

Understanding the patient perspective for treatment outcomes and preferences in functional bowel disorders

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IMPACT PARAGRAPH

The majority of patients presenting for medical consultation with a gastroenterologist suffer from disorders of the gut-brain interaction (DGBIs). These disorders are characterized by persistent and recurring gastrointestinal symptoms. Common illnesses of DGBIs include functional bowel disorders such as irritable bowel syndrome (IBS), functional constipation and fecal incontinence. Many appropriate treatments are available for the treatment of functional bowel disorders. Because of the lack of biomarkers to evaluate the effect of a therapy and a clinical heterogeneous population, the management of these disorders remains challenging. Shared-decision making is therefore an important key during consultation.

The main goal of this thesis was to improve the management of functional bowel disorders. Relevant subthemes were insight into treatment preferences that can be used during shared decision-making and examining the long-term outcomes of surgical procedures. A better management of these disorders, can result in improvement of QoL of patients and decreased health care demands and costs.

We developed an algorithm to calculate utility scores for the disease-specific questionnaire, the IBS-QoL, for usage in economic evaluations. Moreover, we explored which treatment aspects are important for patients during decision-making and we revealed their specific treatment preferences and weights regarding IBS therapies. Finally, we examined the long-term outcomes (continence, complications, quality of life) of three surgical procedures for the treatment of constipation and fecal incontinence. All these novel aspects could be discussed and used during consultation of the treatment-seeking patient. These results of the thesis are relevant for clinicals, patients but also for health policy makers.

Scientific relevance

The results are or will be published in international peer-reviewed journals. Moreover, these research findings are presented at (inter)national congresses, such as the Dutch Digestive Disease Days, Lowlands Health Economic Study Group (LolaHESG) conference, European Society of Coloproctology congress, the European NeuroGASTRO meeting and the United European Gastroenterology (UEG) congress.

Different research findings contribute to novel scientific knowledge which are useful for researchers in the field of DGBIs. We were the first to compare the responsiveness of two frequently used PROMs in IBS patients and to develop an algorithm to convert IBS-QoL scores to utility scores for use in trial-based economic evaluations. In clinical

trials where IBS-QoL might be more relevant to use due to disease-specific domains than a general health related questionnaire like the EQ-5D-5L, the IBS scores can now be transformed into utility scores and ultimately QALYs.

Furthermore, we are the first to identify treatment preferences and estimate their trade-offs in patients with IBS. This could not only be relevant for patients and health care decision makers, but also for developers of novel therapies.

We also examined the long-term outcomes of three surgical procedures: the MACE, SNM and the ABS. These studies reveal novel scientific knowledge regarding the use on long-term, continence rates, complication rates and quality of life scores of patients. This is relevant for the manufactureres of medical technology to adapt their devices according to patients' needs.

Impact on health care providers and patients

These results are not only relevant for patients suffering from DGBIs, but also for different health care providers, such as gastroenterologists, surgeons, general practitioners, dieticians and psychologists. We performed semi-structured interviews with IBS patients to examine their wishes and important aspects of disease management. Moreover, we revealed the strong preference for dietary interventions among IBS patients and different preferences according to a specific subgroup. We encourage health care providers to use shared-decision making as the underlying strategy to discuss treatment options with the treatment-seeking patients. The identification of patients' perspective may help health care providers in understanding patients' wishes. These research findings can also encourage patients to consider what aspects of management are important and which trade-offs apply. A well-considered therapy may lead to better compliance with the prescribed treatment, which is crucial for treatment success. Consequently, patients will experience less disease burden and an improved quality of life. Future research could include the development of a clinical decision tool with the input of the preference data, to help giving an overview of all potential management options personalized on patient- and disease characteristics.

The disappointing results of the surgical procedure, ABS, has reached clinicians and has resulted in the fact that the ABS is no longer prescribed as therapy. This protects patients against possible harm. Patients with a SNM or a MACE may experience a better QoL due to symptom reduction. These studies have revealed potential benefits, limitations and expectations regarding continence and QoL which now could be discussed with patients during consultation.