ISSN 2564-0127 (Print)
ISSN 2564-0135 (Online)

Canadian Journal of Medicine 6(2024) 69-81

Canadian Journal of Medicine

WWW.CIKD.CA
journal homepage: https://www.cjm.cikd.ca

Review

A Scoping Review of Doctor-patient Communication in Inflammatory Bowel Disease

Immanuel Sani[1]*, Hussain Bux[2]

[1]Leicester Medical School, George Davies Centre, Leicester, United Kingdom
[2]The University of Manchester, Manchester, United Kingdom

Keywords:
communication, education, inflammatory bowel disease

Received
21 July 2024
Received in revised form
27 July 2024
Accepted
28 July 2024

Correspondence:
Immanuel.sani@gmail.com

ABSTRACT

The effectiveness of doctor-patient communication in Inflammatory Bowel Disease (IBD) is crucial to ensure patients' needs are addressed sensitively. The literature on the evaluation of doctor-patient communication in IBD is limited. This scoping review was conducted to understand the current methods of doctor-patient communication in IBD. Two authors completed the literature search using four electronic databases from inception to 2021 in accordance with the PRISMA guidelines. The reference lists of the retrieved studies were also examined. Relevant data from eligible studies were extracted by a single author. A second author verified the accuracy of the extracted data and analysed for discrepancies. Each paper was then assessed using the Cochrane risk of bias tool for quality assessment. We found 572 articles and included seven studies involving 4369 participants. Evidence suggests that patients diagnosed with IBD require their information needs to be met directly by the doctor or through reliable internet sources. Involving patients in their care through shared decision-making is vital. The role of doctor-patient communication has evolved, and the aim is to actively involve the patient in the forefront of services. This review highlights the importance of keeping patient education at the core of care for patients living with IBD. Patients living with IBD want to be actively involved in the decisions surrounding their care. There is a need to cultivate a culture that includes patients living with IBD in service planning to drive reform in patient education and shared decision-making. Delivering information and education tailored to individuals' needs can enhance the quality of care and improve the health-related quality of life of patients living with IBD.

Introduction

Inflammatory Bowel Disease (IBD) is an umbrella term used to describe a long-term condition of the gastrointestinal tract (GI) [1]. The prevalence of IBD in the United Kingdom (UK) is between 0.5-1% and is thought to be increasing, with approximately 620,000 people affected [2]. A recent study found that between 1990 and 2017, the worldwide prevalence of IBD increased from 3.7 million to more than 6.8 million, an increase of over 85% [3].

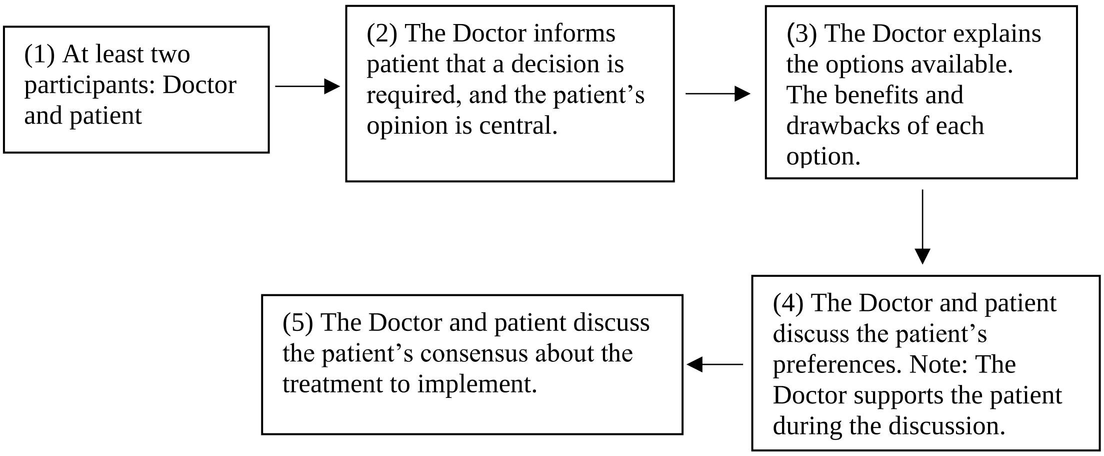
The two main subtypes of IBD are Crohn's Disease (CD) and ulcerative colitis (UC) [4]. In CD, chronic transmural inflammation may occur in any part of the GI tract from the mouth to the rectum [5]. In contrast, in UC, chronic mucosal inflammation originates from the rectum and can spread across the entire length of the large intestine [6].

