

The proxy problem: child report versus parent report in health-related quality of life research

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This study evaluates the agreement between child and parent reports on children's health-related quality of life (HRQoL) in a representative sample of 1,105 Dutch children (age 8–11 years old). Both children and their parents completed a 56 item questionnaire (TACQOL). The questionnaire contains seven eight-item scales: physical complaints, motor functioning, autonomy, cognitive functioning, social functioning, positive emotions and negative emotions. The Pearson correlations between the child and parent reports were between 0.44 and 0.61 ($p < 0.001$). The intraclass correlations were between 0.39 and 0.62. On average, the children reported a significantly lower HRQoL than their parents on the physical complaints, motor functioning, autonomy, cognitive functioning and positive emotions scales (paired t -test: $p < 0.05$). Agreement on all of the scales was related to the magnitude of the HRQoL scores and to some background variables (gender, age, temporary illness and visiting a physician). According to multitrait-multimethod analyses, both the child and parent reports proved to be valid.

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Introduction

Until recently, it was very difficult to keep children with severe diseases alive. Consequently, mortality was most frequently used as an outcome of paediatric

treatment.¹ As medical treatments improved, outcome measures such as morbidity, health status and the psychological and social consequences of medical treatments were increasingly used to evaluate paediatric treatment.^{2–9} A systematic outcome measurement that combines perceptions of physical, psychological and social functioning is 'quality of life'.^{1,3,10–21}

This article focuses on health-related quality of life (HRQoL). The 'health' component refers to quality of life as a result of a certain health. According to the definition of the World Health Organization (1948), health involves physical and psychological as well as social functioning. The assessment by a person of his or her own health functioning is called health status. To assess the HRQoL of a person not only is health status relevant but also the emotional evaluation of this health status by the person him- or herself. Therefore, HRQoL is defined as a combination of health status and affective responses to problems in health status.^{1,12,22,23} The definition incorporates individual and culturally determined differences in coping with health status problems and reflects internal standards about HRQoL, factors which are emphasized by several authors.^{1,3,12,23–25}

Self-report questionnaires are regarded as the primary method of assessing HRQoL.²¹ However, their use with children is problematic because children may lack the necessary language skills, the cognitive abilities to interpret the questions and a long-term view of events (Vogels *et al*, submitted). Therefore, proxy by parent may be a useful alternative. This explorative study evaluates to what extent parents and children agree on the child's HRQoL and at what age child reports can be reliably and validly obtained. The research population

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consisted of Dutch children aged 8–11 years and their parents. Since agreement between child and parent reports has been investigated only rarely,²⁶ we are obliged to compare our results with studies about proxy in adults. However, these comparisons will be of limited value, because children do not have the same internalized standard as adults for judging their current level of HRQoL.

Special attention was given to assessing agreement on health status, since most previous research on agreement was done on the health status component of HRQoL and thus, without affective evaluation by the patient.^{24,13,21,27} Furthermore, the degree of agreement between child and parent for several background variables was assessed.

Method

Sample

The data were collected from a Dutch sample of 1,122 children between 8 and 11 years old and 1,127 parents. The analytical sample consisted of 1,105 child–parent pairs (17 children and 22 parents were excluded in order to obtain complete child–parent pairs). The children’s sample consisted of 523 children of 8–9 years old and 582 children of 10–11 years old (with equal numbers of boys and girls). Most children attended regular school (97%), and a minority (3%) attended a special school for children with learning disabilities. Fifty-six (5.1%) children were an only-child, 378 (34.5%) were the first-born, 242 (22.1%) were the middle child and 421 (38.4%) were the youngest. The parent forms were completed either by a female care taker, mainly mothers (84%), a male care taker, mainly fathers (11%) or by mothers and fathers together (5%). The parents’ ages ranged from 21 to 55 years (mean = 38.5 years; SD = 4.4 years). Their levels of education were 29% low, 43% moderate and 28% high, according to the Dutch school system.²⁸ Most of the families were native Dutch speakers (96%) and most of the parents were born in The Netherlands (90%). Eighty percent of the parents were divorced or single.

