

## RESEARCH METHODOLOGY

## Measuring quality of life

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Over the past five years there has been an escalation in reports relating to quality of life issues for both adults and children. Measurement of quality of life has become fashionable for a number of reasons—the medical profession is increasingly accountable for its performance when providing health care, measures of outcome are required as a major endpoint for phase III randomised controlled trials,<sup>1</sup> and it may be useful as an adjunct to justification of resource allocation. Emphasis is now also, rightly, being placed on the preferences of the patients, their perception of their own health, and the impact of treatment. But what is meant by quality of life in the context of health, what are the implications of assessing quality of life in children, and how, if at all, can it be measured?

**Defining quality of life**

One of the major criticisms relating to recent publications concerning quality of life is a failure of authors to define the term.<sup>2</sup> While it is accepted that the definition of quality of life is at least in part dependent on the context in which it used (clearly many non-medical issues can have a profound effect on quality of life) and is a uniquely personal matter, it is essential that within the context of health, a consensus with respect to definition is achieved. A comprehensive definition of quality of life in children and adolescents was recently proposed by a group examining quality of life for children with cancer. 'Quality of life in paediatric oncology is multidimensional. It includes, but is not limited to, the social, physical and emotional functioning of the child and adolescent, and when indicated, his/her family, and it must be sensitive to the changes that occur throughout development'.<sup>3</sup> Another useful definition is that of Gill and Feinstein<sup>2</sup>: 'a uniquely personal perception, denoting the way individual patients feel about their health status and/or non-medical aspects of their lives'. Both these definitions are of value and in the majority of circumstances (within paediatrics) one is attempting to measure the impact of the disease, therefore concentrating on the health related aspects of quality of life. In this context the phrase health related quality of life (HRQOL) can be helpful.

In addition to the concept of the definition of quality of life two major challenges remain. Firstly the theoretical framework within which one can apply a comprehensive yet practical

measure of the child's HRQOL; the methodological considerations of the development of such instrument will be considered below. Perhaps even more difficult is the ability to achieve an accurate understanding of the perspective of the child. In particular which dimensions of health are most important, how the child values his or her health status or functional status, and the ability of any instrument to accurately assess the child's conceptual and developmental viewpoint of their quality of life.

**Methodological considerations**

## CONCEPT OF DOMAINS

Measurement of HRQOL is based on the assessment of the individual's perception of the impact of a series of medical and non-medical issues concerned with physical, mental (or emotional), and social functioning.<sup>4</sup> The concepts of global perception of function and well-being can also be addressed.<sup>5</sup> Dimensions or items (questions) are components of a domain of health. For example the domain of physical functioning might include dimensions of self care, activity and mobility; social functioning might include peer and family relationships. The domains/dimensions of health that have been identified must reflect the perceptions and priorities of the individuals within the given population. Once the dimensions have been identified (for a population) through, for example, focus groups or open interviews, questions probing the functioning or perceptions of the individual, specifically relating to these issues are developed. For younger children pictures or videos can be of value as a more acceptable medium within which they can work. Examples of domains used in measures of HRQOL in children are given in table 1.

## VALIDITY

Validity is concerned with whether a measure of health status actually measures what it was intended to measure.<sup>9-11</sup> In the absence of a gold standard for comparison, a number of aspects of validity can be addressed to assess the validity of a measure within different theoretical frameworks. Measures of HRQOL should satisfy standard criteria for validity: face, content, criterion, and construct.

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### Face validity

Face validity represents a simplified version of content validity and relates to how sensible a given measure/indicator is to an intelligent audience.<sup>11</sup> If something is not sensible at face value or is ambiguous then face validity is unconvincing.

### Content validity

Content validity provides data on whether the domains and dimensions defined by researchers adequately capture all the potential concepts and restrictions perceived to be relevant by and to the population being assessed.<sup>12-14</sup> For example, are all potential aspects of physical functioning represented and do the chosen items correspond to what its constructors claim that they are measuring?

### Criterion validity

Criterion validity relates to the extent to which a measure of HRQOL produces the same results as an existing (superior) measure or 'gold standard'—in a predictable manner.<sup>12-13</sup> Predictive validity and concurrent validity can also be tested. If a domain produces results that correlate with those obtained using the gold standard this demonstrates concurrent validity. Predictive validity refers to the measures capacity to correlate with existing measures in predictable ways. There are, however, no gold standards for overall child HRQOL measurement, and validity must therefore be determined by other means.

