

## Do Educational Interventions with Mothers Enhance the Quality of Life of their Children with Chronic Functional Constipation in a Randomized Trial?

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### Abstract

**Aim:** To analyse the effect on the quality of life of children with chronic functional constipation when performing educational intervention on mothers, using the technique of focus groups, in a prospective randomized trial.

**Method:** This study was conducted on the paediatric gastroenterology clinic of the teaching hospital of the Federal University of Pernambuco, from November 2012 to May 2013. A prospective study of educational intervention in health was applied on two randomized groups (experimental and control) that was formed from a sample of 55 participants according to the Rome III criteria. Mothers from the experimental group participated of a focus group that used active methods of teaching and learning in order to elucidate the biopsychosocial issues surrounding constipation. Children from both groups kept the usual treatment held by the paediatric gastroenterologist during the monthly medical visits. In order to measure the primary outcome - quality of life - the questionnaire PedsQLTM 4.0 Generic Core Scales was applied to both groups before and after the intervention. The data related to clinical parameters and quality of life of participants before and after the intervention were analytically compared in both groups with the significance level  $p \leq 0.05$ .

**Results:** This study included 55 mothers of children and adolescents with disorders of defecation, 11 in the educational intervention group and 44 in the control group. After monitoring the mothers that participated in focus groups for six months, the outcome quality of life was represented by a total score of 89.13, whilst the total score before the intervention was 78,26 ( $p=0,00$ ).

**Conclusion:** The quality of life of patients with functional constipation improved after the intervention. Therefore, the educational intervention on focus groups with mothers configure a therapeutic alternative to patients and families living with defecation disorders.

**Keywords:** Quality of life; Constipation; Child; Health education

### Introduction

Chronic functional constipation (CFC) affects about 30% of the children over the world [1]. A conceptual model that was published on a recent research shows that the genetic predisposition and stressful events that occur in early life make children more vulnerable to evolve gastrointestinal functional disorders (GFDs) [2] causing a negative impact on the Quality of Life (QoL) of patients and on their family dynamics [3-5].

Children with CFC are conditioned to withhold faeces. The evacuation reflection is inhibited due to the fear of defecating and the pain of passing dry stools, which leads to suffering and emotional and behavioural changes [6,7].

Faecal soiling episodes also disturb some paediatric patients<sup>8</sup>. They cause embarrassment to the children at school and censorship from their parents/carers within their family context. It is also known that the behaviour of parents and family has a strong influence on the children's welfare. In this context, mothers play a substantial role on

the regulation of the humour of their children. Therefore, these children may present changes of physical and mental aspects due to the psychological stress experienced after the faecal incontinence episodes [1,8-10].

Furthermore, the fact that the carers do not appreciate the complaints of their children and/or adolescents may result in the chronicity of the symptoms related to functional defecation disorders, which leads to a poor adjustment on the act of defecation and also to harms on the QoL of these patients, considering the physical, social, emotional and cognitive domains [2, 9,10].

The standard treatment for CFCs is based on the biomedical model and comprehends faecal disimpaction, toilet training, rational use of laxatives and ingestion of dietary fibre. This treatment has not been considered successful, since only 5 to 6 patients are cured from a total of 10, due to the influence of biopsychosocial factors [7,11]. Therefore, the opportunity to reserve a time to exchange experiences with other mothers can contribute to their comprehension and reflection on the foundations of a complex problem and on biopsychosocial conflicts experienced by their children. Mothers feel encouraged and

empowered to perform their child's care, enhancing the QoL of the patient and its family.

In pursuit of a complementary approach, the educational intervention using the focus group technique [12] on mothers of children and adolescents with CFC may constitute a change in the health care model. It consists of a participative and permanent education, which arises from the real living conditions of patients and their families, in order to facilitate the comprehension of the environmental stimuli that leads to the fear of pain on the defecation, and mainly to improve the QoL.

Therefore, this study aims to analyse the effect of an educational intervention using the focus group technique on mothers of children and adolescents with chronic functional constipation and the quality of life of their children. The hypothesis was that the educational intervention might increase the quality of life of the patients.

## Method

This survey was conducted in the Paediatric Gastroenterology Clinic (PGC) located at the Clinics Hospital of the Federal University of Pernambuco (HC-UFPE) from November 2012 to May 2013. This place is a reference centre that accepts children and adolescents nominated by paediatricians, who diagnoses and monitors difficult cases of CFC.

A quantitative analysis was performed on the results of QoL questionnaires that were applied before and after an educational intervention [13]. A prospective study evaluated the impacts of the educational intervention in health by making comparisons within an experimental group and also within a control group.

