Child health psychology

Contributions to paediatric medicine

How do we measure the quality of life facing children with long-term or chronic health problems? **Christine Eiser** *looks at the progress in this article, originally given as the 1997 C.S. Myers Lecture.*

IMPROVEMENTS in medical care mean that survival rates in children with a wide range of chronic conditions have improved significantly within the relatively recent past. It is now possible to treat children with chronic or life-threatening conditions in a way that was not possible even 20 years ago. The result is that survival among children with serious and life-threatening conditions is significantly improved.

There is a downside to these improvements in medical care. Children with chronic conditions cannot be cured. Instead they face a lifetime of medical care. They must learn to be responsible for their own health in a way that is not expected of healthy children. Those with diabetes, for example, must learn to monitor their own blood sugar-levels, inject their own insulin and monitor their diet and exercise. Children with cystic fibrosis need daily physiotherapy to remove mucous from their lungs; they also need to monitor their diet.

In all chronic conditions, children must master many practical demands of their treatment. Chronic disease raises questions about life and death and the relationship between immediate compliance with treatment and long-term health. Questions are also likely to be raised regarding the relationship between child and family. It may be possible to extend survival but the cost for the individual child may be a much compromised quality of life (QoL). In this article, I would like to describe progress made in the development of measures of QoL and consider their potential value in modern health care.

Quality of life

Traditionally, the success of any medical intervention has been measured in terms of survival statistics. Increasingly, this is seen to be too limited. Treatments are aggressive and result in unpleasant and sometimes highly distressing side-effects. While many clinicians and parents accept these side-effects, at least in the short term, it is increasingly clear that some children continue to experience complications following completion of therapy. If survival statistics do not tell the full story, we must turn to more nebulous concepts such as quality of life.

Theoretical approaches

We need first to consider definitions and conceptual frameworks commonly adopted. This is essential because the theoretical framework adopted determines the approach to QoL measurement and the suitability of the measure for use in different clinical contexts. Definitions of QoL have varied greatly, although three main approaches are generally recognized:

- The *multidimensional approach* makes the assumption that QoL is the result of an interaction between the individual's physical health, psychological health, level of independence and social relationships.
- The *cost-effectiveness approach* is based on decision theory. A number of decision models are in use, and share many features. Common to many is the idea of expressing the benefits of treatment in terms of well-years.
- The *goal-orientated approach* uses pragmatic task analysis to focus on perceived differences between an individual's hopes and expectations and their present experience.

Multidimensional approach

In order to reflect the broad-based definition, most QoL measures include an *ad hoc* selection of items, or domains. This selection is invariably driven by intuitive beliefs about the meaning of QoL, and is not based on any theoretical framework which takes into account definition and meaning of QoL for children and their families. Those who adopt this multidimensional definition tend to work within a psychometric model of scale construction.

Initially, items must be selected to cover the whole range of possible attitudes. In the context of health care, the most useful original sources are patients' interviews, and more recently focus groups. This preliminary stage is often overlooked and can be poorly reported in journals since it relies on the use of 'soft' or interview data. Clearly, the source of the original items is crucial. Consideration needs to be given to the particular concerns of special groups, such as children. Although there may be some overlap between children and adults in terms of their perceptions of the impact of a disease on QoL, children also have a unique perspective and one that may best be represented through careful preparatory work. Measures which rely on clinicians or nurses to provide the items are likely to be less adequate as the basis for measures of patient-evaluated QoL.

Cost-effectiveness approach

The cost-effectiveness model is derived from economic decision theory and is most commonly used to compare alternative treatments based on subjective preferences for treatment effects. Respondents are asked to imagine a specified health condition and to express their relative preference for that condition as a choice between quantity and quality of life (between a shorter life with less dysfunction and a longer life with-more dysfunction). Responses are quantified in terms of quality adjusted life years (QALYs).

In child work, two models are most in use. The Quality of Well-being Scale (Bradlyn *et al.*, 1993) has been modified directly from adult work. The child version involves a structured 15-minute interview which includes questions about the child's mobility, physical functioning, social activity and symptomatology. Parents are asked to respond according to their child's behaviour over the previous six days. The multi-attribute health status classification system (Feeny *et al.*, 1995) based on the Health Utility Index, has been used for work in neonatal intensive care and oncology. In this model, four attributes or components of health were identified and each attribute consisted of between four and eight levels of function. Proponents of this schema argue that one of the merits lies in the potential to determine almost a thousand health states, by combining the scores on each level from each attribute.

