

# Health related quality of life of children with a chronic illness

## Parent versus child report

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### Summary

*This study evaluates the agreement between child and parent reports on children's Health Related Quality of Life (HRQoL) in a sample of 416 Dutch children (8 to 15 years) with a chronic disease. Both children and their parents completed a 56 item questionnaire (TACQoL) with seven eight-item scales: physical complaints, motor functioning, autonomy, cognitive and social functioning, positive and negative emotions. The correlations between child and parent reports varied from -.10 to .99 amongst the various chronic conditions. Children reported lower HRQoL on the physical complaints, motor functioning and positive emotions scales. Parents reported lower HRQoL on the social, and negative emotions scales. The child and the parent provide different information on HRQoL. Knowledge of both judgements seems necessary in the care of children with a chronic illness and their parents.*

### Introduction

The definition of health provided by The World Health Organisation (WHO) as 'a state of complete physical, mental, and social well being, and not merely the absence of disease or infirmity' (WHO, 1948) has been highly influential in defining the quality of life (QoL) construct. The physical, mental and social dimensions have remained central to the construct of QoL. Health-related quality of life (HRQoL) was initially developed and operationalised in adult illness populations. The concept refers to the specific impact of an illness, injury or medical treatment on an individual's QoL.

A general criticism of both adult and paediatric HRQoL is the absence of theoretically driven frameworks to guide research. The multidimensional definition of health proposed by WHO (1948) is consistent with a biopsychosocial model of functioning. This model emphasises the interdependent relationships among biological, psychological, and social functioning of a child. The HRQoL construct can be viewed here as a method of translating a child's experience of ill-

ness into a quantifiable outcome. This outcome can be integrated into medical practice and research (Drotar, 1998).

One of the important questions in the field of HRQoL assessment with child-major informants in paediatric HRQoL assessments (Haverkamp & Noeker, 1998). However, parental reports may be significantly affected by their own anxiety and adjustment level. Furthermore, because parents are not with their children in every setting in which the child functions, their reports may be incomplete. It may overlook the child's subjective experience and perceptions of life quality (Drotar, 1998).

However, the use of HRQoL assessment in (young) children can be problematic because children may lack the necessary language skills, as well as the cognitive abilities to interpret the questions, and the long-term view on events (Kamp-huis, 1987).

Agreement between child and parent HRQoL reports has already been investigated in a normal population (Theunissen et al., 1998). Therefore, this study evaluates in a sample of children with chronic disorders to what extent parents and children agree on the child's HRQoL.

### Method

#### Sample

The analytical sample consisted of 416 children with a chronic illness between 8 to 15 years old (213 boys and 203 girls) and their parents. Both children and their parents received a questionnaire by mail. The children with coeliac disease and metabolic disorder were randomly selected from the membership records of the Dutch Coeliac Patients Society and the Dutch Society of Children with Metabolic Diseases. The children with idiopathic short stature were randomly selected from a group of children that formerly participated in a multicentre growth hormone study. The other groups of children with a chronic illness in this study (asthma, rotation plasty for osteosarcoma, diabetes, juvenile chronic arthritis, leukaemia and spinal cord injury) received clinical care in the Leiden University Medical Centre (LUMC). Criteria about informed consent and anonymity were met in accordance with the LUMC Medical Ethics Committee.

#### Measures

Data on HRQoL were collected using the TNO-AZL Children's Quality of Life questionnaire (TACQoL). The instrument was developed as a generic instrument intended for broad use with many types of diseases, treatments, and groups of individuals across the core HRQoL domains (Vogels et al., 1998).

Two parallel questionnaires for child's HRQoL were available with parallel items: A child form (CF) and a parent form (PF). The items were adjusted to the type of informant: Has your child had... in the PF and Have you had... in the CF. The TACQoL contains seven scales of eight items each: Physical complaints, motor functioning, autonomy, cognitive functioning, social functioning, positive and negative emotions. A concrete and specifically formulated problem, if reported, leads to a question about the emotional response. Examples of items are given in Table 1.

Items were scored on a 0-4 scale. The eight item scales were scored on a 0-32 scale, with higher scores representing better HRQoL. Items on (positive and negative) emotional functioning were scored on a 0-2 scale (0 = often, 1 = sometimes, 2 = never) and scale scores ranged from 0-16.