The sample was selected by 12 representative regional community health services in The Netherlands. They each drew a sample of 140 children, stratified according to gender and age (8–9 and 10–11 years old). Both the children and their parents received a questionnaire by mail. The criteria about informed consent and anonymity were met according to the TNO Medical Ethics Committee. A reminder was sent if questionnaires were not returned within 3 weeks. The result was a response rate of 67%. Three hundred (27%) children were completely healthy, 603 (54%) children had temporary illnesses such as a cold or influenza due to a winter epidemic, 40 (4%) children had at least one chronic illness and 162 (15%) children had both a chronic and temporary illness at the time of the data collection.

Measures

The data on HRQoL were collected using the TNO-AZL Children’s Quality of Life (TACQOL) questionnaire. Two parallel questionnaires for children’s HRQoL were available with identical items: a child form and a parent form. The items were adjusted to the type of informant: ‘Has your child had...’ in the parent form and ‘Have you had...’ in the child form (Verrips *et al.*, submitted). The instrument was developed as a generic instrument intended for HRQoL assessment in medical research and clinical trials (Vogels *et al.*, submitted). The TACQOL contains seven scales of eight items each: physical complaints, motor functioning, autonomy, cognitive functioning, social functioning, positive emotions and negative emotions. The instrument was constructed to measure HRQoL, defined as the combination of health status and affective evaluation of problems in health status. A concretely and specifically formulated health status problem, if reported, leads to a question about emotional response. Figure 1 shows an example of such a question. The items were scored on a 0–4 scale (added to Figure 1 in italics in parentheses). The eight item scales were scored on a 0–32 scale, with higher scores representing better HRQoL.

Figure 1. An example of a parent form TACQOL question translated from the Dutch original. The child form TACQOL equivalent of the question is ‘Have you had difficulty running?’ and ‘During this I felt’.

Has your child had difficulty running?	<input type="checkbox"/> never [4]	<input type="checkbox"/> sometimes	<input type="checkbox"/> often
During this my child felt:			
<input type="checkbox"/> (very)good [3]	<input type="checkbox"/> not so well [2]	<input type="checkbox"/> rather bad [1]	<input type="checkbox"/> bad [0]

No affective responses about (positive and negative) emotional functioning were assessed, since this would have led to illogical items. The item scores on emotional problems were on a 0–2 scale (0 = often, 1 = sometimes and 2 = never) and the scale scores ranged from 0 to 16. The child and parent form TACQOLs were supplemented with questions assessing—among others—gender and age, chronic illnesses and temporary illnesses. The item scores were also encoded excluding the affective evaluation to obtain health status scores (0 = often, 1 = sometimes and 2 = never). The health status scales were scored on a 0–16 scale, with higher scores representing better health status.

Analytic strategy

All of the following computations were done for both HRQoL and health status. Overall, a *p* value of 0.05 or less was assumed to represent a significant result.

The results of the children's and parents' reports were summarized with mean scores and standard deviations. The mean, expressed as a percentage of the maximum score, was added to enable a comparison between the HRQoL and health status group means. The differences in the means between the child and parent reports were tested with paired Student's *t*-tests. Agreement between the children and parents was further quantified using the means of the absolute differences, the means of the differences (mean bias)

and the associated standard deviations,²⁹ Pearson correlation coefficients and the intraclass correlations (ICC).^{30,31} Differences between the HRQoL and health status agreement correlations were tested using computations of Fisher's *Z*-scores.³²

The reliability of the health status and HRQoL scales was tested using Cronbach's α coefficient. The convergent and discriminant validity was evaluated using multitrait-multimethod analyses (MTMM).^{33,34} A model was fitted onto the MTMM data using the computer program EQS (BMDP Statistical Software, Los Angeles).³¹ Goodness of fit indices (Bentler-Bonnett Normed fit Index, Bentler-Bonnett Non Normed fit Index, Comparative fit Index) above 0.90 were assumed to represent a good fit. Seven latent variables for the seven scales were constructed, with no restrictions on their correlations and two additional sources of variations: child versus parent reports and measurement error.^{35,36}

Possible relationships between the magnitude of the scores and the amount of proxy agreement could give scatter bias or random fluctuation. The possible occurrence of this phenomena was estimated by regressing the child reports against the parent reports.^{21,31} Forward, stepwise, linear regression analyses were computed for each scale, to reveal possible relationships between absolute proxy agreement and the background variables of gender, age, health of the child (chronically ill or temporary ill), visits to a physician, life events, position of the child in the family (e.g. first-born), age of the parents

