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ORIGINAL ARTICLE

Assessment of health-related quality of life in children with functional defecation disorders

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Abstract

Objective: To evaluate the health-related quality of life in children with functional defecation disorders.

Methods: One hundred children seen consecutively were enrolled and subdivided into three subsets according to the Roma II classification criteria: functional constipation (n = 57), functional fecal retention (n = 29) and nonretentive functional soiling (n = 14). The generic instrument Child Health Questionnaire - Parent Form 50 (CHQ-PF50®), was used to measure quality of life and to assess the impact of these disorders from the point of view of parents. The instrument measures physical and psychosocial wellbeing in 15 health domains, each of which is graded on a scale from 0 to 100, with higher values indicating better health and greater wellbeing. Ten of these are then used to obtain two aggregated and summary scores: the physical and psychosocial scores.

Results: No statistically significant differences were detected between subsets in terms of demographic or anthropometric characteristics. In 14 domains, children with defecation disorders scored lower than healthy children. When subsets were compared, statistically significant differences were detected between children with nonretentive functional soiling (lower scores) and those with functional constipation. Physical and psychosocial scores for the entire sample were lower than those for the group of healthy children used as controls.

Conclusions: The CHQ-PF50® was considered adequate for demonstrating compromised quality of life in children with functional defecation disorders, as has been reported for other diseases, being a useful tool for making treatment decisions and for patient follow-up.

J Pediatr (Rio J). 2006;82(6):421-5: Quality of life, defecation disorders, constipation.

Introduction

Functional defecation disorders are a common problem and require detailed clinical and laboratory investigation with long-term treatment. Constipation is diagnosed in 3% of visits to a general pediatrician and in up to 25% of visits to a pediatric gastroenterology clinic;[1,2] the worldwide prevalence among the pediatric population varies widely and is estimated to range between 0.3 and 8%.[3] The fact that the symptoms of functional defecation disorders are chronic leads children into a process of ill-adaptation to the act of evacuation, conditioning them to inhibit it, which results in emotional consequences, such as increased anxiety levels, negative self-esteem and withdrawal from social intercourse, especially at school.[4,5]

The growing advances in the treatment of children and adolescents with chronic diseases bring concerns with health-related quality of life (HRQOL).[6] This concept is related to objective and subjective indicators of happiness and satisfaction and can describe a subjective feeling of health, wellbeing, social function, lack of psychological stress or organic symptoms, or a combination of these parameters.[7] In 1993, the World Health Organization (WHO) defined quality of life as being the "individual perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[8] Therefore, HRQOL is a multidimensional entity with physical, mental, social and behavioral wellbeing and function components.[9] Although it is subjective, it can be "measured"

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precisely, using scales specifically for the purpose, by means of instruments adapted to the language and development of children and adolescents.[10,11] These "measurements" should be centered on the individual, should employ self-administered questionnaires and, whenever possible, should include both generic and specific modules, with emphasis on aspects related to the study of health. Recently, Landgraf et al.[12] developed a version of an instrument for children and adolescents designed to be completed by parents, named the Child Health Questionnaire - Parent Form 50 (CHQ-PF50®). This instrument has been adapted for several languages, including a Brazilian Portuguese version.[13]

We performed a search on the MEDLINE databases for the terms "quality of life" and "chronic constipation" and "childhood," finding three reports of generic instruments between 1990 and 2005[14-16] and one report of a specific questionnaire,[17] used for assessing the quality of life of children with chronic intestinal constipation. Sood et al.[14] assessed the quality of life of five patients with chronic intestinal constipation and 11 patients with soiling, with the latter exhibiting greater repercussions from the problem. Youssef et al.[15] studied 80 children with constipation using the Pediatric Quality of Life Inventory (PedsQL) and compared them to control patients without constipation: inflammatory bowel disease, gastroesophageal reflux and healthy children, reporting lower physical scores for children with chronic constipation, but no differences between children with and without soiling. Kinservik[16] assessed the repercussions of chronic constipation for the quality of life of 25 children between 2 and 5 years of age and observed that both the children and their families were negatively affected in the physical, emotional and social aspects, and that parents' concerns about the problem were correlated with lower quality of life scores. Voskuijl et al.[17] developed the first instrument specifically for children with constipation and functional nonretentive fecal soiling, the Defecation Disorder List (DDL). They studied 27 children from 7 to 15 years of age and considered the DDL to be promising in the assessment of HRQOL in children with defecation disorder.