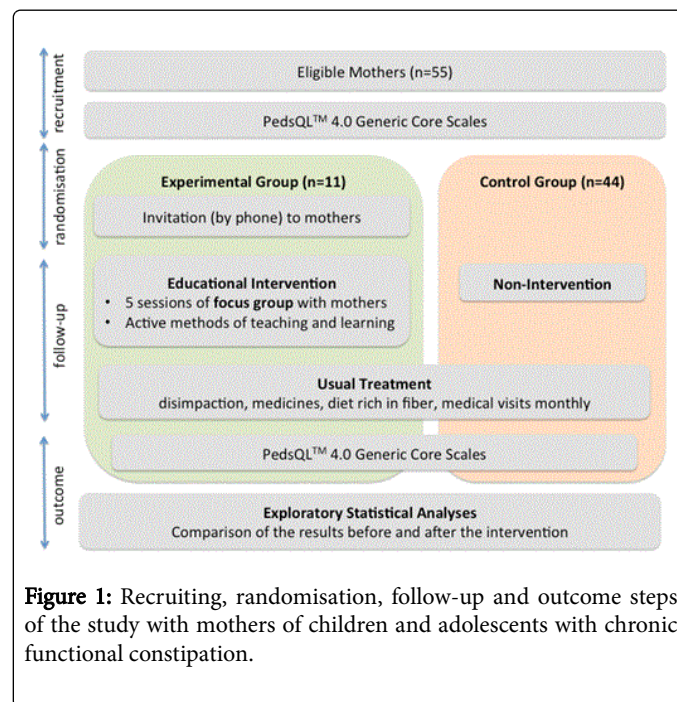
Patients were included in the research when diagnosed with CFC according to the Rome criteria III [14], i.e., when they presented two or more of the following characteristics: 1) two or fewer defecations per week, 2) minimum of one episode of faecal incontinence per week, for children who already have toilet training, 3) report of voluntary stool retention, 4) report of painful bowel movements or elimination of hard stools, 5) presence of large amounts of stool in the rectum, and 6) report of elimination of bulky stools that obstruct the toilet. Children older than four years must present the above characteristics for a minimum of two months. Patients who had been using medicines composed of calcium and heme were excluded from this research.

The sample consisted of 55 mothers of school-age children (6-10 years) and adolescents (>10 years) diagnosed with CFC who had registered to the PGC and were assisted in this place. All mothers of paediatric patients who met the inclusion criteria in the beginning of the study were invited and accepted to participate of the intervention. Figure 1 depicts the method applied to this prospective study.

Firstly, the recruitment of mothers of children and adolescents with CFC was carried out. These mothers were invited to participate in the study and have signed a form of free consent.

Afterwards, they have attended to an initial interview whereas a QoL questionnaire was applied to them in order to characterize the sample. This questionnaire is the Pediatric Quality of Life Inventory (PedsQLTM) 4.0 Generic Core Scales [15], which was translated to Portuguese and validated in Brazil [16]. It is a report filled out by parents about their children, and it is composed of 23 items which are comprised in four dimensions: physical (8), emotional (5), social (5), and school (5) functioning. A fifth dimension, the psychosocial score,

was calculated from the results of the emotional, social, and scholar ones, as recommended by the author. Therefore, the report allowed the verification of five health scales and a total QoL score. On each item, mothers answered with one of these five alternatives about the presence of problems within their children: 0 (never), 1 (almost never), 2 (sometimes), 3 (often) and 4 (almost always).



**Figure 1:** Recruiting, randomisation, follow-up and outcome steps of the study with mothers of children and adolescents with chronic functional constipation.

The randomization phase in this type of study aims to form the experimental group, in which the educational intervention takes place. Since the literature recommends focus groups to be formed from 8 to 12 members [17], a group of 12 mothers was randomly chosen from the sample using the "Random number list generator" from the Epi Table calculator of Epi Info v6.04 (CDC, Atlanta, Georgia, USA) by a person not involved in the study. Nevertheless, after a new contact to book the first meeting, only 2 of them were accessible and agreed to come. Therefore, other mothers from the sample were randomly contacted until a group of 11 of them had accepted to participate. These 11 mothers, which were recruited to interact among themselves in the educational intervention, composed the experimental group, while the other 44 mothers formed the control group.

In the experimental group, mothers participated of focus groups that used active methods of teaching and learning in order to elucidate the biopsychosocial issues surrounding constipation. The focus group was held in six months and included five meetings with the researchers, in which problem situations that reflected the participant's experiences were used to lead the discussion [18]. Each meeting lasted around 1 hour and 30 minutes and took between 20 and 40 days to happen, according to the mothers' availability. All the meetings were recorded.

