

## Quality of life is impaired in children with functional defecation disorders

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Functional constipation (FC) and functional non-retentive fecal incontinence (NRFI) are common gastrointestinal complaints in children.<sup>1</sup> Systematic review of the literature shows a prevalence of constipation ranging from 0.7% to 29.6% (median 8.9; interquartile range 5.3-17.4) both in Western and non-Western countries.<sup>2</sup> Recently, in Dutch children living in Amsterdam, a prevalence of functional fecal incontinence of 4.1% was found in a 5- to-6 age group and 1.6% in a 11- to-12 age group with a 1.5-fold higher prevalence in boys.<sup>3</sup>

Fecal incontinence as result of constipation and as single symptom is a source of embarrassment for the child, who must deal with taunting by peers. These children may suffer from significant emotional setbacks as a result of this problem with social withdrawal, shame, fear of discovery, loss of self-esteem and confidence. Despite the high prevalence of fecal incontinence and the enormous impact on the child and family, scarce data are available regarding the consequences of constipation and fecal incontinence with respect to behavior and quality of life (QoL) in these children.

In contrast to earlier belief, between 15-30% of the children with these functional bowel disorders continue to have infrequent painful defecation, abdominal pain and fecal incontinence far beyond puberty.<sup>4,5</sup> Chronic childhood

disorders may cause significant and permanent interference with a child's physical and emotional growth and development. Children and adolescents with less visible disabilities, but who live with insecurity about the outcome of their illness, might pay a greater social, psychosocial and emotional price. Functional defecation disorders are good examples of invisible illness.

In this issue of the journal, Faleiros & Machado showed the importance of evaluating QoL in children with functional defecation disorders using the generic instrument Child Health Questionnaire – Parent Form 50 (CHQ-PF50®).<sup>6</sup> Not surprisingly, both physical and psychosocial scores for children with FC, functional fecal retention (FFR) and NRFI were lower compared to healthy children. These findings are in accordance with earlier reports on children and adolescents with functional gastrointestinal complaints. In a case control study impaired QoL was reported by children with FC as well as by parental assessment.<sup>7</sup> Surprisingly, QoL scores were significantly lower in children with FC when compared to QoL scores of children with inflammatory bowel disease and gastroesophageal reflux disease, suggesting that symptoms such as constipation and fecal incontinence, which do not usually lead to major illness and school absenteeism, seriously affect the daily life of children and this is often underestimated by caregivers.

A recent study by Youssef et al. demonstrated that QoL was also impaired in children with functional abdominal pain.<sup>8</sup> The authors suggested that anxiety might be an important factor underlying impaired QoL. Increased anxiety may also influence social well-being in children with functional defecation disorders. Children with fecal

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incontinence have more anxiety/depression symptoms, family environments with less expressiveness and poorer organization, greater social problems, more disruptive behavior and poorer school performance compared to children without fecal incontinence.<sup>9,10</sup> Parents reported higher rates of attention and activity problems, obsessions and compulsions and oppositional behavior in children with fecal incontinence. Self-report by the children showed higher rates of involvement in overt bullying (as both perpetrator and victim) and antisocial activities compared to children without fecal incontinence.<sup>10</sup>

Faleiros & Machado compared QoL in the different subgroups (FC, FFR and NRFI). Significant lower physical scores were detected in children with NRFI when compared to FC. It is unclear from this study why children with NRFI suffered the greatest physical impact in the opinion of their parents. In their study, all children with FFR and NRFI suffered from fecal incontinence. In contrast to children with FC and FFR, children with NRFI have a normal defecation frequency and normal consistency of stools.<sup>11</sup> Furthermore, symptoms such as abdominal pain, difficulties with defecation or poor appetite occur significantly less frequently in these children than in children with constipation. Long-term follow-up studies showed a success rate of approximately 30% after 2 years of intensive behavioral treatment in NRFI children.<sup>5</sup> In contrast, the success rate in constipated children was more than 60% after 1 year.<sup>3</sup> Longer duration of symptoms and frustrating results of therapy might explain why parents reported lower QoL scores in NRFI children in this study.

Using the Child Behavior Checklist, Van der Plas et al. reported behavioral problems, mostly internalizing problems, in a subgroup of 35% of children with NRFI.<sup>12</sup> However, successful treatment led to a significant improvement of the behavioral profile in these children. These data suggest that behavioral problems are secondary to the presence of fecal incontinence. To date, no studies in children with functional gastrointestinal disorders have been performed evaluating Health Related-QoL (HR-QoL) before and after treatment. Two studies in adults with constipation showed improvement in HR-QoL following successful treatment for constipation.<sup>13,14</sup> One study reported overall HR-QoL as good or improved by at least 87% of patients at 6 months, 3 years and 5 years following surgery for constipation. These studies suggest that treatment of constipation can indeed lead to sustained improvement in HR-QoL.

Faleiros & Machado<sup>6</sup> used the generic instrument Child Health Questionnaire – Parent Form 50 (CHQ-PF50®) to measure quality of life. The advantage of a generic measure is that it permits comparison between normative data from healthy control populations and data from diseased groups. The main disadvantage to generic measures is their insensitivity to important clinical change

as a result of the lack of disease-specific dimensions in the questionnaire. By including disease-specific questions, these questionnaires are more sensitive to disease-related changes in a patient's health status. Voskuil et al. recently developed an HR-QoL questionnaire for pediatric patients with FC and NRFI.<sup>15</sup> However, translation of this questionnaire to the mother tongue of the studied patient population is required to reliably compare data across populations. Translation alone, without consideration of cultural differences, may not be sufficient.

A shortcoming of the paper by Faleiros & Machado is the lack of self-reported QoL of the children. Recommendations with respect to the minimum age of the child to self-complete HR-QoL instruments vary from 7-9 years.<sup>16</sup> Interestingly, parents' perceptions of QoL for children with constipation, functional abdominal pain and inflammatory bowel disease were all lower than their children's self-reported scores.<sup>7,8,17</sup> The latter observations could be explained by the fact that parents are more worried about health status and social and motor development, whereas the child reports only obvious current problems. Youssef et al. concluded that parents' perceptions of a significantly impaired QoL may reflect the severity of the disease itself, frustration with the evaluation process and treatment modalities, or the parents' personal experience with functional symptoms.<sup>8</sup>

Constipation and fecal incontinence are frustrating symptoms for children, the parents and the caregivers. Early recognition of symptoms and adequate treatment are necessary for successful outcome. In those children with refractory symptoms it is important for both the parents and the doctors to recognize impaired QoL in these children. Therefore, the ultimate goal of measuring HR-QoL both in the child and parents is to improve patient care by bridging the gap between providers and their patients. If doctors can learn what questions to ask, and if children and their parents provide the right information, then this exchange might be more valuable than any vital sign or individual symptoms could ever provide. It is therefore important for problems identified in the HR-QoL domains to be recognized and addressed as early as possible. HR-QoL assessment can enable this recognition and may provide targets for additional (non-medical) intervention.

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