

# Health Related Quality of Life in Children with Constipation-Associated Fecal Incontinence

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**Objectives** With a disease-specific questionnaire, this study aimed to evaluate health-related quality of life (HRQoL) in children with constipation in association with clinical characteristics.

**Study design** Children with constipation-associated fecal incontinence (n = 114), 8 to 18 years, filled out the Defecation Disorder List at a Dutch tertiary hospital. Correlations and linear regression analysis between clinical characteristics and scores on emotional and social functioning were calculated. Specific concerns of children were described by individual item scores of these domains.

**Results** Higher frequency of fecal incontinence episodes was associated with lower emotional and social functioning. Linear regression analysis showed a significant association between social functioning and fecal incontinence, but the variance of the model was low (adjusted  $R^2 = 0.08$ ). Between 70% to 80% of children were concerned about experiencing fecal incontinence unnoticeably and the attendant social consequences. Children did not report having fewer friends and participated well in social events.

**Conclusion** Lower HRQoL regarding disease-specific emotional and social functioning was reported in children with frequent episodes of constipation-associated fecal incontinence. However, other nonspecified factors may also influence HRQoL of these children. Most children reported relatively more emotional concerns than social consequences. (*J Pediatr* 2009;154:749-53)

Childhood constipation is worldwide one of the most common pediatric gastrointestinal disorders, with prevalence in the general population ranging from 0.7% to 29.6%.<sup>1</sup> Functional constipation is characterized by a low defecation frequency, passage of hard and large stools, and painful defecation without an underlying organic cause.<sup>2</sup> Up to 84% of children with constipation experience frequent episodes of fecal incontinence, which is believed to be overflow caused by fecal impaction.<sup>3</sup>

Functional constipation and secondary fecal incontinence are sources of distress and concern for a child and their family. Symptoms often persist for years, and relapses are common.<sup>3-6</sup> Furthermore, fecal incontinence may cause feelings of guilt and embarrassment and is associated with behavior problems, both internalizing (social withdrawal, anxiety, and depression) and externalizing (delinquent behavior and aggression).<sup>7-9</sup> Successful treatment is often associated with improvement of behavior.<sup>10-12</sup> Nonetheless, it remains the question whether behavior problems are the result of fecal incontinence or vice versa.

The impact of chronic diseases on children is assessed by measuring health-related quality of life (HRQoL). HRQoL refers to the specific impact of an illness on physical, social, and emotional functioning.<sup>13</sup> In a recent study, parents reported lower HRQoL regarding both physical and psychosocial functioning, and general health and behavior aspects in their children with functional defecation disorders compared with healthy children.<sup>14</sup> Both self-report and parental assessment showed that long duration of symptoms and physical complaints associated with constipation may result in impaired HRQoL in children with constipation.<sup>15</sup> HRQoL in these studies was measured by a generic questionnaire and thus may lack precision and sensitivity to identify important effects of distinctive symptoms of functional constipation, such as fecal incontinence. Recently, a disease-specific questionnaire, the Defecation Disorder List (DDL), was developed to assess the impact of functional constipation and fecal incontinence on HRQoL in children.<sup>16</sup> Using this questionnaire, we aimed to describe HRQoL in children with constipation with fecal incontinence and to investigate to what extent clinical characteristics are associated with reported HRQoL.

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DDL	Defecation disorder list	HRQoL	Health-related quality of life
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## METHODS

All consecutive patients between 8 to 18 years of age referred by general practitioners (GP) and pediatricians to the gastrointestinal outpatient clinic at the Emma Children's Hospital between September 2001 and November 2005 were eligible. Children fulfilled the definition of pediatric functional constipation, comprising the presence of at least 2 of the following 4 symptoms: (1) spontaneous defecation frequency <3 per week, (2) fecal incontinence episodes  $\geq 2$  per week, (3) passage of large-diameter stools that may obstruct the toilet, and (4) palpable abdominal or rectal mass on physical examination.<sup>17</sup> Children with organic causes of constipation, including Hirschsprung's disease, muscle disorders, prior rectoanal surgery, spina bifida, mental retardation, or hypothyroidism were not eligible. The study protocol was approved by the medical ethical committee of the Academic Medical Center of Amsterdam. All children or parents gave informed consent.

