

PATIENT PERSPECTIVES AND EXPECTATIONS IN INFLAMMATORY BOWEL DISEASE: A SYSTEMATIC REVIEW

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Background: Shared decision making is gaining favour in clinical practice and increasingly patients want to be involved in their disease process.

Aims: In this systematic review, our objective was to assess inflammatory bowel disease (IBD) patient preferences and perspectives relating to their disease diagnosis, treatment, knowledge needs and telemedicine.

Methods: This study was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA). Four databases and conference proceedings were searched between January 1, 1980, and May 1, 2020. The methodological quality of the included studies was assessed using the Standards for reporting qualitative research (SRQR) checklist.

Results: Our search identified 240 citations and 51 studies met the inclusion criteria. The major expectations of the patients are symptomatic and pain control, quality of life and normal endoscopy. Patients' main concerns are access to information and healthcare, and shared decision making. At the time of diagnosis, patients expressed a greater need for knowledge about their IBD, preferentially by their treating gastroenterologist. The main treatment expectations in active disease are efficacy, safety and convenience. Patients are willing to accept relatively high risks of complications from medical therapy to avoid a permanent ostomy and to achieve durable remission. Patients are more interested in disease monitoring, research and development during the time of remission. Telemedicine and self-management with supervised e-health tools are feasible and acceptable amongst IBD patients.

Conclusions: This systematic review demonstrates that IBD patients expect more information about their disease process, shared decision making and symptom control. Further research is needed to help align patient and physician expectations in order to improve the quality of care provided to IBD patients.

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