Considering the chronicity of functional defecation disorders for children, the objective of this study was to assess the HRQOL of children with functional defecation disorders, as defined by the Roma II criteria,[5] and to evaluate the impact of these disorders, from the point of view of patients' parents, using the CHQ-PF50® instrument.[12]

Methods

The group with functional defecation disorders (DDC) consisted of 100 children at the initial evaluation and were recruited from the Pediatric Gastroenterology Clinic at Hospital das Clínicas, Botucatu Medical School, Universidade Estadual Paulista (UNESP), between April 2002 and September 2003. The sample size calculation returned a figure of 93 children, based on the following parameters: three groups, alpha of 0.05, statistical power of 0.80, minimum detectable difference of 10 and a standard deviation of 22. During the visit the parent was requested by the research coordinator to answer the CHQ-PF50® questionnaire. All questionnaires were completed in the outpatient clinic. Inclusion criteria were: age from 5 to 12 years; functional defecation disorder, according to the Roma II criteria,[18] subdivided in three subgroups: functional constipation (FC), for which the age criterion was not considered, functional fecal retention (FFR) and nonretentive functional soiling (NRFS); a literate parent, able to complete the questionnaire. Exclusion criteria were: chronic health problems (neurological, genetic or mental diseases or disorders of growth and development) and defecation disorders of organic etiology. The variables studied were: demographic (age, gender and position in the family, parents ages and schooling, marital status, number of rooms, people and children at home); clinical (age of onset of symptoms, age at initial evaluation, symptom duration, characteristics of evacuation, presence or not of soiling) and anthropometric (weight and stature). Epi-Info 2002 (www.cdc.gov/epiinfo/) was used to calculate body mass index (BMI) and z scores for weight, stature and BMI.[19]

The CHQ-PF50® is a generic instrument for measuring HRQOL, with 50 item questions which assess physical and psychosocial wellbeing for children aged 5 to 18 years, measuring these two variables by means of 15 health concepts named domains. Each domain is scored from 0 to 100, with higher scores indicating better HRQOL. Ten of the 15 domains are transformed into two summary scores: physical score (PhS) and psychosocial score (PsS). These are: physical functioning (PF), role functioning: emotional/behavioral (REB), role functioning: physical (RP), bodily pain/discomfort (BP), behavior (BE), mental health (MH), self-esteem (SE), general health perceptions (GH), parental impact: emotional (PE), and parental impact: time (PT). The other five domains are: general global health (GGH), general behavior (GBE), change in health (CH), family activities (FA), and family cohesion (FC). Reference values for healthy children (HC) for the 15 domains, PhS and PsS were provided by a study of 314 Brazilian children, also using the CHQ-PF50®.[13]

Descriptive statistics are presented as means and standard deviation. The Kruskal-Wallis test was performed to compare demographic, anthropometric and clinical variables and for comparisons between the PhS and PsS of the subsets of patients. Comparisons of each one of the CHQ-PF50® domains and of the PhS and PsS for the DDC and the healthy children were analyzed using independent *t* test for unpaired samples. All tests are two-tailed, and significance was set at $p < 0.05$. The statistical program used was GraphPad Prism, version 3.0. 1999. Approval to conduct the study was obtained from the Research Ethics Committee, at the Botucatu Medical School (UNESP).

Results

Table 1 shows the means and standard deviations for the sociodemographic variables, with no statistically significant differences between the different subsets of defecation disorders. The children's ages varied from 60 to 144 months, with the following proportions of boys: DDC (54.0%), FC (43.8%), FFR (72.4%) and NRFS (57.0%). Among the respondents, mothers predominated, with 66% of cases with stable marital status. There were no statistical differences between subsets in z scores for weight ($p = 0.3402$), stature ($p = 0.6956$) and BMI ($p = 0.3106$) and for age of onset of symptoms ($p = 0.4312$), age at initial evaluation ($p = 0.2878$) or symptom duration ($p = 0.6657$). Soiling was present in 52% of children with FC and 100% of children with FFR. Figure 1 represents the means for the CHQ-PF50® domains for the DDC and HC groups, demonstrating that all DDC scores were lower ($p < 0.001$), with the exception of the CH domain. Figure 2 compares subsets of PhS (FC = 26.3±21.3; FFR = 23.3±27.1; NRFS = 9.4±20.1), with statistically significant differences only between FC and NRFS; and PsS (FC = 36. 0±15.4; FFR = 36.8±13.8; NRFS = 33.0±15.4), with no differences between subsets. Figure 3 shows the means and standard deviations for summary scores for the DDC (DDC PhS = 23.1±23.4; DDC PsS = 35.8±14.9) and the HC (HC PhS = 55.0±3.6 HC PsS = 53.0±7.0). A statistically significant difference was observed between the two scores, with lower levels among the population of children with defecation disorders.