For assessment of clinical symptoms of functional constipation, children and their parents were asked to record defecation frequency and fecal incontinence episodes, together with passage of large amounts of stools, presence of painful defecation, abdominal pain, and urinary incontinence in a diary 1 week before their first visit to the outpatient clinic. During this week laxative treatment was discontinued. This was done to obtain a similar baseline measurement in all children. At the first visit, a standardized interview was conducted to determine defecation pattern including defecation frequency, stool consistency, painful defecation, passage of large amount of stools, fecal incontinence episodes, abdominal pain, and urinary incontinence. Furthermore, information was collected regarding age of onset of symptoms, treatment history, and family history of gastrointestinal disorders. Abdominal and rectal examination was performed to evaluate the presence of fecal impaction.

The DDL was handed out to all children at the second visit to the outpatient clinic. This second visit was scheduled 1 week (maximal range to 2 weeks) after the first visit. Three days in advance of this second visit, disimpaction with rectal enemas or bisacodyl suppositories once daily was prescribed, to achieve complete disimpaction in all children. At the start of the second visit, the interviewer explained the questionnaire and stayed in the room. Children were asked to fill out the DDL by themselves without discussion with their parents. Maintenance treatment in the form of oral laxatives was started after this second visit.

### Instrument

The DDL was developed to assess the impact of functional defecation disorders in children between 7 and 15 years in a study with 27 children. Tested in children with constipation and functional nonretentive fecal incontinence, it was found to be a valid and reliable instrument.<sup>16</sup> The questionnaire consists of 37 items encompassing 4 domains: (1) constipation related (3 items); (2) emotional functioning (13 items); (3) social functioning (11 items); and (4) treatment/

interventions (10 items).<sup>16</sup> Items are phrased as statements in the first person and in the present tense, except for 4 items addressing feelings or symptoms in the past 2 weeks. Children were asked to indicate whether they agree with a statement on a 5-point Likert scale. Depending on the kind of question, the following answering options were used: "very much/much/quite a lot/a little/not at all" or "always/often/sometimes/rarely/never." For calculation of domain scores, items were reverse scored so that higher scores indicate a better HRQoL. In the calculation of the domain scores a maximum of 30% of missing items per domain was allowed for. These missing values were then replaced by the mean value of the nonmissing item scores. The previous study by Voskuil et al<sup>16</sup> on the development of the DDL reported satisfactory reliabilities (Cronbach's alphas) for the 4 domains: (1) constipation related 0.65; (2) emotional functioning 0.76; (3) social functioning 0.63; and (4) treatment/interventions 0.61.

### Statistical Analysis

Statistical analysis was performed by use of SPSS windows version 12.0.2 (SPSS Inc., Chicago, Illinois). Clinical symptoms of functional constipation at baseline are presented in a descriptive way. Differences between children included or excluded for analysis were tested for significance by Mann-Whitney U test for continuous data or  $\chi^2$  test for categorical data. Reliability was assessed by examining the "internal consistency," referring to the extent to which the items in a domain assess the same characteristic. Internal consistency was measured with the Cronbach alpha and considered satisfactory if the Cronbach alpha value was >0.6 and excellent if >0.9.<sup>16</sup> For domains with satisfactory reliability, the correlations between sum scores of the domain and clinical characteristics (sex, age at intake, durations of symptoms, defecation frequency per week, and fecal incontinence frequency per week) were calculated by Pearson correlation or Spearman rho. Linear regression analysis was performed with the above mentioned characteristics included in the model. For both regressions, the explained variance (adjusted R square) was determined, and it was tested with the F-test. T-values and their significance level were calculated to test the hypothesis whether the contribution (the regression coefficient [ $\beta$ ]) of an entered variable significantly differed from zero. Furthermore, individual item scores of the domains with satisfactory reliability are presented.

