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Parent-child agreement on health related quality of life in children with functional constipation in primary care

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Short title:

Parent-child agreement on HRQoL in childhood functional constipation

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Abstract

Objective Functional constipation (FC) has a major impact on the health related quality of life (HRQoL) of children.The aim of this study was to evaluate parent-child agreement on HRQoL in children (8 to 17 years) with FC in primary care.

Methods Children diagnosed with FC by their clinician were eligible. HRQoL was measured with the Defecation Disorder List (DDL, score 0-100), and the EuroQol™-5-Dimension-Youth Visual Analogue Scale (EQ-5D-Y-VAS, scale 0-100). Parent-child agreement was examined with discrepancy scores, Intraclass Correlation Coefficients (ICC) and Bland-Altman plots.

Results Fifty-six children, median age of 10 years (IQR 8-12) and their parents were included. Parent-child agreement at a group level was good, with an ICC of 0.80 (95%-CI 0.67-0.88) for the DDL, and 0.78 (95%-CI 0.65-0.87) for the EQ-5D-Y-VAS. Mean discrepancy scores for the DDL and EQ-5D-Y-VAS were small: -2.6 and -2.9, implying that parents were slightly more positive about the HRQoL than their children. Bland-Altman plots showed considerable discordance between individual parent-child pairs. Limits of agreement were -19.7 and 14.6 for the DDL and -27.6 and 21.8 for the EQ-5D-Y-VAS.

Conclusion There is good parent-child agreement on HRQoL in children with FC at group level. However, a substantial number of parent-child pairs differed considerably on their rating of the HRQoL of the child. Therefore, we recommend clinicians, if they want to have an impression of the impact of the FC on the HRQoL of the child, to ask both the child and the parent(s).

Keywords: Parent proxy-report, child self-report, health outcomes, quality of life.

What is known?

- Functional constipation (FC) has a major impact on the Health Related Quality of Life (HRQoL) of children.
- Children and parents may report on different aspects of the child's HRQoL.

What is new?

- There is good parent-child agreement in children with FC on a group level.
- A substantial number of individual parent-child pairs differed considerably on their rating on the HRQoL of the child.
- When clinicians want to have an impression of the impact of the FC on the HRQoL of the child, it is recommended to assess HRQoL of the child to both the child and the parent.

Introduction

Functional constipation (FC) is a common disorder in children, with a pooled prevalence rate of 9.5 percent.(1) FC has a major impact on the health related quality of life (HRQoL) of children and their families, with the greatest influence on the emotional and social aspects of life.(2-5) Parental emotional perceptions of illness are correlated to treatment adherence in children with FC.(6) Therefore, it is important for clinicians to ask for the consequences of the FC for the wellbeing of the child.(7) In research, HRQoL is identified by experts as an important outcome measure in clinical trials evaluating new interventions for childhood FC.(7, 8)

There is substantial debate in the health outcomes literature regarding the most appropriate respondent for assessing children's HRQoL: the child self or the parent(s).(9-13) As HRQoL pertains to an individual's subjective perceptions, a child's self-report would represent the child's situation best.(10, 12) A parent might provide more valid information concerning more abstract health related concepts, i.e. the emotional impact of illness.(10) However, a potential drawback of a parent's report might be that it is affected by the impact of the child's condition on the family life.(10, 14) Therefore, information about the agreement between child and parent perceptions of HRQoL of the child is important in order to answer the question whether child self-reports and a parent proxy-reports are interchangeable.

In young children, a parent-proxy report will be the only option to assess HRQoL.(10, 15) In children from the age of 8 years clinicians and researchers can rely on a parent proxy-report and a child self-report when they need to be informed on the HRQoL.(15, 16) However, for practical reasons one often relies on one of the two reports. Previous studies investigating the agreement between child and parents perceptions of HRQoL reported inconsistent results.(10, 13, 17, 18) In general, it seems that parents were more negative than their child on the HRQoL if

their child had a chronic disease, and more positive if the child was healthy.(10, 13, 17-19) In addition, parent-child agreement might be influenced by age and gender of the child, but the relationship between the child's age and gender and parent-child agreement is uncertain.(17)

Only one previous study has examined parent-child agreement in children with FC. This was a population from a university hospital.(20) The level of agreement in that study was low, and therefore, the authors advised to use both a parent proxy and a child self-report to measure HRQoL. In the Netherlands, children with FC are first seen in primary care. Children with diagnostic or therapeutic problems will be referred to the pediatrician or pediatric gastroenterologist. Therefore, the selection of patients with FC seen in primary care is different from that seen in a university hospital. This difference in case-mix might influence parent-child agreement. Therefore we designed a study to examine parent-child agreement on HRQoL in children (aged 8–17 years) with FC in primary care. Secondary aim was to investigate whether agreement was associated with age or gender of the child.

