No pain, no gain? Integrating QoL assessment in paediatrics

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Perspective on the paper by de Wit *et al* (see page 434)

The arguments for assessing health-related quality of life (QoL) in children undergoing medical treatment are persuasive. Consideration of QoL places the child at the centre of the assessment, and emphasises the autonomy of the family in decision-making. Over-reliance on physiological indices neglects the important question of how illness or treatment impacts on children's own ratings of their health or well-being. However, assessment of QoL, especially in paediatrics, has proved challenging, and there remain many questions about whether or not it is possible to measure a concept as subjective as QoL, and indeed what could be gained beyond the traditional assessment of outcomes. Perhaps any new undertaking is inevitably associated with considerable pain. It seems timely to assess whether the anticipated gains (increased awareness of children's views and improved communication) have been achieved. This is not a comprehensive review of the literature, but where possible, arguments are illustrated from recent publications in *Archives of Disease in Childhood*.

THE PAINS

The pains involved in instituting QoL measurement alongside clinical assessment have been considerable. There has been much debate about the definition of QoL, approaches to measurement and the merits of generic or disease-specific measures. Furthermore, there have been questions about how far measures can be developed for younger children, given their cognitive and linguistic competence. One solution, to rely on proxy ratings, has not been the panacea it was hoped for. Children and parents do not necessarily agree about the child's QoL, raising questions about who is the most reliable informant.¹

There have also been disappointments, to the extent that findings have not always been as expected. In particular, informal observations that treatments are associated with improved QoL have not been confirmed when formal measures are used. For example, parents spontaneously report

that QoL improves in children with otitis media with effusion following treatment with ventilation tubes (grommets). Disappointingly, formal assessment of QoL has not confirmed parental anecdotes.² In these circumstances, it is customary to point to methodological problems inherent in study design and the limitations of QoL measures. Finally, there have been pains involved as clinicians, nurses, behavioural scientists and economists try to work together despite differences in training and priorities. Perhaps it is testament to the potential value of QoL assessment in research and clinical practice that it remains of such interest, despite the pains.

THE GAINS

Improved communication and clinical care

In reviewing the different QoL measures available for those working with children with diabetes, De Wit *et al*³ acknowledges first some of the pains but emphasises the potential gains and implications for clinical practice. In paediatrics, the goal of much treatment is to improve patient and family QoL. This applies, for example, to treatment of children with disabilities as well as children with chronic conditions. Thus, in diabetes, the aim is to improve QoL by balancing the demands of treatment with patient life-style. In follow-up of survivors of childhood cancer, the goal is to identify and monitor treatment induced late effects and improve patient knowledge and self-care without creating unnecessary anxiety.

Use of QoL measures in clinical practice should lead to improved communication and enhanced patient satisfaction with the encounter, and provide a standard score against which change can be monitored. Use of computerised QoL measures is acceptable to adult patients,⁴ and given the interest and competence of children and young people with computers, such methods should be more than acceptable to them. An additional benefit may be in increasing parents' awareness of their child's views about illness and treatment, and ultimately enhanced family communication.

Evaluation of interventions

The goal of many interventions is to increase (or maintain) survival rates or reduce physical morbidity, with improvement in QoL as a secondary goal. Thus, reduced obesity is desirable for the child's immediate and future health but also for anticipated improvements in QoL.⁵

QoL measures are potentially valuable in assessing different kinds of health care. This applies, for example, to the impact on QoL of home- or hospital-based treatment. Generally families do prefer home-based care, but this is not necessarily associated with differences in QoL. Stevens *et al*⁶ compared home- and hospital-based chemotherapy for children with leukaemia in terms of QoL, safety, care giver burden and costs. In the home treatment phase, children were better able to keep up with regular activities than when receiving hospital care but experienced more emotional distress. Thus, the problem may relate to the rather simplistic research design often used: is home-based care better than hospital-based care? The answer is more complex and depends on the specific treatment and the domains of QoL assessed.

Evaluation of clinical trials

Traditional evaluation of outcomes in clinical trials involves regular assessment of physiological severity based on laboratory measures. Such assessments fail to answer whether children themselves (or parents) see any change in their health as a result of treatment. Limited correlations between physiological indices and children's ratings necessitate inclusion of QoL assessment, and some funding bodies now recommend routine inclusion of QoL measures in trials.

While the child's view is central to definitions of QoL, parents shoulder much of the burden of care for the child. Care-giving demands fall into three categories: (i) physical demands of direct care, including help with everyday living; (ii) emotional demands including dealing with the patient's concerns and those of other family members and (iii) financial burden.⁷ Comprehensive evaluation of a trial should take into account the child's own QoL, and also demands on parent's time, work and emotional well-being.

Decision-making

Many decisions in paediatrics are difficult and there are no simple answers. Families often seek advice about different courses of action and may benefit from knowledge about how others coped in similar circumstances. Again using the example of home- or hospital-based care, families may find it helpful to draw on the

experiences of others. Growth hormone treatment (GHT) may be recommended for children after cancer treatment. In these cases, parents and children must weigh up the potential benefits (increased height and perhaps energy) against the need for continued monitoring and hospital appointments. Decisions about treatment need to take into account the QoL of children who are short, whether this is a consequence of medical treatment or not.⁸ While the hope is that GHT will be associated with improved QoL, this has not yet been shown.

Treatment of orbital rhabdomyosarcoma can include radiotherapy or chemotherapy only. Children treated with orbital radiotherapy alone have a good chance of survival but risk reduced vision and facial asymmetry. Chemotherapy alone does not carry comparable risks of late effects, although the risk of recurrence is higher, and if this happens, both radiotherapy and chemotherapy are used. Thus, the decision lies in whether to spare radiotherapy in some cases and thus reduce subsequent risk to QoL, against the additional risk involved in treating relapse for a subset of the same patients.

Where it is not possible to cure a child with cancer, parents and clinicians face difficult decisions about initiating palliative care. The goals of palliative care are to relieve pain and physical symptoms and generally ensure that the child has as optimal a QoL as possible. Reports of the incidence and prevalence of adverse effects related to corticosteroid use vary widely.⁹ The prevalence of adverse effects related to corticosteroid use increases

with prolonged courses, but once initiated it may be very difficult to reduce or stop corticosteroid treatment because of recurrence or worsening of symptoms for which the initial prescription was initiated. Systematic assessment during the palliative phase is necessary because families may be prepared to tolerate greater compromised QoL than at other times. Information about the side-effects experienced by children during steroid treatment may well help families in similar positions.

CONCLUSIONS

There have been enormous strides in the development of QoL measures, especially those for very young children. Routine use of electronic questionnaires should be feasible and could be completed in clinics, thus facilitating clinic completion of QoL and hopefully improving doctor–child communication. The limiting factors may be availability of space and computer access in clinics, as well as clinician attitudes. Lack of time is often cited as a reason for not assessing QoL, but several measures are relatively quick to complete.

As a consequence of the increased awareness of QoL, children have a voice in their care. QoL measures have also offered us a means to evaluate trials and interventions where major changes in survival rates are not anticipated. Much treatment involves a balance or trade-off between short-term pain and longer-term gain. The same could be said for the current status of QoL assessment in paediatrics. We have been through a period of considerable pain, and it is

now time that we started to gain from past experiences. Including routine assessment of QoL is likely to be of considerable benefit to children and their families, and can only enhance the quality of delivered care.

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