



REVIEW ARTICLE

Identification of areas of functioning and disability addressed in inflammatory bowel disease-specific patient reported outcome measures

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Review
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Abstract

Background and aims: Patient-reported outcome measures (PROMs) make it possible to assess health-status problems from the perspective of persons suffering from a disease. The objective of the paper is to examine and compare the contents of PROMs related to IBD based on the World Health Organization's International Classification of Functioning, Disability and Health (ICF) as the frame of reference.

Methods: A systematic literature review (1999–2009) in the databases Medline, EMBASE, PsycINFO, CINAHL and CENTRAL was performed to select IBD-specific PROMs. Abstracts and full-text articles were checked applying predefined eligibility criteria; IBD-specific PROMs

Abbreviations: CGQL, Cleveland Global Quality of Life; CENTRAL, Cochrane Central Register of Controlled Trials; CINAHL, Cumulative Index to Nursing and Allied Health Literature; EMBASE, Excerpta Medica Database; IBDQOL, Inflammatory Bowel Disease Quality of Life Questionnaire; IBDSI, IBD Stress Index; IBDQ, Inflammatory Bowel Disease Questionnaire; ICF, International Classification of Functioning, Disability and Health; MEDLINE, Medical Literature Analysis and Retrieval System Online; PROM, Patient-reported outcome measure; RFIP, Rating Form of IBD Patient Concerns; SIBDQ, Short Inflammatory Bowel Disease Questionnaire; WPAI: CD, Work Productivity and Activity Impairment: Crohn's Disease.

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were identified. The contents of the identified PROMs were examined by linking the items to ICF categories. The linked ICF categories of the PROMs were then compared.

Results: The review resulted in the selection of eight IBD-specific PROMs (e.g., Cleveland Global Quality of Life, Inflammatory Bowel Disease Quality of Life Questionnaire, Inflammatory Bowel Disease Questionnaire-32, Rating Form of IBD Patient Concerns, Short Inflammatory Bowel Disease Questionnaire). In total, 129 items were identified, the majority of which (n=90; 69.8%) could be linked to specific ICF categories. None of the linked categories were contained in all PROMs. The most frequently identified categories were 'b1300 Energy level', 'b5254 Flatulence', 'd910 Community life' and 'd920 Recreation and leisure'.

Conclusion: The present study provides an overview of IBD-specific PROMs and their items. The results of the content comparison provide valuable information to facilitate and account for the selection of appropriate PROMs for different purposes of data collection in clinical and research settings.

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1. Introduction

Inflammatory Bowel Disease (IBD) is a chronic disabling disease of the gastrointestinal tract.^{1,2} The most common entities are Crohn's disease (CD) and ulcerative colitis (UC) with symptoms like diarrhea, rectal urgency, abdominal discomfort and weakness.^{3,4} Symptoms may not be limited to the intestine but can also have extraintestinal manifestations affecting e.g. the skin, joints and eyes.⁵ The disease is strongly associated with limited performance of everyday activities and restrictions in work and employment, recreation and relationships with others,^{6,7} as well as reduced quality of life.⁸⁻¹⁰ Thus, suffering from IBD includes not only impairment of body functions and structures but also limitations in activities of everyday life and restrictions in participation. Consequentially, a comprehensive approach to functioning and disability is required when addressing the impact of IBD.

A large number of outcome measures assess health-status problems of persons with CD or UC.¹¹ Many of these measures used in clinical practice or research are classification or scoring systems that refer to disease activity and symptomatology in IBD in terms of impaired body functions and structures (e.g., Crohn's Disease Activity Index (CDAI),¹² Harvey Bradshaw Index).¹³ Hence, disability and functioning from a comprehensive point of view are poorly addressed in these measures and do not cover the whole spectrum of problems persons with IBD have to deal with.^{14,15}

Patient-reported outcome measures (PROMs) provide the possibility to assess health-status problems from the perspective of persons suffering from a disease. The number of IBD-specific PROMs which focus on aspects of functioning, disability and health (e.g., Inflammatory Bowel Disease Questionnaire (IBDQ-32)¹⁶, Rating Form of IBD Patient Concerns (RFIPC)¹⁷, Inflammatory Bowel Disease Stress Index (IBDSI)¹⁸) has increased over the last years so that the selection of the appropriate PROMs for specific purposes or subpopulations has become a challenge. However, up to now it has remained unclear whether these PROMs cover the whole spectrum of functioning and disability.

The International Classification of Functioning, Disability and Health (ICF) endorsed by the World Health Assembly as a common language of functioning and disability¹⁹ is a proven and useful tool for the examination and comparison of the content of outcome measures.²⁰⁻²² In 2010, Reichel et al. published a paper on the linking of Crohn's disease health-status measurements to the ICF.¹⁵ To our knowledge, no overview has been published so far that examines the content of IBD-specific PROMs using the ICF as a reference. Such an overview would facilitate the selection of PROMs by clinicians and researchers.

The objective of this paper is, therefore, to examine the content of IBD-specific PROMs using the ICF as a reference. The specific aims are to identify (1) IBD-specific PROMs applied in studies of persons with IBD based on a systematic

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