Risk factors in IBD are based on complex interactions between genetics, environment, and gut microbiota that are experienced across the lifespan of an individual. Risk factors include having a first-degree relative with IBD, being of Caucasian ancestry, cigarette smoking, and eating a diet high in refined sugar [7-11]. The clinical presentation can vary and change over time in individuals with IBD; however, common signs and symptoms of IBD include abdominal pain, diarrhoea, fatigue, GI bleeding, and unexplained weight loss [4]. Despite the progress in research, the aetiology of IBD remains inconclusive and the disease remains incurable [12]. From a National Health Service (NHS) and societal viewpoint, the estimated cost of individuals living with IBD in the UK is £1 billion, with an average cost of £3000 per person per year [13]. The reduced health-related quality of life (HRQoL) and capacity for work, as well as increased disability, all contribute to the high societal and personal cost of IBD [12-15].

Whilst there is a large amount of literature on the pathogenesis and pharmacological management of IBD, currently, there is limited research focussing on the behavioural and social implications of IBD, particularly evaluating the doctor-patient communication in IBD [16,17]. The UK IBD Standards were developed by patient and professional organisations in response to a 2009 UK-wide audit that revealed disparities in IBD care [14-19]. The UK IBD Standards demonstrate the level of high-quality care required from the IBD service at every aspect of a patient's journey from initial symptoms to surgery, and ongoing care [19]. The UK IBD Standards state that individuals with IBD should have high-quality personalised care, early and accurate diagnosis, and newly-diagnosed patients with IBD should receive the right treatment and support [19].

The IBD UK Standards also promote the use of shared decision-making (SDM), particularly for key decisions such as surgery [19]. SDM is a communication technique defined as the process of collaboration between the clinician and the patient who wishes to be a part of the decision-making process [20]. SDM is most often defined as a collaborative approach that involves a five-step process (Figure 1). For long-term conditions, such as IBD, active involvement in the SDM process has become integral for patients. As advancements in therapies are reached and new side effects become recognised, the risk versus benefit for the patient along with patient preference may become more difficult for the doctor to interpret. Hence, the main goal of SDM is to actively involve patients in decisions regarding their care so they can be educated about their therapy choices, assured about their plan, adherent to their treatment choice, and ultimately improve their HRQoL [21].

Figure 1. The five-step process of SDM [22,23].



Often, the patient is only involved in the final stage of the SDM process – being told the information needed to take the treatment [23]. Recently, SDM has become a popular approach when treating patients [20,21]. Despite the importance of SDM, challenges in delivering SDM are often reported including the finite time available with patients, the perceived limited patient health literacy by healthcare professionals and the inadequate training in SDM [22].

Whilst there is a large amount of literature on the pathogenesis and pharmacological management of IBD, currently there is limited research focussing on the behavioural and social implications of IBD, particularly evaluating the doctor-patient communication in IBD [16,17]. Thus, this scoping review aims to explore the current methods of doctor-patient communication throughout the journey of someone living with IBD. This review will explore the themes set by the IBD UK standards: information needs, shared decision-making (SDM), and patient education.

Method

Search Strategy

We performed a scoping review according to the PRISMA-ScR using Cochrane Library, PubMed, and Scopus from Elsevier databases from the inception of the journal to 2021 [24]. We used five search strings in Scopus and fourteen search keys in Pubmed; nine of the fourteen search strings in Pubmed were formulated in the Advanced Search builder and all MeSh terms (Table 1).

Table 1. Search items.

Search terms included in Scopus and Pubmed	Inflammatory bowel disease, IBD, Crohn's, colitis, ulcerative colitis, doctor, patient, communication, education, shared decision making, patient centred care, engagement, partnership, support, carer, family. All search keys had synonyms for patient communication and inflammatory bowel disease. In the Scopus search, synonyms for patients or users had to be mentioned within five words before or after the synonyms for patient engagement.

Eligibility Criteria and Study Selection

Studies were included if they explored the method and outcomes of doctor-patient communication in IBD. The eligibility criteria for this review included adults aged 18 years old or over with active disease, and a confirmed diagnosis of IBD. The eligibility criteria also included both qualitative and quantitative study designs.

The exclusion criteria for this review included papers in languages other than English and studies that did not specifically involve communication between a doctor and patient.

We followed the Arksey and O'Malley methodology for scoping reviews [25]. One author (HB) screened the title of articles and then read the abstracts if the title suggested that the article satisfied the inclusion criteria. Following this, IS also reviewed the titles and abstracts of those deemed eligible before two authors (HB, IS) independently read the full papers to assess eligibility based on the inclusion criteria.

The reference lists of each article were searched by one author to detect any further relevant articles. Any discrepancies between authors regarding eligibility and the quality of potential articles were resolved through discussions. If discrepancies in judgement were indeterminable, the authors intended to consult a third reviewer (JL). All justifications for the exclusion of articles were documented.

