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Healthcare as perceived by persons with inflammatory bowel disease – a focus group study

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Abstract

Aims and objectives: The aim of this study was to explore the perceptions of healthcare among persons living with inflammatory bowel disease.

Background: The quality of care plays an important role in the life of persons with a chronic disease. In order to define what persons with inflammatory bowel disease perceive as high quality care, greater focus must be placed on the individual’s own perspective of living with the condition.

Design: A qualitative exploratory study was conducted based on focus groups.

Methods: Five focus groups were conducted with adult persons living with inflammatory bowel disease, fourteen men and twelve women aged 19-76 years. The interviews were performed between January and June 2014.

Results: The perceptions of healthcare from the perspective of persons living with inflammatory bowel disease were summarized in two categories: “Professional attitudes of healthcare staff” and “Structure of the healthcare organization”. Persons with Inflammatory bowel disease want to be encountered with respect, experience trust and obtain information at the right time. They also expect shared decision-making, communication and to encounter competent healthcare professionals. Furthermore, the expectations on and perceptions of the structure of the healthcare organization comprises access to care, accommodation, continuity of care, as well as the pros and cons of specialized care.

Conclusion: The findings show the importance of establishing a respectful and trusting relationship, facilitating healthcare staff and persons with inflammatory bowel disease to work as a team in fulfilling individual care needs – but there is room for improvement in terms of quality of care. Relevance to clinical practice: A person-centred approach, which place the individual and her/his family at the centre, considering them experts on their own health and enabling them to collaborate with healthcare staff, seems important to reach a high quality healthcare organization for patients with IBD.

Key words: Focus group interview, inflammatory bowel disease, quality of care
Introduction

Chronic diseases are the leading cause of illness and disability worldwide, affecting many people and placing great demands on healthcare (HC) organizations. Persons living with chronic disease often have frequent and long-term contact with HC professionals, which highlights the importance of quality care (WHO 2011). Inflammatory bowel disease (IBD), which mainly comprises Crohn’s disease and ulcerative colitis, is a common chronic disease often diagnosed early in life (peak age 15-35 years) (Cosnes et al. 2011). Sweden is one of the countries with highest prevalence and incidence in the world, with a total incidence of 41.7/100,000 inhabitants/year (Sjoberg et al. 2013, 2014). It is estimated that more than 4 million people in Europe and North America alone live with IBD—around 1 in every 240 individuals (Burisch et al. 2013). Because of the early age at onset and the absence of curative treatment, the vast majority of patients require lifelong medical care, which periodically leads to outpatient contact and hospitalizations. For some persons IBD has a negative effect on everyday-life and health-related quality of life, why quality of care is important (O’Connor et al. 2013). There are great inconsistencies in care and a high level of unwarranted variation in care is often used as an indicator of low overall quality of care (Kappelman et al. 2010).

Background

In addition to physical symptoms, persons with IBD commonly experience psychological distress (Dudley-Brown 2002) and worry about the course of the disease, disease-related complications, not achieving their full potential in life, energy level, bowel control and being a burden on others (Casati et al. 2000, Pihl-Lesnovska et al. 2010, Stjernman et al. 2010).

Summary box: 'What does this paper contribute to the wider global clinical community?

• In order to achieve high quality of care both the professional attitudes of HC staff and structure of the HC organization needs to be considered.
• When HC staff and persons with IBD work as a team to meet individual care needs with a person-centered approach it appears to leads to developing a high quality HC organization.
IBD is complex with a risk of serious complications and early death if not managed adequately. Persons suffering from IBD require regular monitoring, emergency assessment at relapse and inpatient care in the event of a severe relapse or complications. To the best of our knowledge, no previous studies have used qualitative interviews to explore the perspectives on HC among persons with IBD. Instead, their perceptions of the quality of care have been measured using questionnaires containing closed questions. One example of this method is QUOTE-IBD (Masachs et al. 2010, Pallis et al. 2003, van der Eijk et al. 2001), a questionnaire based on three general HC components; structure, process and outcome (Donabedian 2005, van der Eijk et al. 2000). Structure covers the characteristics of the setting in which care is delivered, process indicates the steps taken by HC professionals in the care of an individual, while outcome describes the result of the care. Studies using QUOTE-IBD (Masachs et al. 2010, Pallis et al. 2009, van der Eijk et al. 2001) revealed that persons with IBD reported suboptimal care in areas such as accommodation, accessibility and information, as well as psychological and physical well-being. Also surgery, younger age and longer disease duration, plays an important role in the experience of the quality of care (Masachs et al. 2010, Pallis et al. 2009, van der Eijk et al. 2001).

