



## ORIGINAL ARTICLE

# Validation of questionnaires to assess quality of life related to fecal incontinence in children with anorectal malformations and Hirschsprung's disease



Arthur Loguetti Mathias<sup>a</sup>, Ana Cristina Aoun Tannuri<sup>a</sup>,  
Mariana Aparecida Elisei Ferreira<sup>b</sup>, Maria Mercês Santos<sup>a</sup>, Uenis Tannuri<sup>a,\*</sup>

<sup>a</sup> Instituto da Criança do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo (USP), São Paulo, SP, Brazil

<sup>b</sup> Faculdade de Medicina da Universidade de São Paulo (USP), São Paulo, SP, Brazil

Received 15 March 2015; accepted 16 June 2015

Available online 28 December 2015

### KEYWORDS

Digestive system abnormalities;  
Hirschsprung's disease;  
Quality of life;  
Questionnaire;  
Children;  
Adolescents

### Abstract

**Objective:** Surgical treatment of anorectal malformations (ARMs) and Hirschsprung's disease (HD) leads to alterations in bowel habits and fecal incontinence, with consequent quality of life impairment. The objectives were to create and validate a Questionnaire for the Fecal Incontinence Index (FII) based on the Holschneider score, as well as a Questionnaire for the Assessment of Quality of Life Related to Fecal Incontinence in Children and Adolescents (QQVCFA), based on the Fecal Incontinence Quality of Life.

**Methods:** The questionnaires were applied to 71 children submitted to surgical procedure, in two stages. Validity was tested by comparing the QQVCFA and a generic quality of life questionnaire (SF-36), and between QQVCFA and the FII. A group of 59 normal children was used as control.

**Results:** At two stages, 45.0% (32/71) and 42.8% (21/49) of the patients had fecal incontinence. It was observed that the QQVCFA showed a significant correlation with the SF-36 and FII (Pearson's correlation 0.57), showing that the quality of life is directly proportional to improvement in fecal incontinence. Quality of life in patients with fecal incontinence is still globally impaired, when compared with control subjects ( $p < 0.05$ , Student's *t*-test). There were also significant differences between the results of children with ARMs and children with HD.

**Conclusions:** QQVCFA and FII are useful tools to assess the quality of life and fecal incontinence in these groups of children. Children with ARMs submitted to surgical procedure and HD have similar quality of life impairment.

© 2015 Sociedade de Pediatria de São Paulo. Published by Elsevier Editora Ltda. This is an open access article under the CC BY license (<https://creativecommons.org/licenses/by/4.0/>).

\* Corresponding author.

E-mail: [uenist@usp.br](mailto:uenist@usp.br) (U. Tannuri).

**PALAVRAS-CHAVE**

Anomalias do sistema digestivo;  
Doença de Hirschsprung;  
Qualidade de vida;  
Questionário;  
Crianças;  
Adolescentes

## Validação de questionários para avaliação da qualidade de vida relacionada à continência fecal em crianças com malformações anorretais e doença de Hirschsprung

**Resumo**

**Objetivo:** O tratamento cirúrgico das malformações anorretais (MAR) e da doença de Hirschsprung (DH) leva a alterações do hábito intestinal e incontinência fecal com prejuízo da qualidade de vida. Os objetivos foram criar e validar o Questionário para o Índice de Continência Fecal (ICF), baseado no Holschneider Criteria, bem como o Questionário para Avaliar a Qualidade de Vida Relativa à Continência Fecal em Crianças e Adolescentes (QQVCFCA), baseado no Fecal Incontinence Quality of Life.

**Métodos:** Os questionários foram aplicados em 71 crianças operadas, em duas etapas. A validade foi testada por meio da comparação do QQVCFCA e um questionário genérico de qualidade de vida (SF-36) e entre o QQVCFCA e o ICF. Um grupo de 59 crianças normais foi usado como controle.

**Resultados:** Nas duas etapas, 45,0% (32/71) e 42,8% (21/49) dos pacientes apresentaram incontinência fecal. Verificou-se que o QQVCFCA apresentou correlação significativa com o SF-36 e o ICF (correlação de Pearson 0,57) e mostrou que a qualidade de vida é diretamente proporcional à melhoria da continência fecal. A qualidade de vida no paciente com incontinência fecal está ainda comprometida globalmente, em comparação com os indivíduos controles ( $p < 0,05$ ; teste  $t$  de Student). Não houve ainda diferença significativa entre os resultados de crianças com MAR e crianças com DH.

**Conclusões:** O QQVCFCA e o ICF são instrumentos úteis para a avaliação da qualidade de vida e da incontinência fecal nesses grupos de crianças. Crianças operadas de MAR e DH apresentam comprometimentos semelhantes da qualidade de vida.

© 2015 Sociedade de Pediatria de São Paulo. Publicado por Elsevier Editora Ltda. Este é um artigo Open Access sob a licença CC BY (<https://creativecommons.org/licenses/by/4.0/deed.pt>).

**Introduction**

Anorectal malformations and Hirschsprung's disease are congenital disorders affecting approximately 1:5000 live births. Surgical correction should be done early and the main objective is the anatomical reconstruction of structures with normal bowel habits.<sup>1</sup> However, constipation and/or fecal incontinence are frequent, with important consequences on personal, social, and professional spheres that may reflect in adulthood. Thus, patients may suffer strong negative impact on quality of life (QoL). QoL is defined by the World Health Organization as "the individual's 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".<sup>2</sup> Thus, QoL is a subjective data comprising several areas and should be evaluated individually and based on the expectations of patients and their relatives.

In the Pediatric Surgery and Liver Transplantation Service of the Children's Institute of Hospital das Clínicas da Faculdade de Medicina da USP—where 15 new cases are attended on average per year—fecal continence is assessed subjectively on three levels (good, fair and poor) that do not objectively reflect reality. In this service, the issue of quality of life is not thorough. Only cases in which psychosocial problems are externalized or are more serious are referred to a psychologist or social worker. Thus, it became necessary to apply questionnaires to evaluate physical (fecal continence)

and psychosocial (quality of life) performance of patients, so that pediatrician and surgeon can perform effective and positive interventions during the follow-up. We did not find instruments that met the needs of our target population in the literature. The objective of this study was to develop and validate new questionnaires to assess quality of life and fecal incontinence, from a population of children undergoing surgery for anorectal malformation repair or Hirschsprung's disease in clinical follow-up in our clinic.

**Method**

The Questionnaire for the Fecal Incontinence Index (FII), based on the Clinical Evaluation of Fecal Continence (Holschneider Criteria)<sup>3</sup> and the Questionnaire for the Assessment of Quality of Life Related to Fecal Continence in Children and Adolescents (QQVCFCA), based on the Fecal Incontinence Quality of Life (FIQL) were created.<sup>4</sup> The created questionnaires were submitted to the translation and cultural adaptation processes, then the validation step was initiated. For this, they were sent along with the Short-Form 36 (SF-36)<sup>5</sup> questionnaire via mail to volunteers, and without the presence of an interviewer.

The Clinical Evaluation of Fecal Continence (Holschneider Criteria) is an established and widely used index in pediatric surgery; however, it has not validated translation into Portuguese and its questions are fit for interview application. Thus, the Fecal Incontinence Index (FII; available

Download English Version:

<https://daneshyari.com/en/article/4176180>

Download Persian Version:

<https://daneshyari.com/article/4176180>

[Daneshyari.com](https://daneshyari.com)