Data Extraction

We extracted the following information from the eligible studies:

- Study characteristics (authors, date of publication, study design)
- Participants (patient groups)
- Methodological approach
- Potential limiting and enabling factors for involving patients in the study
- Patient outcomes following care for IBD

A single author (HB) extracted the relevant data by populating an electronic table with columns that reflect the information collected above. A second author (IS) verified the accuracy of the extracted data by independently populating a separate electronic table and then comparing the collected data to that of the first author for any discrepancies. The methodological quality of each paper was also assessed by the second author using the Cochrane risk of bias tool for quality assessment.

Data Analysis

We conducted a thematic analysis to combine study findings [26]. Initially, this was an inductive thematic analysis followed by a deductive approach to group the findings into three overarching themes based on UK IBD Standards: information needs, SDM, and patient education. Two authors (HB, IS) independently analysed the data and JL was consulted to discuss the themes and ensure agreement.

Results

Study Characteristics

Overall, 572 articles were found during the initial search (Figure 2), and seven studies involving 4369 participants met the inclusion criteria. In this review, a total of two studies adopted a mixed methods approach involving focus groups and questionnaires (Table 2). There were three overarching themes: information needs, SDM, and patient education.

Figure 2. The Prisma flowchart [27].

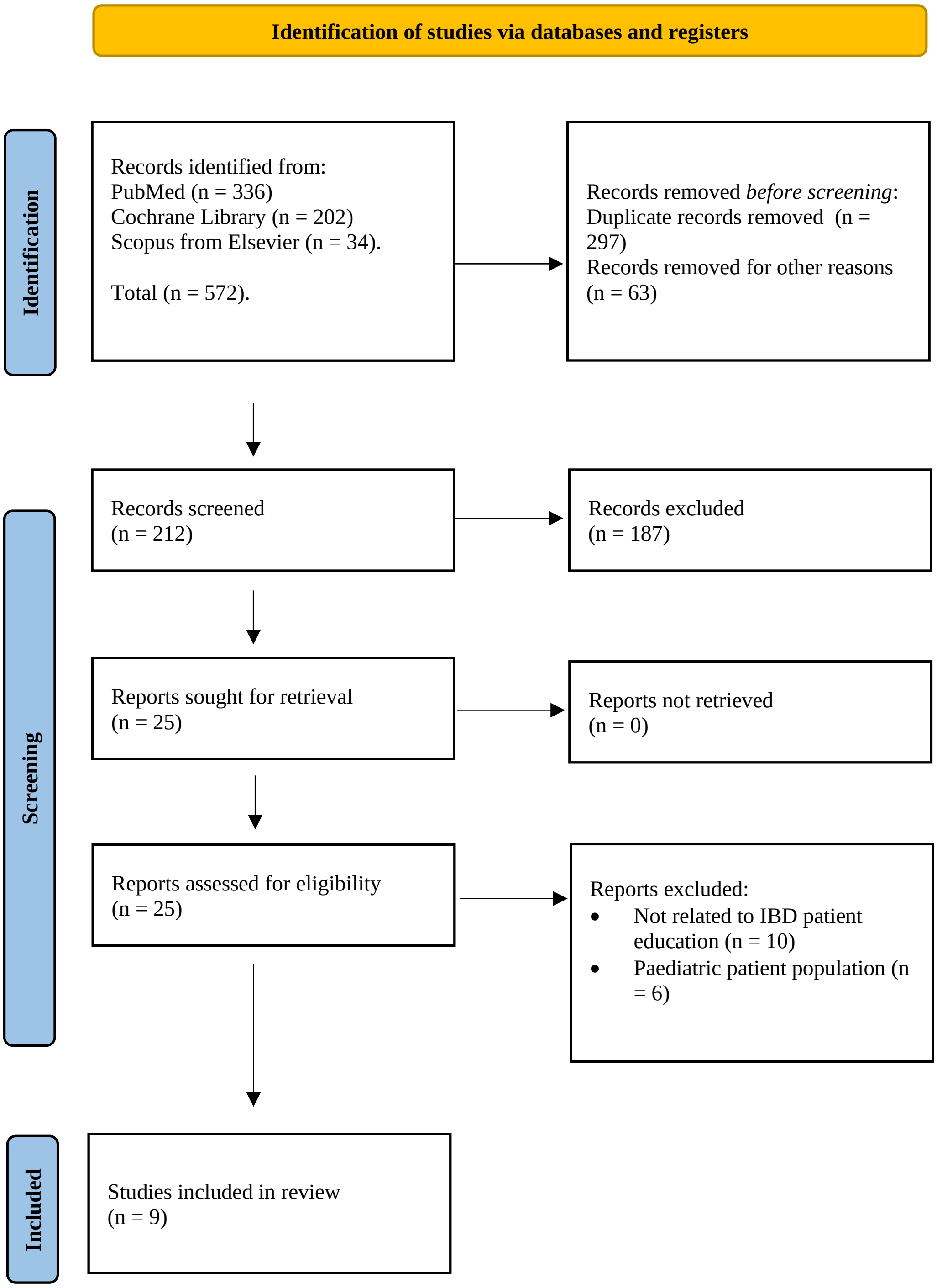


Table 2. Overview of selected studies in review

Author	**Type of IBD: CD, UC, or both.**	**Study method**	**Method of doctor-patient communication**	**Number of participants**
Bernstein et al. [28]	Both	Survey	Face to face with clinicians and the internet.	74
Pittet et al. [29]	Both	Mixed-methods, survey and focus groups	Face to face with clinicians, internet, books or TV, family, friends.	1506 (survey); 14 (focus group)
Veilleux et al. [30]	Both	Survey	Face to face	200
Baars et al. [31]	Both	Survey	No preference for online or face to face. Patients preference was to have a say in their treatment plan.	1067
Morishige et al. [32]	Both	Survey	No preference for online or face to face. Patients preference was to have a say in their treatment plan.	1068
Siegel et al. [33]	Neither. Gastro-enterologists interviewed.	Interview and survey.	Majority use a form of shared-decision making with patients.	106 gastro-enterologists
McDermott et al. [34]	Both	Mixed-methods, focus groups and survey.	Preference was internet for general information. Face to face with specialist clinicians for education.	12 (focus group); 322 (survey)
Linn et al. [35]	Both	Qualitative, retrospective analysis of consultations.	Face to face.	58
Wong et al. [36]	Both	Survey	Face to face. Acceptable to also use brochure and website.	271

Information Needs: Initial Symptoms and Diagnosis of IBD

