

Inflammatory bowel disease: patients' and professionals' perceptions of shared decision-making

Doença inflamatória intestinal: percepções dos pacientes e dos profissionais de saúde sobre a tomada de decisão compartilhada
 Enfermedad inflamatoria intestinal: percepciones de los pacientes y de los profesionales de la salud sobre la toma de decisiones compartida

María Carmen Villar Bustos¹  <https://orcid.org/0000-0002-4023-5651>

Elena Andina-Díaz²  <https://orcid.org/0000-0001-9687-1967>

How to cite:

Villar Bustos MC, Andina-Díaz E. Inflammatory bowel disease: patients' and professionals' perceptions of shared decision-making. Acta Paul Enferm. 2021;34:eAPE000765.

DOI

<http://dx.doi.org/10.37689/acta-ape/2021A0000765>



Keywords

Shared decision-making; Inflammatory bowel disease; Continuity of patient care

Descritores

Decisões; Doenças inflamatórias intestinais; Continuidade da assistência ao paciente

Descriptores

Decisiones; Enfermedades inflamatorias del intestino; Continuidad de la atención al paciente

Submitted

April 7, 2020

Accepted

March 1, 2021

Corresponding author

Carmen Villar Bustos
 E-mail: mcvillarb@gmail.com

Abstract

Objective: To describe perceptions of implementing law 41/2002 on patient autonomy in inflammatory bowel disease patients and professionals in relation to shared decision-making.

Methods: Qualitative descriptive study using a phenomenological approach. We conducted semi-structured interviews to 10 patients belonging to the Association of Patients with Crohn's Disease and Ulcerative Colitis in Zamora (Spain) as well as focus group to 7 gastroenterologists and nurses from the ostomy clinic and inpatient gastroenterology unit at the Virgen de la Concha Hospital in Zamora. Data thematic content analysis was performed.

Results: Two main categories and seven sub-categories emerged: Information (with professionals' and patients' knowledge, trust in the professional, time and attitude to information) and Shared decision-making (with attitude to information, coping-resignation and support for decisions). Shared decision-making is a complex process where not only the information is the main value for the patients, but other issues like support, time of illness or emergency are important for patient decision.

Conclusion: To describe patients' and professionals' perceptions of shared decision-making, who saw it as a complex process. To improve the information provided to patients about their illness and their rights can influence participation in shared decision-making and change attitudes. Patients did not permanently adopt an active or passive role in relation to shared decision-making, but instead oscillated between roles depending on multiple factors. Consequently, it is important for health professionals to engage in the process of understanding patients and their needs to facilitate shared decision-making. In addition, greater investment by the authorities is needed to ensure continuity of care and create multidisciplinary inflammatory bowel disease units as measures to improve shared decision-making.

Resumo

Objetivo: Descrever as percepções de implementação da lei 41/2002 sobre a autonomia do paciente com doença inflamatória intestinal e profissionais em relação à tomada de decisão compartilhada.

Métodos: Estudo qualitativo e descritivo, utilizando abordagem fenomenológica. Foram realizadas entrevistas semiestruturadas em dez pacientes pertencentes à Associação de Pacientes com Doença de Crohn e Colite Ulcerativa de Zamora (Espanha), e grupo focal com sete gastroenterologistas e enfermeiros da clínica de ostomia e unidade de gastroenterologia hospitalar do Hospital Virgen de la Concha de Zamora. Foi realizada análise do conteúdo temático dos dados.

Resultados: Surgiram duas categorias principais e sete subcategorias: Informação (com conhecimento dos profissionais e dos pacientes, confiança no profissional, tempo e atitude em relação à informação) e Tomada

¹Hospital Virgen De La Concha, Zamora, Spain.

²Universidad de León, León, Spain.

Conflicts of interest: none to declare.

de decisão compartilhada (com atitude em relação à informação, enfrentamento/resignação e apoio às decisões). A tomada de decisão compartilhada é um processo complexo, onde não somente a informação é o principal benefício para os pacientes, mas outras questões como apoio, tempo de doença ou emergência são importantes para a decisão do paciente.