The Swedish HC system consists of primary HC and hospital care services. It is mainly publicly funded through taxes and has been recognized internationally for its inclusion of all residents and its equal distribution of care (Westerling 2012).

Specialized gastroenterology departments in Swedish hospitals are responsible for the management of IBD care. The study was performed at a gastroenterology department that provides care for 1,700 persons with IBD and comprises an outpatient clinic, an inpatient ward, a day care unit, an endoscopy unit and a pelvic functional unit. Persons with suspected IBD are referred to the hospital from primary HC, where investigation including endoscopy is performed at the department of gastroenterology. If the investigation results in an IBD diagnosis, the person is followed up in accordance with the HC pathway (Figure 1).

In order to deliver high quality care, greater focus must be placed on the individual’s own perspective of living with the disease, instead of that of HC professionals. Thus the aim of the study was to explore the perceptions of HC among persons living with IBD.
**Methods**

**Design**

A qualitative explorative study was performed, in which the data were collected by means of focus group interviews in order to gain a more complete understanding of the perceptions of HC among persons with IBD and as this method stimulates interaction between participants that might reveal both conscious and unconscious beliefs and experiences (Kitzinger 1995, Krueger & Casey 2015).

**Data collection**

Purposive sampling was used to obtain a wide variation in perceptions of HC. Inclusion criteria specified enrollment of adults older than 18 years with a confirmed diagnosis of IBD, with equal distribution between ulcerative colitis, Crohn’s disease, gender and different age groups. The sample size was five focus groups with three to seven participants in each group (table 1) and two individual interviews, totally 26 participants.

The study participants were recruited by an experienced nurse working at the clinic (first author, KPL) based on sex, diagnosis, time since diagnosis and age.

Data were collected between January and June 2014. The principal investigator provided the persons with IBD with information about the study. Those who agreed to participate returned their written informed consent in a pre-paid envelope and were contacted to arrange a time and date for the interview. A total of 26 persons diagnosed with IBD, 14 men and 12 women, aged 19-76 yrs. (Md 62 yrs.) participated in the study (table 1).

Seven persons with IBD were invited to each of the six planned focus group interviews, and the number of patients that effectively participated in each meeting were three to seven (table 1). The principle of homogeneous groups in terms of sex and age was adhered to (Krueger & Casey 2015), thus the groups consisted of younger, middle-aged and elderly men and women. A small group design was thus used (Kitzinger 1995). The interaction in the groups is more important than the actual number of participants in the groups. Younger men did not want to participate in group interview and to not miss out the perception of HC from the perspective of young men; individual interviews were performed with these two younger men.

All interviews took place in a room outside the hospital clinic. A semi-structured interview guide with open-ended questions based on the HC outcome, structure and process...
(Donabedian 2005) was developed. Interviews were guided with the following questions: Please describe how you perceive HC at the gastroenterology department? How do you perceive a good care for a person with your disease? What expectations do you have on HC? What expectations do you have on HC professionals? Based on your disease which needs do you have? Probing questions were used to elicit more details. All interviews were conducted by the principal investigators (first author), a specialist IBD nurse. Two nurses (the second and the fifth author) with experience of qualitative research acted as an assistant moderator in two respectively three groups. The role of the assistant moderator was to support the moderator by posing probing questions, observing the group interaction, making notes on it and evaluating the moderator’s interviewing technique (Krueger 1998). A debriefing took place immediately after each focus group interview, at which the moderator’s role, the group interaction and any aspects requiring change were discussed.