Information needs appear to be high in the first four months following the diagnosis of IBD [28,29]. Bernstein et al. [28] found that participants sought information from the gastroenterologist and the internet within the first two months of diagnosis. Several advantages of using the internet were reported by Bernstein et al. [28] and Morishige et al. [32] including access to up-to-date information available in a variety of formats, the ability for patients to read in their own time, skip over topics of less interest, share information electronically, and the ability for hospital providers to update the information accordingly when required as there is no requirement for printing or storage. However, the quality and variety of sources were reported as a concern within the studies. Moreover, approximately one-quarter of participants living with IBD feel dissatisfied with the information they receive from their clinician following diagnosis [28, 29, 32]. Information about the disease course, treatment, symptoms, and self-management was viewed as being very important [28,29]. Participants diagnosed with CD were more pleased with the information they received about their disease and expressed fewer concerns when compared to patients diagnosed with UC [29]. Pittet et al. [29] found a correlation between the participants' perceived lack of information about IBD and increased stress, and stress was reported as the most recurrent psychological factor inducing flare-ups in IBD [29].

Patients were keen to receive information and education on a range of topics following their diagnosis of IBD [34,35]. In particular, patients wanted to receive information on medications, prognosis of the disease, living with IBD, diet, and educational content for their family [34]. In addition, patients wanted information about the impact this may have on an individual's quality of life including living with IBD, self-care, and medication options [28,34-36].

Despite the advantages of using the internet [28,32], patients were wary of the trustworthiness of internet information and worried about disconcerting stories online [35]. As a consequence, Linn et al. [35] found that healthcare professionals warned patients of the potential misinformation that can be found on the internet as well as countered any false pretences patients had on IBD. However, Linn et al. [35] were unable to find whether the strategies from the healthcare professionals were effective in reducing patients' concerns, but McDermott et al. [34] found patients living with IBD would prefer reliable sites recommended by healthcare professionals in the future. Providing reliable internet sources could be a positive step in providing patients with information needs, reducing patients' concerns, and tackling the misinformation found on the internet.

Shared Decision Making: Flare Management and Surgery

SDM is something that is appreciated by people living with IBD [30-32]. SDM was linked with increased patient satisfaction and lower levels of anxiety in therapy choices, as well as higher levels of adherence during treatment following SDM with their doctor [30]. Baars et al. [31] found that 82% of patients diagnosed with IBD stated it was very important to be included in the SDM process. Morishige et al. [32] found over 55% of patients living with IBD wanted to have an active involvement in their management. Morishige et al. [32] also found that patients living with IBD and being treated in university hospitals showed a greater interest in participating in SDM when compared to IBD patients who visited clinics or general hospitals [32]. The severity of IBD can be an important factor as to why certain patients want to actively participate in their IBD management, as typically, those seen in university hospitals tend to be seen by a specialist in the field, which infers greater disease severity. Consequently, patients living with IBD who have greater disease severity, particularly seen in flare-ups or awaiting surgery, may benefit from SDM.