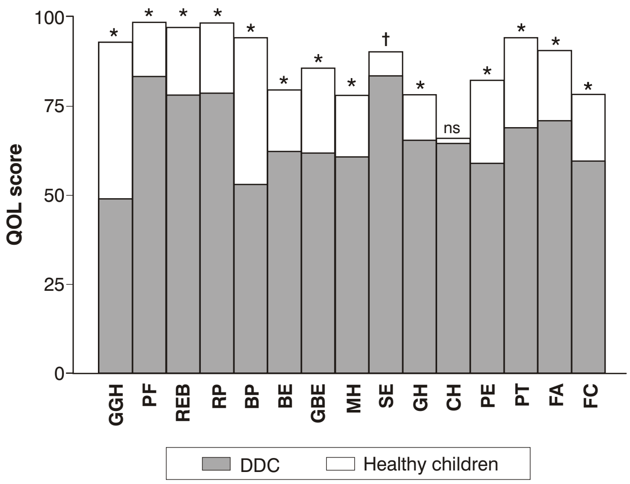

Figure 1 - CHQ PF50® domains, of all children with functional defecation disorders (DDC) and the group of healthy children (HC) (mean values)

GGH = general global health; PF = physical functioning; REB = role functioning: emotional/behavioral; RP = role functioning: physical; BP = bodily pain/discomfort; BE = behavior; GBE = general behavior; MH = mental health; SE = self-esteem; GH = general health perceptions; CH = change in health; PE = parental impact: emotional; PT = parental impact: time; FA = family activities; FC = family cohesion.

* $p < 0.0001$; † $p < 0.001$.

Discussion

In the era of evidence-based medicine, treatment should be directed by scientific evidence that corroborates accumulated clinical experience. Since 1993, HRQOL has been included as a primary measurement and essential outcome of clinical research.[20,21] The questionnaire-based approach to quality of life allows for biopsychosocial

Table 1 - Demographic data: all children with functional defecation disorders and the subsets functional constipation, functional fecal retention and nonretentive functional soiling (mean and standard deviation)

	DDC (n = 100) mean ± SD	FC (n = 57) mean ± SD	FFR (n = 29) mean ± SD	NRFS (n = 14) mean ± SD	p*
Child's age (months)	97.8±24.5	97.8±23.8	89.7±23.4	98.7±29.4	0.5198
Mother's age (years)	30.9±5.1	31.0±4.8	31.7±6.2	28.8±3.9	0.4410
Mother's schooling (years)	7.0±3.3	6.8±2.9	7.0±3.9	8.0±3.5	0.7671
Father's age (years)	35.1±6.2	35.8±6.1	35.1±6.5	32.8±6.0	0.5791
Father's schooling (years)	7.4±3.3	7.1±3.2	7.6±3.6	8.9±3.1	0.4189
Number of rooms	4.9±2.0	4.7±1.4	4.9±2.2	6.1±3.4	0.6278
Number of people	4.3±1.4	4.2±1.1	4.6±2.0	4.1±1.3	0.9088
Number of children	2.0±0.8	2.0±0.8	2.2±1.0	1.9±0.8	0.8373

DDC = all children with functional defecation disorders; FC = functional constipation; FFR = functional fecal retention; NRFS = nonretentive functional soiling; SD = standard deviation.

* Kruskal-Wallis test was calculated to compare the subsets FC, FFR and NRFS.

