



Research article

Qualitative study about the perception of patients with inflammatory bowel disease: A descriptive observational study

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ABSTRACT

The main aim of this study was to identify the perceptions of people suffering from inflammatory bowel diseases (IBD) regarding the need for specialised nursing care, based on their opinions from their own experience. A qualitative design with an inductive approach based on constructivist grounded theory was conducted using a questionnaire. Almost 63 % of respondents felt that a nursing intervention was necessary for the patient's self-care and supported the care of the environment of the patient with IBD in need of care. Approximately 75 % of respondents felt that the initial nursing consultation following diagnosis of IBD was essential to address all aspects of the patient's daily life and environment for quality care and follow-up. More than 87 % of respondents felt it was important for nurses to recognise the need for referral to other professionals when caring for IBD patients and their environment to maximise their wellbeing. The percentage of females who answered yes to this last question was significantly higher than that of males ($p = 0.025$). Some 67.1 % of respondents felt that nurses should be responsible for informing the patient and those around them of the steps to be taken following diagnosis and what these consist of. More than 94 % of all respondents felt that IBD patients and their carers should have a plan and time for specific and appropriate education on this topic. More than 80 % of respondents agreed that the progression, monitoring, and management of their IBD should be supervised by a nurse in addition to their specialist doctor to achieve an optimal level of quality. In conclusion, this study shows that patients suffering from IBD consider the role of the nurse to be crucial in the diagnosis, management and treatment of their disease and highlights the need for specialised nurses in inflammatory bowel disease who can provide patients with high-quality healthcare.

1. Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is characterised by recurrent chronic intestinal inflammation that can lead to flare-ups, serious complications, and functional, physical, and psychological disability. It is a

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disease with an unknown cause, although all scientific evidence suggests that it is due to an immune mechanism [1] triggered by a combination of genetic and environmental factors. IBD is considered a severe public health problem as it occurs worldwide [2], with a higher incidence in industrialised countries, such as those in North America and Europe, than in developing or underdeveloped countries [3]. Additionally, the rate has increased significantly over in the last 50 years. According to current data, the annual incidence of IBD in North America is 20 per 100,000 people/year, and the annual incidence of IBD in Europe is 24.3 per 100,000 people/year [4]. Worldwide, CD and UC affect around five million people between the ages of 15 and 35. In Spain, an increase in incidence has been observed in recent years, with an increase of 42.2 % for cases of CD and 87.8 % for UC [5] with estimated standard mortality ratio of 4.83 (CD: 3.28 and UC: 6.51) [6]. Because of the high and increasing rate of incidence of IBD and its increasing burden on healthcare systems, it is crucial to fully understand IBD patient experiences, particularly in terms of nursing care.

The nursing profession supports and assists both patients and their caregivers, on equal footing to ensure high-quality care. As a monitoring process, this includes a specific service, nursing indications, health education and advice on the steps to be followed, preparations of the patient and their environments for future prevention and opportunities to participate in the process [7]. Although numerous studies have addressed chronically ill patient perceptions of the healthcare received, few have attempted to find out what patients suffering from IBD are like clinically and what they and their caregivers think about the nursing profession, specifically how it can improve their daily quality of life. To date, there has been no study performed in Spain concerning patient opinions of the role of the nursing for IBD care. Studies of this type in Spain could have a direct impact on patient care, as it would likely support the creation of specialised IBD nursing practice and on health policies, as the nurse could play a role in helping the patient adapt better to the disease and the IBD nurse specialist could acquire an intermediary role, without the patient having to first be sent back to the general practitioner for referral to the appropriate specialist.

The main aim of this study was to identify the perceptions of people suffering from IBD regarding the need for specialised IBD nursing care, based on their own experience. The secondary aim was to investigate whether there was a relationship between patient perceptions and patient gender-identity, academic level, or the type of IBD.

Contribution of the paper

What is already known

In Spain, few studies have tried to discover what patients suffering from IBD are like clinically.

What this paper adds

This study of patients in Spain begins to discover patients suffering from IBD experience while living with their disease, and their perceptions of their healthcare environments, particularly the significance of nursing in that care.

