence the status of this work in clinical practice and research. However, the focus on QoL has done much to raise the profile of children's views about treatment and organisation of care. Recognition of the shortcomings of currently available measures must not be used as a reason to ignore QoL issues. At the least, attention to QoL has emphasised the need to consider the outcomes of paediatric medicine in terms of the whole child rather than focus on a narrow range of clinical indicators.

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