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

Christine Eiser

CRC Child and Family Research Group, Department of Psychology, University of Exeter, Exeter, Devon EX4 4QG

Correspondence to: Dr Eiser.

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.[1] 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.[2] 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.[3]

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

directly associated with the treatment, as well as experiencing compromised learning and academic achievement, and difficulties finding employment and life insurance. The need for a measure that can encapsulate these diverse experiences seems attractive.

There has been much energy expended in defining quality of life and in developing measures. There is a consensus that quality of life is a multidimensional measure; it is not restricted to either physical or psychological effects of treatment. Quality of life reflects the child's or family's view about the impact of treatment; it is not directly related to disease state or traditional clinical measures of severity. Definitions have been based on function or disabilities or in terms of a match between aspirations and experience.[4] However translating this nebulous concept into empirical terms has proved difficult in adult work, even more so for children.

It is apparent that children differ from adults in their views about quality of life. While the elderly rate their ability to live independently as a central indicator, the young are more optimistic. For young children quality of life is about having very shiny hair, lots of friends, or running like Linford Christie; it is not about achievement of basic functional tasks.[5] For this reason alone, the debate about how far adults can rate a child's quality of life is a non-starter; they do not share a similar framework. We might even go further and suggest that very close parent-child agreement is indicative of poorer quality of life; childhood is about gaining autonomy and independence from parental views.

In addition, children change. This is too often cited as a reason for abandoning the idea of child centred measurement. The practical implications are that any measure needs to have an in-built sensitivity to accommodate the normative changes that would be expected to occur during childhood.

Why do we want to measure quality of life?

Perhaps there is more agreement about *why* we want to measure quality of life compared with *how* it should be done. First, measures of quality of life are potentially useful in comparisons of alternative treatments. Where there are no implications for survival, it might be useful to know how quality of life was affected as a consequence of, for example, intermittent or continuous treatment. In the case of a child with a bone tumour, families may be offered a choice between amputation or limb salvage procedures.[6] The decision is not easy, especially as either treatment is associated with possible complications and need for further treatment and surveillance. It might be helpful to quantify the impact on quality of life in order to aid decision making, either by staff or the family.

Second, it is anticipated that quality of life measures have some potential in addition to survival data in evaluations of clinical trials. Although these measures have become more standard in adult work, they have yet to be integrated routinely in paediatric clinical trials.

Third, the measures have potential in evaluations of interventions. It is established that some children with chronic disease and their families can experience difficulties that require professional intervention. In the current economic climate there is an expectation that advocates of any intervention need to provide hard evidence that the approach works and justifies expenditure. Quality of life measures have the potential to fulfil this role.

Fourth, quality of life measures could be used as a screening tool to identify children with particular difficulties and therefore in need of remedial or counselling help.

Fifth, there are a number of measures that relate to quality of life—for example, self esteem, physical functioning, anxiety. However, the use of general scales developed for different purposes has many disadvantages, especially as this can result in much overlapping and duplication of items. In the absence of a single measure, we would be forced to use a whole battery of tests, which would be unacceptable for clinical and statistical reasons.

A measure of quality of life may therefore have a place in paediatrics. The form of the measure is likely to depend on the specific purpose for which it is required, practical constraints regarding use of the measure, and the theoretical orientation of the test developer.

Generic or disease specific measures

Perhaps the most basic question concerns the appropriateness of generic or disease specific measures. Generic measures can be used with both sick and healthy populations, and therefore have special merit in situations where comparisons across disease groups or between sick and healthy groups are required. Such comparisons may be involved in making decisions about the allocation of resources related to health, education, or social services. Since generic measures can be used with healthy children, they have the advantage of being based on large samples, and population norms are often available. The disadvantages reflect the fact that generic measures lack sensitivity. They do not reflect specific impacts of treatments on quality of life. For example, a generic measure will yield no information about how treatment induced alopecia affects a child with cancer. Currently available generic measures are possibly too lengthy for use with sick children[7]; they also tend to be based on American samples and may not therefore be culturally appropriate.

In contrast, disease specific measures can be much more sensitive to the implications of different treatments and are probably more appropriate for evaluations of interventions or for comparing the impact of alternative treatments.