2. Materials and methods

2.1. Ethics and other permissions

The study was conducted in accordance with the Ethical Principles for Medical Research Involving Human Subjects, the Declaration of Helsinki, by the 18th World Medical Assembly (WMA) in Helsinki, Finland, in 1964 and revised in 2008. Data was collected using a proprietary questionnaire approved by the Ethics Committee for Research with Medicines of HM Hospitals (ID code: 05.21.1853-GHM) after being approved by Dr Moreno-Almazán (Head of the Service of Gastroenterology and Digestive System and Head of the Digestive Inflammation Unit). In the preparation of our questionnaire, other already validated questionnaires were considered *e.g.*, the IBDQ 32, an instrument to assess patient quality of life. In our case, a self-administered questionnaire of closed-ended questions was distributed, along with a patient information sheet and an informed consent. There was a deadline for questionnaire submission and dismissal of those who did not comply (6 weeks). In addition to the above, each participant also received a withdrawal declaration. The promoter and the principal investigator, in this case one and the same person, guarantees the confidentiality of the subject data and ensures compliance with the provisions of Spanish Organic Law 3/2018 of 5 December on Protection of Personal Data and Guarantee Digital. This law is the adaptation of the Spanish legal system to Regulation (EU) 2016/679 of the European Parliament and of the Council of April 27, 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). For this purpose, each participant recruited was assigned a unique study identification number, meaning that datasets submitted to sponsor centers and all study documentation exclude participant names.

2.2. Theoretical framework

A qualitative approach was selected to best capture participant perceptions of their health conditions, specifically Constructivist Grounded Theory (CGT). Grounded Theory (GT), first defined by Glaser and Strauss (1967) and revised to Constructivist Grounded Theory (CGT) by Kathy Charmaz [8], is a method in which hypotheses and theories are constructed throughout the research process by the researcher and also participants. This type of qualitative research begins with a general reading of the topic to assess and familiarise oneself with the intention and nature of the research carried out up to that point; this first step was mainly performed AG. The method also involves a series of data collections coupled with on-going inductive analyses to refine understanding, a process all researchers were involved in.

2.3. Design and data collection

The study was conducted using a qualitative study design to assess IBD patient perceptions following the guidelines of a descriptive observational study. Data were analysed cross-sectionally and prospectively. As this was an exploratory study, it was not necessary to calculate the sample size. Therefore, the sample used for the study was an intentional, non-random selection, with maximum variation in age, gender and IBD experience. This purposive sample was chosen because it is the only way to select participants who are considered relevant to the research, patients who have chronically suffered from IBD and met the inclusion and exclusion criteria described below.

Participants were recruited from the Hospital Universitario Madrid Montepríncipe (Boadilla del Monte, Community of Madrid), the Fisoalpe Physiotherapy Clinique (Alpedrete, Community of Madrid), and social networks, national associations and working groups, such as Spanish Association of Crohn’s Disease and Ulcerative Colitis (ACUC), Spanish Working Group on Crohn’s Disease and Ulcerative Colitis (WGCUC), and Inflammatory Bowel Disease Nursing Working Group (IBDNWG) and Facebook groups named “Chron CU equipo C”, “Enfermedad de Crohn y Colitis Ulcerosa España”, and “Sociedad Científica de Enfermería y Enfermedad Inﬂamatoria Intestinal”. Participants recruited in person were patients who attended either the Gastroenterology Clinic of the Hospital Universitario Madrid Montepríncipe or the Fisoalpe Physiotherapy Clinic and their questionnaires were completed privately in person between October 7th, 2021 and December 30th, 2021. Participants recruited through social networks were contacted by email using the email addresses provided on the notice boards of the corresponding social networks, national associations and working groups. After indicating their willingness to participate, patients received all the documents required for participation in the study via email. Data for