The views of the clinicians within SDM are an important factor to consider. Siegel et al. [33] explored gastroenterologists' views of SDM as part of the consultation with patients living with IBD. A total of 106 gastroenterologists completed the questionnaire, and 77% were familiar with SDM and reported attempting to use SDM with their patients (80%) [33]. The gastroenterologists perceived SDM as being a key part of the decision-making process for surgical procedures, and they also acknowledged the potential for improving patient satisfaction and clinical outcomes [33]. However, only 12% reported having a systematic and consistent approach to SDM [33]. Moreover, three main barriers to the application of SDM in practice were reported and included time (74%), reimbursement (70%), and a lack of SDM support tools (51%) [33].

Discussion

This scoping review aimed to understand the current methods of doctor-patient communication in IBD. Overall, we found that patients living with IBD have high information needs following their diagnosis and want to be actively involved in the decisions surrounding their care. Every patient diagnosed with IBD is unique and at different points in their life; therefore, it is important to see the person in the patient and fulfil their knowledge needs accordingly [37,38]. Patient education and tailoring the information to the needs of the individual may be two ways of ensuring information needs are met, and HRQoL is improved.

For long-term conditions, including IBD, optimal healthcare encompasses a collaborative partnership between the doctor and patient [39]. Collaboration is defined as any behaviour, initiated by the physician or the patient which allows for the inclusion of the patient's views or preferences in the treatment plan [40]. The doctor is often seen as the medical expert whilst the patient is an expert in their own life; therefore, to reach an appropriate decision both the doctor and the patient are reliant upon the expertise of each other. The collaboration between the doctor and the patient has been linked with improved treatment adherence, enhanced patient satisfaction, and generally greater health outcomes [39-42]. The importance of providing sufficient information for patients to understand their condition and management in order for this collaboration to be effective is recognised within the IBD UK Standards [19]. Insufficient information can result in patient disempowerment, missed appointments, and poorer self-management of their condition [39-41].

There is a disparity in the patient's expectations for information they would like to receive and what the doctor provides upon the diagnosis of IBD. Whilst it seems that patient expectations are not being met by healthcare professionals upon diagnosis, it is important to understand the range and complexity of topics patients living with IBD were interested in at diagnosis. Topics included the long-term prognosis, fertility, children developing IBD, risk of cancer, managing pain, surgery, and counselling [28]. An optimal education programme would address a patient's needs with elements of all three aspects. For example, informal group sessions led by patients, one-to-one tailored information taught by doctors or nurses, as well as a dedicated online resource with text, videos, and podcasts may be an effective approach to ensuring patients feel their information needs have been met [34].

We found the internet to be a commonly used source to gain information. With the general dissemination of false health information across the internet, it is imperative to pay attention and care when patients access information from alternative, non-official web sources [43]. There is a risk that the patient may follow non-evidenced-based treatment, reducing adherence to their prescribed treatment and thus impacting their health [44]. Despite the surge in the use of technology and the benefits the internet provides, it is important to note that the majority (68%) of patients still prefer to discuss information with their doctor [28,29]. Nevertheless, patients have rated website recommendations from clinicians with a high level of acceptability. Therefore, providing recommended internet-based sources tailored to the patient's needs and discussing the risk of using alternative websites may be helpful. A combination of doctor-patient consultations and internet sources may provide an optimal and tailored communicative approach to information-giving for newly diagnosed patients living with IBD [28,29].

Doctors must be able to communicate with patients in a way that allows the patient to understand their condition, recognise risk behaviours, and make informed treatment decisions [45]. Patient education is the cornerstone of modern healthcare, and improving the education provided for patients about their condition can optimise patient care [46]. The IBD UK Standards, as well as other IBD regulatory bodies, have emphasised the importance of providing education to patients living with IBD along with their families and carers, as this can help patients living with IBD to have clarity when making informed decisions, improve patient confidence in managing their condition and consequently enhance health outcomes and improve the quality of care [19,42]. Despite the emphasis on patient education, a recent UK IBD audit that evaluated UK IBD services found that 52% of providers offered newly diagnosed

IBD patients a teaching session to better understand the disease [47]. The audit also found that 48% of health services offer regular education opportunities to people living with IBD and their families [47]. This is a great opportunity missed by healthcare services. Providing education to patients can enable patients to make informed decisions and thus be part of the SDM process. Facilitating patients to be part of the SDM process has a plethora of benefits for both the patient and the doctor [24, 30,31,48]. Patients have reported greater adherence, optimal satisfaction, and a higher probability of patients reporting increased confidence in decisions regarding their care [24,49]. From a clinician's viewpoint, there was also lower decision regret when SDM was effectively utilised [24].