The problem situations were based on clinical, social and emotional conditions of children with CFC, according to the narrative of mothers to the Paediatric Gastroenterologist during their monthly medical visits. Two situations were formulated about the hostility to children and adolescents with CFC, one addressing family context, and the other regarding social and school contexts.

The focus group discussed themes related to the concept of functional constipation, how to recognize factors that are associated with the fear of defecation (pain on defecation, retention, or "other fears"), and proposals of preventive care. These discussions can be hypotheses solutions to be incorporated into these participants' daily lives in order to improve the QoL of children and adolescents with the diagnosis of CFC.

In both experimental and control groups, the usual treatment (disimpaction, medicines, diet rich in fibre) was held by the responsible paediatric gastroenterologist at PGC during the monthly medical visits.

Finally, the PedsQLTM 4.0 Generic Core Scales report, the same used in the initial phase, was applied at the end of the educational intervention to the 55 mothers of patients with CFC.

The quantitative data regarding the characterisation of the sample and QoL was inputted in double entry into a database using the Epi Info v6.04 software. After the typos and collection issues were fixed, exploratory statistical analyses were performed on it.

The scoring procedure allows the analysis of the PedsQLTM 4.0 Generic Core Scales. Items are reversed scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). The psychosocial score is calculated as the sum of the items over the number of items answered on the Emotional, Social, and School Functioning scales, while the total score is the sum of all items over the number of items answered on all the scales. Higher scores indicate better QoL.

The results of the clinical parameters and QoL report, collected before and after the educational intervention, were analytically compared in both groups (control and experimental), considering p-value  $\leq 0.05$ . Fisher's exact test was applied to the proportion of the numeric and categorical variables with a normal distribution, while Mann-Whitney or Wilcoxon test was applied to the asymmetric distributions, for instance, the dimension scores, represented by their respective interquartile intervals.

Three researchers (two Nurses and one Paediatric Gastroenterologist) conducted this research project, which was approved by the Research Ethics Committee of Pernambuco Cancer Hospital under the certificate #0039.0.447.000-11.

## Results

In six months of treatment, fifty-five (55) mothers of children and adolescents were followed-up, 11 in the educational intervention group and 44 in the control group. Despite all mothers agreed to participate of the focus group when invited during the initial interview, most of them were not available to attend when further contacted to schedule the focus group meetings. Therefore, the initial experimental group consisted of two focus groups of 5 and 6 participants each. Two of the mothers missed one of the meetings, but they justified that they had "incompatibility in their schedule" and "health problem in the family". They were not excluded from the research since they had participated in the other subsequent steps of the experiment.

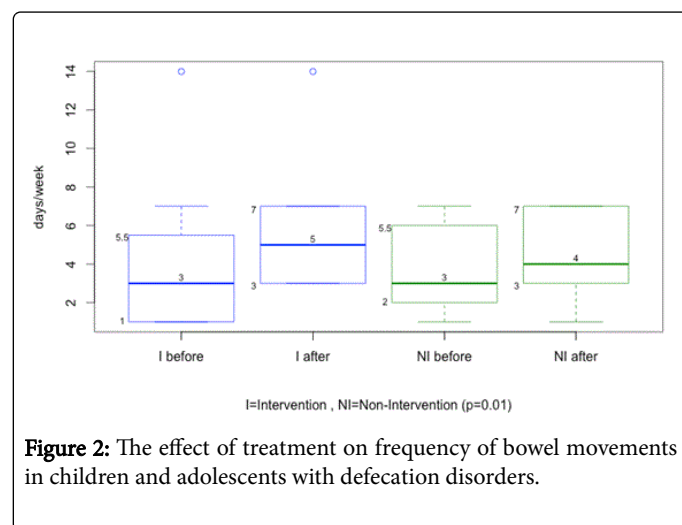
Table 1 presents the biological, demographic and socioeconomic characteristics of children and adolescents with CFC. It shows that there is no statistically significant difference in both groups. The difference in the age of the patients between the two groups were also not statistically significant (54.5% in the experimental group versus

65.9% in the control group), and there was a predominance of females in both groups (54.5% in the experimental group versus 61.4% in the control group).

