



# A Multicenter Study on Childhood Constipation and Fecal Incontinence: Effects on Quality of Life

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**Objective** To describe the effects of childhood functional constipation compared with functional constipation plus fecal incontinence on quality of life, evaluating effects on physical, psychosocial, and family functioning.

**Study design** This prospective, multicenter study collected data from 5 regional children's hospitals. Children meeting Rome III criteria for functional constipation were included. Parents completed the following 5 instruments: Pediatric Quality of Life Inventory (PedsQL), PedsQL–Family Impact Module, Functional Disability Inventory–Parent Version, Pediatric Inventory for Parents (PIP), and Pediatric Symptom Checklist–Parent Report.

**Results** Families of 410 children aged 2–18 years (mean [SD], 7.8 [3.5] years; 52% male) were included. Children with functional constipation+fecal incontinence had worse quality of life than children with functional constipation alone (PedsQL Total Score,  $P \leq .03$ ). Older children with functional constipation + fecal incontinence had lower quality of life than their younger counterparts (PedsQL Total Score,  $P \leq .047$ ). Children with functional constipation+fecal incontinence had worse family functioning (PedsQL–Family Impact Module Total Score,  $P \leq .012$ ), greater parental stress (PIP–F Total Score,  $P \leq .016$ ; PIP–D Total Score,  $P \leq .013$ ), and poorer psychosocial functioning (Pediatric Symptom Checklist Total Score,  $P \leq .003$ ). There were no statistically significant between-group differences in physical functioning based on the functional Disability Inventory.

**Conclusion** Fecal incontinence significantly decreases quality of life compared with functional constipation alone in children. Older children with functional constipation+fecal incontinence may be at particular risk. Strategies for early identification and treatment of constipation along with diagnosis and treatment of related adjustment difficulties may mitigate the negative impact of this highly prevalent condition. (*J Pediatr* 2015;166:1482–7).

Childhood constipation is a chronic condition, which continues to affect 25%–50% of youth into adulthood.<sup>1–3</sup> Approximately one-half of children with functional constipation have fecal incontinence as well.<sup>1–4</sup> Although functional constipation continuing into adulthood has adverse effects on both physical and psychological health,<sup>5,6</sup> fecal incontinence in a growing child has additional, profound psychosocial consequences.<sup>7</sup>

Although conventional wisdom suggests that childhood fecal incontinence has negative psychosocial effects, there is no consensus in the scientific literature about its actual effects.<sup>8,9</sup> Furthermore, the consequences of both functional constipation and fecal incontinence on family psychosocial well-being are not known. Limited research suggests that fecal incontinence is negatively associated with emotional and social functioning and overall quality of life.<sup>8,10–15</sup> Specifically, children with fecal incontinence reportedly exhibit more antisocial aggressive, disruptive, and withdrawn behaviors and problems with low self-esteem, anxiety, depression, attention, school performance, and social competency.<sup>8,16–19</sup> Higher frequency of incontinence episodes seem to be associated with poor treatment response,<sup>1</sup> and caregivers reportedly perceive higher rates of emotional and behavioral problems in children with fecal incontinence.<sup>10,20</sup> Methodological limitations of previous studies include the use of single instruments to measure the target outcome, small patient populations, and no assessment of the family environment.<sup>8,21</sup>

The aim of the present study was to expand our understanding of the relative effects of childhood functional constipation with or without fecal incontinence on patient and family quality of life, physical functioning, parenting stress, and emotional and behavioral well being of the affected child. We also evaluated the relative effects of functional constipation alone compared with functional constipation + fecal incontinence across measures by different age domains. We hypothesized that fecal incontinence has added adverse effects on child

FDI	Functional Disability Inventory
FIM	Family Impact Module
PedsQL	Pediatric Quality of Life Inventory
PIP	Pediatric Inventory for Parents
PSC	Pediatric Symptom Checklist

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and family quality of life and general functioning, and that older children with fecal incontinence have a lower quality of life and poorer general functioning.

## Methods

This was a multicenter, prospective study using data obtained from 5 large regional academic medical centers: Medical College of Wisconsin, University of South Alabama, Boston Children's Hospital, Nationwide Children's Hospital, and University of Texas Southwestern Medical Center. This study was approved by the respective Institutional Review Board committees at each participating institution. English-speaking parents of children aged 2-18 years were invited to participate. All subjects met pediatric Rome III criteria for functional constipation.<sup>22</sup> Subjects with at least 1 episode of fecal incontinence per week were classified as functional constipation+fecal incontinence. In the youngest age category (2-4 years), fecal incontinence was defined according to the Rome criteria for functional constipation with overflow incontinence (minimum of 1 incontinence episode per week after the acquisition of toileting skills).<sup>23</sup> Exclusion criteria included a diagnosis of developmental delay, coexistence of a chronic disease that can affect quality of life (eg, cerebral palsy, spine deformity or malformations, severe mental illness, celiac disease), or nonretentive fecal incontinence.