Doctor-patient communication should include SDM whereby patients are active participants in the decision-making process due to the significant benefits this provides such as improved patient satisfaction, adherence to treatment, and lowering anxiety when deciding on treatment [30]. Although barriers to SDM have been mentioned by clinicians. Given the range and complexity of the topics patients diagnosed with IBD would like to discuss, doctors may find it difficult to communicate the information satisfactorily due to time constraints in consultations. Perhaps this can be rectified by sharing the responsibility of SDM with other healthcare professionals in the multi-disciplinary team. For example, physician associates and specialist nurses can work together to explain the treatment options available to the patient, the risk versus benefits of each treatment, listen to the patient's preferences, and make the final decision.

Sharing the responsibility of SDM or creating a web-based SDM tool may help to overcome this challenge. The use of tools for SDM such as the 'Ottawa Decision Support Framework' has been used to help form decisions for patients with CD when deciding on the therapy of choice [35]. The tool has been recommended by experts in IBD, and a recent study found that after reviewing the tool, 64% of patients felt the 'Ottawa Decision Support Framework' displayed a balanced presentation of the treatment options, with 82% of patients confirming that most or all information was clearly accessible [49]. However, it should be noted that tools used for SDM were not necessary to engage patients in decision-making, rather, it was the competency in the SDM skill and the clinician's attitude that were essential when implementing SDM [49].

Reasons for patients not participating in SDM can include a lack of interest, a lack of understanding or education as well as a preference for the clinician to decide [33]. Additionally, due to cultural variation, some patients are accustomed to paternalistic healthcare and satisfied with it [33]. Therefore, the best practice may be for doctors to use SDM as a default but be cognisant of cues wherein the patient may want the doctor to lead the decision-making process [33].

Limitations

There are a number of limitations within the review. Firstly, a small number of studies were included. Secondly, the studies included did not generally separate their findings into those living with CD or UC, rather, they used the umbrella term IBD. There may have been key differences in the information needs between patients with CD and UC. Therefore, the findings may not be representative of everyone living with IBD. Nevertheless, our findings contribute to the existing knowledge of doctor-patient communication within IBD and advance our understanding of what patients value when speaking with their clinicians.

Future Research

Further work is necessary to explore the perception of doctors' understanding of how to effectively deliver information, SDM, and patient education. It is also important to explore whether there are any differences in the information needs of patients with CD and UC, as this can allow doctors to provide a tailored communicative approach to patients newly diagnosed with CD or UC. This understanding would enable the creation of an optimised management programme for patients living with IBD.

Conclusion

This scoping review aimed to understand the current methods of doctor-patient communication in IBD including patient information needs, SDM, and patient education. The review found that patients diagnosed with IBD seek information directly from the doctor or through reliable internet sources.

Patients living with IBD want to be actively involved in the decisions surrounding their care and receiving adequate information to help make informed decisions can improve their competence and confidence in managing their long-term condition.

Delivering information and education to patients living with IBD through group sessions led by patient educators and clinicians, tailored one-to-one sessions with doctors or nurses, and education via the internet (in text, videos, and podcasts) can enhance the quality of care and improve HRQoL.

Practice Implications

People living with IBD, as well as their family and carers, want to be actively involved in their own care [31,32]; therefore, it is important for IBD patient education to be a central part of ongoing care. In light of the recent COVID-19 pandemic, it would be helpful to consider the provision of an online education programme that addresses the needs of individuals living with IBD and includes text, videos, and podcasts [34]. Individuals living with IBD may be immunocompromised and the implementation of an online education programme may reduce the risk of viral infections, as well as reduce the amount of time needed to attend appointments. However, it is important to note not all patients have access to online resources.

To help overcome the current barriers in patient information needs, communication, and SDM, there is a need for innovative leadership at both individual and organisational levels. An augmented leadership drive can help support healthcare professionals and provide them with adequate communication skills training in SDM. These desired outcomes for healthcare professionals can be achieved through regular in-service training, consultation simulations with patients living with IBD, and e-learning modules.

Lessons for Practice

- Patients with IBD and their caregivers seek active involvement in care, highlighting the importance of centralizing IBD patient education in ongoing care.

- Considering the impact of COVID-19, an online education program with diverse content formats is suggested for IBD patients, potentially reducing infection risk and appointment time.
- Leadership at individual and organizational levels is crucial to address barriers in patient information, communication, and shared decision-making. Initiatives like communication training and patient simulations can enhance healthcare professionals' skills in SDM through in-service training and e-learning modules.

Declarations

Acknowledgements

Not applicable.

Disclosure Statement

No potential conflict of interest was reported by the authors.

Ethics Approval

Not applicable.

Funding Acknowledgements

Not applicable.