In developing the multi-attribute health status classification, Feeny *et al.*, (1995) began by asking parents of children in the general population to identify important components of health for their children. From these data, six domains were identified: sensation, emotion, cognition, mobility, self-care and pain. A seventh domain — fertility — was added as this was felt to be important to parents of children treated for cancer, though not an issue for parents of healthy children. For each attribute, three to five levels of functioning were identified. The child's health status score is a computation of functioning on the different levels for each domain.

Although this measure has now been modified to allow completion by parents and older children, it fails to address the key component of QoL; i.e. it does not tap the child's perspective but focuses on the views of the clinician. There are also problems with the schema itself. The attributes are not completely independent. (If you score badly on the mobility attribute it is almost inevitable that you will also score badly in terms of self-care.) In part recognition of some of these problems, later versions dropped the self-care attribute. The system does not allow for better than average functioning. Thus, in terms of cognition for example, ratings are made from severe morbidity to normality. Thus, the system fails to recognize children who function better than average.

Goal-orientated approach

An emerging hypothesis in adult work is that good QoL is a consequence of a match between perceived current functioning and expectations for the future. Poorer QoL occurs where individuals perceive a gap between these two perceptions of self. There are implications for interventions which must address unrealistic expectations and bring future expectations in line with current functioning, or make patients more realistic or practical. This approach leads to an assessment of QoL whereby patients rate their current and expected future functioning in a number of different domains on conventional Likert scales, and a difference score is computed.

Whether or not such a theoretical framework is appropriate for use with children rests critically on whether or not children are able to make judgements about their future functioning. However, some work suggests that, with simple instructions, the idea of a future self is within the grasp of three- to four-year-olds (Eder, 1990).

Application of adult measures

Distinctions have also been made between generic and disease-specific measures. Generic measures have the advantage where comparisons between individuals and disease groups are to be made, and allows comparisons with normal groups; disease-specific measures are preferable where the concern is with the implications of a condition, or where changes are to be monitored, as in clinical trials or evaluating the effectiveness of an intervention.

Most authors have recognized the need to make some changes to adult measures of QoL in order to be appropriate for use with children. The extent of these modifications has varied greatly, however. At one extreme, researchers have made very simple adaptations to adult measures. Relatively minor changes are made to simplify the language or reduce the length of the scale, and items relating to sexuality or sexual functioning are also removed.

Others have followed a similar procedure as used in adult work but have been more sensitive to children's needs. A number of examples can be found especially among disease-specific measures. Juniper and colleagues modified their adult QoL measure for use with asthma largely by making changes to the list of activities to be rated in terms of how far they were affected by asthma (Juniper *et al.*, 1996). Vacuuming and gardening were replaced by skipping and rollerblading, but the task demands remain the same. Children were asked to rate the symptoms on the same seven-point scales as adults; a task that may require finer discrimination than many children are able to achieve.

More recently, there has been a call to develop measures specifically for children. Advocates of this approach point to developmental differences between children and adults in their understanding of health and illness, and the differential impact of a disease depending on age and the social or family context. These authors have tended to adopt the multidimensional approach to definition of QoL, but do not assume that the specific domains will be the same for children and adults. For this reason, interviews or focus groups with children are essential to identify the relevant domains.

Can adults rate a child's QoL?

There are many indications that QoL ratings between different respondents — patients, partner or clinician — are not identical. Given that adults clearly do not share the same perspective, we should not be surprised to find that children's ratings of the impact of a disease, or acceptability of treatment, does not necessarily correspond with that made by parents or clinicians.

In addition, there are other considerations to be made; children who are very sick, or those with motor or neurological handicap, may be unable to respond for themselves. For children below five years of age, and older children in special circumstances, it may be necessary to rely on judgements made by others.

It is likely that parents may be able to describe the child's QoL in some situations more than others. Parents appear accurate in their reports about 'externalizing' or acting out problems. They are less able to report 'internalizing' problems such as anxiety or sadness. In addition, they lack direct information which enables them to make competent ratings about difficulties the child experiences at school or in interactions with friends. Explanations about lower than expected correlations between parent and child report have focused on parents' own anxiety levels, but appear to be dependent on other factors including child age and gender.

Conclusions

The extension of quality of life research, from a small area of well defined and serious health problems such as childhood cancer and diabetes, to include measures of the well being of children in general, and in particular to look at those children whose needs span the inter-disciplinary and inter-agency professional boundaries, is an essential step towards measuring health gain and efficiency within an integrated children's service. Although theoretical distinctions between impairment, disability and perceived handicap have been recognized, these may be less helpful for families, who must deal with the consequences for their own and the child's QoL.

