

EDITORIAL

Clinical & Experimental Allergy

Differing views of Children and Parents: some cautionary tales!

This editorial discusses the findings of the paper in this issue by van der Velde et al. [3] pp. 1431–1439.

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Both in medical research and clinical practice, traditional outcome measures, such as reduction of symptoms or days off work, are increasingly being augmented by quality-of-life (QOL) assessment. Within health care, QOL is determined not only by the patient's health status problems but also by their response and interpretation of the restrictions, and various instruments have been developed to measure this, both cross-sectionally and over time. Over the last 15 years, there has been increasing interest in QOL in children. As in adults, researchers have identified three distinct QOL perspectives; generic, health-related quality of life (HRQOL) and disease-specific quality of life (DSQOL). Generic measures of QOL can be used with both ill and healthy children. HRQOL focuses on health status and the individual's response to problems in health status. As such, the concept of HRQOL refers to the part of QOL that is primarily influenced by health status. DSQOL measurements assess changes in functioning and patients' sense of well-being in relation to a particular illness.

Because QOL is concerned with an individual's perceptions, self-reported questionnaires are the primary method of assessment. Early work assumed that children are unreliable respondents and lack the reading, linguistic and cognitive skills necessary to respond to QOL measurements [1]. Further justification for the use of parents as proxy reporters was claimed as it was recognized that parents act as the primary health-care provider and as the gatekeepers to paediatric health care.

The development of paediatric QOL questionnaires lagged behind the equivalent process for adults. Ravens-Sieberer and Bullinger [2] estimated that only approxi-

mately 13% of all QOL literature published from 1980 to 1994 was specific to children. Most children's QOL literature at that time pertained to children between 13 and 18 years old; very few studies dealt with children between the ages of 6 and 12 and only 9% of the literature involved children's self-reporting. By 2006 the landscape had been transformed, and there were 14 generic and 26 condition-specific instruments to measure paediatric QOL. In this issue of *CEA*, researchers have investigated areas of agreement and disagreement between child and parent reports of the impact of food allergy on QOL, using the child and parental forms of the recently developed Food Allergy Quality of Life Questionnaire (FAQLQ-C and FAQLQ-P, respectively) [3].

Like many studies before it, this study found that parental proxy reports of QOL are only moderately correlated with child-reported QOL. The fact that correlation is weak is not perhaps surprising – one only has to look at everyday life to recognize discordance between parents' and children's opinions, whether it be the truculent toddler or the wayward adolescent.

The underlying reasons for the differences in QOL scores remain largely unknown. Discordance may arise for a variety of reasons. Parents and children may base their answers on different experiences; they may use different response styles, or they may interpret items differently; parental views may also be influenced by their own physical and psychological well-being.

In interpreting van der Velde et al.'s [3] paper in this journal, and indeed any other paper on proxy QOL measures, one needs to remember two issues that are not entirely self-evident: firstly context dependence (i.e. the significance of the difference depends on how the questionnaires are being used), and secondly the fact that apparent agreement does not necessarily represent true concordance.

To elaborate, the clinical implications of differences in parental and child responses depends on how the questionnaires are intended to be used in practice, that is whether the parental response is to be used to provide substitute or complementary data [1]. The term 'substitute

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perspective' is used in the literature when the parent only acts as a proxy reporter: the parent questionnaire is completed (most frequently by the mother) and this data acts as a substitute for the child's response. The term 'complementary perspective' is where both a parental and a child perspective are used. The underlying philosophy of the complementary perspective is that children from 8 years onwards can be accurate reporters of their own QOL, and the parental perspective provides an additional or secondary insight.

The frequent reporting, in papers on the development of children's QOL measures, of correlations and degrees of consistency between the parent's and child's response is inappropriate and contradictory. Parental responses should be used to provide additional insight into the child's QOL and there is no reason to seek or expect any particular level of agreement [4]. However, questionnaires used to derive a substitute perspective do need to reflect the child's experience accurately, and so in this case, we do need to see the degree of correlation between child and parent reports to understand the validity of using the parental response as a proxy measure. In both situations, what is most interesting from a clinical perspective is the direction of any differences and why these might arise.

So in the context of the work of van der Velde et al. reported in this journal, the chief difference was that the parents assessed greater impact of illness on QOL than their children [3]. So in a situation where a child was unable to complete a QOL questionnaire for themselves, one might conclude reasonably that 'true' impact as perceived by the child was less than that reported by the parent. But this does not address why such differences arise.

Qualitative research methods are good for understanding 'why' questions and there are a handful of studies have begun to explore this area. The best of these comes from researchers in Australia and Germany [5] who used a 'think-aloud' technique to assess whether parents and children base their responses on different experiences, whether they have different styles of response or whether their interpretation of the same event differs. The focus of

their research was a generic HRQOL instrument (KIDSCREEN). 'Think aloud' is an observation technique, pioneered over 40 years ago [6]. It has its origins in problem-solving theory technique, but has become a common approach to user research in many disciplines. The think-aloud technique allows for the examination of individuals' thinking processes and decisions that are being considered while carrying out a specific task, e.g. problem solving, diagnosis, etc. Today it is used in a variety of settings including health care.

Users are asked to verbalize everything that comes into their minds while carrying out a particular task – this is best suited to situations in which participants have a clear, well-defined task, e.g. completion of a questionnaire. The basic concept is simple: after explaining the task to the participant, you ask them to think aloud as they do it. If the user is silent for more than a set length of time, standardized neutral prompts are used to get them talking again.

Through this technique, Davis et al. [5] have begun to derive a better understanding of QOL concordance between parent-child pairs and the reasoning behind any discrepancies. A content analysis was performed on the commentary provided by children and adults while completing the KIDSCREEN questionnaires. Two types of parent-child concordance were examined: concordance when choosing response category and concordance for the reasoning behind their answers. Theoretically, variation and similarity between parents and children's answers can fall into four types: same rating scale and reasoning; same rating scale but different reasoning; different rating scale and same reasoning; different rating scale and different reasoning.

The results of Davis and colleagues's study demonstrated that parents' and children's answers to HRQOL items may be the same but they are based on different reasoning. This highlights a problem within the literature where it has been assumed that if parents and children report similar scores this indicates concordance. In this situation it could be argued that any similarity is coincidence rather than concordance.

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