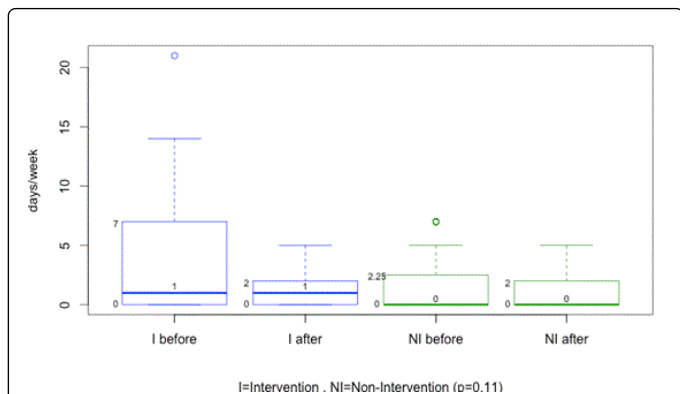
Variables	Experimental Group	Control Group	p
	N=11 (%)	N=44 (%)	
<b>Age (years)</b>			
6 - 9	6 (54.5)	29 (65.9)	0.73
10-18	5 (45.5)	15 (34.1)	
<b>Gender</b>			
Male	5 (45.5)	17 (38.6)	0.94
Female	6 (54.5)	27 (61.4)	
<b>Sewage</b>			
No sanitation	1 (9.1)	16 (36.4)	0.14
Septic tank	3 (27.3)	5 (11.4)	
Sewage network	7 (63.6)	23 (52.3)	
<b>Carer</b>			
Other	0 (0)	16 (36.4)	0.04
Mother	11 (100)	28 (63.6)	
	<b>Median (IQR)</b>	<b>Median (IQR)</b>	
<b>Family Income</b>	800 (700-1000)	700 (600-1000)	0.23
<b>Maternal Education</b>	12 (9-12)	10 (8-12)	0.53

**Table 1:** Sociodemographic characteristics of patients with chronic functional constipation that were assisted in the HC-UFPE in 2013.

Figures 2 and 3 depict the secondary outcomes. The frequency of bowel movements was higher in the group that underwent the intervention, with statistically significance when compared to the control group (p=0.01). However, a decrease in the episodes of faecal incontinence could not be noticed.



**Figure 2:** The effect of treatment on frequency of bowel movements in children and adolescents with defecation disorders.



**Figure 3:** The effect of treatment on retentive faecal incontinence in children and adolescents with defecation disorders.

Table 2 shows that the total score for QoL, which is the primary outcome of this research, increased after the seven months of focus groups with the mothers of children and adolescents with defecation disorders. Most of the dimensions that were measured in the experimental group showed up a statistically significant improvement, except those relating to social and educational aspects. Even though, they have also had a positive evaluation.

Dimensions	Before Median (IQR)	After Median (IQR)	p
Physical	84.38 (59.38-96.88)	93.75 (90.63-100)	0.01
Emotional	80 (50-100)	85 (70-100)	0.05
Social	100 (90-100)	100 (100-100)	0.37
School	75 (60-80)	85 (60-90)	0.23
Psychosocial	85 (68.33-88.33)	86.67 (76.67-96.67)	0.02
<b>Total score</b>	<b>78.26 (70.65-86.96)</b>	<b>89.13 (76.09-94.57)</b>	<b>0.01</b>

**Table 2:** Quality of life of 11 pediatric patients with chronic functional constipation that participated of the experimental group of an educational intervention with focus group of mothers and that were assisted in the HC-UFPE in 2013.

Table 3 shows the scores for the physical, emotional, social, educational and psychosocial domains. There was a decline in the scores of all these dimensions in the control group, with statistical significance.

Dimensions	Before Median (IQR)	After Median (IQR)	p
Physical	82.81 (64.06-93.75)	76.56 (59.38-89.06)	0.00
Emotional	67.5 (52.5-90)	62.5 (47.5-85)	0.00
Social	100 (87.5-100)	95 (80-100)	0.00
School	72.5 (50-85)	65 (47.5-80)	0.00
Psychosocial	76.67 (65-90)	75 (60-85)	0.00

Total score	77.71 (67.39-85.87)	72.85 (61.96-84.78)	0.00
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**Table 3:** Quality of life of 44 pediatric patients with chronic functional constipation that participated of the control group of an educational intervention with focus group of mothers and that were assisted in the HC-UFPE in 2013.

## Discussion

There was a positive change in QoL scores of patients with CFC after the completion of the educational intervention, which applied the focus group technique to their mothers, while the score worsened in all dimensions in the control group. This result confirms the clinical trial of Ferraz et al. which evaluated positively the QoL of women with chronic abdominal pain after performing visceral manual therapy [19]. In another study that used psychological intervention, one patient with CFC also reported improvement in her QoL after undergoing on cognitive-behavioural therapy sessions [20]. This highlights the importance of multidisciplinary treatment and on recognizing the multifactorial etiology of GFDs with focus on the biopsychosocial aspects [6,7,20,21].

