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.

(Arch Dis Child 2001; 86:205–211)

Keywords: quality of life; chronic illness

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-
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, 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 (CCTR), 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

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measures of quality of life, health status, or wellbeing</td>
<td>Quality of life measured only by clinical indicators (for example, haemoglobin level)</td>
</tr>
<tr>
<td>The presence of an ICD-10 diagnosis of a chronic disease or condition</td>
<td>Quality of life restricted to demographic or environmental factors</td>
</tr>
<tr>
<td>Children aged 18 years or under</td>
<td>Review articles or comments about the measurement of quality of life in children</td>
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</table>

| Measures that include minimum psychometric properties (some reliability or validity data) | Single (generic or disease specific) or proxy measures (batteries) |
| Measures that include facility for completion by child or proxy or both |

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<table>
<thead>
<tr>
<th>Measure</th>
<th>Report</th>
<th>Child age (y)</th>
<th>No. of domains</th>
<th>No. of items</th>
<th>Reliability</th>
<th>Validity</th>
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<td>Parent</td>
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### 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, it 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 three11 20 27 generic measures and two disease specific measures35 38 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

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**Table 2** Generic measures of quality of life identified

### 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 one40 41 and 17.17 The total number of items ranged between one40 41 and 153.10 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.

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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 is one of the more thoroughly developed measures currently available. In asthma, the measure by Juniper and colleagues has much to recommend it. 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 Questionnaire

### Table 3 Disease specific measures of quality of life identified

<table>
<thead>
<tr>
<th>Measure</th>
<th>Report</th>
<th>Child age (y)</th>
<th>No. of domains</th>
<th>No. of items</th>
<th>Reliability</th>
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</table>

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 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 or HUI2 and HUI3 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 Questionnaire...
Measures of quality of life for children

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

(1) Confusion about the definition and measure-
ment of QoL—This is reflected in the overlap 
between measures of QoL and health or func-
tional status, and the variability in definition 
and number of domains assessed. This variabil-
ity means that there may be little relation 
between QoL as assessed by different meas-
ures. 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 meas-
ures, asthma, cancer, and epilepsy have re-
ceived 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 avail-
able. Disease specific measures are inappropri-
ate where a child has more than one condition. 
Furthermore, the low incidence of some 
conditions will preclude development of dis-
ease 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.20

(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 
aris between child and proxy and the implica-
tions 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 percep-
tions 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 ill-
ness and treatment,7 there is a widely endorsed 
view that children should rate their own QoL 
wherever possible.20 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 chil-

(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 physi-
cal, 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 empha-
sis 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 activi-
ties. There is even greater variability in content 
of social domains.

(6) Cultural appropriateness of measures for use 
in the UK—Many measures have been devel-
oped outside the UK, which may prove unaccept-
able to British children, given cultural 
differences in the meaning of illness, relation-
ships between parents and children, and 
organisation of health care services. Considera-
tion 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 colleagues20 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 “can-
cer”) may be unacceptable to some paediat-
rians and families in the UK. Translating a 
QoL instrument for use in different countries 
may appear a cheap and satisfactory option,
but in fact requires extensive work to establish true comparability.57

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

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