The first focus group served as a pilot interview (included in the study) (Krueger & Casey 2015) and some minor changes were made to the wording. The group interaction was lively and all participants were actively involved. The interviews were digitally recorded and transcribed verbatim. The duration of each focus group interview was approximately 1.5 hrs, while the individual interviews lasted for about 30 minutes.

Data analysis

Data collection and analysis proceeded simultaneously in accordance with Krueger (Krueger & Casey 2015). The transcribed interview texts formed the basis for the inductive analysis, supplemented by the assistant moderators’ field notes about the group interaction (Krueger 1998).

The texts were read several times in order to identify patterns and the participants’ perceptions of HC were marked. The analyse was performed through cut up paper transcript and during the data analysis we took account of how often something was said, how many said it and the strength of the perception (Krueger 1998). Statements with a similar meaning were brought together in sub-categories labelled as close to the text as possible. Throughout the analysis the sub-categories were continuously compared to the text as a whole. Those with a similar meaning were then brought together to form categories (Krueger 1998). In order to ensure validity, verbatim quotations were used to illuminate the results and verify the categorization, which was performed jointly by the team members (Krueger 1998). An

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example of the categorization is presented in (Table 2). Our experience from this study is that no further data was obtained after four interviews.

Ethical considerations

The study was approved by the Regional Ethics Review Board at the University of Linköping (No. M209-09) and carried out in accordance with the Declaration of Helsinki, including written informed consent (World Medical 2013). The audio files and transcripts were numerically coded and the way which the data were analysed and presented ensured the participants’ confidentiality. The participants were also assured that they could withdraw from the study at any time without explanation. The data are stored in a locked filing cabinet at the principal investigators (KPL) workplace.

Results

A total of 26 persons diagnosed with IBD participated in the study. They ranged in age from 19-76 years (Md 62 years) and comprised 14 men and 12 women (table 1). Two categories emerged from the analysis; 1) Professional attitudes of HC staff and 2) Structure of the HC organization. The first category covers respect and mutual trust, receiving information at the right time, shared decision making, competence and communication, while the second involves access to care, accommodation, continuity of care and the pros and cons of specialized care (Table 3).

Professional attitudes of HC staff

Respect and mutual trust

From the perspective of a person living with IBD, one important aspect of HC was encountering staff that treated them with respect and created trust. This included being taken seriously and met with understanding of what it means to live with a disease, being shown empathy and being comforted. Trust was vital, as it enabled them not only to talk about the illness but also about their everyday life with openness and humour. They expected to be
given sufficient time and adequate help as well as encountered with kindness and warmth, which provided a sense of humanity and of having a personal relationship.

“I am so glad to have got Dr.X, as the two I had previously were not good. It now functions really well and what makes it so good is that he listens to me and treats me with respect. He takes me seriously.” *P2 (4) (participant 2 in focus group 4).

The participants wanted to encounter HC staff who exhibited job satisfaction, a positive attitude and curiosity about them as a person. It was important to be remembered and listened to. A professional approach helped the participants to cope with a difficult situation and was thus crucial in terms of mental support. They also expected that the HC staff should understand the difficulty of talking about faeces, flatulence and intestines, thus highlighting the importance of staff not giving the impression of being tired of or bored with the subject.

Several participants described medical check-ups during which they were not treated in the manner they wished and expected, nor encountered with understanding of what it is like to live with IBD. Those who perceived being badly treated stated that they had become reluctant to seek medical advice as a result of such experiences. Negative encounters were also considered stressful and the consultation as awkward and pointless. Some participants who had experienced lack of trust felt diminished or that they had been treated in a derogatory manner.

