

# Challenges in child and adolescent quality of life research

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Quality of life (QoL) of children and adolescents has only recently received the attention it rightfully deserves. Reviews of the effects of a number of the most common chronic childhood conditions (1) show an enormous diversity of impact and associated needs. Before the introduction of QoL instruments, there was a dearth of appropriate means for comparison across conditions. The foremost advantage of QoL measurements is that they can be used for evaluating core dimensions associated with a life of quality, giving direction and guidance in providing appropriate services. Because it is still in its early stages, research on QoL in children and adolescents has several serious limitations.

First, there is poor agreement on the core quality of life dimensions. While many specific schemas have been proposed, they, in fact, overlap considerably (2).

Second, most research on children used proxy reports. We need to make a compelling argument for the use of information obtained from youths themselves. Average correlations between biomedical tests of disease parameters and patient reports of well-being are fairly low, especially in children (3). Therefore, it is not surprising that the ability of physicians and nurses accurately to rate their patients' QoL is limited. Both under- and over-estimation of limitations, pain and psychological impact occur (4). Moreover, we frequently see a discrepancy between efficacy of a treatment from the provider's and the patient's point of view. Similarly, ratings of behavioural and emotional functioning by youths themselves tend to have a low correlation with ratings by parents, teachers, or mental-health workers (5, 6). Insights such as these have led to the reasoning that QoL is best understood from the perspective of the individual (7, 8). While this is well acknowledged in the field of adult QoL research, methods to obtain children's and adolescents' views on their QoL are only beginning to be developed.

Third, the *modus operandi* has been to develop setting- or condition-specific QoL instruments, almost for each separate research project or clinic. This approach has made it virtually impossible to develop a knowledge base on the impact of chronic conditions on children or what are effective and efficacious interventions or policies for improving their QoL. We need to move towards the adoption of a select few QoL instruments that can be applied generically to summarize information from children and adolescents as well as their parents, caretakers and health providers. Of course, we are interested in learning about disease impact. However, QoL and disease impact are theoretically distinct concepts and need to be measured separately.

The paper by Loonen et al. (9) in this issue of *Acta Paediatrica* skilfully deals with a number of issues in QoL assessment. It shows that adolescents with inflammatory bowel disease (IBD), especially those with Crohn's disease, differ from their healthy peers in body complaints, motor functioning, autonomy and negative emotions. The study makes strong use of well-developed and validated, truly health-related instruments that ask about the emotional response to recent health problems. The balanced conclusions reflect the relative merits of generic and disease-specific instruments, which prove to be differentially sensitive to the number of disease-related symptoms. By using both generic and disease-specific measures, the study also shows that young people with chronic disease may experience considerable disease impact, although without reduced QoL on generic domains. If impact measures only had been used, we would not know that at least one-third of the young patients with IBD rate their QoL optimal regarding motor functioning, cognitive functioning, social functioning, positive emotions and autonomy. It also shows that in general QoL is mainly affected by severe symptomatology. Only by using a generic measure, could the QoL of these patients be compared with that of their age peers in the general population.

Many instruments have been developed in a relatively short period of time to measure QoL in young people. This reflects the rapidly growing interest shown over the past decade in the broad impact of health conditions and interventions on young people's lives, mirroring, albeit in the typically delayed fashion, what has transpired in adult populations. Spieth (10) reviews some 17 generic QoL instruments in detail. However, from this pool, it is difficult to select a few specific instruments that are worthy of further consideration. They were clearly developed for different purposes, such as epidemiological surveys, policy and program evaluation, and patient assessment. Those labelled by Spieth as health profiles and multidimensional instruments come closest to the conceptualization of QoL that we would like to emphasize. Each instrument within these two categories, however, has shortcomings, such as being overly long, targeting only adolescents, or requesting only self- or parent reporting. Nonetheless, from among these instruments we recommend that further consideration be given the RAND Health Status Measure of Children (11), the Child Health Rating Inventories (12), How Are You? (13), and Quality of

Life Profile (14), as well as the PedsQL (15) and the TACQOL (16). None of these instruments is completely satisfactory at present, but they all contain elements that will serve as a good base for further work. In addition, a large number of disease-specific instruments have been developed (1), many of which can be found at the website: <http://www.mapi-research-inst.com>. In our view, those instruments purported to be disease-specific QOL measures may be useful for measurement of the more limited construct of *perceived disease impact*.

The common denominator of most of the applications of the QoL notion is that QoL is viewed from a patient group perspective. That is, the main focus has been on how a specific patient group can be described in terms of needs and effects, to enable recommendations for clinical care in that patient population. This use of QoL should be helpful to evidence-based medicine, in which systematized knowledge is collected on the effects of treatment regimens. Likewise, QoL considerations should inform managed care plans by providing information about economic, yet effective use of services. As detailed elsewhere (17) among others, QoL measurements may be used to determine QoL differences between different groups; to determine how complications unrelated to disease activity affect QoL; to determine whether condition-related differences exist between different subgroups; to use in intervention trials; to determine the association between childhood QoL and other prognostic factors and outcome in prospective studies; to assess the relationship between medical and environmental support and QoL outcomes; to assist in the allocation of resources and public policy decision-making.

Some authors maintain that QOL research “will be fully accepted by [healthcare] practitioners only when it answers questions directly related to clinical programs and therapeutic choices” (18). This reflects the limited focus of QoL research in one of its major fields of application. Many would feel that separate attention to QoL issues would be outside their circle of influence and competence. Many consider it unnecessary and not useful to address QoL as an outcome of medical treatment beyond disease impact. Many healthcare providers are still unfamiliar with QoL concepts and their measurement. This is certainly very different from biomedical measures. In addition, there is considerable disagreement on whether QoL is an appropriate goal for healthcare. The lack of familiarity with QoL concepts and psychosocial measurement as a whole is expressed as scepticism against “subjective” data. There is also resistance to the use of structured or standardized formats to assess QoL as well as toward posing “private” questions. Admittedly, before healthcare providers are prepared to spend time and money on QoL, there are numerous issues that have to be resolved. These include a better definition of the QoL domain and its relevance for the practice of care, as well as the still limited guidelines for care that can as yet be derived

from our current state of knowledge based on QoL. To this end, combined research and practical efforts need to address the issues mentioned in this commentary.

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