Conclusão: Descrever as percepções dos pacientes e dos profissionais sobre a tomada de decisões compartilhadas, que as viam como um processo complexo. Melhorar as informações fornecidas aos pacientes sobre sua doença e seus direitos pode influenciar a participação na tomada de decisão compartilhada e modificar atitudes. Os pacientes não adotaram permanentemente um papel ativo ou passivo em relação à tomada de decisão compartilhada, mas, por múltiplos fatores, oscilaram entre os papéis. Consequentemente, é importante que os profissionais de saúde se envolvam no processo de compreensão dos pacientes e de suas necessidades para facilitar a tomada de decisão compartilhada. Além disso, é necessário maior investimento por parte das autoridades para garantir continuidade dos cuidados e desenvolver unidades multidisciplinares para doenças inflamatórias intestinais como forma de melhorar a tomada de decisão compartilhada.

Resumen

Objetivo: Describir las percepciones de la implementación de la ley 41/2002 sobre la autonomía del paciente con enfermedad inflamatoria intestinal y profesionales con relación a la toma de decisiones compartida.

Métodos: Estudio cualitativo y descriptivo, que utiliza el enfoque fenomenológico. Se realizaron entrevistas semiestructuradas a diez pacientes pertenecientes a la Asociación de Pacientes con Enfermedad de Crohn y Colitis Ulcerosa de Zamora (España); y un grupo focal de siete gastroenterólogos y enfermeros de la clínica de ostomía y de la unidad de gastroenterología hospitalaria del Hospital Virgen de la Concha de Zamora. Se realizó un análisis del contenido temático de los datos.

Resultados: Surgieron dos categorías principales y siete subcategorías: Información (con conocimiento de los profesionales y de los pacientes, confianza en el profesional, tiempo y actitud con relación a la información) y Toma de decisiones compartida (con actitud respecto a la información, enfrentamiento/resignación y apoyo a las decisiones). La toma de decisiones compartida es un proceso complejo en el que no solamente la información es el principal beneficio para los pacientes, sino que también hay otras cuestiones importantes para la decisión del paciente, como el apoyo, el tiempo de enfermedad o la emergencia.

Conclusión: Describir las percepciones de los pacientes y de los profesionales sobre la toma de decisiones compartida, que era vista como un proceso complejo. Mejorar la información ofrecida a los pacientes sobre su enfermedad y sus derechos puede influir en la participación de la toma de decisiones compartida y modificar actitudes. Los pacientes no adoptaron un papel permanentemente activo o pasivo respecto a la toma de decisiones compartida, sino que oscilaban entre los dos papeles debido a múltiples factores. Por lo tanto, es importante que los profesionales de la salud se involucren en el proceso de comprensión de los pacientes y de sus necesidades para facilitar la toma de decisiones compartida. Además, son necesarias mayores inversiones por parte de las autoridades para garantizar una continuidad de los cuidados y desarrollar unidades multidisciplinares para enfermedades inflamatorias intestinales como forma de mejorar la toma de decisiones compartida.

Introduction

Recent decades have witnessed the emergence of a trend towards patient participation based on the idea that patients' expert knowledge and experience of managing their illness should be leveraged when making decisions about their treatment and could encourage others to make crucial decisions during the treatment process. This has the potential to increase personal satisfaction and improve quality of life and disease management.^(1,2)

However, some studies have reported that patients may find it difficult in practice to assert their autonomy, because taking greater control of decisions affecting their health may be viewed negatively by the patients themselves or by professionals.⁽²⁾ Patients want to be well informed, however, the right to participate in their treatment by taking autonomous decisions is not viewed as a necessity and they generally prefer to leave decision-making to their physician, as González Mestre affirmed.⁽²⁾

Shared decision-making (SDM) is a collaborative process in which patient and health professional exchange information (personal and medical), discuss the various and reach a consensus decision. Professional and patient work together to choose from among the available therapeutic or preventive options based on the scientific evidence, selecting the one best tailored to the patient's preferences and values, which includes the option of doing nothing.^(3,4)

The main barriers to implementing SDM include lack of time and resources in the health system, resistance and scepticism.⁽⁵⁾ The use by professionals of communication skills such as active listening and empathy encourages patient participation in this process^(5,6) and is essential for its implementation.^(7,8) Patient motivation and perceptions of the positive impact of the process and its results also facilitate SDM.⁽⁹⁾

Patient participation in SDM is associated with greater satisfaction with treatment and lower levels of anxiety about medical procedures,

which improves adherence to treatment.⁽⁹⁾ This may vary according to patients' level of education, health awareness and age, and is significantly higher in young people.⁽⁶⁾ Other studies have shown that the most important decisions elicit more active participation.^(7,10)

Patients' participation in their illness and in SDM varies widely according to country. For example, some studies at European level have reported differences in factors attributable to both professionals and patients.⁽¹¹⁾ In Spain, where the present study was conducted, law 41/2002 on patient autonomy and rights and obligations regarding medical information and documentation in health care⁽¹²⁾ establishes the legal right to patient autonomy as a basic principle.