Methods

Study design and participants

This study was designed as an agreement study. We used baseline data of a RCT on the effectiveness and cost-effectiveness of physiotherapy in children with FC aged 4 to 17 years (Netherlands Trial Register, number 4797). Children diagnosed with FC by their general practitioner or pediatrician were included in that trial. Exclusion criteria for the RCT were children who had: 1) already received physiotherapy or urotherapy for FC in the past three years, 2) psychopathology affecting protocol adherence, and 3) serious or terminal illness. The RCT was approved by the Medical Ethical Board of the University Medical Center Groningen

(number METc 2013/331. Both parents and child (if aged ≥ 12 years) provided informed consent to participate in the study.

For this agreement study only data of children aged 8 to 17 years were used, because children below eight years are too young to provide a self-report of their HRQoL.(10, 15)

Measurements

HRQoL was measured with a disease specific questionnaire, the Defecation Disorder List (DDL) and a health status questionnaire, the Euroqol-5-Dimensions-Youth (EQ-5D-Y).(21-23) The questionnaires were completed both by the child and by one of the parents. Children and parents were instructed to fill in the questionnaires independently.

Disease specific Quality of Life

We used the emotional and social functioning subdomains of the Defecation Disorder List (DDL) as these two subdomains of the DDL measure HRQoL.(21, 22) These two subdomains of the DDL together consist of 25 statements, answered on a 5-point Likert scale, to indicate to what extent the user agrees with that statement. This corresponds with a score of 0, 25, 50, 75 or 100 points per statement. The (subdomain) scores are computed as the sum of the items divided by the number of items answered. The lowest possible score is 0 (poorest quality of life) and the maximum score 100 (best quality of life).

Health status

Of the Euroqol-5-Dimensions-Youth (EQ-5D-Y) the visual analogue scale (VAS) was used to measure health status.(23) The lowest possible score was 0 (worst health you can imagine) and the highest score was 100 (best health you can imagine).

Demographic and symptom related information

Demographic and health information, in particular age, gender, type of symptoms, duration and onset of symptoms and (information on) the use of laxatives, was assessed based on a questionnaire completed by the parents. Symptoms related to FC were assessed using a Dutch version of the 'Questionnaire on Pediatric Gastrointestinal Symptoms Rome-III' (QPGS-RIII).(24)

Statistical analysis

Appropriate descriptive statistics were used to present patient characteristics, symptoms of FC and the quality of life outcomes. Less than 1% of the statements on the DDL questionnaire remained unanswered (missing). The discrepancy scores (Δ) between parent-proxy and child-self reported HRQoL were calculated for all outcomes (DDL total score, DDL emotional and social subdomain scores and EQ-5D-Y-VAS score).

The level of parent-child agreement on HRQoL on group level was analyzed using intra-class correlation coefficients (ICC), using a two-way random model, single measures with absolute agreement. To indicate the level of agreement the conservative criteria of Portney and Watkins (2009) were used: an ICC of ≤ 0.75 is then classified as poor to moderate agreement; an ICC of 0.75-0.90 as good agreement; and an ICC of >0.90 as "reasonable agreement for clinical measurements".(25, 26)

Individual parent-child agreement was evaluated by visual inspection of the Bland-Altman plots. Perfect agreement between a child and a parent entails that the discrepancy score (Δ) is equal to zero. No systematic bias is assumed when the 95% confidence intervals around the mean discrepancy scores include zero. Limits of agreement were computed as follows: mean difference±1.96*standard deviation of the difference. Approximately 95% of the differences between child and parent reported HRQoL will lie between the limits of agreement.

In order to determine whether age and gender of the child influenced parent-child agreement we conducted multivariate linear regression analyses. Statistical analyses were performed using SPSS Version 24.0 (IBM corp., Armonk, New York, USA).