Table 1. Central tendency of child reports and parent reports of HRQoL and health status

Scales	Child			Parent		
	Mean	% ^b	SD	Mean	%	SD
HRQoL: physical complaints	24.95	78	5.12	26.97	84	4.01*
Health status: physical complaints	12.09	76	2.62	13.09	82	2.17*
HRQoL: motor functioning	29.82	93	3.22	30.66	96	2.71*
Health status: motor functioning	14.61	91	1.87	15.08	94	1.75*
HRQoL: autonomy	31.21	98	1.94	31.35	98	1.61*
Health status: autonomy	15.48	97	1.21	15.52	97	1.17
HRQoL: cognitive functioning	28.45	89	3.90	28.71	90	3.89*
Health status: cognitive functioning	13.49	84	2.47	13.48	84	2.74
HRQoL: social functioning	29.70	93	2.78	29.71	93	2.63
Health status: social functioning	14.42	90	1.88	14.44	90	1.59
HRQoL/Health status: positive emotions ^a	13.56	85	2.55	14.69	92	2.13*
HRQoL/Health status: negative emotions ^a	11.57	72	2.72	11.52	72	2.48

^aOn these scales health status = HRQoL.

^bPercentage of maximum score.

*Paired Student's *t*-test: *p* < 0.05.

Range of HRQoL 0–32; high score = high HRQoL; range of health status 0–16; high score = high health status.

and education level of the parents. The child score was considered as a dependent variable, whereas parent score and background variables were considered as independent variables.²¹

Results

The TACQOL questionnaires proved to be reliable. The Cronbach's α coefficient range of the HRQoL scales was 0.65–0.84 and the range of the health status scales was 0.64–0.84. Table 1 presents the means of the HRQoL and health status scales. The children reported lower HRQoL than their parents for the scales relating to physical complaints, motor functioning, autonomy, cognitive functioning and positive emotions (paired *t*-tests: $p < 0.05$). The situation for health status was slightly different: the children reported a significantly lower health status than their parents for the physical complaints, motor functioning and positive emotions scales (paired *t*-tests: $p < 0.05$). Without affective evaluation, the group means of the autonomy and cognitive

functioning scales were alike, whereas the group means differed when affective evaluation was included.

Several indices quantifying the agreement between the child and parent reports are shown in Table 2. The mean absolute difference and mean bias are largest for physical complaints, which indicates less agreement on these scales than on the other scales. This holds for both the health status and HRQoL scales. The Pearson correlation coefficients on HRQoL ranged from 0.44 to 0.61 ($p < 0.001$). The absolute agreement mimicked the relative agreement, the ICC and Pearson correlation coefficients were alike.

Although the differences between the correlations were small, the HRQoL correlations were significantly lower than the health status correlations on motor functioning and autonomy. The physical complaints social and cognitive functioning correlations were not significantly different.

Figure 3 shows the MTMM Pearson correlation matrix of HrQOL together with the four validity tests. Convergent validity was completely confirmed and discriminant validity mostly confirmed. Discriminant test number 4 (see the legend to Figure 3) was met

Table 2. Agreement between child and parent reports of HRQoL and health status

Scales	Mean bias ^b	% ^c	Mean absolute difference ^d	%	SD of difference	<i>r</i> **	Z scores	ICC
HRQoL: physical complaints	-2.01*	6	3.10	10	4.15	0.61	-0.07	0.54
Health status: physical complaints	-1.00*	6	4.89	31	2.16	0.61		0.56
HRQoL: motor functioning	-0.84*	3	1.67	5	3.00	0.50	-2.82*	0.48
Health status: motor functioning	-0.47*	3	1.02	6	1.77	0.54		0.52
HRQoL: autonomy	-0.14*	0	0.75	2	1.84	0.48	-4.30*	0.47
Health status: autonomy	-0.04	0	0.50	3	1.17	0.53		0.53
HRQoL: cognitive functioning	-0.26*	1	2.21	7	3.45	0.61	-0.85	0.61
Health status: cognitive functioning	0.01	0	1.49	9	2.30	0.62		0.62
HRQoL: social functioning	-0.01	0	1.68	5	2.69	0.51	1.61	0.51
Health status: social functioning	-0.02	0	1.04	7	1.78	0.48		0.48
HRQoL/Health status: positive emotions ^a	-1.13*	7	1.81	11	2.49	0.44		0.39
HRQoL/Health status: negative emotions ^a	0.05	0	1.78	11	2.47	0.55		0.55

^aOn these scales health status = HRQoL.