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Table 1 Examples of scale-items of the TACQOL Parent form

Scale	Item example (Parent form)
Physical complaints	Has your child had a headache?
Motor functioning	Has your child had difficulty walking?
Autonomy	Has your child have difficulty dressing him/herself?
Cognitive functioning	Has your child have problems understanding his/her schoolwork?
Social functioning	My child was quiet and not talkative with us, parents
Positive emotions	Enthusiastic
Negative emotions	Worried

Response categories: 'Never' / 'Sometimes' / 'Often'  
 If the answer is 'Sometimes' or 'Often', the next question in the first five scales is:  
 'During this my child felt' (PF) / 'During this I felt' (CF): ('Very) good' / 'Not so well' / 'Rather bad' / 'Bad'

**Statistical analyses**

The results of the children's and parents' reports on group level were summarized with the mean expressed as a percentage of maximum score (to enable comparison between HRQOL group means). The differences in mean between child and parent reports were tested with paired student's t-tests. Agreement between children and parents was further quantified using Pearson correlation coefficients (PCC) and intraclass correlations (ICC). Partial correlations between child and parent reports were calculated for each chronic condition. The correlations were controlled for gender and age because these variables differed substantially between disorders. Linear regression analyses were computed for every scale, to reveal possible relationships between child and parent reports and the variables gender and age.

**Results**

Cronbach's alpha coefficient range of HRQOL scales was .75 to .89 (PF) and .68 to .84 (CF). Only the CF social functioning scale showed an alpha below .70 (.68).

In Table 2 the agreement between child and parent reports is shown at group level. The difference is largest on physical complaints and positive emotions,

Table 2 Agreement between child and parent reports on HRQOL (Tacqol CF and PF)

Scales	M		SD		t	PCC	ICC
	Child	Parent	Child	Parent			
Physical complaints	77	82	(16)	(14)	**	.64*	.60*
Motor functioning	89	90	(14)	(14)	**	.64*	.64*
Autonomy	96	95	(9)	(9)		.62*	.62*
Cognitive functioning	87	86	(13)	(14)		.62*	.62*
Social functioning	91	90	(10)	(11)	**	.57*	.57*
Positive emotions	84	88	(17)	(17)	**	.46*	.44*
Negative emotions	72	70	(17)	(15)	**	.55*	.54*

Mean score and standard deviation score are recorded (range 0-100) to allow for comparison of scales with different range of scores

High score = high HRQOL

PCC = Pearson coefficient correlations, ICC = intraclass correlations

\* p < 0.05, \*\* paired student's t-test; p < 0.05

Table 3 Partial correlations (controlled for sex and age) between child and parent HRQOL reports

Chronic Disease	N	PhC	Mot	Aut	Cog	Soc	Pos	Neg
Diabetes Mellitus	(23)	.59*	.03	.40	.51*	.14	.51*	.45
Short stature	(19)	.40	.31	.16	.70*	.20	-.10	.53*
Metabolic Disease	(30)	.83*	.99*	.86*	.98*	.23	.16	.51
Spinal Cord Injury	(22)	.88*	.54	.94*	.32	.69*	.54*	.74*
Juvenile Chronic Arthritis	(85)	.68*	.76*	.73*	.51*	.73*	.55*	.41*
Rotation plasty	(14)	.84*	.57	.51	.66	.64	.38	.64*
Asthma	(55)	.46*	.34	.10	.72*	.60*	.67*	.56*
Coeliac disease	(153)	.59*	.55*	.59*	.64*	.61*	.47*	.61*
Leukaemia	(15)	.57*	.43	.82*	.70*	.08	.30	.69*

PhC = Physical complaints; Mot = Motor functioning; Aut = Autonomy; Cog = Cognitive functioning; Soc = Social functioning; Pos = Positive emotions; Neg = Negative emotions

which indicates less agreement between child and parent report. Children reported lower HRQOL on the physical complaints, motor functioning and positive emotions scales. Parents reported lower HRQOL on the social and negative emotions scales. Pearson correlations ranged from .46 to .64 (p < .001). Intraclass correlations were alike and ranged from .44 to .64.

Table 3 presents the partial correlations (controlled for gender and age) between the children and their parents on the HRQOL scales for every chronic condition. Although PCC's for the whole sample were moderate (.46 - .64), and 43 out of 63 correlation coefficients were above .50, the range of partial correlations

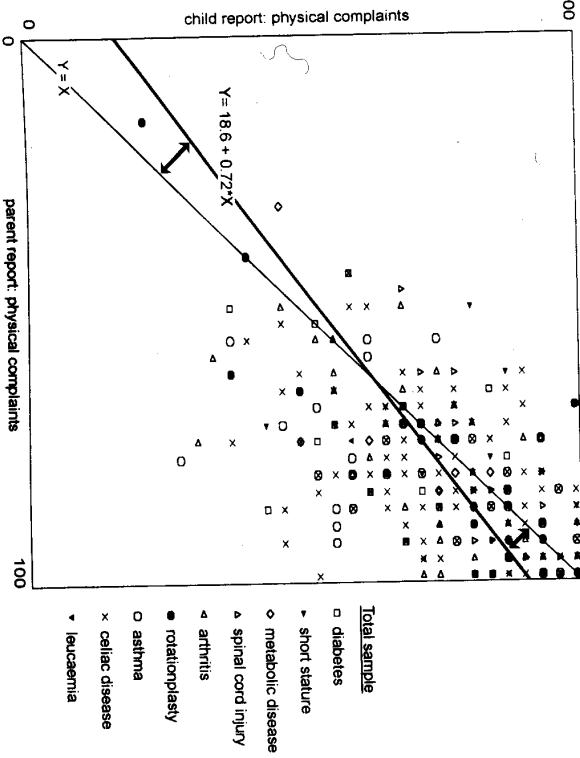


Figure 1 Regression on physical complaints together with the score of individual child-parent pairs

was wide. Considering motor functioning in the various chronic conditions, for instance, the child-parent correlation was .03 (ns) in the diabetes group, and .99 ( $p < .001$ ) in the metabolic disease group.