Sample size

An adequate sample size is important in order to obtain a reliable ICC parameter with acceptable precision. When expecting an ICC of 0.8, using two observers per patient (child-report and parent proxy-report), and a 95%CI with a width of 0.2, a minimal sample size of 50 patients is required.(27) In addition, a sample size of approximately 50 patients is required to provide a reasonable number of dots in a Bland Altman plot to estimate the limits of agreement.(28)

Results

Participants

Among the 134 children participating in the RCT, 56 children fulfilled the inclusion criteria for this agreement study, i.e. were between 8 and 17 years of age. These were 24 boys and 32 girls, with a median age of 10 years (IQR 8 – 12). Patient characteristics are presented in Table 1. Disease specific HRQoL and health status of the children reported by the children and the parents are shown in Table 2.

Level of parent-child agreement

The mean discrepancy scores and the corresponding 95%CI intervals between child self and parent proxy-reports were for the DDL total score, DDL emotional functioning subdomain, DDL social functioning subdomain and EQ-5D-Y-VAS, -2.6 (-4.9 – -0.2), -2.2 (-5.2 – 0.7), -3.0 (-5.9 – 0.0), and -2.9 (-6.3 – 0.5), respectively. A negative score indicates that parents rated the HRQoL higher than the children did.

The level of parent-child agreement was good for the DDL total score (ICC: 0.80, 95%-CI 0.67–0.88), the DDL social functioning subdomain (ICC: 0.78, 95%-CI 0.65–0.87), and the EQ-5D-Y-VAS (ICC: 0.78, 95%-CI 0.65–0.88), and poor to moderate for the DDL emotional functioning subdomain (ICC: 0.73, 95%-CI 0.58–0.83) (Table 2).

Bland-Altman plots are shown in Figure 1. Observed limits of agreement for the DDL total score were -19.7 and 14.6, for the emotional functioning subdomain -23.9 and 19.5, for the social functioning subdomain -24.2 and 18.3, and for the EQ-5D-Y-VAS -27.6 and 21.8. With a range on the scores between 0 and 100, the intervals between the limits of agreement showed that the level of agreement varied considerably between individual parent-child pairs. **Factors associated with parent child agreement**

Multivariate linear regression analyses showed that age and gender of the child were not significantly associated with parent-child agreement for all outcomes (data not shown).

Discussion

Main findings

This study showed that parent-child agreement on HRQoL in children with functional constipation was good on group level. In general, parents reported a minimally better disease specific HRQoL and health status than the children did. However, for individual child-parent pairs the level of agreement varied considerably. This is shown in the wide intervals between the limits of agreement, that were -19.7 and 14.6 (DDL total score,), and -27.6 and 21.8, (EQ-5D-Y-VAS). Therefore, it is sufficient to use only one report (parent or child which is more convenient), when one is interested in the HRQoL of a group of children with FC in primary care. However, when one is interested in the HRQoL of an individual child, we recommend to

use both reports. Age and gender of a child did not affect parent-child agreement on HRQoL in children with FC in primary care.

Comparison to literature

Consistent with our study, three other studies on FC, performed in a hospital setting, reported small mean discrepancy scores between child self and parent proxy reported HRQoL.(20, 29, 30) In our study parents were in general slightly more positive on the child's HRQoL. This overestimation of the child's HRQoL is in accordance to studies measuring parent-child agreement in healthy children.(10, 13, 17-19) In contrast, the three studies on parent-child agreement in a university hospital setting showed that parents were in general slightly more negative on the HRQoL of their child than the child was. Parents of children with other chronic conditions also tend to underestimate the child's HRQoL.(10, 13, 17-19) However, as stated before, on average the differences between parents and children were small.

Our findings of good parent-child agreement concerning HRQoL are consistent with another study in children with FC.(20) The level of parent-child agreement concerning HRQoL found in our study was better (ICCs between 0.73 and 0.80), than the parent-child agreement in the other study (ICCs between 0.55 and 0.74). Theoretically, these differences could be explained by either the other questionnaires that were used (DDL/EQ-5D-Y-VAS in this study vsPedsQL 4.0 Generic Core Scale in the other study), their clinical settings (primary care vs tertiary care) or the limitation of comparing ICCs for the level of parent-child agreement.(31)

Strengths and limitations

This is the first study examining agreement for HRQoL in children with FC for individual parent-child pairs. In addition, parent-child agreement was assessed for two different type of questionnaires measuring HRQoL, a disease-specific and a generic questionnaire. Disease

specific instruments are more sensitive to detect small but relevant changes in the patient's HRQoL, while generic instruments are more useful to compare HRQoL across different patient groups.(32) By analyzing different aspects of agreement, such as by using discrepancy scores, ICCs, and Bland-Altman plots, our study attempts to comprehensively report on the nature of discrepancies between parent proxy and child self-reports concerning HRQoL in children with FC.