“When I was in hospital a doctor implied that I had taken a medication that I had not and I think I know that better than he does.” P2 (5)

Poor treatment by HC staff included joking among themselves and not including the person with IBD or talking with colleagues about what they had done during their break or in their free time. It could also involve HC staff talking openly about their lack of knowledge about the person with IBD and what they felt unsure about. Some participants reported that the service and treatment were worse when there were many new staff members or they themselves had worked or still worked in the HC sector, as it was expected that they would assist in their own care and treatment. Several participants were of the opinion that some staff had no understanding of what it means to be admitted and did not help with personal hygiene or stoma care.
“… one can see that they don’t want to do certain things… when one needs a little extra help they are unwilling to provide it! I have a stoma so perhaps at times they don’t want to deal with… things like helping me to shower … No, sometimes they have difficulty understanding …” P3 (3)

According to several participants, some staff members lacked insight and the ability to understand other people. Some felt obliged to undergo certain examinations, which created pressure and a sense of guilt when they did not want to participate. A number of participants also experienced a lack of understanding about how psychologically challenging it could be to undergo endoscopic procedures. It was evident that some staff members were only concerned about the physical procedure and pain relief, while disregarding the psychological aspect. Others experienced little understanding of their need to be accompanied by a next of kin despite being an adult. In general, understanding of the need to be accompanied was considered greater in paediatric care. They also perceived the negative view of gastrointestinal disorders as offensive, especially when HC staff referred to the gastroenterology department as the “sewage department”.

Information at the right time

The participants expected to be provided with a greater amount of information about ongoing research concerning the disease and that, as in the case of pregnancy, the consultation would focus more on ‘life’, hereditary factors and diet and less on technical and medical aspects. The participants also wanted more information on different options, such as various treatment strategies before examinations or surgery. Moreover, some perceived a lack of support for managing and learning to live with the illness. They wanted information about how to recognize symptoms and what to do when they were about to have a relapse. Many also lacked information about the rights of persons with IBD. A combination of oral and written information was considered best. The participants wanted clear and structured factual information, as it helped to create a sense of security and calm. They also wished to obtain answers to all their questions during the consultation.
Moderator – In your contacts with this unit, is there somebody whom you have trusted (nods towards P2), whom you could ask to sit down with you for an hour to discuss….

“Yes and no, I mean Dr. X is as expected and is nice and kind.” P2 (5)

“But the thing is that you feel everything is so stressed. You have sort of fifteen minutes to be informed about what is to be done. And I didn’t know that a nurse could sit down and talk to you.” P1 (5)

“No, but how could I know that?… It is lack of it [information] that is like a thread [through the entire HC system] and causes a lot of frustration.” P3 (5)

“If they had told me about the possibility to sit down and talk like that, I really would have accepted.” P1 (5)

How the information was communicated was also important. It was suggested that the information should be provided on an ongoing basis and not all at the same time. The participants did not want to receive information when they were very ill because such a state made the information more difficult to assimilate. They also considered that HC staff should put more thought into how and where information is provided.

“When I’m so very ill I can’t concentrate on anything but my stomach, I can’t take anything in. They should repeat [the information] as you can’t take it in when you are ill.” P1 (5)

“Then you are perhaps so focused on the pain, completely immersed in yourself that you can’t remember.” P2 (5)

“It’s the same if they enter your room when you’re an inpatient; you are very ill and full of pain killers. You don’t have a single brain cell left, they are all asleep.” P3 (5)

The participants did not want to receive information during an examination when they were focused on coping with and getting through the procedure, but in private afterwards. Furthermore, some had not been informed about how to contact the Gastroenterology clinic if their condition worsened outside office hours, including who to contact and how long it was safe to remain at home with symptoms of a relapse. However, they did not keep on demanding such information, as they feared that nursing staff might become irritated if they insisted.
The concern about the way information was provided varied between participants. Several wanted to meet others with the same diagnosis for group discussions, preferably with HC staff involved. They wished to exchange experiences with others in the same situation, e.g., about how to cope at work. Should you tell your supervisor that you have a chronic illness? Should you tell your colleagues? Achieving a balance between having one’s health situation acknowledged in the workplace and not being labeled as disabled was perceived as difficult.

“Small groups where you can share experiences, it would have been good to exchange ideas and [discuss things like] what are your experiences and what did you do to feel better?” P2 (3)

“Yes just like a local patient group.” P1 (3)

Shared decision making

The participants expressed that they wished to encounter HC staff who provide individualized care and are aware that not everyone fits into the same mould. They wanted it acknowledged that a person who lives with IBD knows her/his body best. Although most of the participants wanted to be involved in their care, some elderly women did not and were concerned about the need to play an active role in decision making.