## RESULTS

A total of 136 children with constipation participated in the study. The DDL could not be retrieved in the medical notes in three children, who were therefore excluded from the study. As the DDL aims to measure the consequences of constipation and fecal incontinence, children with no fecal incontinence at baseline or no answers to specific questions on fecal incontinence (8 items of the in total 37 DDL-items) were excluded for analysis. On the basis of this criterion, the DDL of 19 children were excluded. In total, the DDL of 114

**Table I. Baseline characteristics of 114 children with constipation and fecal incontinence**

Demographics		
Age at intake, mean (SD), y	10.8	(2.0)
Age group at intake, No (%)		
8-12 y	88/114	(77.2)
≥12 y	26/114	(22.8)
Boys, No (%)	78/114	(68.4)
History		
Duration of symptoms, mean (SD), y	6.7	(2.5)
Period of treatment, median (IQR), mo	18.0	(6.0-48.0)
Positive family history, No (%)	43/111	(38.7)
Clinical symptoms		
Defecation frequency/week, median (IQR)	2.0	(1.0-3.0)
<3 times per week, No (%)	82	(71.9)
Fecal incontinence frequency/week, median (IQR)	8.4	(3.5-14.0)
≥ 7 times per week, No (%)	67	(58.8)
Large amount of stool, No (%)	82/113	(72.6)
Painful defecation, No (%)	62/110	(56.4)
Abdominal pain, No (%)	81/113	(71.7)
Urinary incontinence, No (%)	27/114	(23.7)
Physical examination		
Abdominal scybalus, No (%)	28/102	(27.5)
Rectal scybalus, No (%)	53/109	(48.6)

y, year; SD, Standard Deviation; IQR, Inter quartile range.

patients with constipation-associated fecal incontinence could be included for analysis.

Most children (77.2%) were between 8 to 12 years of age at intake (Table I). Mean duration of symptoms was 6.7 ± 2.5 years, with a median period of treatment before intake of 18.0 months (range 0-132 months). Before enrollment, 13% of children had only been seen by their general practitioner (GP), 45% visited both their GP and a general pediatrician, 41% visited not only their GP or a pediatrician, but also a psychologist or a physiotherapist. Eighty percent of all children, with varying duration, had received oral laxatives (lactulose or polyethylene glycol) at some point in the 18 months before enrollment. Rectal enemas were not part of maintenance therapy in this group of patients and were given sporadically in less than 10% of children as disimpaction therapy. In addition, recommendations to introduce a fiber-rich diet were made in 10% of children, in 30% advice to start with toilet training and a reward system was given, 50% received recommendations about both a fiber-rich diet and toilet training/reward system, and in 10% of children no advice on dietary changes or behavioral strategies was given. Adherence to oral laxative treatment and these recommendations might have varied and could not be determined retrospectively.

At intake, a defecation frequency of less than three times per week was found in 71.9% of all children and 58.8% experienced 7 or more episodes of fecal incontinence per week. The group of patients excluded from analysis consisted of significantly fewer boys compared with the group of children included for analysis (45.5% vs 68.4%,  $P = .04$ ). No

other differences in baseline characteristics were found between these 2 groups (values not given).