In practice, QoL measures may be considered potentially useful in a range of situations:

1) **Commissioning programmes of care**
   Large areas of potential study crossing many professional and social boundaries may be opened up by this approach, as QoL issues are central to the thinking of not just those responsible for the provision of health care services but also those responsible for children's education and their social welfare. Thus the measurement of the impact on children's lives of poverty, social deprivation and other inequalities is fundamental to the systematic review of quality of life.
2) **Evaluating interventions**
   A systematic approach to the determinants of QoL would provide a basis for more appropriate interventions. With few exceptions, interventions have targeted physical symptoms at the expense of more social or behavioural consequences. QoL instruments may have a role in the community setting, where they could be used, for example, to evaluate the impact of school health nurse interventions from the child's perspective. Such an approach may give a broader picture compared with reliance on more traditional indicators such as school absence.
3) **Comparing outcomes in clinical trials**
   Inclusion of QoL measures in adult studies has resulted in some surprises. For example, it was initially assumed that patients treated by limb salvage surgery would enjoy better QoL than those treated by amputation, but this has not been established. Differences between adults and children in their social and family structure, or work situation mean that it is not possible to infer directly from adult studies as to how similar surgery will affect children. Accurate measures which reflect the impact of treatment from the child's perspective are urgently needed and could become a useful additional measure of outcome of individual randomised studies. Such information may have implications for planning of future randomised studies.
4) **Evaluating new treatments**
   Intensive care medicine has made important contributions to the survival of critically ill patients, but requires expensive equipment and a large staff. Notwithstanding the impact on mortality and morbidity for a particular target condition, there are important quality assurance issues that have to be resolved. These involve equity of access to care in different regions, how the distance to a PICU (paediatric intensive care unit) may affect referral patterns and the impact on families both socially and financially who have to travel long distances to receive services. Decisions about the appropriateness of different settings and care arrangements for the child with terminal illness may need to take QoL into account.
   There is a large-scale investment in services to detect and treat severe hearing loss. As with any intervention, the impact of cochlear implantation itself needs to be distinguished from the confounding effects of the intensive rehabilitation programme that accompanies surgery and indeed from normal developmental programmes. The dissemination of relevant quality of life research in this field would help to realign existing service provision to accommodate such innovations in practice.
   New epidemics of disease also need to be assessed in terms of QoL. The incidence of childhood asthma appears to have risen considerably, though the impact of the disease has to a great extent been offset by the use of metered dose inhalers for both relief of symptoms and for prevention of attacks. The costs for the healthcare system are increasing and disease severity measures have not always considered the impact on the child's self perception or lifestyle as a result of both the disease and treatment.
5) **Audit work**
   Brief, reliable instruments may be of value in audit work, enabling decisions to be made regarding the appropriateness of alternative care arrangements or service provision, based on standardized measures of patient satisfaction and well-being. For example, questions about the most suitable place for care of adolescents have been raised. A QoL measure suitable for adolescents could be used to supplement information from clinic staff or parents about the relative merits of care in a paediatric, adolescent or adult setting.
6) **Neuro-disability programmes**
   The special circumstances of childhood disability warrant particular consideration. From the disclosure of the diagnosis, through the early stages of support and assessment of families to the involvement of the young people themselves, there runs an important and measurable set of phenomena that reflect the quality of the lives of both child and family. Standardized measures of QoL would be invaluable in the assessment of early intervention programmes. They also have a potential role in the evaluation of cost-effectiveness of integrated assessments.
   For patients with neurological conditions (epilepsy, brain tumours), emotional status and social functioning may be as critical indices of impairment as physical functioning measures. In other circumstances emotional and mental health considerations may be paramount.

This is potentially an exciting time to be working in health psychology. Given reorganizations within the NHS, we now have unprecedented opportunities for collaboration. It is important that we do develop a working partnership in which the skills of different professionals are harnessed to mutual advantage. Psychologists have developed expertise in measurement and experimental

design, and we have some skills in translating theory into practice. We must not be left behind in the establishment of an evidence-based medicine but must contribute by tightening our own research methods. We need to develop more critical appraisal skills regarding our own studies, pay more attention to issues of power calculations (too often research is reported that is inadequate on methodological grounds) and we must seek to make sure that psychology is an integrated part of medical evaluation. This means that we should not settle for a quality of life measure to be appended to the evaluation of a clinical trial. Rather, we must clarify the psychological processes underlying patients' involvement in decision making and seek to establish a theoretically sound evidence based health psychology.

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