Participation could concern being involved in the decision about the amount of medication or whether they wanted to receive a copy of their medication list.

“And I experience having some kind of say in relation to my own body and can sense what is best for me and I can discuss it with him, which feels good”. P4 (3)

Many also participated in and were knowledgeable about their care. If not allowed to be involved, they considered that they could not interpret their symptoms, which had a negative impact on how health and illness were perceived and addressed. Some described participation as a form of collaboration and when not allowed to be involved in the decision-making process, several reported a condescending attitude on the part of the HC staff. A few participants were of the opinion that too much responsibility had been placed upon them and that there had been a shift towards increased responsibility. A clear follow-up strategy was the factor most frequently mentioned as being of importance for high quality care. Although most were aware that they had an individualized care plan, they were not informed about the
content and expressed the need to receive more information about the next treatment step, why certain examinations and samples were required, what to expect and the probable outcome. They also wished to have a structure for managing various symptoms and side effects.

“I would like better follow up after having received a new medication – How do you feel? – How did you react? Is it beneficial? And what the next step will be if it [the medication] makes you feel unwell, I would like structure and order.” P2 (3)

Competence

Most took it for granted that anyone employed in the HC sector has high qualifications and specific skills and became frustrated when this was not the case. Individuals who had lived with IBD for a long time believed that medical skill today is higher than previously. In addition to medical and professional competence, there was an expectation of interpersonal skills.

“Knowledge does not only involve, for example, surgery, it’s also about dialogue. Being able to encounter people in the right way and if they lack the social skills it can easily become like a screen between them and others and then it won’t really work.” P2 (2)

In the past when medical treatment was not as good as it is today, comforting patients with IBD was of greater importance. The participants appreciated when the HC staff asked the right questions, created trust, had expertise and knowledge of the disease and treatment, thus encountered them in “the right way”.

Communication

Communicating and creating a dialogue were important and implied that the participants encountered HC staff members who were able to answer their questions. They wanted to have a dialogue about their health, treatment and care, in which they were listened to and their views taken into account. The participants provided examples of consultations when HC staff had not familiarized themselves with their case in advance or sat staring into the computer instead of asking questions. Many described encounters during which they were asked open-ended questions, allowed time to pose their own questions and talk freely. A sense of security
was created when the participants perceived that the HC professionals communicated with each other were calm and not stressed.

“Being encountered in a fantastic way… meeting this fantastic person, this wonderful human being whom you just loved.” P4 (1)

“Yes, I had him too, I found him super. You could talk to him about everything.” P3 (1)

“Yes, he was super to talk to. I find that it has deteriorated lately, because I haven’t been allocated a new doctor.” P2 (1)

The participants described situations in which communication was lacking, e.g., not receiving examination or test results. Some had been encouraged to put questions to HC staff when first diagnosed, but this was perceived as frustrating because at that point in time it was difficult to know what to ask about.

Structure of the HC organization

Access to care

Access to care primarily concerned being confident of receiving the care required when the need was greatest.

“I think the most important thing is being able to come here when you are in bad shape. I don’t think that it’s important to come here regularly, but knowing that I can come when necessary.” P2 (4)

The participants also wanted clear instructions about where and when it was possible to contact the HC organisation for advice and support. Several reported that it was sometimes difficult to contact staff over the telephone and preferred other means of contact, such as e-mail. Ideally, they wanted a direct number that they could phone on a 24 hour basis without being put on hold or encountering an engaged tone. If an open telephone line was not an option, they would like to be able to leave their number on an answering machine and be told when to expect a return call. E-mail was perceived as better than the phone for prescription renewals and various certificates.
They wished to be informed about the time of consultations and examinations well in advance, in order to arrange time off from work or school. Being cared for in a room with three other persons with IBD was described as stressful and a single room was considered desirable when first admitted. Several persons had experienced that there were no vacant beds when they were admitted to hospital. Not knowing whether they could get a bed or would be forced to receive care in a corridor due to lack of ward space was extremely stressful.