Inflammatory bowel disease (IBD) is a chronic disease of unknown cause and uncertain prognosis. It encompasses several autoimmune pathologies that cause chronic inflammation of the intestine and present with flare-ups of inflammatory activity (active phase) and periods of remission (dormant phase). The severest but also most prevalent forms are Crohn's disease (CD) and ulcerative colitis (UC), with an average age at diagnosis of 30 years.⁽¹³⁾ The incidence of IBD is rising in Europe, and is currently estimated at 24.3/100,000 inhabitants/year for UC and 12.7/100,000 inhabitants/year for CD.⁽¹⁴⁾ In Spain, estimates are 5.6-9.4/100,000 inhabitants/year for UC and 8.9-10.8/100,000 inhabitants/year for CD.⁽¹⁵⁾ In 2015, the direct annual cost per patient with UC in Spain was €1754.10 (indirect cost: €399.32),⁽¹⁶⁾ and a report in 2016 estimated a total annual cost of 1.8% of public health spending.⁽¹³⁾

In the present study, we examined knowledge and application of law 41/2002 in health care for patients with IBD, a highly complex chronic disease that presents at an early age, and one in which patients participate in multiple SDM-related situations due to their long experience of their disease. Few studies in the literature have examined patients' and professionals' perceptions of SDM;⁽⁶⁻⁸⁾ consequently, it would be helpful to determine the points of view of both groups in order to shed light on the reasons for patient participation.

Given the above, the objective of the present study was to describe perceptions of implementing law 41/2002 on patient autonomy in IBD patients and professionals in relation to SDM.

Methods

This was a qualitative descriptive study using a phenomenological approach. The purpose of phenomenology is to describe and clarify the meaning of particular phenomena, or the appearance of things, as lived experience. It is the lived experience that gives meaning to each individual's perception of a particular phenomenon.⁽¹⁷⁾ Thus, a phenomenological approach allowed to analyse the perceptions of patients and professionals in relation to the phenomena of SDM.

The study was conducted in the city of Zamora (Spain). The study population consisted of patients belonging to the Association of Patients with Crohn's Disease and Ulcerative Colitis (Spanish initials: ACCU) in Zamora as well as gastroenterologists and nurses from the ostomy clinic and inpatient gastroenterology unit at the Virgen de la Concha Hospital in Zamora. To access the group of patients, we contacted the president of ACCU Zamora (face-to-face); while for the group of professionals we contacted the unit head and nursing supervisor of the gastroenterology unit at the Virgen de la Concha Hospital (face-to-face). They facilitated the first access to participants and helped to conduct theoretical sampling and subsequently convenience sampling (snowball method).⁽¹⁸⁾ In the case of the group of patients, the president of ACCU introduced us to patients, and this fact helped to establish rapport with them. In the case of the group of professionals, the fact of IP was a nurse in the hospital -although in a different service- helped to establish rapport with professionals (empathy). We contacted subjects who met the inclusion criteria (being over 18 years old and not having cognitive deficits/mental illness [both groups]; having or being related to someone with IBD [patient group]; and being knowledgeable about and having experience of the IBD process [professional group]), and

invited them to participate in the study. No participant refused to participate in the study [both groups]. In selecting participants, we sought to obtain a comparable number of patients with CD and UC and of professionals from different categories, as well as an equitable distribution by sex in patients and professionals.