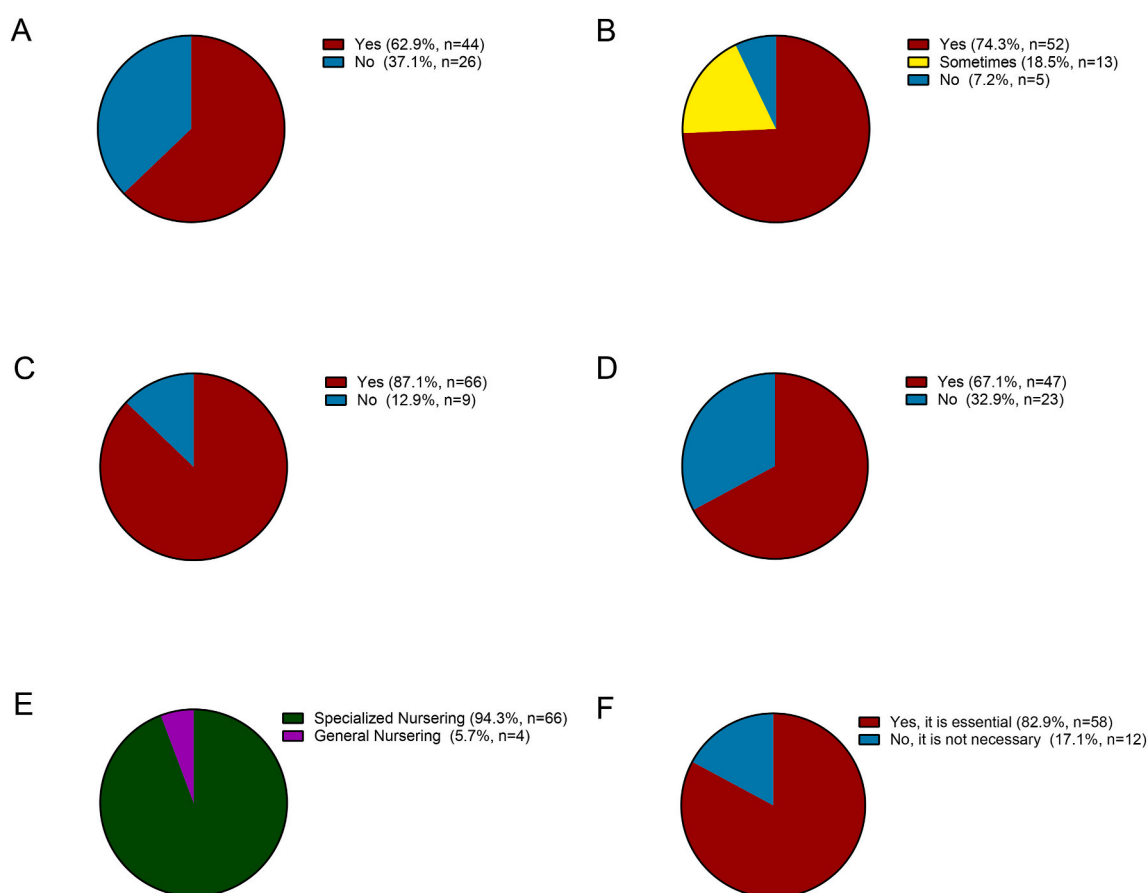


Fig. 1. Graphical representation of the results obtained in the questionnaire of this study by question. (A) Is nursing intervention for both the IBD patient’s self-care and care supported by family/carers? (B) For high-quality care and effective follow-up, do you think that the initial nursing consultation after the diagnosis of IBD is essential to address all aspects of the patient’s daily life and environment? (C) For the IBD patient to achieve the highest level of physical, psychological and spiritual well-being, do you think it is important for the nurse to recognise the need for referral to other professionals, such as dieticians, physiotherapists, psychologists, sexologists, etc.? (D) Do you think that the nurse should be responsible for informing the patient and their family/carers about the steps to follow and what these consist of? (E) Do you understand that the nurses who will care for you and those around you must have a plan and time for specialised and appropriate training on this topic, or on the contrary, do they work in the same way as general nurses? (F) In order to achieve the highest-quality care, do you think that the process of disease awareness, monitoring and treatment of your IBD needs to be managed by a nurse in addition to your specialist doctor? *Note: Next to each answer to the questionnaire in each graph, the exact percentage and number of participants representing that answer is given.*

virtual participants were collected between July 5th 2021 and December 30th 2021. All participants gave written consent regardless of the method of recruitment. All data were collected using the questionnaire issued by the same researcher (AG-A). For either data collection method, AG-A was available should participants require assistance. Data collection and analysis were carried out simultaneously, as required by CGT, with constant comparison of the two. Such comparison was supported by literature review throughout the study.

2.4. Inclusion and exclusion criteria

The target population met the following criteria. The inclusion criteria were (1) being of legal age for health (≥ 16 years), (2) having their disease monitored by gastroenterology consultation, (3) having been diagnosed at least 12 months prior to study participation and therefore fully aware of the chronic nature of IBD, and (4) having volunteered to participate in the study by signing the informed consent. Exclusion criteria were (1) being unable to participate in the study due to their physical or mental state, (2) not having correctly filled in at least one of the contact details of the informed consent, and (3) having been diagnosed within the last 12 months.

Table 1

Percentages (n) per question and variable evaluated in this study. IBD: Inflammatory bowel disease. CD: Crohn’s disease. UC: Ulcerative disease. $p < 0.05$ are highlighted in bold.