^bChild group mean – parent group mean.

^cPercentage of maximum score.

^dMean of absolute difference between parent–child pairs.

* $p < 0.05$.

**Pearson correlations all $p < 0.001$.

Range of HRQoL 0–32; high score = high HRQoL; range of health status 0–16; high score = high health status.

Figure 2. (a) Regression of the child's positive emotions on the parent's positive emotions. (b) Regression of the child's positive emotions on the parent's positive emotions by age. A higher score represents a better HRQoL.

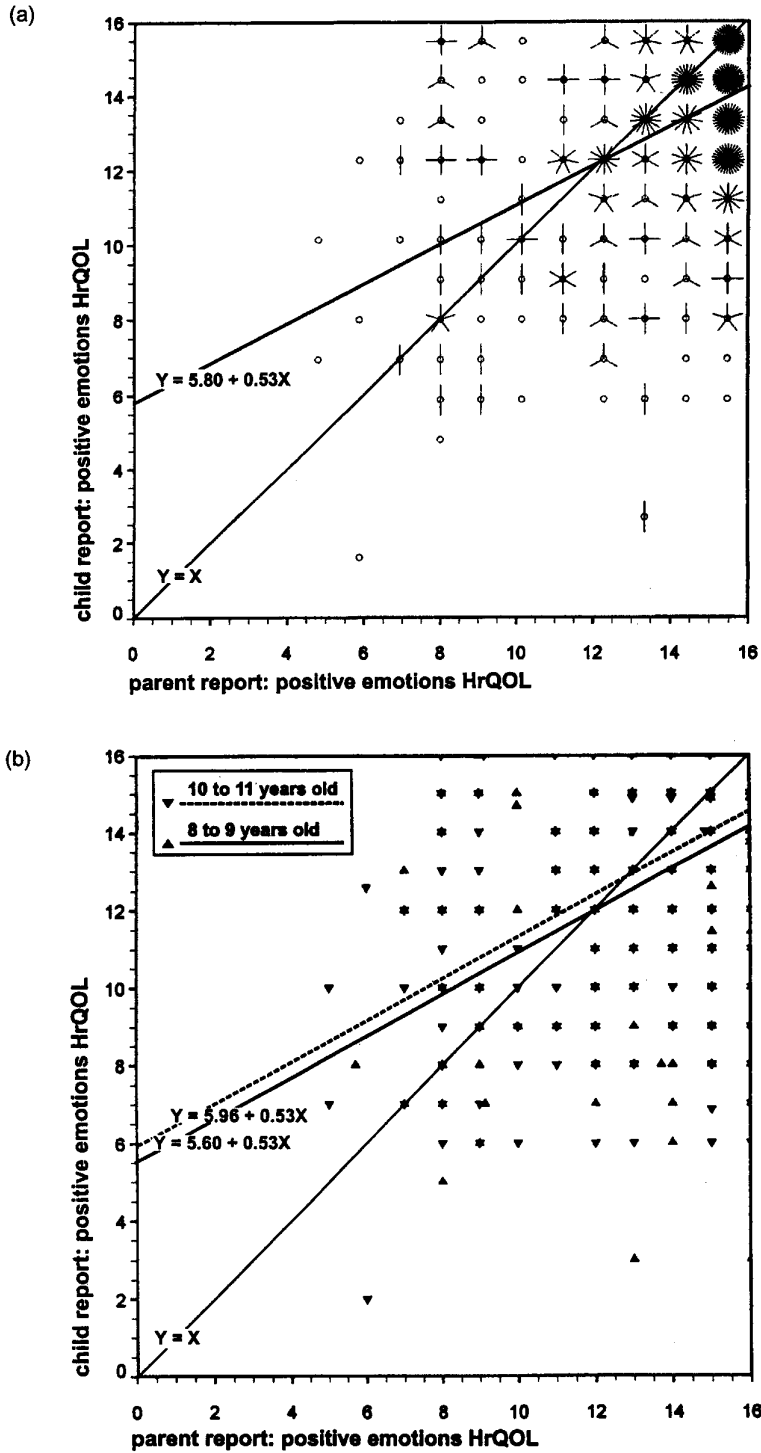


Figure 3. MTMM Pearson correlations between the child and parent reports (methods) for seven HRQoL scales (traits).