### DDL Domain Reliabilities

Previously found reliabilities of 2 of the domains could not be replicated in this study.<sup>16</sup> In this study, internal consistency of the constipation related domain and treatment/interventions domain were low with Cronbach alpha of 0.35 and 0.53, respectively. The internal consistency of the emotional functioning domain and social functioning domain (Cronbach's alphas of 0.72 and 0.65, respectively) corresponded with previously found reliabilities (Cronbach's alpha's of 0.76 and 0.63, respectively).<sup>16</sup> Although the difference between the Cronbach's alphas of the domains from the original study and this study was not statistically tested,<sup>18</sup> the constipation related domain and treatment/interventions domain were removed from further analysis, because in general a Cronbach alpha of >0.60 is considered as a satisfactory reliability in terms of homogeneity, and an alpha ≤0.60 is considered as insufficient.<sup>19,20</sup>

### DDL Domain Sum Scores

The missing value count was 1.0% for domain emotional functioning and 0.3% for domain social functioning. A minimum score of 13 and a maximum score of 65 can be obtained for the domain emotional functioning and a score of 11 to 55 for the domain social functioning. Mean sum score was 43.1 ± 7.4 for domain emotional functioning (range 22-57; mean item score 3.3) and 39.2 ± 6.1 for domain social functioning (range 23-51; mean item score 3.6). The association of clinical characteristics on domain sum scores is shown in Table II. The presence of more episodes of fecal incontinence was significantly related to lower emotional and social functioning (correlation: -0.32;  $P = .001$  and -0.28;  $P = .002$ , respectively). Other factors (sex, age at intake, duration of symptoms, and defecation frequency per week) had no association with domain sum scores. Regression analysis showed that emotional functioning was not significantly explained by these five factors combined ( $F = 1.64$ ,  $df = 5$ ,  $P = .16$ ; adjusted  $R^2 = 0.03$ ). Social functioning could be significantly explained by these clinical characteristics ( $F = 2.99$ ,  $df = 5$ ,  $P = .01$ ; adjusted  $R^2 = 0.08$ ). Of these clinical characteristics, only fecal incontinence was significantly related to social functioning ( $\beta$ -value -0.30;  $P = .002$ ).

### Specific Concerns

The individual item scores of the emotional functioning and social functioning domains are shown in Table III (available at [www.jpeds.com](http://www.jpeds.com)). For description we clustered these individual scores into 2 categories: always, often and sometimes versus rarely and never or very much, much and quite a lot versus a little bit and not at all.

Scores on emotional functioning showed that two thirds of the children were afraid of having feces in their underwear, and 70% were afraid that this happened and they

**Table II. Association between clinical characteristics and emotional and social functioning scales**

	Emotional functioning				Social functioning			
	Correlation*	P value	$\beta$ -value†	P value	Correlation*	P value	$\beta$ -value‡	P value
Sex	-0.05	.63	-0.03	.79	0.12	.21	0.13	.19
Age at intake	0.009	.92	-0.002	.99	0.08	.39	0.05	.65
Duration of symptoms	0.05	.60	-0.01	.92	0.08	.41	0.01	.99
Defecation frequency/week	0.02	.83	-0.05	.61	0.10	.30	0.09	.38
Fecal incontinence frequency/week	-0.32	.001	-0.28	.006	-0.28	.002	-0.30	.002

\*Pearson correlation for normally distributed data or Spearman rho for not normally distributed data.

†F = 1.64, *df* = 5, *P* = .16; adjusted *R*<sup>2</sup> = 0.03.

‡F = 2.99, *df* = 5, *P* = .01; adjusted *R*<sup>2</sup> = 0.08.

would not notice. A total of 78% of the children abhorred having feces in their underwear, and 50% reported being ashamed of their fecal incontinence. In the weeks before filling out the DDL, 37% percent of the children had been angry about having a defecation problem. Less than 40% of the children believed they are able to solve their defecation problem by themselves, but 80% believed that this problem will not become worse in the future. Almost two thirds of the children stated that their defecation problem did not influence their family. In general, the vast majority of children were happy with their life.

The social functioning domain showed that 80% of the children were worried about the odor arising from their fecal incontinence. Around two thirds of the children were worried that fecal incontinence happens during school time, and 40% try to hide their defecation disorder. Most children report they had no problem using toilets somewhere else or at home, but the toilet at school was perceived as unclean. The vast majority of children indicated that fecal incontinence did not result in fewer friends. Bullying by other children was reported by 23% of all children. Children did not miss out on hobbies or social events, but for half of the children their defecation problem did cause problems with these events.