Caregivers of children aged 2-18 years completed the following 5 questionnaires: Pediatric Quality of Life Inventory (PedsQL)–Parent Report, PedsQL–Family Impact Module (FIM), Functional Disability Inventory (FDI)–Parent Version, Pediatric Inventory for Parents (PIP), and Pediatric Symptom Checklist (PSC)–Parent Report. Information on age of presentation, symptom onset, bowel movements, and frequency and severity of fecal incontinence was collected using a demographic questionnaire. Written informed consent for participation was obtained from parents. Written assent was obtained from children aged 7 years and older.

The PedsQL is a 23-item parent-report inventory that measures quality of life in relation to health. Items are rated on a 5-point scale (0 = never a problem to 4 = almost always a problem). The instrument assesses functioning in 4 areas: physical, emotional, social, and school. A total score and 2 subscale scores (physical health and psychosocial health) are computed. Internal consistency ( $\alpha$ ) reliability for the 3 scales are as follows: total scale (0.88 for child report, 0.90 for parent report), physical health (0.80 for child, 0.88 for parent), and psychosocial health (0.83 for child, 0.86 for parent).<sup>24,25</sup>

The PedsQL-FIM is a 36-item parent-report instrument that assesses the impact of a child's chronic medical conditions on physical, emotional, social, and cognitive functioning, along with communication and worry regarding the child's illness. It also measures family daily activities and family relationships. A 5-point response scale (0 = never a problem to 4 = almost always a problem) is used to report a score of 0-100, with higher scores indicating better functioning. Internal consistency reliability of the validation sample ( $\alpha$ ) for the PedsQL-FIM Total Score is 0.97.<sup>26</sup>

The FDI is a 15-item parent-report measure that assesses the child's difficulty in completing daily activities in 4 domains: home, school, recreational, and social. A 5-point Likert scale (0 = no trouble; 1 = a little trouble; 2 = some trouble; 3 = a lot of trouble; 4 = impossible) is used to compute a total score (0-60), with higher scores indicating greater illness-related disability. The internal consistency reliability of the validation sample ranges from 0.86 to 0.91. Validity is supported by significant correlations between child-reported and parent-reported FDI scores.<sup>27</sup>

The PIP is a 42-item parent-report questionnaire that measures the frequency (PIP-F) and difficulty (PIP-D) of parenting stress related to the child's illness. A 5-point scale computes a total score (range, 42-210), with higher scores indicating greater parenting stress. Four dimensions are included: communication (range, 9-45), medical care (range, 8-40), role functioning (range, 10-50), and emotional distress (range, 15-75). Internal consistency reliability of the validation sample ( $\alpha$ ) ranges from 0.80 to 0.96. PIP scores are significantly correlated with state anxiety as well as with parenting stress, demonstrating construct validity.<sup>28</sup>

The PSC is a 35-item parent-report questionnaire that identifies psychosocial problems based on the child's emotional and behavioral problems. Each item is rated on a 3-point scale (0 = never present; 1 = sometimes present; 2 = often present). A total score (range, 0-70) is computed, with a score  $\geq 28$  suggesting a recommendation for further mental health evaluation. Case classifications with the PSC were found to closely agree (92%) with those by clinicians ( $\kappa = 0.82$ ; sensitivity, 88%; specificity, 100%); a comparison with other measures has provided additional validity support.<sup>29,30</sup>

## Data Analyses

For data analysis, the children were divided into 2 groups: functional constipation only and functional constipation + fecal incontinence. Comparisons between these groups were performed in 4 age subgroups: 2-4 years, 5-7 years, 8-12 years, and 13-18 years. The 2 groups were compared using 1-way ANOVA on the total scores for the 5 quality of life measures: PedsQL, PedsQL-FIM, FDI, PIP, and PSC. Further analyses were conducted on the instrument subscales when the total scores yielded statistically significant differences. Based on our hypothesis that older children with fecal incontinence have a lower quality of life, one-way ANOVA was used to compare the 2 groups across measures in the 4 age subgroups. One-way ANOVA was also used to compare the 2 groups in terms of age at time of study, age at symptom onset, age at which medical help was sought, and symptom duration. Statistical analyses were performed with SPSS version 19 (IBM, Armonk, New York). An unadjusted *P* value of  $\leq .05$  was considered significant.

## Results

A total of 468 patients and families were enrolled in the study. Of these, 410 had sufficient data and met inclusion criteria, and 28 were excluded owing to the presence of other chronic

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