Citation to this article

Sani I, Bux H. A scoping review of doctor-patient communication in inflammatory bowel disease. Canadian Journal of Medicine. 2024 Jul 24;6(2):69-81. doi: 10.33844/cjm.2024.6039

Rights and Permissions

References

[1] The Facts About Inflammatory Bowel Diseases. [Internet]. Crohnscolitisfoundation.org. 2014. Available from: https://www.crohnscolitisfoundation.org/sites/default/files/2019-02/Updated%20IBD%20Factbook.pdf [cited 20 March 2021].

[2] Molodecky N, Soon I, Rabi D, Ghali W, Ferris M, Chernoff G et al. Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. Gastroenterology. 2012;142(1):46-54.e42.

[3] Alatab S, Sepanlou S, Ikuta K, Vahedi H, Bisignano C, Safiri S et al. The global, regional, and national burden of inflammatory bowel disease in 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet Gastroenterology & Hepatology. 2020;5(1):17-30.

[4] de Jong M, van der Meulen-de Jong A, Romberg-Camps M, Degens J, Becx M, Markus T et al. Development and Feasibility Study of a Telemedicine Tool for All Patients with IBD. Inflammatory Bowel Diseases. 2017;23(4):485-493.

[5] Wilkins T, Jarvis K, Patel J. Diagnosis and management of Crohn's disease. Am Fam Physician. 2011;84(12):1365-75.

[6] Azzouz L, Sharma S. Physiology, Large Intestine. Florida: StatPearls. 2021.

[7] Abegunde A, Muhammad B, Bhatti O, Ali T. Environmental risk factors for inflammatory bowel diseases: Evidence based literature review. World Journal of Gastroenterology. 2016;22(27):6296.

[8] Ananthakrishnan, A. Epidemiology and risk factors for IBD. Nature Reviews Gastroenterology & Hepatology, [Internet]. 2015;12(4):205-217.

[9] Ellinghaus D, Bethune J, Petersen B, Franke A. The genetics of Crohn’s disease and ulcerative colitis –status quoand beyond. Scandinavian Journal of Gastroenterology. 2014;50(1):13-23.

[10] Kaplan G, Ng S. Understanding and Preventing the Global Increase of Inflammatory Bowel Disease. Gastroenterology. 2017;152(2):313-321.e2.

[11] Malik T. Inflammatory Bowel Disease. Surgical Clinics of North America. 2015;95(6):1105-1122.

[12] Cosnes J, Gower–Rousseau C, Seksik P, Cortot A. Epidemiology and natural history of inflammatory bowel diseases. Gastroenterology. 2011;140(6):1785-1794.e4.

[13] Royal College of Physicians. Report of the results for the national clinical audit of adult inflammatory bowel disease inpatient care in Scotland. National Organisational Audit of Adult IBD Services in the UK, 2012; 2021;6.

[14] Molodecky N, Soon I, Rabi D, Ghali W, Ferris M, Chernoff G et al. Increasing Incidence and Prevalence of the Inflammatory Bowel Diseases With Time, Based on Systematic Review. Gastroenterology. 2012;142(1):46-54.e42.

[15] Clearfield H. How does IBD affect quality of life?. Inflammatory Bowel Diseases. 2008;14:S45-S46.

[16] Baumgart D, Sandborn W. Inflammatory bowel disease: clinical aspects and established and evolving therapies. The Lancet [Internet]. 2007;369(9573):1641-1657.

[17] Laass M, Roggenbuck D, Conrad K. Diagnosis and classification of Crohn's disease. Autoimmunity Reviews. 2014;13(4-5):467-471.

[18] Pittet V, Vaucher C, Froehlich F, Maillard M, Michetti P. Patient-reported healthcare expectations in inflammatory bowel diseases. PLOS ONE. 2018;13(5):e0197351.

[19] IBD Standards [Internet]. IBD UK. 2021. https://ibduk.org/ibd-standards [cited 29 March 2021].

[20] Global Health Estimates: Life expectancy and leading causes of death and disability. World Health Organisation International. 2021. https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates [cited 29 March 2021].

[21] Hesse B, Hansen D, Finholt T, Munson S, Kellogg W, Thomas J. Social Participation in Health 2.0. Computer. 2010;43(11):45-52.

[22] Mathijssen E, van den Bemt B, Wielsma S, van den Hoogen F, Vriezekolk J. Exploring healthcare professionals’ knowledge, attitudes and experiences of shared decision making in rheumatology. RMD Open. 2020;6(1):e001121.

[23] Stiggelbout A, Pieterse A, De Haes J. Shared decision making: Concepts, evidence, and practice. Patient Education and Counseling. 2015;98(10):1172-1179.

[24] Tricco A, Lillie E, Zarin W, O'Brien K, Colquhoun H, Levac D et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Annals of Internal Medicine. 2018;169(7):467-473.

[25] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology. 2005;8(1):19-32.

[26] Clarke, V., Braun, V., & Hayfield, N. (2015). Thematic analysis. Qualitative psychology: A practical guide to research methods, 222(2015), 248.