“Hospital beds are important and I think that construction work is ongoing to provide more beds. But single-bed rooms should be available, as not everyone is happy in a four-bed room with a lot of disturbance or when it [the hospital] is filled to capacity and you are not even allocated a room but a place in the corridor.” P1 (1)

Accommodation

It was important that the signage and way finding systems at the hospital were clear, with the majority reporting that it was easy to find their way around the hospital. A great need was having access to a private toilet when admitted to or visiting the hospital, because one of the most bothersome symptoms of their disease is frequent diarrhea.

“You should be able to use the toilet when you want without it being occupied by somebody else. That is important when you spend 13 hours each day on the toilet.” P1 (1)

In general, the participants considered that the content of the care was more important than the accommodation. However, the lack of parking spaces when visiting the hospital was perceived as problematic.

Continuity of care

An HC system that is organized to ensure continuity of care was considered important, as it creates a sense of security during periods of relapse. Encountering the same HC staff also made the situation easier, as it provided a personal touch that led to more relaxed consultations. Not having to explain everything all over again to another staff member was appreciated, while regular contact and continuity facilitated the follow-up consultation.
“But it’s good to have one and the same doctor and the same team. So that they recognize you and you recognize them”. P2 (2)

Some participants reported being frustrated by the fact that they had encountered a different physician at each of their previous visits.

Pros and cons of specialized care

The fact that HC in Sweden today is highly specialized meant that the participants considered that no one took full responsibility for diseases unrelated to IBD or its complications. HC professionals are only responsible for their own area.

“You mentioned previously that you have to seek care elsewhere for each new condition.”

(Turns to P4) P3 (1)

“Yes, you get many other diseases that may be related to the gastrointestinal disease. And then you are no longer allowed to come here but you have to go to primary care instead.” P4 (1)

Older participants with multiple diseases perceived that it was better in the past when a physician or other HC staff member took a holistic approach. However, the advantage today was that the high level of specialization ensured that they received the best possible care and were always referred to specialized HC staff.

Discussion

This study is unique as it provides patients’ perceptions of HC, which revealed that some needs are unmet. The main findings were the participants’ perceptions that “Professional attitudes of HC staff” and “Structure of the HC organization” were the most important aspects of HC.

Although we know a little about patients’ perceptions of the quality of the care they receive, much still remains unknown. The present study revealed that mutual trust and being treated with respect were salient aspects of healthcare and were related to professional attitudes of HC staff. Respect and mutual trust were described as being listened to, taken seriously, met with empathy and seen as an individual in a social context of working life, family life and leisure time. Mutual trust and being treated with respect are often taken for granted, but the
results of the present study reveal that this is not always the experience of persons with IBD. Other studies (Ekman et al. 2011, Future 2013) show that the meaning of disrespect encompasses long waiting times, receiving incomplete information about their condition or HC staff not being truthful in the event of a medical error (Ekman et al. 2011, Future 2013). Although the outcome of treatment in Western countries is good (Future 2013), persons with IBD consider that being confirmed and treated with respect are sometimes lacking (Future 2013).