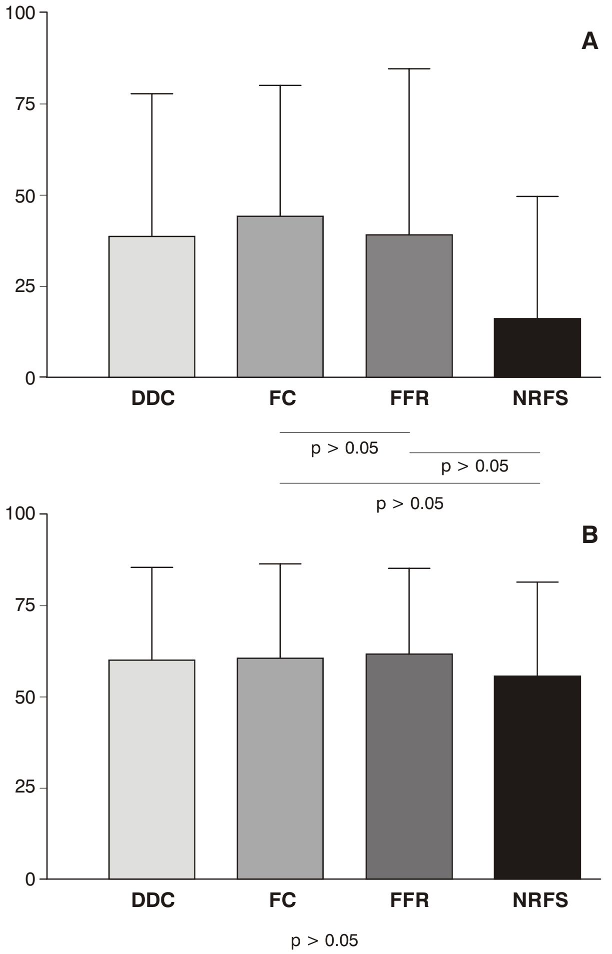

Figure 2 - Physical (A) and psychosocial (B) scores for all children with functional defecation disorders and for functional constipation, functional fecal retention and nonretentive functional soiling (mean and standard deviation)

DDC = all children with functional defecation disorders; FC = functional constipation; FFR = functional fecal retention; NRFS = nonretentive functional soiling.

integration of the determinants of health at different levels, in a hierarchy based on personal factors, such as attitudes, beliefs, cultural inheritance, and social, family, school and community influences, in addition to social variables such as opportunity and education.

In contrast with the objective measurements used for organic diseases, such as clinical, laboratory and radiology variables, the impact of functional disorders may be better evaluated using instruments capable of measuring quality of life from the point of view of patients or their parents. Although some instruments have traditionally been self-administered or within the scope of the patients' own cognitive development, instruments that measure by proxy, as the CHQ-PF50®, are an alternative option for children less than 12 years old.[22,23] Nevertheless, differences have been observed between parents when instruments have been applied to both independently. Parents' opinions are relevant and important when they are active carers and able to estimate global wellbeing and behavioral changes, as well as carrying out daily monitoring. In this study we identified the NRFS subset as suffering the greatest physical impact in the opinion of their parents. Sood et al.[14] also found evidence of poorer quality of life among children with soiling. All questionnaires were checked with the objective of avoiding unanswered questions or non-unique answers. Previous studies have shown an association between stressful events and problems with defecation.[5,24-26] Beninnga et al.[27] used the Child Behavioural Checklist (CBCL) and observed behavioral abnormalities among children with functional intestinal constipation and nonretentive soiling, but not among children with recurrent abdominal pain or normal children. Youssef et al.[15] found evidence of greater repercussions on the quality of life of children with intestinal constipation when compared with healthy children, as well as in our study. Although the subsets were different in terms of functional diagnosis and clinical characteristics, their demographic and anthropometric variables were homogeneous, and the CHQ-PF50® scores identified differences between children with defecation disorders and the HC group, providing evidence of compromise to quality of life in all dimensions of the children's lives. The CH domain, which evaluates changes in health in the last year, was the only one which did not differ from the HC group. The use of summary scores has been adequate and valid for a wide range of chronic diseases.[28,29]

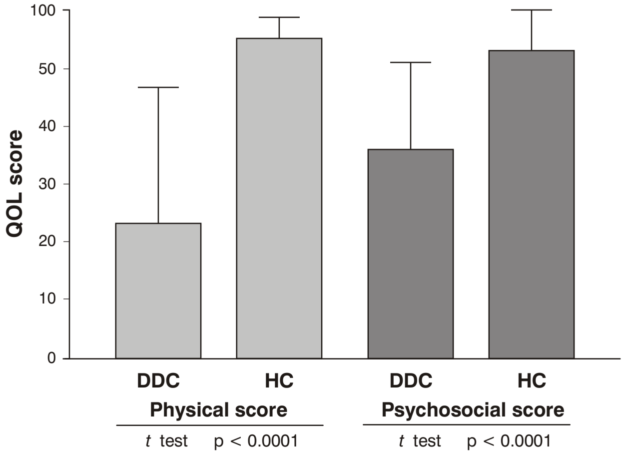

Figure 3 - Physical and psychosocial scores for all children with functional defecation disorders and for the healthy children (mean and standard deviation)

DDC = all children with functional defecation disorders; HC = healthy children.

The CHQ-PF50® was well accepted by parents under non-supported conditions, due to an appropriate Brazilian cultural adaptation and translation into Portuguese.[13] The use of generic instruments to evaluate quality of life is indicated when subsets of children with the same problem are compared or when comparing children with chronic condition and healthy children. In our study we do not have a gold standard for assessing the quality of life of defecation disorder patients, although Voskuijl et al.[17] have proposed a specific instrument for the assessment of children with constipation and encopresis named Defecation Disorder List (DDL). The impact in the quality of life among children with functional defecation disorders, as demonstrated in this study, gave us a more holistic approach, a more effective management and a better doctor-patient relationship.

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