In Figure 1 the regression on physical complaints is given, together with the scores of individual child-parent pairs. The greater the distance between the regression line and the  $Y=X$  line, the lower is the agreement between parents and children. If child and parent both reported a high HRQOL (right-hand top corner), then the child scores were relatively lower than the parent scores. If both reported a low HRQOL (left-hand bottom corner) child scores were relatively higher. Overall, child scores were less extreme than the parent scores. The six other TACQOL scales followed the same pattern. The child's gender was related to agreement on physical functioning and negative emotions scales ( $p < .05$ ). If HRQOL scores were high, boys were more in agreement with their parents than girls. The child's age was not related to agreement between child and parent reports.

## Discussion

In this sample of children with a chronic illness and their parents, we found HRQOL patterns comparable with the results of the former study in the open population (Theunissen et al., 1998).

Firstly, in both studies the HRQOL scores showed a ceiling effect and were generally good for both children and parents.

Secondly, the mean differences between the children and the parents were comparable between studies, although different in detail. In Theunissen et al. (1998) children on average reported a significant lower TACQOL score than the parents on the physical complaints, motor functioning, positive emotions, autonomy and cognitive functioning scales. In the present study the same results were found on the first three scales, but not on the autonomy and cognitive functioning scales. On the social functioning and negative emotions scales, Theunissen et al. (1998) found no statistical differences, whereas in this study children reported significantly higher HRQOL than their parents.

Thirdly, correlations between children and parents were moderate in both studies.

Lastly, in both studies child scores were less extreme than parent scores. When parents were pessimistic, children were less despondent, and when parents were optimistic, children were less confident.

According to previous studies, agreement was relatively good for observable measures (Ennet et al., 1991, Epstein, Hall, Tognetti, Son & Conant, 1989; Sprangers & Aaronson, 1992). Evidence of physical and social activity is generally available to the parent. Therefore, the parent could describe the child's status as well as the child would. In contrast cognitive functioning, for example, is more likely to be experienced as private thoughts and opinions on the part of the child. This is difficult to observe for the parent, and as a result agreement could be low. This study showed different results. Parent and children reports agreed on cognitive functioning and not on social, physical and motor functioning. Parents seemed to be well informed about their child's results at school.

An explanation of the contrasting results on social, physical and motor functioning flows from the context in which parents make inferences about their child's HRQOL. Their interest may be in confirming prevailing beliefs and theories about the future impact of the disease on HRQOL of their developing children. The lack of correspondence between parent and child could be related to

the influence of 'halo effects' on parents' ratings. Parents seem to express the thought given the circumstances, my child does reasonably well. For some scales (physical functioning and negative emotions) this effect is stronger in regard to their daughters.

With regard to emotional functioning, negative feelings and opinions may be more likely to be displayed than positive ones (Epstein et al., 1989). For example, if a doctor's office visit went well, a child might make no comment to a parent, but if it went badly the parent might hear about it in some detail. A parent would therefore infer more overall negativity than the child actually experiences. Furthermore, there is a tendency for observers to give more weight to negative than to positive information when forming impressions of others. Negative expressions, such as weeping or complaining, are surely more salient and memorable than more positive ones. Therefore, even if children revealed their negative and positive feelings equally, parents' impressions would be more influenced by the negative, with the result that their opinion of the child's condition would be biased negatively. The results of this study were in line with this hypothesis. Children reported less negative emotions.

Correlations of the total group of children with a chronic illness and their parents were modest although the range of the correlations in the various chronic conditions varied. In the studies previously mentioned, correlations between self and proxy reports varied from low to high amongst children, adults and elderly people. When the proxy lived with the subject, correlations tended to be stronger (Epstein et al. 1989). However, all children lived with their parents, so this does not explain the wide range of correlations we found in the various chronic conditions. Future research in larger groups of children with a chronic condition have to confirm these correlations.

In conclusion, the results of this study indicate that parent reports cannot be substituted by child reports. There is a large variation in parent-child agreement on the various scales and the various chronic conditions. However, child scores appear to be less extreme than parent scores. When parents are pessimistic, children seem to say 'it isn't so bad', and when parents are optimistic, children seem to say 'it isn't that good'. Knowledge of the feelings and opinions of both the parent and the child may be helpful to improve the care of children with a chronic illness.

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