We used two techniques for data collection. For the patient group, the principal investigator conducted semi-structured interviews (duration between 27 and 69 minutes), held on ACCU Zamora premises, in a quiet room, away from noise (to facilitate pleasant contact), within the association (February-May, 2018). Interviews were conducted until reaching data saturation (10 interviews). For the professional group, a focus group was held (duration 50 minutes) in the board room of the gastroenterology unit at the Hospital (quiet room, away from noise), moderated by the principal investigator (May, 2018). 10 patients and 7 professionals in the focus group were considered sufficient to achieve data saturation. The interviews and focus group were audio recorded and additional notes were taken. The same guide was used for interviews and the focus group, which contained a list of ad hoc questions in accordance with the study by López Cortés.⁽¹⁹⁾

Interview and focus group recordings were transcribed verbatim, and data analysis was performed using the software programmes Excel® and Weft QDA1.0.1®. After one general and several in-depth readings, both researchers analysed content. The analysis of the content was carried out following the proposal of Giorgi.⁽²⁰⁾ Firstly, an in-depth reading of the data was carried out. Secondly, a new reading of the data, in order to extract all units of meaning. Thirdly, the units of meaning were grouped into main categories/subcategories, according to their shared characteristics. Finally, two major categories emerged from the data (information and SDM), seven sub-categories, and their corresponding units of meaning. The analysis was agreed by consensus of the two members of the research team.

To ensure validity, audio transcriptions were sent by email to patient group. They confirmed

their discourses, and the main themes/categories that researchers had identified in the analysis (categories). In the professional group, a face-to-face meeting was carried out, with the same purpose. Similarly, an external researcher (with expertise in the subject) validated the results. In the participants in whom contradictory information was detected in their speeches, this moment was used to clarify it.

Consistency in discourse was achieved through triangulation of data and methods. A self-critical attitude was maintained throughout the process. To avoid bias in the formulation of the research questions (since both researchers were nurses), questions were elaborated in accordance with previous studies.⁽¹⁹⁾ To avoid influence in data collection, sample recruitment, and choice of location, the researchers only knew the topic in a superficial manner (as health professionals) and it was not their usual work/theme of research. Both researchers began the analysis after the first interview, in order to verify constantly that was in line with objectives, and in order to be prepared in case of any change was necessary to make in the research design (it was not necessary).

This study respected the ethical requirements of the Declaration of Helsinki and organic law 3/2018 on personal data protection and digital rights and was approved by the Ethics Committees (ETHICS-ULE-001-2018 and Hospital (Zamora)).

Patients and professionals received detailed written information about the study and signed an informed consent form. Patients were anonymised with a number (001, etc.) and professionals with the letter P and a number (P1, etc.).

Results

The composition of the final sample is shown in tables 1 and 2.

We detected two main categories on which the principles of the law are based: 1) information needed to make a decision and 2) Shared Decision Making, from which seven sub-categories emerged, described below.

Table 1. Composition of the final sample (patients)

	Sex	Age	Level of studies	Age of diagnoses	Type of disease
001	M	66	Primary studies	35	Ulcerative Colitis
002	V	51	Primary studies	17	Crohn's Disease
003	V	38	University studies	30	Ulcerative Colitis
004	M	23	University studies	16	Ulcerative Colitis
005	M	59	University studies	23	Crohn's Disease
006	V	60	Primary studies	48	Ulcerative Colitis
007	V	58	University studies	38	Crohn's Disease
008	V	28	University studies	28	Crohn's Disease
009	M	49	University studies	36	Ulcerative Colitis
010	M	57	Primary studies	39	Ulcerative Colitis

Table 2. Composition of the final sample (professionals)

	Sex	Age	Professional
P1	V	52	Gastroenterologists
P2	M	44	Gastroenterologists
P3	M	61	Nurse
P4	M	61	Nurse
P5	M	N.C.	Gastroenterologists
P6	M	42	Gastroenterologists
P7	M	58	Nurse

1) Information needed to make a decision:

Most patients reported having little or no knowledge of law 41/2002, while the professionals only knew about it in general terms, but both groups said they knew about patients' rights.

No... and this law... why is this law not reported... to... patients? (002)

Well, I think that the law of the patient who would have to... to whom it would have to be directed to be studied and put into practice is the professionals themselves (006)

The patients reported receiving information about their illness but said they would have liked it to be easier to understand. They also indicated that professionals should choose the best moment to impart information and take patient characteristics into account (not everyone is equally receptive to information or needs to know the same thing). In addition, they emphasised the importance of receiving more information when treatment changed, or symptoms worsened.

They preferred to receive information directly from the physician rather than from other channels.