Is nursing intervention for both the IBD patient’s self-care and care supported by family/carers?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Yes	59.5 (25)	67.9 (19)	0.480	37.5 (3)	58.3 (14)	71.1 (27)	0.179	56.1 (23)	72.4 (21)	0.164
No	40.5 (17)	32.1 (9)		62.5 (5)	41.7 (10)	28.9 (11)		43.9 (18)	27.6 (8)	
For high-quality care and effective follow-up, do you think that the initial nursing consultation after the diagnosis of IBD is essential to address all aspects of the patient’s daily life and environment?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Always	78.6 (33)	67.9 (19)	0.537	87.5 (7)	70.8 (17)	73.7 (28)	0.560	78.0 (32)	69.0 (20)	0.596
Sometimes	16.7 (7)	21.4 (6)		0.0 (0)	25 (6)	18.4 (7)		14.6 (6)	24.1 (7)	
Never	4.8 (2)	10.7 (3)		12.5 (1)	4.2 (1)	7.9 (3)		7.3 (3)	6.9 (2)	
For the IBD patient to achieve the highest level of physical, psychological and spiritual well-being, do you think it is important for the nurse to recognise the need for referral to other professionals, such as dieticians, physiotherapists, psychologists, sexologists, etc.?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Yes	95.2 (40)	75 (21)	0.025	87.5 (7)	91.7 (22)	84.2 (32)	0.779	92.7 (38)	79.3 (23)	0.148
No	4.8 (2)	25 (7)		12.5 (1)	8.3 (2)	15.8 (6)		7.3 (3)	20.7 (6)	
Do you think that the nurse should be responsible for informing the patient and their family/carers about the steps to follow and what these consist of?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Yes	66.7 (28)	67.9 (19)	0.917	75.0 (6)	79.2 (19)	57.9 (22)	0.195	73.2 (30)	58.6 (17)	0.202
zNo	33.3 (14)	32.1 (9)		25.0 (2)	20.8 (5)	42.1 (16)		26.8 (11)	41.4 (12)	
Do you understand that the nurses who will care for you and those around you must have a plan and time for specialised and appropriate training on this topic, or on the contrary, do they work in the same way as general nurses?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Specialised Nursing	90.5 (38)	100 (28)	0.144	100 (8)	95.8 (23)	92.1 (35)	1.000	92.7 (38)	96.6 (28)	0.637
General Nursing	9.5 (4)	0.0 (0)		0.0 (0)	4.2 (1)	7.9 (3)		7.3 (3)	3.4 (1)	
In order to achieve the highest-quality care, do you think that the process of disease awareness, monitoring and treatment of your IBD needs to be managed by a nurse in addition to your specialist doctor?										
Possible answers	Gender			Academic level				IBD		
	Female	Male	<i>p</i>	Basic	Intermediate	Higher	<i>p</i>	CD	UC	<i>p</i>
Yes, it is essential	81.0 (34)	85.7 (24)	0.751	87.5 (7)	83.3 (20)	81.6 (31)	1.000	85.4 (35)	79.3 (23)	0.536
No, it is not necessary	19.0 (8)	14.3 (4)		12.5 (1)	16.7 (4)	18.4 (7)		14.6 (6)	20.7 (6)	

2.5. Statistical analysis

Qualitative variables are presented with their frequency distribution and percentage. In contrast, quantitative variables are presented with their mean and standard deviation when they were normally distributed, and with median and interquartile range when they were not normally distributed. To determine whether there was an association or dependence between the responses obtained in the surveys and the independent variables of participant gender and academic level, the χ^2 test was used, and in cases where more than 20 % of cells in the contingency table had an expected frequency of less than 5, Fisher's exact test was used. If any of those associations were significant, the effect size (ES) was calculated by using Cramer's V. For absolute values of ES, ≤ 0.2 is regarded as weak, 0.2–0.6 as moderate, ≥ 0.6 as strong. IBM® SPSS software version 27 was used for all analyses. A significance level was set at $\alpha = 0.05$.

3. Results

Forty-three patients were recruited from the Hospital Universitario Madrid Montepríncipe, 16 patients were recruited from the Fisioalpe Physiotherapy Clinique, and 21 patients contacted through social networks and national associations and working groups. The total number of study participants was 80, of whom 10 were excluded because they did not fulfil the inclusion criteria. The sample size was also considered sufficient as information saturation was reached and further interviews were required to obtain additional relevant data for the study. Among the 70 patients, 60 % were women, who had a mean age 35.3 ± 13.8 (16–64) years, and the remaining 40 % were men, who had a mean age of 39.3 ± 13.6 (20–70) years.