Our findings should be interpreted in the light of the following limitations. Parents and children have completed the questionnaires at home. The instruction was to complete the questionnaires independently. Although this study showed that the level of agreement between individual child-parent pairs varied considerably, there is a possibility that they colluded, and therefore both parties might have given more moderate responses, which would enhance agreement and minimize differences.(17) Secondly, we did not collected demographic data of the parents. Thirdly, because of a limited sample size we only evaluated if age and gender of a child influenced parent-child agreement. We performed some hypothesize generating post hoc analyses but we found no indication that the number of Rome III criteria in a child, or separate Rome III criteria, influenced parent-child agreement on HRQoL (data not shown). In addition, there is limited knowledge about the psychometric properties of the DDL questionnaire. Finally, a limitation of the comparison of parent-child agreement using the ICC is that the ICC is an index of absolute agreement and consists of the ratio of between-subject variability and total variability.(31) Less heterogeneity in HRQoL scores between children may generate lower ICCs for parent-child agreement. In primary care children were seen with recent onset symptoms but also children with symptoms of longer duration. Therefore, it can be expected that there is much heterogeneity in HRQoL between children, which will lead to a better ICC. Thus, for the

comparison of the level of parent-child agreement between studies, it is important to use several methods to evaluate agreement, i.e. discrepancy scores, ICCs, and Bland-Altman plots.

Implications for research

On a group level parent-child agreement concerning HRQoL was good. Therefore, in research focusing on group results, one can use either a parent-proxy report or a child-self report to assess HRQoL. For research looking at the individual patient's level, it is recommended to assess both the parent's, and the child's perception of the impact of the disease. More research into factors like severity of disease, duration of symptoms, parent-child relationship or mother or father's as proxy raters, that may influence parent-child agreement is needed. In addition, more research is needed into how and if a discrepancy between parent and child influence clinical decision making.

Implications for clinical practice

We found in our study that children and their parents may rate the impact of the FC on the quality of life of the child differently. Perceptions of the emotional impact of the FC may influence treatment adherence, as was found in a recent study.(6) Therefore, we advise clinicians to pay attention as well to the parent's perception of the child's HRQoL as to that of the child. A short question, like "we would like to know how good or bad your health is today on a scale from 0 to 100" which is used in the EQ-5D-Y-VAS, will be most suitable in clinical practice. However, as FC influenced especially the emotional and social aspects of HRQoL, the DDL questionnaire will be better in detecting relevant health issues of children with FC.(5)

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Legends

Figure 1. Bland-Altman plots. Top left: DDL total score, Top right: EQ-5D-Y-VAS score, Bottom left: DDL emotional functioning domain score, Bottom right: DDL social functioning domain score. Discrepancy scores (Δ) were calculated by subtracting each parent's score from their child's score. Abbreviations: DDL, Defecation Disorder List; EQ-5D-Y-VAS, Euroqol-5-Dimensions-Youth Visual Analoge Scale; LOA, Limits of Agreement.