They considered the internet an unreliable source of information and preferred material provided by the association.

Each patient and each body is different... my disease is very particular and affects each person in a way... Now... if you tell me, that you are my doctor, or a person who collaborates with me, well look... I would like to give it to me (002)

1.a Patients' and professionals' knowledge:

These perceived information as better or worse depending on their personal knowledge. For professionals, depending on the knowledge of the illness:

Each patient needs particular information at a particular time; IBD is highly complex and these are special patients (P2)

For patients, depending on self-perceptions of knowledge according to educational level and knowledge of patient rights and their own disease:

Then there's also cultural level, it helps a lot if patients know about their disease, and if they have a good understanding of the treatment, they find it much easier (P6)

I think that the law on patients should be... should target and be studied by and put into practice by the professionals themselves (005)

They think they know more than they do because when you start explaining to them... (P3)

Finally, depending on the knowledge of their peer groups (associations in the case of patients, other professionals in that of professionals):

Actually, it was thanks to the association that I found out more about the disease and learnt about all the symptoms (004)

First, in general, they don't perceive themselves as capable, they're very complex, difficult patients. They're frightened (P6)

1.b Trust in the professional:

The relationship established between professional and patient influenced perceptions of the information received, whereby the more the professional was trusted, the more positive the perceptions of the information received:

It also depends on the professionals... when you go in they're writing, they don't look at you... and they still don't even know your name... (005)

It seemed wrong that I was asking for my own reports... I mean no... what I should have done was report them for not having given them to me, because they're mine... (004)

I trust the doctor, it's always what the doctor says (006)

I've always trusted the doctor because among other things I've had no option... (002)

Information was received better if the professional showed empathy:

For patients, a pat on the back is much more effective... / reassurance with a few words does a lot more than medicine (001)

1.c Time:

Lack of time was considered an important barrier to providing information, considering two different times: the timing of the illness (for example, a flare-up):

When you get here the queues are enormous, the doctor is stressed and has barely any time for... I think the only thing is that we should have had more time, not just us, but them too, the doctors, who couldn't give us as much time as they would have liked (006)

I'm the kind of person who needs time to think about things... / and afterwards, going over it... I would think of other questions... but I can't ask anyone because I'm back home (002)

And the time spent during an appointment:

Let's see, at first I remember that when they told me about having an ostomy and an urgent operation, well... I just dug in my heels, I didn't want to know anything about it (004)

When they're admitted to hospital it's because of a flare-up and sometimes there are no options (P6)

An IBD unit would be great because what these patients want is continuity and obviously, you're not always there... (P1)

It's colitis, it's not anything else... and of course, you're relieved but only sort of... afterwards, when you find out more about it, that's another matter!... It's not the scariest word, like cancer for example, but there isn't any cure... (010)

1.d Attitude to information:

It depends on professionals' attitudes to providing information, for example, communication skills, desire to inform:

Is it possible to make it easier to understand? Well... I wouldn't say no... maybe... (P1)

And, on patients' attitudes to receiving it (wanting to be informed):

You don't need much information at first... when you're a bit... assimilating... (003)

And sometimes they tell you it's better not to read it because if I do I won't sign it. Because with what they tell me here... (P3)

Both aspects were considered key in the entire process.

2) Shared Decision Making:

This was directly related to perceptions of the quality of the information received.

For the patients, trust in the professional played a major role when deciding about SDM, consider-

ing that the professional should be the one “who knows”, the one who takes the final decision or the responsibility together with the patients.

I'm the patient and she... the doctor, the one who understands more about the subject, she is the one who has a little more say (008)

2.a Attitude to SDM:

Patients reported viewing SDM as a shared responsibility.

Sometimes there are options... / you can think about continuing with what they're taking and waiting a little longer or when introducing a new treatment, then they're capable of taking a decision (P2)

However, they would feel better equipped to take an important decision, “even against medical advice”, if they had more information about it:

Decision-making should be supported by lots and lots of information... then you can decide (004)

It's wrong to say it... but there've been times when I wasn't taking anything at all, and I'm the one who made that decision without discussing it... (003)

Meanwhile, the professionals reported that SDM should be a consensus decision with the patient:

Sometimes it's possible to decide from among various options, but other times it isn't (P6)

Nevertheless, they maintained a somewhat paternalistic attitude:

It would be a situation in which you explain everything to the patient and then the patient decides... but in the end you're the one directing it (P1)

2.b Coping-resignation:

One factor that was considered key in SDM by patients and professionals alike was coping/resignation

as characteristics of an active/passive patient. This is determined by the stage, chronicity or complexity of the illness:

Because if you have a lot of flare-ups, it exhausts you (005)

Time goes by and you say to yourself this isn't changing, and you see that it's not getting better... you don't like it, but well... that's what there is and you have to live with it, obviously... (010)

I've had it for four years, between one thing and another... I go to one doctor who tells me this is Crohn's disease, I go to another who isn't so sure... /and meanwhile I have all these symptoms... (008)

Sometimes, it is also determined by uncertainty, about whether something works, about where to start, about prognosis or about new treatments:

Yes, but it's different with other chronic illnesses... because of the complexity of this one... At other times you don't have any options, there is no alternative, you have to treat it, there's no other option... there's no alternative (P1)

And it doesn't work, you might be taking it continuously, it's working well, you stop taking it for some reason /... and after maybe two years it comes back... and it hasn't worked... (005)

Even the doctor has often told me... “I don't seem to be able to control your case”... so it's a bit worrying... (008)

Some members have been in remission for maybe a year and then they suddenly have a terrible flare-up... what can they do? (004)

I tried the latest treatments that came out but they didn't... They didn't work... (010)

2.c Support for decisions:

Patients reported that their support networks (partner, family, the authorities, the multidisciplinary

team and the patient association) also contributed to SDM.

Regarding family, partner or friends, and patient association:

Your partner also has a huge influence... when your partner supports you, when you feel accompanied by your partner or when things aren't going well with your partner... (009)

I get a lot of support from friends, colleagues, others from the association (008)

Sometimes we helped each other, "come and sleep at my house, come and take a shower, rest" /... this was a very important aspect of what we did at the association (005)

Both patients and professionals alike agreed that more support from the authorities was necessary to improve medical appointments by increasing the allotted time and ensuring continuity of care.

More human resources, more protocols and more adherence to protocols. Less busy appointment schedules (P6)

They indicated that a good solution would be to have a specialist IBD unit with a multidisciplinary team to cater for the demand for continuity and expertise. Both groups noted a lack of interest on the part of the authorities:

It must be a multidisciplinary unit where all processes are fully integrated, a surgeon with a radiologist because otherwise there's no point (P2)

It's true that we could have a lot, but there isn't a specialised unit in Zamora, so... (003)

Discussion

The data obtained have enabled us to describe patients' and professionals' perceptions of SDM, who saw it as a complex process. This is an interesting

finding given the limited number of studies identified that have explored this question in depth.⁽⁶⁻⁸⁾

In recent decades, patient participation has been encouraged in various contexts, SDM can lead to an increase in patient satisfaction, helping to improve quality of life and disease management.^(1,2)

The data obtained in our study reveal that although law 41/2002 has been in place in Spain since 2002, few of our participants knew about it. Law 41/2002 states that the information given to patients during their illness must be easy to understand in order to help them make decisions;⁽¹²⁾ however, our results indicate that this has yet to be achieved satisfactorily.

The most important factors influencing participants when assessing the information received were trust in the professional, the timing of the illness and knowledge about the process on the part of patient and professional alike. Other studies have identified lack of time as the main barrier reported by both professionals and patients.^(7,10)

Our results are in agreement with the literature⁽²¹⁾ and indicate that the patients wanted fuller information about their illness and reported that professionals needed communication skills and should select the right time to provide information. They also preferred to receive information directly from a professional rather from other sources.

Similar studies⁽⁷⁾ have reported patients' preference for receiving information directly from a specialist or their family doctor, indicating that the information provided on the internet or in leaflets is useful but could also generate more anxiety in some patients.

Our results show that quality of the information and trust between professional and patient directly influenced participation in SDM, in agreement with other studies conducted in different contexts in Spain.^(22,23)

Our participants also identified other factors that could influence the capacity for SDM, including the stage of the illness, knowledge acquired, emotional factors, support networks and the degree of coping/resignation. In this respect, Martín-Fernández⁽⁷⁾ has shown that the impact of the deci-

sion, shared responsibility with the professional and family support are factors that facilitate this process.