### Construct validity

Construct validity is concerned with formulating and measuring theoretical constructs or hypotheses and identifying whether the instrument adequately reflects the stated hypotheses. If the hypotheses are proved then validity is seen to be sound. A construct can be applied to different populations which are known to differ in terms of the concept being measured. For example, patients with poorer respiratory function assessed by physiological measurement could be hypothesised to achieve lower scores in the dimensions of perceived exercise capacity or mobility.

Construct validity can also be separated into convergent validity, which focuses on the extent to which several measures of the same concept correlate with each other in measuring the same concept at item (question) level, and

discriminant validity, which demonstrates that a measure does not correlate with other measures, which are unrelated and intended to be different.<sup>12-15</sup> Statistical methods can also be used to provide evidence of construct validity, such as factor analysis or principal component analysis. These methods can identify items which correlate and can provide a statistical basis for the identification of dimensions. These theoretical constructs can be used to test for correlations with other measures.

### RELIABILITY

The reliability of a measure is the extent to which it consistently yields the same results in repeated applications on an unchanged population or phenomenon,<sup>11-16</sup> in a reproducible manner.<sup>17</sup> The two key components of reliability are stability (test-retest) where respondents give consistent responses over time (where there is no change in health status) and equivalence, or inter-rater reliability, where respondents are shown to give consistent responses to different data collection personnel.

### GENERIC VERSUS DISEASE SPECIFIC MEASURES

There are two basic types of measure of HRQOL—generic and disease/population specific. Deciding which to develop will be dependent on the aims, methodological concerns, and practical constraints of the investigation. Generic measures summarise a spectrum of domains and dimensions of health that apply equally and broadly to diverse conditions or populations, and usually contain the domains of physical, mental, and social health. Generic measures, however, are not designed to identify important, disease specific dimensions, which are often essential for the measurement of the outcome of a particular disease, or for detecting important clinical changes.

Disease or population specific measures contain domains and dimensions that are designed to be valid only for a specified condition or population.<sup>10</sup> Disease specific measures, therefore, maximise content validity and provide for greater sensitivity and specificity; however they cannot be used to compare HRQOL across conditions or populations (including control groups from the general population) and may be less relevant for measuring the general HRQOL of the target condition/population. In many situations both generic and disease specific measures are of value and

Table 1 Examples of dimensions of health used in measurement of HRQOL in children and adolescents

HRQOL measure	Dimensions
Child Health and Illness Profile (CHIP), child completed, ages 11-18 <sup>6</sup>	Activity, comfort, satisfaction disorders, achievement, resilience
Child Health Questionnaire Parents Form (CHQPF50), proxy completed, ages 5-15 <sup>7</sup>	Physical functioning, role/social: emotional/behavioural/physical, bodily pain, general behaviour, mental health, self esteem, general health perceptions, change in health, parent impact: emotional/time, family activities, family cohesion
Minneapolis Manchester Measure of Quality of Life (MMQL), child completed, ages 8-12, 13-20 (MEM Jenney, unpublished)	Physical activity, energy, mood, body image/self esteem, peer/family relationships, pain/discomfort, school, outlook
Childhood Asthma Questionnaire B (CAQ-B), child completed, ages 8-11 <sup>8</sup>	Active aspects of living with asthma, passive aspects of living with asthma, perceived disease severity, distress

can be used in combination to facilitate the investigator's ability to compare between populations (generic) and identify specific areas of problems for different patient groups (disease specific).

### The challenge of measuring a child's quality of life

There is evidence to suggest that proxy responses by parents correlate poorly with the perceptions of the child they are representing.<sup>18-20</sup> If one accepts that, ideally, measurement of quality of life should be from the individual's own perspective then the greatest challenge in paediatrics is to develop a measure that takes into account the normal physical, emotional, and social development changes that occur and the child's ability to understand the concepts that are being addressed. In some circumstances this is not possible—the child may be too sick or too young to address such issues. A child with severe learning difficulties may be unable to address even simple issues of preference. In these situations the use of proxies can be of value, but wherever possible the opinion of the child should be sought.