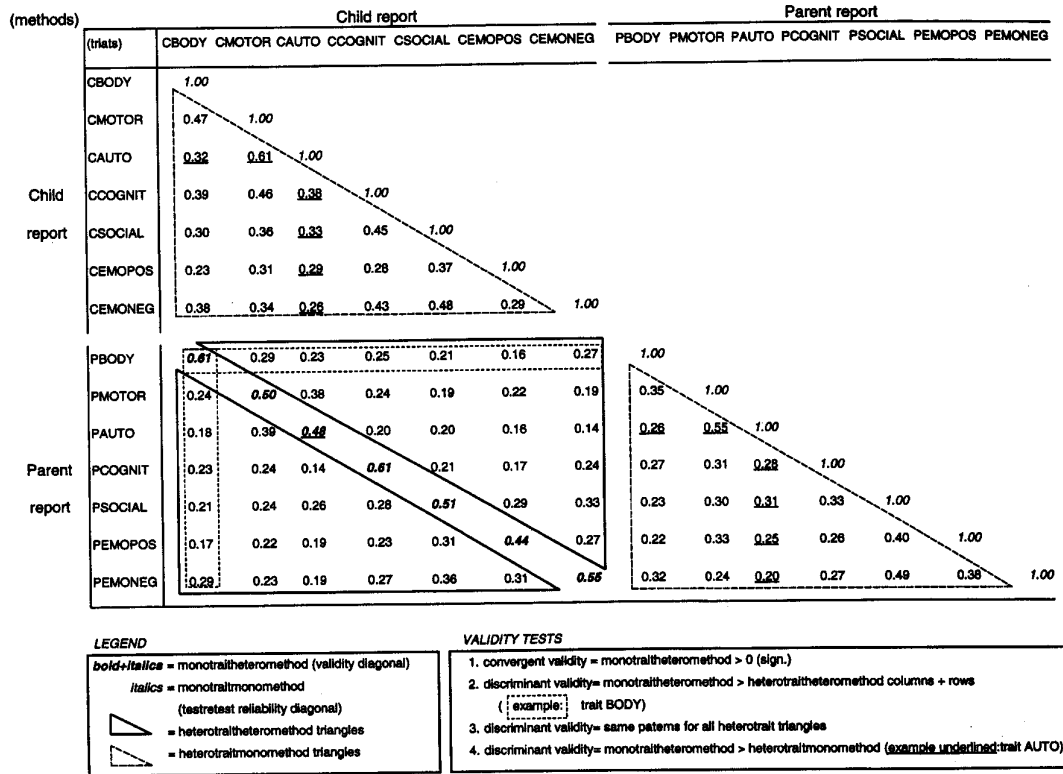
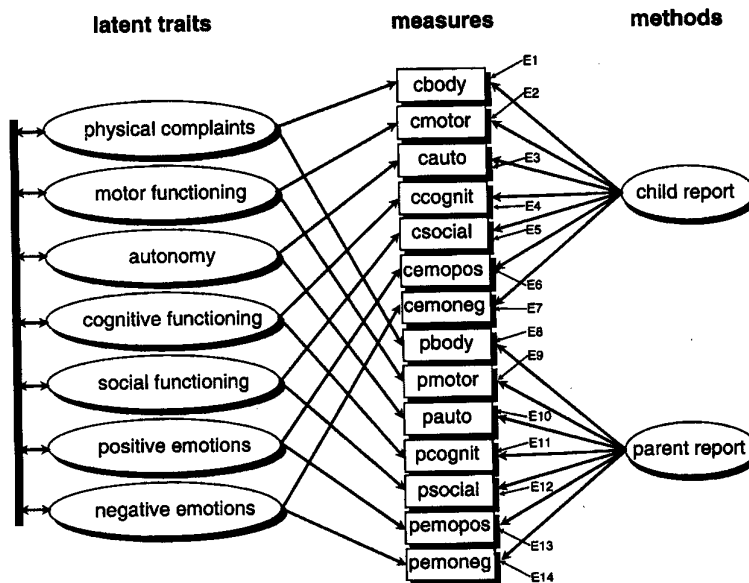