Studies in other countries⁽²⁴⁾ have also concluded that information alone is insufficient, and that other, very important factors must be taken into account for SDM to be effective. Not even support for SDM in chronic diseases has been shown to be effective by itself.⁽²⁵⁾

One important finding of our study was that patients presented different attitudes to SDM. Due to factors such as those outlined above, patients oscillated between active and passive roles over the course of their illness. In other words, there is no such thing as a permanently active or passive patient; rather, this role changes over the course of the disease.

Lastly, our results are consistent with those reported in a recent systematic review of studies on different health systems and cultures,⁽²³⁾ which found that interventions like help-tools do not appear to increase SDM compared with direct attention from health professionals.

Limitations of our study include being based on the perceptions of patients with one specific illness (belonging to an association) and of professionals working exclusively in hospital care. Future research should broaden the study participants to include patients with other chronic diseases and primary care professionals, both in Spain and other countries.

Conclusion

The study objective was achieved, namely to describe perceptions of the application of law 41/2002 on patient autonomy in IBD patients and professionals in relation to SDM. SDM was revealed as a complex process facilitated by trust and empathy with the professional. In addition, it appears that patients require more information on the implications of law 41/2002. Our results are in agreement with studies published in other countries, which have indicated that improving the information provided to patients about their illness and their rights can influence participation in SDM and change attitudes. According to patients, such information is

best transmitted verbally, complementing the information with other kinds of support. In this respect, professionals need to improve their communication skills. We found that patients did not permanently adopt an active or passive role in relation to SDM, but instead oscillated between roles depending on multiple factors. Consequently, it is important for health professionals to engage in the process of understanding patients and their needs in order to facilitate SDM. In addition, greater investment by the authorities is needed in order to ensure continuity of care and create multidisciplinary IBD units as measures to improve SDM.

Collaborations

Bustos MCV and Andina-Díaz E participated in the concept and design of the present study; analysis and interpretation of data; draft or revision of the manuscript; and they have approved the manuscript as submitted. All authors are responsible for the reported research.

References

1. World Health Organization (WHO). Regional Office for Europe. A European policy framework and strategy for the 21st century. Health 2020: policy framework and strategy. Geneva: WHO; 2013.
2. González Mestre A. La autonomía del paciente con enfermedades crónicas: de paciente pasivo a paciente activo. *Enferm Clin.* 2014;24(1):67-73.
3. Participación del paciente en la toma de decisiones. *Boletín Infac.* 2014;22(3):1-6 [citado en 2018 Ago 1]. País Vasco: Servicio Central de Publicaciones del Gobierno Vasco; 2014. Disponible: https://www.euskadi.eus/contenidos/informacion/cevime_infac_2014a/es_def/adjuntos/INFAC_Vol_22_n_3_Decisiones_compartidas.pdf
4. Pons Ràfols JM, Moharra Francés M. Decisiones compartidas [editorial]. *Med Clin (Barc).* 2016;146(5):205-6.
5. Ruiz-Azarola A, Perestelo-Pérez L. Participación ciudadana en salud: formación y toma de decisiones compartida. *Informe SESPAS 2012.* *Gac Sanit.* 2012;26(S):158-61.
6. Ruiz Moral R, Peralta Munguía L, Pérula de Torres LÁ, Olloqui Mundet J, Carrión de la Fuente T, Sobrino López A, et al. Opiniones y percepciones de los pacientes sobre su participación en la toma de decisiones en las consultas de medicina de familia. *Aten Primaria.* 2011;4(4):5-10.
7. Martín-Fernández R, Abt-Sacks A, Perestelo-Pérez L, Serrano-Aguilar P. Actitudes de las mujeres diagnosticadas de cáncer de mama frente a la toma de decisiones. *Rev Esp Salud Pública.* 2013;87(1):59-72.