The results obtained are represented in Fig. 1 and detailed in Table 1.

To the question "Is nursing intervention for both the IBD patient's self-care and care supported by family/carers?", more than 62.9 % of the respondents answered yes (Fig. 1A), with significant differences for gender, academic level or type of IBD ($p > 0.05$) (Table 1).

To the question "For high-quality care and effective follow-up, do you think that the initial nursing consultation after the diagnosis of IBD is essential to address all aspects of the patient's daily life and environment?", 74.3 % of respondents answered *always*. 18.5 % thought that the initial nursing consultation after the diagnosis of IBD is *sometimes* essential to address all aspects of the patient's daily life and environment (Fig. 1B). No significant differences were found in response for gender, academic level, or type of IBD ($p > 0.05$) (Table 1).

When asked "For the IBD patient to achieve the highest level of physical, psychological and spiritual well-being, do you think it is important for the nurse to recognise the need for referral to other professionals, such as dietitians, physiotherapists, psychologists, sexologists, etc.?", most respondents answered yes (Fig. 1C). This opinion was not influenced by academic level or type of IBD ($p > 0.05$), but the percentage of females who answered yes was significantly higher than that of males ($p = 0.025$). For this association between gender and the need for the nurse to be able to recognize the need for referral, the ES was moderate (ES = 0.296) (Table 1).

When asked "Do you think that the nurse should be responsible for informing the patient and their family/carers about the steps to follow and what these consist of?", 67.1 % of respondents answered yes (Fig. 1D). No significant differences were found for gender, education level or type of IBD ($p > 0.05$) (Table 1).

To the question "Do you understand that the nurses who will care for you and those around you must have a plan and time for specialised and appropriate training on this topic, or on the contrary, do they work in the same way as general nurses?", 94.3 % of all respondents thought that nurses must have a plan and time for specialised and appropriate training on this topic (Fig. 1E). Again, no significant differences were found for gender, academic level, or type of IBD ($p > 0.05$) (Table 1).

When asked "In order to achieve the highest-quality care, do you think that the process of disease awareness, monitoring and treatment of your IBD needs to be managed by a nurse in addition to your specialist doctor?", more than 80 % of respondents agreed (Fig. 1F). No differences were found for gender, academic level, or type of IBD ($p > 0.05$) (Table 1).

4. Discussion

To our knowledge, this is the first Spanish study of IBD patients' perceptions of the role of nursing in their treatment and their environments. Although some studies have investigated the needs of IBD patients in meeting and communicating with healthcare professionals by exclusively recruiting patients from specialised gastroenterology outpatient clinics at hospitals [9], this study recruited participants from both healthcare clinics and via online means, as was recently done in survey of IBD units and patients in the United Kingdom [10].

In the treatment of patients with chronic illnesses, nurses are crucial. Most respondents felt that nursing intervention is necessary for the IBD patient's self-care and for supported care of and by family and/or carers. More specifically, for high-quality care and follow-up, participants also recognised the importance of the initial nursing consultation after the IBD diagnosis to address issues with the patient's daily life and their environment. This finding is also in line with what is known about the importance of nursing in patient education. Long-term care and self-maintenance are necessary for patients with chronic conditions, such as IBD. Patients need to educate themselves on their conditions and engage in disease self-management to effectively manage chronic diseases [11]. By educating patients on follow-up care, nurses have the potential to improve patients' self-efficacy, coping, and self-management abilities [11].

Participants in this study understand the value of a direct relationship between nurses and specialist. Patients with chronic conditions often benefit from follow-up visits by nurses, as long as these visits are repeated, extended over time [12]. Due to the chronicity of IBD, relapses often occur, leading to complications that can increase morbidity and mortality [13]. The extraintestinal manifestations (EIM) of IBD form a heterogeneous group of diseases that affect numerous organs and systems, which is why they are

considered systemic diseases [14]. This means that EIM must be correctly suspected and identified to make a timely diagnosis and referral to the appropriate specialist. Respondents in this study mirror what previous research has shown: the importance of the IBD specialist nurse to be able to recognise the need for referral to other health professionals when caring for IBD patients. An IBD specialist nurse with the power to appropriately and directly refer such chronic patients to the relevant health specialist would be of enormous help to the patient, but also help to the gastroenterologist or the primary care physician, whose schedules would be freed up from consultations in which they act only as intermediaries [15,16]. Curiously, a higher percentage of females than males ($p = 0.025$) thought it important that a specialist nurse could recognise the need for referral. More research is needed to understand the specific role gender plays in patient and their caregivers' perceptions of not only their IBD nursing care, but the full range of medical professionals.