Domains

Implicit within any definition of quality of life is the notion that it is a multidimensional measure. Although there may be some core domains that are included in most measures of

Table 1 Some common quality of life scales for children

Scale	*Components*	*Respondents*	*Age range*	*Validity*
Cancer specific				
Play performance[12]	None	Parents, physicians	1–16	Global function, research interviews
Quality of wellbeing[13]	Mobility, physical function, social activity, symptoms	Parents	4–18	Play performance, treatment toxicity
Quality of life[14]	Physical function, emotional distress, reaction to treatment	Parents	Very wide	Play performance, child behaviour, checklist
Multiattribute health status[15]	Mobility, cognition, sensation, pain, self care, fertility, emotion	Physicians	8–25	Population norms
PIE[16]	Appearance, activity, disclosure, school, peer rejection, parental behaviour, manipulation, preoccupation with illness (treatment)	Child, parents	11–16	Depression, play performance, symptom checklist
Diabetes specific				
Quality of life[17]	Satisfaction, impact, worry diabetes, worry social/vocational	Young adult	15–28	None
Psychosocial adaptation[18]	Emotional difficulty, attitude	Child, parent	10–17	Anxiety, depression, self esteem
Asthma specific				
Childhood asthma[19]	Severity, enjoyment of passive distress, enjoyment of active pastimes	Child	4–7, 8–12, 13–16	Parent and clinician ratings of severity, peak expiratory flow rate
Paediatric asthma quality of life[20]	Activity limitation, symptoms, emotional functioning	Child	7–17	Feeling thermometer, global rating

PIE=perceived illness experience.

quality of life, there is little consensus among researchers. At the least, it is important that a measure includes the basic domains of quality of life that have been identified: functional status, disease and treatment related physical symptoms, psychological and social functioning.[8]

Proxy ratings: can children make judgments?

The fact that there may be a discrepancy between children and their parents in the way in which they make judgments about quality of life (and other issues) is often cited as a problem. In fact, it is naive to expect very close correspondence. Clinicians and parents differ in their evaluations of the impact of treatment on quality of life and low correlations between raters is the norm.[9] Children differ from adults in their understanding of health, the causes of illness, and their beliefs about how medications work.[10] For all these reasons, we cannot expect significant correlations between child and parent ratings.

It is more important to recognise the contexts in which parents are normally able to make reasonably accurate judgments for their children. These may include the impact on the family, sibling relationships, and to a lesser extent school progress. Parents are less able to make judgments regarding symptom experience, peer relationships, or future worries. The only solution is to regard each assessment as valid and contributing to the total picture regarding the child's quality of life.

Currently available measures

The state of the art in terms of instrument development is sadly not sophisticated. Nevertheless, we can broadly define the standards that should be achieved. Quality of life measures need to conform to scientific standards for instrument development; they should be reliable and valid.[11] They should reflect the multiple domains identified in the definition, assessing a wide range of behaviours and activities. They should be sensitive to normative changes in quality of life and children's ability to understand the causes of, and treatment for, illness. By preference they should be completed by children, though parallel proxy ratings need to be considered. From a clinical point of view, it is frequently argued that a measure should be brief, to facilitate completion by a sick or handicapped child. This may be more difficult to achieve; it may not be possible to develop a brief measure for a concept which is as broadly defined as quality of life.

Approaches to measurement development

In practice, two approaches to instrument development in this area can be identified. The psychometric approach has a longstanding tradition in psychology and mimics methods developed in the physical sciences to measure concepts such as height or temperature.[11]

The difficulty is that quality of life is not the same as these physical concepts. It is therefore difficult perhaps to demand that a quality of life scale should attain the same level of statistical rigour as can be achieved in the physical sciences.

The second approach has its roots in health economics and is based on the concept of quality adjusted life years. Patient or population derived preference weights are assigned to different states of health. These weights are then used to make decisions about the acceptability of different end states or treatment outcomes.

Disease specific measures

The most commonly used disease specific measures are summarised in table 1.