Besides respect and mutual trust, the study demonstrated that persons with IBD experienced a great need for information about the disease and symptoms in order to manage their daily life. How and when the information was provided and communicated was important. The participants also stated that while they often received more information than they required, they still had a need for information that had not been provided. It was also perceived as difficult to achieve a balance between what the person with a chronic disease needs to know in order to manage her/his condition and what she/he wants to know. This is in agreement with previous results (Masachs et al. 2010) showing that information was the most important aspect of high quality care in terms of informing about examinations and possible physical problems unrelated to IBD in clear and understandable language (Masachs et al. 2010). Other researchers (Protheroe et al. 2008) have concluded that more individually adapted information, how it is provided, by whom and at what point are key factors for facilitating patients' motivation to be involved in the management of the disease. Access to information that is easy to understand is important (Protheroe et al. 2008), indicating that self-management initiatives that involve information may be more successful in motivating people if the information is tailored to the type of condition and illness stage (Protheroe et al. 2008). The ECCO-EpiCom study revealed that in Western Europe, significantly more patients felt able to consult a nurse regarding their questions about IBD than in Eastern Europe (21% vs. 3%). It was concluded that IBD-related information provided by means of education plays an important role in patients' management of IBD, insight into its pathogenesis and understanding of the importance of therapy, which might subsequently improve patient compliance, satisfaction and coping strategies (Burisch et al. 2014). Information is central to improving the quality of life of persons with a chronic illness such as IBD, as well as their motivation to participate in decision-making.
In the present study, shared decision-making was identified as important and most of the participants wanted to be more actively involved in their care. Shared decision-making based on the needs of well-informed patients may result in an individualized care plan and lead to a greater degree of satisfaction with the care, adherence and thus better health. It has been previously stated that HC professionals often make decisions for the patient based on their own values, knowledge and experience (Siegel 2012). However, while we have a responsibility to inform and recommend care to the patient, the process of deciding how to act should be shared (Siegel 2012). Previous studies have revealed a desire for active involvement in the decision-making process (Baars et al. 2010, Siegel 2012) among persons with IBD. Shared decision-making requires willingness to participate in the process and age is one of several factors that affect it (Clark et al. 2009). Unlike older individuals represented by the group of elderly women in this study, younger persons more often consider shared decision-making the preferred form of interaction with HC staff (Clark et al. 2009).

In this study access to care was perceived as an important aspect of the second category “Structure of the HC organization”. The participants expressed that access meant the possibility of obtaining care during relapses, as well as being informed about different contact and communication options, for example personal visits, telephone consultations and e-health solutions. This knowledge may enable the HC organisation to reduce the routine follow up for those in stable sustained remission, thus freeing up resources to prioritize easy access for patients who suffer a relapse. Receiving things on demand has become the norm in modern society, with the exception of healthcare (Hill 2014). Access to care is often perceived as limited and sometimes it takes a long time to get an appointment (Leape et al. 2012). Our study revealed that access to care and meeting the same HC staff increased the sense of security, which is important to consider when structuring the HC organization for persons with IBD. Other studies have demonstrated that because of the complexity, impact on the patient’s life and lifelong nature of IBD, it should ideally be managed by a multidisciplinary team characterised by continuity of care (Bortoli et al. 2014, Calvet et al. 2014, Louis et al. 2015).
Methodological considerations

Several steps were taken to ensure that the results are trustworthy and accurate. The open-ended questions allowed the participants to describe their perceptions of HC. Because of the aim of the study, a smaller group design (3-7 members per group) was considered appropriate for gaining a more in-depth insight. The importance of interaction between research participants is more important than the number of participants in each group (Kitzinger 1995). The assistant moderators were not involved in the care of the participants with IBD. Young men who were unwilling to participate in a focus group are represented by two men who agreed to participate in individual interviews. The emerging main categories were represented in all focus groups as well as in the individual interviews. The advantage of a focus group over an individual interview (Krueger & Casey 2015) is that a group has the capacity to become more than the sum of its parts. Furthermore, group interaction can provide insight into complex areas where opinions or attitudes are conditional or when the area in question is associated with multifaceted behaviour, motivation or perception. One limitation of focus groups is the risk that participants may feel under pressure to agree with and conform to others. To minimise this risk the participants were informed before the interview that the aim was not to reach consensus on the perceptions of HC but instead to explore different views. The participants might also suppress information due to embarrassment (Krueger 1998, Krueger & Casey 2015).

As the study was carefully designed, conducted and analysed, we believe that the results therefor may be transferable to other people with IBD living in similar context (Krueger 1998, Lincoln & Guba 1989).

Conclusion

The findings show the importance of establishing a respectful and trusting relationship, facilitating HC staff and persons with IBD to work as a team in meeting individual care needs. Our result shows that there is room for improvement in terms of quality of care, and areas of importance that were raised by the participants included for example: respect, mutual trust, a personal relationship between persons with IBD and HC staff and shared decision-making. The encounter between the patient and HC staff is fundamental to the formation of the
partnership. Shared decision-making involves patients in decisions that optimize and match their personal care preferences.

