

Short Communication

Health-Related Quality of Life Measure for Children—the TACQOL[†]

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Health related quality of life (HRQOL), defined as the patients' own evaluation of their health status, is an important criterion in evaluating health and health care. Until now, few systematic attempts have been made to develop instruments to assess HRQOL in children. For this reason, the aim of the study was to evaluate the psychometric performance of the TNO-AZL-Child-Quality-Of-Life (TACQOL) questionnaire; a 56-item, generic, multidimensional HRQOL instrument for children aged 5-15 years, to be completed by parents. The parents of 77 patients, aged 5-15, who were visiting the paediatric outpatient clinic of Leiden University Medical Centre consented to participate in the study and to complete the TACQOL. The results indicated that Cronbach's α value for reliability of the TACQOL scales, range from 0.71 to 0.89, and that the correlation coefficients among scales were low, indicating the independence of the scales. The scales structure was confirmed in principal component analysis. Only a minority of parents indicated health status problems in their child and also reported negative emotional feelings contingent on such problems. It is concluded that the psychometric performance of the TACQOL is good, and the instrument may be used to assess group differences in HRQOL in children. In defining HRQOL, relevance of the distinction between health status and negative emotional

reactions to health status problems is supported by the results of the study.

Keywords: Health Status, Quality of Life, Children

INTRODUCTION

Outcome assessment in medicine has been focused for many decades on mortality, morbidity and, more recently, also on functional health status. Such outcome measures are of paramount importance in monitoring children's health and in evaluating the effectiveness of health care (Veen *et al.*, 1991; Saigal *et al.*, 1994a, 1994b; Gemke & Bonsel, 1995). Although necessary and valuable, these outcome measures do not really reflect the patients' 'well-being' properly, in so far as their own, subjective evaluation of health status is not taken into account. What matters in HRQOL is the way patients feel about

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their functioning, and not their functioning in itself (Gill & Feinstein, 1994).

The need to develop proper research tools to measure HRQOL in children is urgent. In the absence of such tools, children's well-being is estimated by researchers or attending physicians who use their own personal reference points and their own experience with similar patients as guidelines. Although these estimations may be valuable, they will be hardly comparable between each other and therefore do not offer a sound base for evaluation of HRQOL in children. Thus, the aim of the study was to evaluate the psychometric performance of the TNO-AZL-Child-Quality-Of-Life (TACQOL) questionnaire; a generic instrument for measuring children's HRQOL, and which is completed by parents. As consensus is growing that generic measures of HRQOL should reflect (affective evaluation of) functioning in different life domains (Kamphuis, 1987; Stein & Jessop, 1990) HRQOL was defined as a multidimensional construct. Consequently, the TACQOL includes seven domains of HRQOL: pain and symptoms, motor functioning, autonomy, cognitive functioning, social functioning, positive emotional functioning, negative emotional functioning. Each domain is represented by an 8-item scale. When parents indicate the presence of some health status problem, they are asked to assess the child's emotional reaction to the problem. For instance, if parents indicate their child has trouble concentrating in school (choosing between 'never', 'sometimes' or 'often'), they are prompted in a subsequent question to indicate how they think the child feels about the problem (good, not so good, rather bad, or bad). The TACQOL uses parents as proxy informants on their child's HRQOL in order to include very young children in the age range of the instrument (5-15-year olds). Generally, parents may be assumed to be the best proxy informant on their children's functioning and emotions. Moreover, they are the ones to decide about treatment options, especially in young children.

MATERIALS AND METHODS

Parents of 77 young patients, aged 5-15 years, who were visiting the paediatric outpatient clinic of Leiden University Medical Centre consented to take part in the study, which was approved by the local medical ethics committee. Children were treated for one or more of various diseases, such as coeliac disease, asthma, congenital heart disease, haemato-oncological problems, juvenile rheumatoid arthritis or diabetes mellitus. The attending paediatrician judged severity of disease on a 7-point Likert scale.

The psychometric performance of the TACQOL was evaluated in three ways. Firstly, reliability was determined by calculating Cronbach's alpha for each of the seven scales. Secondly, to evaluate scale specificity of items, corrected item-scale Pearson's correlation coefficients (PCC) were calculated, as well as PCC of items with all other scales. Thirdly, independence of scales was evaluated by calculating PCC between scales and by principal component analysis.

To evaluate validity of the distinction between health status problems and emotional response to such problems, the percentages of health status problems with and without negative emotional reactions were calculated per scale.

In order to explore convergent validity, TACQOL scales were correlated with the paediatricians judgement on disease severity.

RESULTS

Cronbach's alpha value ranged from 0.71 to 0.89. Of the item-rest PCC some 96% were higher than item-other-scale PCC. Out of 56 items, 78% had a corrected item-rest PCC higher than 0.40 and 35% of the items had an item-rest PCC higher than 0.60. PCC between TACQOL scales were low to moderate (0.20-0.39). A principal component analysis explained 51% of variance and reproduced the scale structure very well: 93% of

items was loaded higher on their proper factor than on other factors.

Only 23% to 30% (dependent on the scale involved) of reported health status problems had led to negative emotional reactions to such problems.

Pearson's correlation coefficient for the paediatricians' judgement of disease severity with TACQOL scales was found to be low, ranging from 0.07 to 0.24.

DISCUSSION

The aim of the study was to evaluate the psychometric performance of the TACQOL, a questionnaire designed for measuring HRQOL in children. Reliability of the TACQOL scales was found to be satisfactory. Low inter-scale PCC and the high item-rest PCC support the assumption that HRQOL should be defined as a concept with multiple independent domains (Eisen *et al.*, 1979; Aaronson, 1988; Fitzpatrick *et al.*, 1992). The domain structure of the TACQOL was confirmed by principal component analysis.

The distinction between health status problems and emotional reactions to such problems, has been suggested by various authors (Collings, 1990; Christie *et al.*, 1991; Gill & Feinstein, 1994; O'Boyle, 1995), and appears to be relevant; most parents, if signalling a problem, did not report subsequent negative emotional feelings in their child. In other words, the HRQOL of children is not necessarily reduced when health problems occur.

The lack of a substantive correlation between the paediatricians' judgements on severity of disease and TACQOL scales suggests that paediatricians' judgements are based on other observations than the parents' judgements of their child's HRQOL. Similar disagreement between various informants has been reported previously in the literature (Sprangers & Aaronson, 1992).

The scoring of items deserves some attention. A scale score of two may mean two things: either

two health status problems without negative emotional reactions were reported, or one health status with subsequent negative emotional feelings. A health status problem without a negative emotional reaction receives one-half the weight of a health status problem that leads to a negative emotional reaction. Other weightings may be more valid. Valuation studies in which patients are asked to judge the severity of various HRQOL states are needed, similar to those performed with respect to health states (Feeny *et al.*, 1992).

In summary, the psychometric performance of the TACQOL was found to be good. The instrument may be used to assess group differences in children's HRQOL, for example in studies evaluating the effects of different treatments.

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