Figure 4. The MTMM model on HRQoL.



except for the traits autonomy (AUTO) and motor functioning (MOTOR). These traits correlated more with each other within both methods (CAUTO-CMOTOR 0.61 and PAUTO-PMOTOR 0.55) than with themselves between methods (CAUTO-PAUTO 0.48 and CMOTOR-PMOTOR 0.50). The MTMM Pearson correlation matrix of health status is not shown in this article. The convergent validity for health status was confirmed completely and the discriminant validity for the most part. Discriminant test number 4 was met with two exceptions. First, autonomy and motor functioning correlated more with each other within both methods than with themselves between methods. Second, positive emotions and social functioning correlated more with each other within the parent report method than with themselves between methods.

The model to be fitted onto the MTMM data in HRQoL by the EQS program is presented in Figure 4. As can be seen in Table 3, the model had a good fit. The children and parent scores were determined primarily by the latent traits (51 and 57%, respectively) and much less by the method (14 and 10%, respectively) and error (35 and 32%, respectively). Therefore, the validity of both methods seemed to be high. The children's scores are explained better by the latent traits physical complaints, motor functioning, positive emotions and negative emotions. The parent scores are explained better by the latent traits physical complaints, motor functioning, positive emotions and negative emotions. The performance was limited for children and parent scores on the autonomy and social functioning scales.

The MTMM model on health status (see Table 4) followed a pattern similar to the pattern of the HRQoL model: good fit, scores determined primarily by the latent trait, and a high overall validity. The children's scores are explained well by the latent trait physical complaints, motor functioning, and positive emotions. The parent's scores are explained well by the latent traits physical complaints, motor functioning, cognitive functioning, positive emotions, and negative emotions. Again, performance was limited for children and parent scores on the autonomy and social functioning scales. HRQoL physical complaints seemed to be explained best by the children's report, Health status physical complaints by the parent's report. To summarize, results of MTMM modelling revealed that the TACQOL was valid as a HRQoL questionnaire as well as a health status questionnaire.

The extent of agreement was related to the level of HRQoL for health status. The regression on positive emotions is given as an example in Figure 2a. If a child and parent both reported low HRQoL, the child

reported relatively higher HRQoL than their parent. If a child and parent both reported a high HRQoL, then the child's scores were relatively lower than the parent scores. All HRQoL and health status scales followed the same pattern. Overall, child scores were less extreme than the parent scores.

The child's age was related to agreement on the autonomy and positive emotions scales (HRQoL and health status: $p < 0.05$). With low autonomy or positive emotions scores children aged 10–11 years were less in agreement with their parents than children aged from 8 to 9 years. Conversely, with high autonomy or positive emotions scores, children aged 10–11 years were more in agreement with their parents than children aged 8–9 years. This age difference with positive emotions is shown as an example in Figure 2b. The greater the distance between the regression line and the $Y = X$ line, the lower the agreement between parents and children.

Table 3. Percentage-explained variance in an MTMM model of HRQoL

Measure method	Latent trait	Method	Error
Physical complaints			
Child	68	8	24
Parent	65	14	21
Motor functioning			
Child	59	10	30
Parent	67	24	9
Autonomy			
Child	41	22	37
Parent	38	5	57
Cognitive functioning			
Child	42	17	40
Parent	54	6	40
Social functioning			
Child	38	30	32
Parent	39	21	40
Positive emotions			
Child	55	6	39
Parent	65	2	32
Negative emotions			
Child	50	5	45
Parent	73	0	26
Total (M%)			
Child	51	14	35
Parent	57	10	32

NFI = Bentler-Bonnett Normed fit Index.
 NNFI = Bentler-Bonnett Non Normed fit Index.
 Goodness of fit (a good fit is > 0.9): NFI = 0.984,
 NNFI = 0.981 and CFI = 0.991.

