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Review Article

Fecal incontinence and quality of life assessment through questionnaires

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ABSTRACT

Background: Fecal incontinence causes a big impact on patient's quality of life. Our study analyzed the main questionnaires about fecal incontinence available internationally, aiming to delineate vantages and limitations of these instruments and their application, to mention the cultural aspects involved in the process of development and validation, as well as to suggest a reflection about the complexity of this matter. **Results:** Four of the instruments (Pescatori score, FISI, MSKCC bowel function instrument, and LARS score) do not include quality of life, working only as diagnostic tools. Two others, 'Jorge and Wexner Fecal Incontinence score', and 'St Marks' Fecal incontinence grading system' can diagnose and grade fecal incontinence, however they are very subtle in assessing quality of life. The 'EORTC Colorectal Cancer-specific', on the other hand, focuses exclusively on quality of life. Although the 'FIQL' questionnaire assesses quality of life related to fecal incontinence, it does not measure leakage. Lastly, the 'RAFIS' assesses both aspects but too superficially. **Conclusion:** None of the questionnaires analyzed were able to simultaneously assess both fecal incontinence and quality of life successfully. Furthermore, the concepts related to fecal incontinence have different meanings depending on the cultural and psychosocial context. These differences are even greater when individuals of developed countries like the ones where these questionnaires were developed are compared to the ones of developing countries, such as Brazil, which makes its very hard for these instruments to be used universally.

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Avaliação da incontinência fecal e impacto na qualidade de vida por questionários

R E S U M O

Palavras-chave:

Incontinência fecal
Qualidade de vida
Sinais e sintomas
Avaliação de resultados
(cuidados de saúde)
Índice de Incontinência Fecal
Avaliação de resultados de
intervenção terapêutica

Contexto: A incontinência anal acarreta grande impacto na qualidade de vida (QV) dos pacientes. Nosso estudo analisou os principais questionários sobre o tema disponíveis na literatura internacional, visando delinear vantagens e limitações desses instrumentos e de sua correta aplicação, bem como citar os aspectos culturais envolvidos no processo de sua criação e validação, e sugerir uma reflexão sobre a complexidade do tema.

Métodos: Nessa revisão assistemática, utilizamos três bases de dados eletrônicas (MEDLINE, LILACS, e DeCS) para encontrar os 9 questionários mais utilizados no mundo, e palavras-chave relacionadas.

Resultados: Quatro dos instrumentos estudados (Pescatori score, FIS, MSKCC bowel function instrument, e o LARS score) não abordam QV, funcionando apenas para diagnóstico. Outros dois, o 'Jorge and Wexner FI score', e o 'St Marks' FI grading system' diagnosticam e gradam bem a incontinência, porém apenas avaliam brevemente a QV. O 'EORTC Colorectal Cancer-specific', por sua vez, foca exclusivamente na QV. O questionário 'FIQL' apesar de conseguir avaliar a QV relacionada à função intestinal, não avalia vazamentos. Por fim, o 'RAFIS' avalia de forma muito simplificada esses aspectos.

Conclusão: Nenhum dos questionários analisados se mostrou eficiente na avaliação simultânea da incontinência e da QV. Além disso, os conceitos que envolvem incontinência anal apresentam significados diferentes dependendo do contexto cultural e psicossocial. Essas diferenças são ainda maiores quando se comparam indivíduos dos países desenvolvidos onde esses questionários foram desenvolvidos, com os de países subdesenvolvidos como o Brasil, dificultando sua aplicação de forma universal.

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Introduction

The fecal incontinence (FI) is an anorectal dysfunction characterized by stool, gas and/or liquid loss, which has serious impact on the patient's quality of life. This condition frequently leads to emotional and social disturbance, impairment of labor relations, loss of self-esteem and depression.^{1,2} Due to the severity of this condition, it is necessary to systematically diagnose patients with FI and assess their degree of impairment. There are several tools that can be used aiming this evaluation, which are known as fecal incontinence (FI) questionnaires. In addition to FI diagnosis, the assessment of quality of life (QoL) has also become an important measure of medical treatment outcomes. And in order to assess it, questionnaires are applied to patients. However, it is not that simple because measuring the functional outcome of a treatment, through a score, does not necessarily translate into a worse QoL even if it reveals the most severe score.

In 1958, John Kenneth Galbraith created the concept of QoL differentiating from the classic quantitative economic perspective. In his concept, the improvement of men's living conditions is the focus of the political-economic and social goals, instead of economical and material growth.³ Similarly, Lyndon Johnson, the American president in 1964, said that the goals cannot be measured by a bank balance, but by the QoL provided to people. He was the first to use QoL as an expression.⁴

QoL and "standard of life" were concepts that interested only social scientists, philosophers and politicians. Whereas, the technological advancements in medical and scientific fields contributed even more to the weakening of the clear definition of these concepts. However, the concern about QoL within the human and biological sciences, in order to value parameters broader than symptom control, mortality decrease and life expectancy increase, contributed to its use in randomized clinical trials as an important aspect to be assessed, beyond drugs' efficacy and safety. The oncology specialty is a good example of how QoL is important, because treatments initially sought only to add "years of life", neglecting the relevance of adding "life to years".⁴

Based on this subject's importance and on the holistic understanding of the concepts surrounding this condition, this review discusses the specific questionnaires for fecal incontinence evaluation. The aim of this study was to suggest a reflection about the complexity of the involved concepts, the limitation of a proper questionnaire application, the transcultural aspect and the creation and validation process of the instruments.

Methods

This is a non-systematic review, which brought together the original FI questionnaires listed below. Medline was searched

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