Quality-of-life measures in chronic diseases of childhood
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Record Status
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Citation

Authors' objectives
The aims of this report are: - To review the state of the art with regard to measurement of quality of life (QoL) for children. - To make recommendations regarding the value of currently available measures for different purposes. - To identify further research needs.

Authors' conclusions
Minimum criteria for new measures: A set of procedures needs to be established for the development of new measures. These need to draw on the experience gained in development of child and adult measures to date. Basic research to enhance understanding of how children interpret questions in QoL measures is recommended. We need to understand the differences in meaning of items between children and adults, and between children of different ages. Some attempt to develop measures for children of 6 years or more have been reported, and these should be further developed.

Development of new measures should: - follow established procedures for the development of measures - take into account theoretical knowledge of childrens understanding of illness, emotion, and ability to complete rating scales - include facility for child and proxy report - include developmentally sensitive age-appropriate sections - include generic core and disease-specific modules.

Clinical appropriateness: There is a need to develop measures that are appropriate for the kind of questions to be answered in practice. Measures are frequently justified in terms of the value in clinical trials, comparing alternative treatments or assessing interventions. In more everyday contexts, QoL measures may potentially help health professionals and childrens families evaluate clinical care. Outcome measures that are sensitive to changes in the childs QoL have considerable value, particularly in children with long-term illness.

To determine how far assessments of QoL can contribute to improved care, we need to move beyond the development of new measures. In order to encourage greater use in clinical practice, it is recommended that:

- developers of new measures need to be clearer about the procedures adopted for identifying the item pool, and more extensive information about their psychometric properties should be provided - those developing new measures should work more closely with clinicians in order to ensure both the quality of the measures and their appropriateness in different clinical settings - families should be encouraged to be more involved in the development and application of measures, in order to improve the face validity of measures, and to challenge criticisms that QoL measures impose an unnecessary.

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