## DISCUSSION

This study shows that higher frequency of fecal incontinence is associated with lower HQoL regarding emotional and social functioning in children with constipation. However, only a small portion of the variability in the domain scores was explained by fecal incontinence. This suggests that other factors, not included in our model, play a role in the HQoL of children with constipation-associated fecal incontinence. Children reported relatively more emotional concerns about experiencing fecal incontinence than social consequences.

Dirty underwear is distressing to children, because they report worrying about experiencing fecal incontinence unnoticeably and during school time. They are conscious of the fact that their defecation problem causes problems when going to school camp or on holidays. This supports previous studies in which parents reported higher rates of internalizing problems such as anxiety and depression symptoms in children with fecal incontinence.<sup>8,9,21</sup> In contrast to their worries, half of the

children reported being ashamed of their fecal incontinence. We hypothesize that children have more difficulties with the perception of feelings of shame, and questions about specific worries are more concrete and easier to comprehend.

Although it is generally assumed that fecal incontinence affects social interaction with their peers,<sup>9,22,23</sup> most children indicated that they have no problem making friends and have not missed out on social events such as hobbies, parties, or school camp. On the other hand, 23% of children reported regular bullying by other children because of their defecation problem. This is a higher percentage than reported prevalence rates in Dutch schoolchildren, that is, 16%, 20%, and 12% in children aged 9 to 11 years, 12 to 14 years, and 15 to 17 years, respectively.<sup>24,25</sup> In a previous study by Joinson et al,<sup>21</sup> it was found that children with fecal incontinence are significantly more likely to be victims, or even perpetrators, of overt bullying behavior. In contrast, Cox et al<sup>26</sup> showed that both mother and child did not indicate peer rejection as a common element of fecal incontinence. Further well-designed prevalence studies are necessary to assess whether children with fecal incontinence are bullied more often than their healthy peers.

The discrepancy between emotional and social concerns raises the question whether children truly experience few social problems. Children's self-report may be influenced by denial of their defecation problem and the consequences. In our clinic we frequently observe that social consequences are of greater concern to the parents than to the child. Although we did not measure parents' perception of HRQoL of their children, previous studies showed that parent's perceptions of QoL for children with constipation, functional abdominal pain, and inflammatory bowel disease were lower than their children's self-reported scores.<sup>15,27,28</sup>

Some limitations of the study need to be addressed. In contrast to sufficient reliabilities of all DDL domains (alpha >0.60) described by Voskuil et al,<sup>16</sup> 2 domains in this study showed an alpha lower than 0.60. These low reliabilities may be explained by the fact that the DDL was developed in a cohort more than 4 times smaller (*n* = 27) than the current study population. Hence, one may hypothesize that the smaller population in which the DDL was developed was less representative with respect to these 2 domains than the larger group of patients in this study.

Low internal consistency is an indicator for random error in clustering the questions within a specific domain. Yet, additional factor analysis did not reveal a better classification of items (analysis not shown). Because interpretation of HRQoL domains with low internal consistency is not reliable, we excluded these domains from analysis. Moreover, we even question whether the constipation-related domain (3 items) truly measures HRQoL. Content reevaluation showed that this domain addresses presence of certain clinical symptoms, such as abdominal pain, but not the child's subjective perception regarding these symptoms. Regarding domain treatment/interventions, 2 of the 3 questions that strongly influenced reliability (analysis not shown), addressed the child's insight in the importance of certain treatment aspects (ie, application of rectal enemas and visits to the doctor). Seventy-seven percent of participating children were between 8 and 12 years of age and possibly too young to understand these statements.