8. Truglio-Londrigan M, Slyer JT, Singleton JK, Worrall PS. A qualitative systematic review of internal and external influences on shared decision-making in all health care settings. *JBI Database Syst Rev Implement Reports*. 2014;12(5):121–94.
9. Bravo P, Contreras A, Perestelo-Pérez L, Pérez-Ramos J, Málaga G. En busca de una salud más participativa: compartiendo decisiones de salud. *Rev Peru Med Exp Salud Publica*. 2013;30(4):691–7.
10. Ortega-Moreno M, Padilla-Garrido N, Huelva-López L, Aguado-Correa F, Bayo-Calero J, Bayo-Lozano E. Barreras y facilitadores para la implementación de la toma de decisiones compartidas en oncología: percepciones de los pacientes. *Rev Calid Asist*. 2017;32(3):141–5.
11. European Commission. Eurobarometer Qualitative Study. Patient involvement. Aggregate Report [Internet]. Belgium: European Commission; 2012 [cited 2021 Feb 14]. Available from: https://ec.europa.eu/eip/ageing/file/336/download_en%3Ftoken=6-zWlwfX
12. España. Gobierno de España. Ley 41/2002 de 14 de noviembre, Básica Reguladora de la Autonomía del Paciente y de Derechos y Obligaciones en Materia de Información y Documentación clínica. Boletín Oficial del Estado. 2002;274 de 15/11/2002. España: Jefatura del Estado; 2002 [citado en 2021 Feb 14]. Disponible: <https://www.boe.es/buscar/pdf/2002/BOE-A-2002-22188-consolidado.pdf>
13. Gomollón F. Enfermedad inflamatoria intestinal. *Gastroenterol Hepatol*. 2013;31:42–6.
14. World Gastroenterology Organization. Guías Mundiales de la Organización Mundial de Gastroenterología. Enfermedad intestinal inflamatoria: actualización agosto de 2015. United States: World Gastroenterology Organization; 2015 [citado en 2021 Feb 14]. Disponible: <https://www.worldgastroenterology.org/UserFiles/file/guidelines/inflammatory-bowel-disease-spanish-2015.pdf>
15. Enfermedad Inflamatoria Intestinal: situación actual y retos asistenciales. Londres: Ernst & Young; 2016 [citado en 2018 Ago 1]. Disponible en: <https://pt.slideshare.net/ernstandyoung/enfermedad-inflamatoria-intestinal-situacin-actual-y-retos-asistenciales>
16. Aldeguer X, Sicras-Mainar A. Costs of ulcerative colitis from a societal perspective in a regional health care area in Spain: A database study. *Gastroenterol Hepatol*. 2016;39(1):9–19.
17. Giorgi A, Giorgi B, Morley J. The Descriptive Phenomenological Psychological Method. In book: *The Sage Handbook of Qualitative Research in Psychology*. Edition: 2nd, Chapter: 11. London: Willig and Rogers; 2017. pp.176–92.
18. Kaplan CD, Korf D, Sterk C. Temporal and social contexts of heroin-using populations. An illustration of the snowball sampling technique. *J Nerv Ment Dis*. 1987;175(9):566–74.
19. López Cortes R. Discapacidad en la Enfermedad Inflamatoria Intestinal. Análisis de los efectos de la enfermedad en la vida cotidiana de los pacientes [tesis]. Granada: Universidad de Granada, Facultad de Ciencias de la Salud; 2017 [citado en 2018 Ago 1]. Disponible en: <http://digibug.ugr.es/bitstream/handle/10481/45857/26504777.pdf?sequence=6&isAllowed=y>
20. Giorgi A. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol*. 1997;28(2):235–60.
21. Ortega-Moreno M, Padilla-Garrido N, Huelva-López L, Aguado-Correa F, Bayo-Calero J, Bayo-Lozano E. Barreras y facilitadores para la implementación de la toma de decisiones compartidas en oncología: percepciones de los pacientes. *Rev Calid Asist*. 2017;32(3):141–5.
22. Veilleux S, Noiseux I, Lachapelle N, Kohen R, Vachon L, Guay BW, et al. Patients' perception of their involvement in shared treatment decision making: Key factors in the treatment of inflammatory bowel disease. *Patient Educ Couns*. 2018;101(2):331–9.
23. Légaré F, Adekpedjou R, Stacey D, Turcotte S, Kryworuchko J, Graham ID, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*. 2018;7(7):CD006732. Review.
24. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns*. 2014;94(3):291–309. Review.
25. Wieringa TH, Rodriguez-Gutierrez R, Spencer-Bonilla G, de Wit M, Ponce OJ, Sanchez-Herrera MF, et al. Decision aids that facilitate elements of shared decision making in chronic illnesses: a systematic review. *Syst Rev*. 2019;8(1):121. Review.