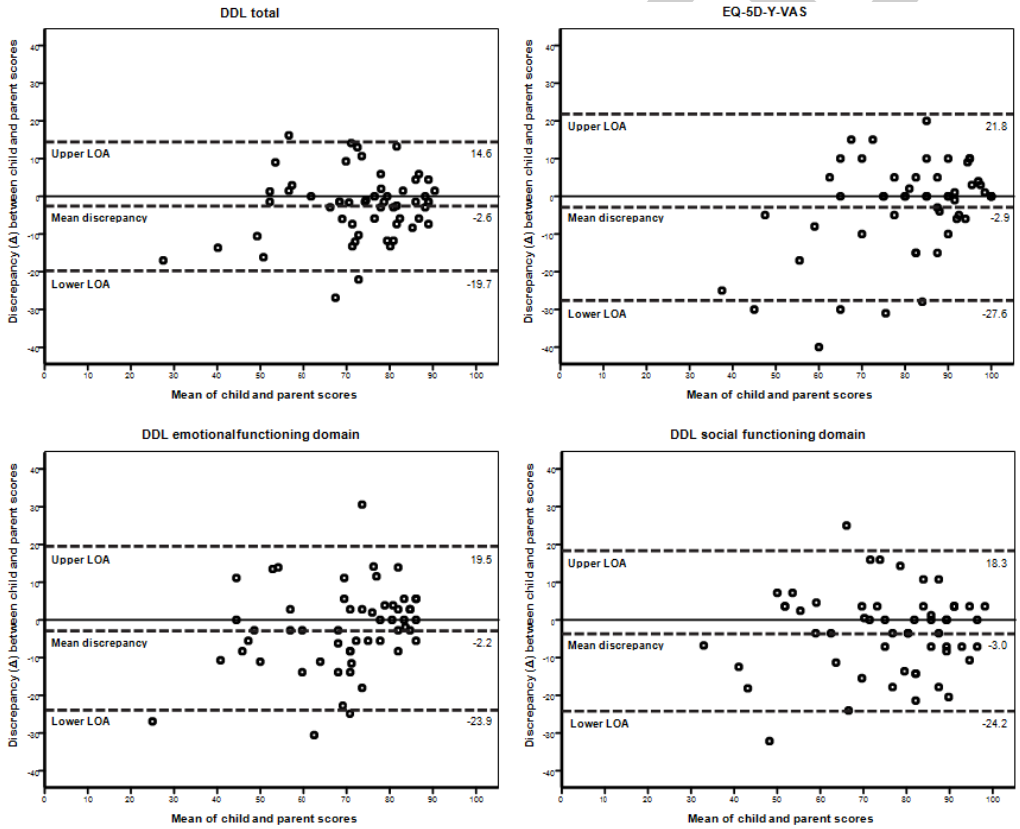

Table 1 – Baseline characteristics of the children aged 8 to 18 years with functional constipation (FC) diagnosed by their general practitioner or pediatrician (n=56)

Age median (IQR) in years	10.0 (8.3–12.0)
Gender (% girls)	57.1
Duration of symptoms (n)	
≤3 months	8/50
3-12 months	6/50
>12 months	36/50
Abdominal pain/discomfort in the previous 4 weeks (n)	
Never	6/56
1-3 times a month	14/56
Once a week	7/56
Multiple times a week	21/56
Every Day	8/56
FC symptoms (Rome-III criteria for FC) (n)	
≤2 defecations in the toilet per week	14/56
Fecal incontinence ≥1 per week	16/56
Stool withholding	10/56
Painful or hard bowel movements	43/56
Large fecal mass in the abdomen or rectum	40/56
Large stools that obstruct the toilet	12/56
Use of laxatives in the previous 4 weeks (n)	
Yes	32/47
No	15/47
Previous episodes of FC (n)	
≥ 2	34/52
1	2/52
0	16/52

Abbreviations: n, number; FC, functional constipation; IQR, Inter Quartile Range

Table 2 – Disease specific quality of life and health status of children with functional constipation (FC) (n=56)

	Reported by		**Results to evaluate absolute agreement**		
	Children	**Parents**			
	Median (IQR)	Median (IQR)	Mean discrepancy score[a] (95%–CI)	Limits of agreement	ICC (95%–CI)
DDL total score	76 (65–84)	78 (67–85)	-2.6 (-4.9– -0.2)	-19.7 – 14.6	0.80 (0.67-0.88)
DDL Emotional functioning	72 (58–83)	75 (62–83)	-2.2 (-5.2 – 0.7)	-23.9 – 19.5	0.73 (0.58-0.83)
DDL Social functioning	79 (64–89)	82 (65–89)	-3.0 (-5.9 – 0.0)	-24.2 – 18.3	0.78 (0.65-0.87)
EQ-5D-Y-VAS	84 (71–92)	85 (75–94)	-2.9 (-6.3 – 0.5)	-27.6 – 21.8	0.78 (0.65-0.87)

[a]Discrepancy scores were calculated by subtracting each parent's score from their child's score. Negative differences indicate that parents evaluated the disease specific quality of life and health status of their children better than the children did. Unlike the individual HRQoL scores reported by parents and children, the mean discrepancy scores were normally distributed in all outcome variables.

Abbreviations: IQR, Inter Quartile Range; CI, Confidence Interval; ICC, Intraclass Correlation Coefficient; DDL, Defecation Disorder List; EQ-5D-Y-VAS, Euroqol-5-Dimensions-Youth Visual Analogue Scale