#### CHILD'S CONCEPT OF HEALTH

Studies that have examined the child's concept of health have clearly demonstrated that it changes as he or she matures.<sup>21-22</sup> In particular older and more cognitively mature children conceptualise illness in terms of specific symptoms and diseases rather than using a global, non-specific understanding,<sup>21-24</sup> and older children are more aware of psychological, emotional, and social implications of illness than younger.<sup>24-25</sup> It has been argued that cognitive maturity/development is as important as an increase in chronological age as a determinant of more sophisticated understanding of health and illness concepts.<sup>26</sup>

#### EXPERIENCE OF HEALTH AND ILLNESS

It has also been suggested that illness is a learning experience for children<sup>27-28</sup> and that developmental changes in concepts of illness may be the result of experience rather than stages of cognitive development.<sup>29</sup> Children with chronic illnesses have a more sophisticated and mature understanding of illness than well peers.<sup>29-30</sup> Conversely, others<sup>31-33</sup> have concluded that a child's understanding of illness is related to cognitive level and age and not directly related to experience with illness.<sup>26</sup>

#### MODE OF ADMINISTRATION

When considering the mode of administration of a quality of life measure a number of issues need to be addressed as a balance of maximising compliance and reducing costs often needs to be made. Three standard formats are generally used: (1) *A self completed questionnaire* is the most cost effective method of administration, but suitable only for older children and adolescents. Response rates tend to be lower than with other approaches but administration costs are minimised and questionnaires can be mailed from the investigating centre. (2) *Face to*

*face interviews* can be used for younger children where their ability to concentrate on the questionnaire is limited or understanding of some of the questions may require assistance. This is costly but compliance is high. It is of course essential to minimise interpretation of the questions by the interviewers and inter-rater reliability should be assessed. Wherever possible the interviewers should be independent of the investigators. (3) *Telephone interview* is less costly than face to face interview administration and achieves a higher compliance rate than self completed questionnaires; however validity issues may be raised, particularly when used with younger children.

The use of pictures, videos, and computers should also be considered with young children to improve compliance and hopefully enjoyment of completion.

### Future considerations

Many measures of quality of life in children are undertaken at present to address particular issues for children with particular diagnoses. Whether a single generic instrument will be appropriate for use with children of different populations and of different ages that is acceptable, reliable, and validated remains to be seen. It is essential now that collaborative research is undertaken to maximise the validity of new measures and to establish generic measures that can be used across certain populations and through which valuable conclusions can be drawn. The ultimate aim of this approach in assessment of quality of life in children is to identify those areas where problems exist, apply appropriate interventions (for example psychological support, exercise therapy, physical support) and enable appropriate targeting of resources to improve the quality of life for these children. Confirmation of such improvement may then be objectively assessed by repeated evaluation of their quality of life. Other objective evidence of the children's quality of life that may support the child's perspective can also be of value. This is particularly appropriate when the child's own report may be deemed unreliable. While one accepts limitations of the use of standardised instruments to measure complex concept such as HRQOL it is reasonable to attempt such measurement if appropriate standards (of reliability, validity, and acceptability) are set. It is recognised that this will not give complete insight into the child's quality of life. One further practical issue is the balance that is required between a need to be as comprehensive as possible in the assessment yet retaining a measure that is sufficiently succinct to ensure that the instrument can be practically administered both in the clinical and research settings.

### Conclusion

When considering quality of life assessment in a given group of patients, particularly children, it is essential to clearly define the question that is to be addressed, to establish the validity of the measure that is being used, and to obtain meaningful data through which valuable information relating to the perception of the child

can be obtained. These are difficult challenges, but many paths may be possible through the use of future collaborative research.

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## Children's quality of life measures

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Significant increases in survival have been reported for a wide range of chronic diseases of childhood. These improvements have generally been achieved through the use of increasingly aggressive treatment protocols, prompting some to question the relationship between quantity and quality of survival. Frequent and lengthy hospitalisations, painful treatments, and lack of certainty about the future may all compromise the quality of life of child and family. Current ability to treat children with chronic disease, coupled with the inability to offer absolute cure, raises the issue of the quality of life of these children. Many clinicians and adults are prepared to accept that some compromise to quality of life is inevitable during the early stages of treatment, but feel more uncomfortable if this continues beyond the initial diagnosis. This applies especially to children with cancer, since quality of life is inevitably compromised during treatment. It is now apparent that statistics based on survival may

not accurately reflect the degree to which quality of life is compromised in the longer term, given the incidence of both physical and psychological difficulties reported by some survivors.<sup>1</sup> The birth of a premature or low birthweight infant has immediate consequences for family quality of life, but again these may well extend into middle childhood and probably beyond.<sup>2</sup> Children with asthma or diabetes may always need medication, but at the same time we hope that this will not result in any significant compromise to quality of life.<sup>3</sup>

### Definitions of quality of life

So what is quality of life? As we become more informed about patients' views, we have to acknowledge that the implications of a chronic condition have an impact on many aspects of life in addition to the specific illness demands (hospital appointments, self care). There is consistent evidence that some children have difficulties in their social or family life that are

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