Two-thirds of respondents considered the nurse responsible for informing the patient and their caregivers of the diagnosis-specific steps to follow and what these consist of. This is in line with the vital role of nurses in chronic disease management where they are responsible for enhancing and of the planning and delivery of the healthcare resources in primary care [17].

More than 90 % of respondents understood that their nurses must have a plan and time for specialised and appropriate training on this topic. Additionally, to achieve the highest-quality care, more than the 80 % of respondents thought that the process, monitoring and treatment of their IBD needs to be managed by a nurse in addition to a specialist doctor. A specialist nurse can provide a high-quality and cost-effective care to patients with chronic diseases, which may have a positive impact on patient, family, and health-care team outcomes [18]. The results can range from patient satisfaction to good clinical outcomes to cost savings [12]. A clear example of the positive outcome associated with nursing intervention in the management of a chronic disease is diabetes. Recently, Cho & Kim [19] showed in their meta-analysis of 23 diabetes intervention studies that the reduction in glycosylated haemoglobin in these patients was directly related to the care programmes, home visits and tailored programmes. Thus, the nursing intervention in the context of IBD would reduce the number of flare-ups and hospital stays and reduce the associated cost, as demonstrated by the Department of Paediatric Gastroenterology and Nutrition, Robert Debre University Hospital (Paris, France) [20].

More than 80 % of respondents believe that, to achieve the highest-quality care, the progression, monitoring and treatment of their IBD should be supervised by a nurse in addition to a specialist. The IBD nurse can play a crucial role in the follow-up and management, especially education, of patients with more severe disease. A descriptive observational study conducted in Chile found that the most common nurse interventions (in descending order) were reinforcement of medical indications, assessment of laboratory results, disease follow-up and IBD education [21]. Recently, the hospital burden since the SARS-CoV-2 pandemic has changed current medicine [22]. These changes include various tools such as telemedicine [23]. Telemedicine could be a useful way to the follow-up of IBD patients, allowing specialist doctors and nurses to work effectively and harmoniously without the constraints of time or location to achieve an optimal level of monitoring and treatment of IBD.

Limitations and future perspective

This study is not exempt from some limitations. First, the number of participants is low; for this, future studies with a higher number of participants could corroborate the findings here asserted, as a larger sample size will be obtained, and the appropriate multivariate study will undoubtedly be conducted to find possible confounding factors. Second, the activity of participation in the study may have created awareness of or changed in some way patient perceptions of IBD specialised nursing and its importance. Third, there may exist some biases often associated with this type of study, e.g., Berkson's paradox [24] or the Hawthorne effect [25]. Berkson's paradox occurs when hospitalised patients are taken as controls, rather than controls from the community of origin of the cases, social-desirability bias [26]; this bias refers to the need of the individual undergoing an experiment to look good to the experimenter, to do what he/she is supposed to do, or to favour in some way the experimental outcome that is desired. The Hawthorne effect [25], a type of human behavioural reactivity in which individuals change an aspect of their behaviour in response to their awareness of being observed, may have affected our results. Future studies could consider how to mitigate such biases during the experimental design. Fourth, it is important to note that there might be some limitations associated with self-reported data, as participants might provide socially desirable responses rather than their true perceptions.

The future relevance of the study highlights the need to explore the nursing personal perception of their own role and the extent to which they match or differ from patients' perceptions. An in-depth study that compares and understands this dichotomy could provide more comprehensive strategies to improve caregiver-centred IBD care. Future studies should also investigate the relationship between patient perceptions, clinical outcomes and quality of life. This would increase the value of the study and thus provide a detailed interpretation linking perceptions of specialised care to patient morbidity, and quality of life would help to underline its clinical importance.

5. Conclusion

In conclusion, patients suffering IBD consider that (1) nursing intervention is necessary for the patient's self-care and supported care for the environment of the patient; (2) the initial nursing consultation after the diagnosis of IBD is essential to address all aspects of the patient's daily life and their environment for their high quality care and follow-up; (3) the nurse is able to identify the need for referring them to other health care professionals when necessary; (4) the nurse should be responsible for informing them and their environment about the steps to follow based on the diagnosis; (5) the nurses should be who care for them and those around them is specialised in IBD; and (6) the process, monitoring and treatment of their IBD needs is managed by a nurse in addition to a specialist

doctor in order to achieve an optimal level of quality. This study shows that patients suffering from IBD consider the role of the nurse to be crucial in the diagnosis, management and treatment of their disease and highlights the need for specialised nurses in inflammatory bowel disease who can provide them with better healthcare.