Table 4. Percentage-explained variance in an MTMM model of health status

Measure method	Latent trait	Method	Error
Physical complaints			
Child	67	11	22
Parent	70	13	17
Motor functioning			
Child	70	9	22
Parent	76	16	8
Autonomy			
Child	36	13	50
Parent	40	6	54
Cognitive functioning			
Child	43	18	39
Parent	55	6	39
Social functioning			
Child	41	25	34
Parent	41	16	44
Positive emotions			
Child	50	5	45
Parent	63	3	34
Negative emotions			
Child	49	3	48
Parent	73	0	26
Total (M%)			
Child	51	12	37
Parent	60	9	32

NFI = Bentler-Bonnett Normed fit Index.

NNFI = Bentler-Bonnett Non Normed fit Index.

Goodness of fit (a good fit is > 0.9): NFI = 0.977,

NNFI = 0.965 and CFI = 0.984.

The child's gender was also related to agreement on the autonomy scale (HRQoL and health status: $p < 0.05$). If the autonomy scores were low, boys were less in agreement with their parents than girls. Conversely, if the autonomy scores were high, boys were more in agreement with their parents than girls.

The presence of a temporary illness was related to agreement on the physical complaints and social functioning health status: $p < 0.05$). With low health status physical complaints or social functioning scores, children with a temporary illness had more agreement with their parents than children without a temporary illness. Conversely, with high health status social functioning scores, children with a temporary illness had less agreement with their parents than children without a temporary illness.

The occurrence of visits to a physician was related to agreement on the autonomy and motor functioning scales (HRQoL and health status: $p < 0.05$). With low

autonomy or motor functioning scores children who visited a physician had more agreement with their parents than children who did not. Conversely, with high autonomy or motor functioning scores, children who visited a physician had less agreement with their parents than children who did not.

The age of the parents was related to agreement on the social functioning scale (HRQoL: $p < 0.05$). With low social functioning scores younger parents had more agreement with their children than older parents. Conversely, with high social functioning scores, younger parents had less agreement with their children than older parents.

Chronic illness, life events, the position of the child in the family and the education level of the parents were not related to agreement between the child and parent reports.

Discussion

Our results showed that measuring health status as well as HRQoL (combining health status with affective evaluation) is possible. The parent and child form TACQoLs had satisfactory internal consistency with regard to HRQoL as well as health status. The convergent validity between the child and parent reports was acknowledged completely and the discriminant validity for the most part. The construct validity of the HRQoL and health status questionnaires was supported by MTMM models. Both the parent and the child reports are valid, but the parent report seemed to perform best on most scales (HRQoL and health status). The child report performed best on HRQoL physical complaints. The performance of both child and parent reports was limited on the autonomy and social functioning scales. Consequently, the questionnaires do not fully meet the criteria on these scales. It is not known however, if these scales have a worse quality than other instruments because MTMM modelling performance of other HRQoL or health status instruments has not yet been studied, and our instrument had good reliability, convergent and discriminant validity and overall construct validity.

As far as generalization is concerned, some reservations have to be made. Many of the children were suffering from minor and temporary illnesses such as a cold or influenza. This appeared to have a relation to agreement on the (health status) physical complaints and social functioning scales. Furthermore, the parent's level of education in our study was a little higher than in the general Dutch population. This was not related to agreement between the

children and parents. Moreover, the sample did not include children with mental disorders. Apart from these reservations, the study sample represented ordinary Dutch families. However, being a sample drawn from the normal population, any generalization to clinical populations may be limited. There is reason to believe that this is not a problem. Firstly, the study contained 202 (19%) children with at least one chronic illness. The effect of chronic illness on proxy agreements could therefore be investigated in this study and appeared to be absent. Secondly, the TACQOL questionnaires were developed and studied by means of a clinical sample. The questions included turned out to be relevant to a clinical population (Vogels *et al.*, submitted).