The fact that the DDL was not validated for use with only 2 components is a second limitation of this study. Psychometric analysis (test-retest reliability and convergent validity) for this short version of the DDL needs to be repeated. Until then no comparison with other studies assessing HRQoL with validated tools is possible. It should further be considered to develop a corresponding parent proxy form, so that HRQoL of the child by self-report and parent-report can be compared. Furthermore, it needs to be assessed whether this short DDL is suitable for measuring changes of HRQoL in relation to treatment outcome, because successfully treated children will be free of fecal incontinence. Additional use of a generic QoL questionnaire could be useful for comparison between children with constipation and healthy control subjects or other patient groups with chronic diseases.

In conclusion, frequent episodes of fecal incontinence are associated with lower HRQoL with regard to emotional and social functioning in children with constipation. However, other nonspecified factors also seem to influence the HRQoL of these children. Emotional concerns about fecal incontinence were more predominant than social consequences, but one needs to be alert to bullying by peers. Further adjustment to the DDL with thorough evaluation of its validity is needed, because a disease-specific HRQoL questionnaire is a valuable tool to recognize and address the possible impact of chronic constipation on children.

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**Table III. Children's reported concerns about fecal incontinence and constipation (n = 114)**

Questions	No.	Answers (%)				
		Always	Often	Sometimes	Rarely	Never
<b>Emotional functioning</b>						
1. I am worried about not being able to defecate	114	7.0	9.6	39.5	19.3	24.6
2. I think defecation will become worse in the future	112	0.9	2.7	16.1	24.1	56.2
3. I feel exactly when I need to go to the toilet to defecate	114	10.5	15.8	46.5	19.3	7.9
4. I am afraid of having feces in my underwear	112	10.7	21.5	34.8	12.5	20.5
5. I am worried about having feces in my underwear unnoticeably	113	8.8	18.6	42.5	13.3	16.8
6. I think it is unfair to have these defecation problems	114	9.6	13.2	23.7	14.0	39.5
7. I have been angry to have this problem in the past two weeks	111	4.4	6.2	26.5	19.5	43.4
		Very much	Much	Quite a lot	A little	Not at all
8. I think having feces in my underwear is awful	114	36.0	24.6	17.5	16.7	5.2
9. I am ashamed for feces in my underwear	114	15.8	13.2	21.0	35.1	14.9
10. I do not like having to stay on the toilet for a long time	112	13.4	9.8	21.4	39.3	16.1
11. I am happy with my life	113	41.7	26.5	12.4	15.0	4.4
12. My defecation problem has influence my family	111	9.9	10.8	19.8	38.8	20.7
13. I think I am able to solve my defecation problems by myself	113	8.8	14.2	12.4	35.4	29.2
<b>Social functioning</b>						
		Always	Often	Sometimes	Rarely	Never
1. I am worried that other people will smell feces in my underwear	113	31.0	19.5	29.2	9.7	10.6
2. Other children bully me because of having feces in my underwear	114	2.6	9.6	10.5	8.0	69.3
3. I am worried about having feces in my underwear at school	114	12.3	20.2	31.6	13.1	22.8
4. I have been missing hobbies/school camp/parties because of my defecation disorder in the past 2 weeks	114	0	2.6	10.5	8.8	78.1
		Very much	Much	Quite a lot	A little	Not at all
5. I do not like going to the toilet somewhere else	114	2.6	6.1	13.2	46.5	31.6
6. I think that the toilet at school is unclean	114	30.7	7.9	20.2	22.8	18.4
7. I think feces in my underwear is dirty	114	43.9	24.6	20.2	10.4	0.9
8. My defecation problems causes problems when going on holiday/school camp	113	15.9	13.3	23.0	33.6	14.2
9. I felt terrible the past 2 weeks	113	2.7	1.8	6.2	29.1	60.2
10. Because of feces in my underwear I have fewer friends	113	1.8	0.9	5.3	8.0	84.0
11. I try to hide my defecation disorder	114	18.4	8.8	10.5	35.1	27.2