[27] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. BMJ. 2021 Mar 29;372.

[28] Bernstein K, Promislow S, Carr R, Rawsthorne P, Walker J, Bernstein C. Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. Inflammatory Bowel Diseases. 2011;17(2):590-598.

[29] Pittet V, Vaucher C, Maillard M, Girardin M, de Saussure P, Burnand B et al. Information Needs and Concerns of Patients with Inflammatory Bowel Disease: What can we learn from participants in a bilingual clinical cohort?. PLOS ONE. 2016;11(3):e0150620.

[30] Veilleux S, Noiseux I, Lachapelle N, Kohen R, Vachon L, Guay B et al. Patients’ perception of their involvement in shared treatment decision making: Key factors in the treatment of inflammatory bowel disease. Patient Education and Counseling. 2018;101(2):331-339.

[31] Baars J, Markus T, Kuipers E, van der Woude C. Patients’ Preferences regarding Shared Decision-Making in the Treatment of Inflammatory Bowel Disease: Results from a patient-empowerment study. Digestion. 2010;81(2):113-119.

[32] Morishige R, Nakajima H, Yoshizawa K, Mahlich J, Sruamsiri R. Preferences regarding shared decision-making in japanese inflammatory bowel disease patients. Advances in Therapy. 2016;33(12):2242-2256.

[33] Siegel C, Lofland J, Naim A, Gollins J, Walls D, Rudder L et al. Gastroenterologists' views of shared decision making for patients with inflammatory bowel disease. Digestive Diseases and Sciences. 2015;60(9):2636-2645.

[34] McDermott E, Healy G, Mullen G, Keegan D, Byrne K, Guerandel A et al. Patient Education in inflammatory bowel disease: A patient-centred, mixed methodology study. Journal of Crohn's and Colitis. 2017;12(4):419-424.

[35] Linn A, Schouten B, Sanders R, van Weert J, Bylund C. Talking about Dr. Google: Communication strategies used by nurse practitioners and patients with inflammatory bowel disease in the Netherlands to discuss online health information. Patient Education and Counseling. 2020;103(6):1216-1222.

[36] Wong S, Walker J, Carr R, Graff L, Clara I, Promislow S et al. The information needs and preferences of persons with longstanding inflammatory bowel disease. Canadian Journal of Gastroenterology. 2012;26(8):525-531.

[37] Goodrich J, Cornwell J. Seeing the person in the patient. The point of care review paper – The King's Fund, 2008.

[38] Lesnovska K, Börjeson S, Hjortswang H, Frisman G. What do patients need to know? Living with inflammatory bowel disease. Journal of Clinical Nursing. 2013;23(11-12):1718-1725.

[39] Arora N. Interacting with cancer patients: the significance of physicians' communication behavior. Social Science & Medicine. 2003;57(5):791-806.

[40] Golin CE, DiMatteo MR, Gelberg L. The role of patient participation in the doctor visit: Implications for adherence to diabetes care. Diabetes Care 1996;19:1154.

[41] Graham S. Do patients understand?. The Permanente Journal. 2008;12(3).

[42] Platt F, Keating K. Differences in physician and patient perceptions of uncomplicated UTI symptom severity: understanding the communication gap. International Journal of Clinical Practice. 2007;61(2):303-308.

[43] Pulido C, Ruiz-Eugenio L, Redondo-Sama G, Villarejo-Carballido B. A new application of social impact in social media for overcoming fake news in health. International Journal of Environmental Research and Public Health. 2020;17(7):2430.

[44] Selinger C, Carbery I, Warren V, Rehman A, Williams C, Mumtaz S, et al. The relationship between different information sources and disease-related patient knowledge and anxiety in patients with inflammatory bowel disease. Alimentary Pharmacology & Therapeutics. 2016;45(1):63-74.

[45] Grüninger UJ. Patient education: an example of one-to-one communication. Journal of Human Hypertension. 1995 Jan;9(1):15-25.

[46] Elkjaer M, Moser G, Reinisch W, Durovicova D, Lukas M, Vucelic B et al. IBD patients need in health quality of care ECCO consensus. Journal of Crohn's and Colitis. 2008;2(2):181-188.

[47] UK IBD Audit summary report 2014. Royal College of Physicians. https://www.rcplondon.ac.uk/file/2441/download [cited 29 March 2021].

[48] Isaacs C, Kistler C, Hunold K, Pereira G, Buchbinder M, Weaver M, et al. Shared decision-making in the selection of outpatient analgesics for older individuals in the emergency department. Journal of the American Geriatrics Society. 2013;61(5):793-798.

[49]Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S et al. Implementing shared decision making in the NHS: lessons from the MAGIC programme. BMJ. 2017;j1744.