Data availability

The data of this study will be available to all those who wish to contact the corresponding author.

CRedit authorship contribution statement

Ángela Gómez-Abraïla: Writing – review & editing, Writing – original draft, Software, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Juan J. Carpio-Jovani:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. **Guillermo Charneco-Salguero:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Ángel Vicario:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Investigation. **José M. Cárdenas-Rebollo:** Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Project administration, Methodology, Investigation.

Declaration of competing interest

The authors declare that they had no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2024.e29765>.

References

- [1] E. Navarro, El papel de enfermería en una unidad monográfica de enfermedad inflamatoria intestinal, una visión de 360, *Enfermedad Inflamatoria Intestinal al Día* 16 (2017) 21–29, <https://doi.org/10.1016/j.eii.2016.09.004>.
- [2] A.M. Lopes, L.N. Bezerra De Moura, R.D.S. Machado, G.R. Freitas Da Silva, Qualidade de vida de pacientes com doença de Crohn, *Eglobal* 16 (2017) 321, <https://doi.org/10.6018/eglobal.16.3.266341>.
- [3] N. Justel Rey, El rol de Enfermería en los pacientes con Enfermedad de Crohn, un agente clave, Bachelor's Thesis, Universidad Autónoma de Madrid (2021) chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/<https://www.enfermeradigital.com/common/img/tfgs/trabajos/TFG%20Nicol%C3%A1s%20Justel%20Rey.pdf>.
- [4] C. Figueroa, Epidemiología de la enfermedad inflamatoria intestinal, *Revista Médica Clínica Las Condes* 30 (2019) 257–261, <https://doi.org/10.1016/j.rmcl.2019.06.003>.
- [5] D. Fernández-Lázaro, N. Hernández-Burgos, R. Cobreros Mielgo, S. García-Lázaro, Evaluación de actividad física como coadyuvante terapéutico para pacientes con enfermedad inflamatoria intestinal: una revisión, *Invest. Clin.* 63 (2022) 304–322, <https://doi.org/10.54817/IC.v63n3a08>.
- [6] C.S. Gismera, G.A. Fernández, C.A. Navascues, R.G. López, A.S. González, G.D. Álvarez, A.P. Galán, A.G. Bernal, A. Martínez, M. Lacort Fernández, J. Antón Magarzo, A. Altadill Arregui, F. Vizoso, Epidemiología de la enfermedad inflamatoria intestinal crónica en Gijón. Asturias, *Gastroenterol. Hepatol.* 24 (2001) 228–235, [https://doi.org/10.1016/S0210-5705\(01\)70160-4](https://doi.org/10.1016/S0210-5705(01)70160-4).
- [7] D. Moreno Lavín, C.A. Pérez More, Ayala Viamonte, E.M. María, EL CUIDADO COMO UN PROCESO DE GESTIÓN, II COLOQUIO VIRTUAL “VICTORIA BRÚ SÁNCHEZ”, vol. 1, 2021 (pdf).
- [8] H. Juanillo-Maluenda, Posicionamiento del investigador de enfermería en la utilización de la teoría fundamentada constructivista, *Enferm.* vol. 16, Univ., 2019, <https://doi.org/10.22201/eneo.23958421e.2019.2.638>.
- [9] J.P. Fallesen, M.L. Krogh, L.R. Minet, M.M. Skjøth, T. Knudsen, J. Kjeldsen, Needs assessment in patients with inflammatory bowel disease in the encounter and communication with healthcare professionals: a fieldwork study, *J. Clin. Nurs.* 32 (2023) 8095–8103, <https://doi.org/10.1111/jocn.16873>.
- [10] A.B. Hawthorne, J. Glatter, J. Blackwell, R. Ainley, I. Arnott, K.J. Barrett, G. Bell, M.J. Brookes, M. Fletcher, R. Muhammed, A.M. Nevill, J. Segal, C.P. Selinger, A. St. Clair Jones, L. Younge, IBD UK Board IBD UK Task & Finish Group, C.A. Lamb, Inflammatory bowel disease patient-reported quality assessment should drive service improvement: a national survey of UK IBD units and patients, *Aliment. Pharmacol. Ther.* 56 (2022) 625–645, <https://doi.org/10.1111/apt.17042>.
- [11] S.W.-C. Chan, Chronic disease management, self-efficacy and quality of life, *J. Nurs. Res.* 29 (2021) e129, <https://doi.org/10.1097/JNR.0000000000000422>.
- [12] L.M.H. Frich, Nursing interventions for patients with chronic conditions, *J. Adv. Nurs.* 44 (2003) 137–153, <https://doi.org/10.1046/j.1365-2648.2003.02779.x>.
- [13] A. Jiménez H., D. Simian M., P. R. Quera, Mortalidad en enfermedad inflamatoria intestinal, *Gastroenterol. Latinoam.* 28 (2017) 231–237.
- [14] A. Luzoro, P. Sabat, L. Guzmán, F. Frias, Manifestaciones extraintestinales de enfermedad inflamatoria intestinal, *Revista Médica Clínica Las Condes* 30 (2019) 305–314, <https://doi.org/10.1016/j.rmcl.2019.06.001>.
- [15] L. Gask, Role of specialists in common chronic diseases, *BMJ* 330 (2005) 651–653, <https://doi.org/10.1136/bmj.330.7492.651>.
- [16] N. Edwards, B. Davies, J. Ploeg, T. Virani, J. Skelly, Implementing nursing best practice guidelines: impact on patient referrals, *BMC Nurs.* 6 (2007) 4, <https://doi.org/10.1186/1472-6955-6-4>.
- [17] C.D. Griffin, A primary care nursing perspective on chronic disease prevention and management, *Delaware Journal of Public Health* 3 (2017) 78–83, <https://doi.org/10.32481/djph.2017.03.011>.