Relevance to clinical practice

Quality improvement in healthcare for persons with IBD is challenging but vital in this important patient population. One way to provide better care for persons with IBD is to acknowledge the new era of person-centred care that now prevails in Swedish, as well as in international HC systems and research. This means placing the individual and her/his family at the centre, considering them experts on their own health and enabling them to collaborate with HC staff to achieve the best outcome. Consequently, the HC professionals have to treat the patient as an active and responsible partner and listening to the patient’s narrative is crucial.

Communication and supporting patients in their understanding of the evidence base medicine is also important and may hold the key to empowering patients to actively participate in disease management. For this reason a person-centred approach appears important for developing a high quality HC organization.

Acknowledgements

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References


<table>
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<tr>
<th>Focus Group</th>
<th>Age range(m)</th>
<th>Sex F=female M=Male</th>
<th>Number of participants</th>
<th>Ulcerative Colitis</th>
<th>Crohn’s Disease</th>
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<tr>
<td>Group 1</td>
<td>67-76 (70)</td>
<td>F</td>
<td>5</td>
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<tr>
<td>Group 2</td>
<td>69-76 (71)</td>
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<tr>
<td>Group 3</td>
<td>27-40 (34)</td>
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<td>Group 4</td>
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<td>Group 5</td>
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<td>Individual interview 1</td>
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<td>Individual interview 2</td>
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<td>Quotation</td>
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<tr>
<td>I feel secure because they take me seriously. When you’re ill you need a little extra time and support and I’ve always had that, it feels good. (focus group 3)</td>
<td>Respect and trust</td>
<td>Professional attitudes of healthcare staff</td>
<td></td>
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<tr>
<td>On coming home from the emergency unit or the consultation, I’ve sometimes thought...what actually happened and what did I learn? What did they say? Well, I think they said something about a particular medication. It has happened that I’ve been at the pharmacy and didn’t know what I had been prescribed. Then I’ve had to phone in the afternoon to say that I hadn’t understood how I should take the medication. (focus group 5)</td>
<td>Information at the right time</td>
<td>Professional attitudes of healthcare staff</td>
<td></td>
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<tr>
<td>In connection with the problem when the intestine had grown together. They operated and removed it but it [the wound] burst open and kept on... I mean it would have been very positive if I could have phoned when I wanted. But in 9 cases out of 10 I didn’t get through. It’s important that the patient make contact by phone. (focus group 2)</td>
<td>Access to care</td>
<td>Structure of the healthcare organization</td>
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<tr>
<td>I think it’s fantastic when you call in the morning and the voice says: yes, this is sister x. And then I relax as I know that she knows who I am. And it feels so good and safe that I know her, not having to relate everything each time.</td>
<td>Continuity of care</td>
<td>Structure of the healthcare organization</td>
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Table 3 Perception and expectations of health care among patients with inflammatory bowel disease

<table>
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<th>Subcategory</th>
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<td>Information at the right time (38)</td>
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<td>Shared decision making (35)</td>
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<td>Competence (35)</td>
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<td>Communication (37)</td>
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<td>Access to care (81)</td>
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<td>Accommodation (7)</td>
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<td>Continuity of care (26)</td>
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<td>Pros and cons with specialized care (14)</td>
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</table>

Symptoms of IBD

Primary Health Care

Referral to the Gastroenterology Department

Gastroenterology Department at the hospital

Physician
Eight to ten weeks after the endoscopy, patients have a consultation with a physician to receive the definitive diagnosis, evaluate treatment, obtain information about the disease and decide about further treatment.

IBD Nurse
Telephones consultation two weeks after the endoscopy to evaluate the medical treatment and symptom burden.

Physician
Three to four months after their visit to the physician, the patient receives an appointment with a specialist nurse for a consultation and information about the disease, treatment and self-management.

Follow up
Thereafter, the patient has an annual visit to the physician over the course of the first three years or until the disease is stable. When the disease is considered stable, the patient has an annual follow-up visit to a specialist IBD nurse only in the context with a physician in the event of a relapse.