The problematizing methodology that was used in this study offered subsidies for a significant discovery learning, which considered the prior knowledge of mothers on the care to their children and on their children's habits, the willingness of mothers to learn and their openness to change their reality. This was made possible by the appreciation of the exchange of experience among them. The contents were presented in the form of problems, and the opinions and beliefs were analysed and interpreted. The knowledge was then created and recreated in a dialogic and participatory relationship between the researcher and the mother [22].

The paediatric patients in the control group have had a worse QoL after six months undergoing to the standard treatment. The scores of the physical, emotional, educational and psychosocial dimensions of these patients had decreased significantly. This result confirms the study of Youssef et al. [23], which concludes that a low QoL reported by the parents can translate the severity of the disorder itself, the frustration in the diagnostic and therapeutic approach underwent to their children or the parents' own experiences with the functional symptoms. Benninga [24] states that children and adolescents with less visible disorders, such as GFDs, and who are uncertain about the outcome of their disease, can be identified with psychosocial and/or emotional disturbance. A recent systematic review also highlights that GFDs in children causes behavioural, social and emotional problems, which negatively affects the QoL of both child and family [25].

Constipation in children and adolescents is associated with the exposure to stressful events [26]. In this study, the socio-economic status of mothers was low, confirming what the literature points out. A clinical research shows that there is a strong association between the childhood stress (such as extreme poverty, the loss of a parent, social deprivation or sexual abuse) and the deficits in learning and memory cognitive functions [2,27]. Regarding the family dynamics, the parents influence the emotional and physical development of their children because if the family structure is not harmonically balanced, the physical symptoms may appear in place of a healthy development. These symptoms include constipation and/or behavioural and psychological expressions [10].

The participatory educational intervention with mothers, who felt they were listened during the focus group meetings, motivated the understanding of the patient and family about the aspects involved in constipation. The provided assistance allows and eases the understanding of the causes and maintenance of the fear to evacuate and of the anxiety disorder, which sometimes settles on the children and on their mothers [28]. Therefore, it is likely that children with high sensitivity to anxiety have an increased risk to develop fear of pain and physical, emotional or behavioural disabilities, which are often irreversible due to its chronic nature [4,24,29].

The educational activity that was performed in this study, which applied the focus group technique, increased the frequency of bowel movements in paediatric patients after 6 months. This shows that the intervention can be used as a complementary measure to the treatment of chronic constipation, which corroborates the study conducted in 2010 with a similar client profile<sup>6</sup>. The persistence of faecal incontinence episodes in children and adolescents may be due to the maintenance of the fear to defecate after retentive behaviours, and to the elimination of bulky stools that obstructs the toilet, which causes emotional problems in social life, such as shame, isolation, and loss of confidence and self-esteem. Due to that, when compared to children without exhaust faecal, children in family atmospheres with low expressiveness and structure, with major social problems, with aggressive behaviour and with low school performance, present more symptoms of depression and anxiety [5,10].

In 2006, a research assessed the QoL of children with functional defecation disorders regarding the perception of their parents. This research used the generic instrument Child Health Questionnaire-Parent Form 50 (CHQ-PF50<sup>®</sup>) to measure the physical and psychosocial well-being of patients. The collected data revealed that children with functional soiling presented lower QoL levels than those who had other defecation disorders. Children with gastrointestinal disorders showed lower rates in 14 domains when compared with members of the healthy control group [9].

It is possible to affirm that the usual treatment for defecation disorders and focused on the disease alone might not be considered to be the only clinical alternative choice for obtaining a satisfactory response to GFDs. A shared educational intervention among the stakeholders (caregiver, patient and health professional) is imperative in the therapeutic approach, with focus on the individual by valuing the biopsychosocial aspects and especially the family [5,20]. In addition, these techniques can be applied by various health professionals such as physical therapists, psychologist and/or nurses [6,21]. In order to carry out the treatment in the GFDs, these professionals should consider their own training in educational health, the availability of appropriate spaces for the implementation of educational activities, the time available for the treatment, the available human resources, the motivation of the involved people, and to continue to produce results in the short, medium and long term [22].

As a conclusion, it is believed that the educational intervention using the focus group technique with mothers is configured as an alternative therapy to adapt/change the behaviour of paediatric patients living with defecation disorders and to positively affect the quality of their lives.

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