CANCER

By far the most extensive literature is in the field of paediatric oncology, and in many ways scale development is more sophisticated in this area than any other. The need to base the

measure on information from children, rather than simplify adult measures is generally recognised. However, given the low incidence of cancer, it has not proved possible to develop a measure that begins to satisfy basic statistical requirements. Most measures are parent[12–14] or physician completed.[15] There have been recent attempts to develop measures for adolescents to complete themselves.[16] All have been developed more or less from a psychometric tradition; the exception being that developed by Feeny and associates, which adopts the health economic approach.[15]

DIABETES

The most frequently used measure in adult diabetes was reported as part of the Diabetes Control Complications Trial. A downward extension of this suitable for 15–28 year olds has been reported.[17] Young people are asked to rate themselves on scales assessing general life satisfaction, diabetes specific satisfaction, and general and diabetes specific worries. Challen *et al* describe a measure of psychosocial adaptation, though this seems to tap many of the same domains as measures of quality of life.[18] This is a self completed instrument for 10–17 year olds. Two subscales were identified through factor analysis: 'emotional difficulty with diabetes' and 'attitude to diabetes'. Some reliability and validity data was reported suggesting that the scale had reasonable statistical properties.

ASTHMA

In recognition of the fact that quality of life may change during the course of childhood, three age specific versions (4–7, 8–11, 12–16 years) of a scale to measure asthma related quality of life have been reported.[19] The measure was developed after consultation with children and appears to be sensitive to issues of concern to them. Adequate reliability and validity for all three versions have been reported.

An alternative asthma specific measure for use with children aged 7–17 years yields three scores for separate domains.[20] These are activity limitation (five items), symptoms (10 items), and emotional function (eight items). Again the authors report good reliability and validity, though the sample involved was quite small (n=52). Although older children could complete the measure themselves, younger ones would need considerable help. The same group have also developed a complementary measure to assess quality of life in caregivers of children with asthma.[21]

Research using quality of life measures

Published reports concerned with quality of life in children with chronic diseases and based on standardised measures are few. Too often, researchers rely on measures assumed to be related to quality of life such as school attendance or physical symptoms.[22 23] Although it has been argued that quality of life measures should be integrated with evaluations of clinical trials, this is not yet common practice.

Key messages

- Decisions about alternative treatments need to take into account quality of life as well as survival
- Quality of life measures are potentially useful in evaluating alternative treatments and interventions and identifying children in special need
- Children's views about quality of life change with age
- Selection of a generic or disease specific measure must be made in relation to the purpose for which the measure is to be used

For the future

The practical problems in developing quality of life measures are certainly real. The demand that measures have robust statistical properties is very difficult to meet, since satisfactory determination of reliability and validity requires the involvement of large numbers of children. While possible with respect to a condition such as asthma, it is almost impossible to meet with a condition like cancer, and could only be achieved through multicentre collaboration.

A second issue relates to the relationship between the different approaches to measurement of quality of life. The assumptions underlying the economic or psychological approaches and methods of data collection and analysis vary enormously. Yet there have been no attempts to determine the relationship between the two.

Third, although there are difficulties to be resolved in measuring quality of life in older children and adolescents, these are inconsequential compared with assessment of younger children. Yet it is precisely this age group who may be of particular concern. Measurement of these children poses a special challenge. For the moment, clinicians must rely on measures completed by parents on behalf of their children. Most notably in the field of asthma, measures suitable for children (from approximately 6 or 7 years of age) to complete by themselves with help have recently become available.[19] There is considerable scope for comparable measures specific to other conditions.

Although some progress has been made in developing measures, there is to date little effort to use the measures in outcome evaluation or intervention work. Despite the growing interest in this area, there remains some scepticism about the ultimate value of including quality of life assessments either in clinical trials or as part of routine assessments. There is a natural concern that the collection of this information is a burden to families.[24] While we must always be sensitive to individual circumstances and acknowledge that some may find it distressing to be asked quality of life information, I think most welcome the opportunity to be asked and feel more confident that the child is receiving the best possible holistic care.

A second barrier is that the value of quality of life measurement in paediatrics is not yet proved. For the moment, we must look to adult work where inclusion of quality of life measures have resulted in some unexpected findings. For example, it is not clear that limb sparing rather than amputation results necessarily in improved quality of life.[25] Quality of life measures need to be more routinely included in evaluations of alterative treatments so that we are able to understand the total burden of treatment experienced by families. For the moment, the value of quality of life work remains in the balance until the measures have been shown to be relevant for the purposes for which they were conceived.

Third, the major failing of research to date is the lack of any theoretical direction to definition and measurement. New measures need to be theoretically driven and take more account of developmental changes in quality of life.

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