- [18] J. Moore, M. McQuestion, The clinical nurse specialist in chronic diseases, *Clin. Nurse Spec.* 26 (2012) 149–163, <https://doi.org/10.1097/NUR.0b013e3182503fa7>.
- [19] M.-K. Cho, M.Y. Kim, Self-management nursing intervention for controlling glucose among diabetes: a systematic review and meta-analysis, *IJERPH* 18 (2021) 12750, <https://doi.org/10.3390/ijerph182312750>.
- [20] C. Martinez-Vinson, S. Le, A. Blachier, M. Lipari, J.-P. Hugot, J. Viala, Effects of introduction of an inflammatory bowel disease nurse position on healthcare use, *BMJ Open* 10 (2020) e036929, <https://doi.org/10.1136/bmjopen-2020-036929>.
- [21] D. Simian, L. Flores, R. Quera, P. Ibáñez, C. Figueroa, J. Lubascher, G. Pizarro, U. Kronberg, The role of an inflammatory bowel disease nurse in the follow-up of patients from a Latin American inflammatory bowel disease program, *Gastroenterol. Nurs.* 43 (2020) E16–E23, <https://doi.org/10.1097/SGA.0000000000000436>.
- [22] J. Crespo, R. Andrade, F. Alberca De Las Parras, F. Balaguer, M. Barreiro-de Acosta, L. Bujanda, A. Gutiérrez, F. Jorquera, J. Iglesias-García, A. Sánchez-Yagüe, J. L. Calleja, Restablecimiento de la actividad en los servicios de Digestivo. Recomendaciones de la SEPD, AEEH, GETECCU y AEG, *Gastroenterol. Hepatol.* 43 (2020) 332–347, <https://doi.org/10.1016/j.gastrohep.2020.04.001>.
- [23] M. Aguas, J. Del Hoyo, R. Faubel, P. Nos, Telemedicine in inflammatory bowel disease: opportunity ahead, *Inflamm. Bowel Dis.* 22 (2016) E4–E5, <https://doi.org/10.1097/MIB.0000000000000676>.
- [24] J.D. Woodfine, D.A. Redelmeier, Berkson's paradox in medical care, *J. Intern. Med.* 278 (2015) 424–426, <https://doi.org/10.1111/joim.12363>.
- [25] C. Berkhout, O. Berbra, J. Favre, C. Collins, M. Calafiore, L. Peremans, P. Van Royen, Defining and evaluating the Hawthorne effect in primary care, a systematic review and meta-analysis, *Front. Med.* 9 (2022) 1033486, <https://doi.org/10.3389/fmed.2022.1033486>.
- [26] N. Bergen, R. Labonté, “Everything is perfect, and we have No problems”: detecting and limiting social desirability bias in qualitative research, *Qual. Health Res.* 30 (2020) 783–792, <https://doi.org/10.1177/1049732319889354>.