Conceptualization of HRQoL as a combination of health status and affective evaluation has consequences for agreement. According to previous studies, agreement seemed to be relatively good for observable measures.^{2,4,21} Affective evaluations are probably less observable for parents than health status. Therefore, it could be expected that agreement between parent and child on HRQoL were lower than the agreement on health status. Indeed, HRQoL agreement on motor functioning and autonomy was significantly lower than health status agreement. However, HRQoL agreement matched health status agreement on the other scales, which indicates that adding affective evaluation does not influence observability. According to other studies, social and psychological HRQoL seem to be less observable than physical HRQoL.^{13,21} Perhaps this kind of health status scales already have a strong subjective component. This could explain the lack of difference in agreement between HRQoL and health status on cognitive and social functioning, positive and negative emotions, but not on physical complaints. The physical complaints scale included questions concerning pain. These are probably less observable than the more visible motor problems. Therefore, adding affective evaluation may not increase the subjectiveness of the aforementioned scales.

By adding affective evaluation to HRQoL, agreement on motor functioning and autonomy became poor, but the level of subjectiveness was more evenly distributed among the HRQoL scales. It would be interesting to see the effect of adding affective evaluation to adult HRQoL research.

In the following paragraphs, the discussion about the results on proxy agreement is grouped around the main domains physical, psychological and social functioning. Our results will be compared with studies about proxy on adults (HRQoL as well as health status) and with studies assessing agreement

between children and their parents.

The TACQOL scales, physical complaints, motor functioning and autonomy cover physical HRQoL. The HRQoL and health status results revealed that on average children had more pessimistic ideas about their own physical functioning than their parents did. A similar result was found in a study assessing pain amongst hospitalized children.²⁷ Conversely, in several studies, on average children, adults or elderly people agreed with their proxies or were more optimistic about their physical functioning.^{2,4,13,21,37} The Pearson correlations between self- and proxy reports varied from low to high in the studies previously mentioned amongst children, adults and elderly people (range: 0.18–0.75). The wide variation in the correlations may be due to the observability of the items assessed, next to age, sample size or differences in health.

The TACQOL scales, cognitive functioning, positive emotions and negative emotions cover psychological HRQoL. The results indicate that on average children agree with their parents or are more pessimistic. Similar results were also found in other studies, along with contrasting results which indicated children as being more optimistic than their proxies about psychological functioning.^{13,21,37,38} In several studies including ours, the Pearson correlations were close to 0.5.^{4,21,26} According to some other studies, the correlation was close to 0.25 or not significant at all.^{38–40} Agreement was irrespective of patients' age and of psychological phenomena (cognitive or emotional). However, our study revealed that with low positive emotions scores older children agreed less with their parents than younger children. Conversely, with high positive emotions scores, the older children agreed more with their parents.

The TACQOL social functioning scale is intended to cover social HRQoL. According to the HRQoL as well as the health status tests in this study, the means of the children's and parents' scores were similar. A comparable result was reported in other studies amongst children, adults and elderly people.^{4,21,37} However, in our study a relation was found between the level of the HRQoL scores and agreement. Furthermore, the correlations in the other studies were modest. The Pearson correlation of these studies is close to 0.5.^{4,21,26} The age of the parents related to agreement on social HRQoL. With low scores younger parents had more agreement with their children, whereas with high scores older parents had more agreement with their children.

The results of this explorative study indicate that parent reports cannot be substituted for child reports. One might consider parents failing as informants

about the child and children as lacking a time perspective. Yet, both the child and parent reports proved to be valid. An important result is that agreement relates to the size of the HRQoL scores. For several scales agreement relates to background variables such as gender, age, temporary illness, age of the parents and visits to a physician. The child scores appear to be less extreme than the parent scores. When parents are very pessimistic, children seem to say 'it is not so bad' and when parents are very optimistic, children seem to say 'it is not that good'. Children with disturbed health seem to place more emphasis on making these statements.

Future studies using a longitudinal design should enable the following factors to be investigated: individual child-parent differences, the impact of the proxy's gender in combination with the gender of the child, the HRQoL agreement stability, the effect of changing health status, the effect of rating experience and the effect of feedback to parents and children about their disagreement. Furthermore, if the observability is influencing agreement, we need to study what exactly parents and children do observe. Until these studies are performed and a consensus is reached about the consequences of the MTMM modelling results, techniques could be developed to help clinical decision making.

In conclusion, the parent report may provide a substitute for children's HRQoL at a group level, but we have shown that large differences can exist in proxy agreement at the individual child-parent level.

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