Patient Experiences with Colonoscopy: A Qualitative Study

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Abstract

Background: Patient perspectives have important roles in improving the quality of colonoscopy services. The purpose of this qualitative study was to obtain the perspectives of patients who recently had undergone colonoscopy procedures, about their experiences with bowel preparation, the procedure itself, and communication of follow-up results and recommendations.

Methods: We recruited adults who had undergone a colonoscopy, to participate in semistructured interviews. Interviews were audiotaped, transcribed and analyzed using inductive qualitative methods.

Results: Twenty-four adults (58% female) with an average age of 53.8 years participated. Results were categorized within the themes of bowel preparation, the colonoscopy procedure and communication of the results. Participants appreciated having clear consistent plain language messages about bowel preparation. Some participants experienced additional challenges to understanding, and navigating, colonoscopy procedures. At the time of the procedure, positive and reassuring interactions with, and between, members of the health care team, in addition to management of physical pain and discomfort, were important. Participants wanted clear and timely information about the results of their test.

Conclusions: Understanding patients’ needs for information and support can promote higher quality colonoscopy services. Our findings suggest that quality indicators should include: patients’ perspectives of the clarity of bowel instructions; the need for supports that are not routinely provided; the extent to which concerns about the procedure are addressed; interactions with the endoscopy team; the endoscopy team’s interactions with each other; comfort during the procedure, and the timeliness and clarity of results and follow-up instructions. These indicators should be included in annual patient surveys.

Keywords: Patient education; Patient experience; Quality; Service delivery

BACKGROUND

Colonoscopy is a frequent medical procedure with approximately 40% of the Canadian population over the age of 50 reporting, in 2012, having received a colonoscopy within the previous 10 years (1). Colonoscopy is widely used as part of screening approaches for colon cancer and to evaluate gastrointestinal symptoms.
Gaining an in-depth understanding of patients’ experiences can assist providers to include the patient perspective in developing resources and processes. Obtaining patient perspectives is increasingly being recognized as important to improving quality of colonoscopy services (2,3). Quantitative studies using surveys have been a common approach to asking patients about their satisfaction and perceptions about some of the aspects of quality of colonoscopy services (4), but there are few qualitative studies that elicit patient perspectives on colonoscopy processes (2). Qualitative studies are important because they provide more in-depth understanding of patient experiences within contexts of complex social interactions and structural processes. The purpose of this qualitative study was to obtain the perspectives of patients who had undergone colonoscopy procedures recently, about their experiences with bowel preparation, the procedure itself, and communication of follow-up results and recommendations.

This study took place as part of a project by the interdisciplinary team to strengthen colonoscopy procedures in a large health region that serves residents of Manitoba, Canada. The information gathered from patients in this qualitative approach was intended to be used to strengthen resources and processes for helping patients to prepare for colonoscopy, attend the procedure and understand the findings they received after the colonoscopy.

**METHODS**

We used qualitative interpretive description methodology (5). The study took place in Winnipeg, Canada, and was approved by the Health Research Ethics Board at the University of Manitoba. All participants provided informed consent.

We purposefully recruited participants through six endoscopists who asked people who had undergone a colonoscopy if they would agree to be contacted by a member of the research team about participation in an interview related to their experience having a colonoscopy. We aimed to recruit a range of individuals with diversity in sex and age, patients with first time and repeat colonoscopies, patients with different types of bowel preparation (split-dose versus day before), and patients living locally and those who had to travel from rural and more remote communities for the colonoscopy. To facilitate diversity in the sample, as the study progressed, we communicated with the endoscopists, who were informing their patients about the study, that we were interested in recruiting more people with specific characteristics. For example, when we noted that many of our sample had good or excellent bowel preparation, we informed endoscopists that we were intentionally recruiting more patients with poor bowel prep. We also asked endoscopists to intentionally provide information about the study to people living outside of the metropolitan area.

Between January and October 2016, 25 people were interviewed. One interview recording was unusable due to technical difficulties. Sampling ceased when we achieved a diversity of participants according the criteria noted above. Of the final 24 participants, 58% were female and the remainder male. The average age of participants was 53.8 years (range = 20 to 69; standard deviation [SD] = 10.6). Five lived outside the greater metropolitan area in which the procedure occurred and had to travel a few hours on the same day as the colonoscopy or arrived in the city a day or more prior to the procedure. The length of time between the date of colonoscopy and the interview date was a median of 3 weeks. Half of the 24 participants were interviewed following their first ever colonoscopy and 58% reported doing a split-dose bowel preparation (half of the laxative preparation taken day before the colonoscopy and half on the day of the colonoscopy). Endoscopists’ ratings of the quality of the bowel preparation were as follows: poor (n = 8); inadequate (n = 2); good (n = 7) and excellent (n = 7).

Interviews were audio-recorded and transcribed verbatim. Two trained research assistants conducted 12 and 13 interviews, respectively taking into consideration participants’ preferences for time and location of the interview. Four interviews were conducted by telephone and the rest were in-person. We collected sociodemographic information from participants and obtained the date of colonoscopy and the quality of bowel preparation (rated on a four-point scale used in clinical practice locally poor, inadequate, good, excellent) from the endoscopy reports. A semistructured interview guide was used to facilitate discussion about participants’ perspectives about their experiences. Topics encompassed participants’ overall experience having a colonoscopy including preparation, the procedure and information they received after the procedure. In addition, we explored participants’ understanding of preparation instructions, what types of supports they accessed to understand preparation and the procedure, their worries or difficulties getting to their appointment for the procedure, and their suggestions to improve the information they received after the colonoscopy.

Transcripts were analyzed inductively using methods described by Miles et al. (6) with NVivo (Version 11) software. One member of the research team (V.M.) read all transcripts, and developed a coding scheme based on line-by-line coding of the transcripts. Codes were categorized under broad headings consistent with the purpose of the study. Next, matrices were created to examine similarities and differences across factors deemed to be important to interpretation of the findings, for example, participant comments about the clarity of the bowel preparation sheets, participants who had different types of bowel preparation laxatives and participants with different quality of the bowel preparation as judged by
the endoscopist. To promote trustworthiness of findings and interpretations, a second member of the team (G.R.) read all transcripts, reviewed the codes and coding scheme and participated in the development of overall themes. In addition, preliminary results were presented and reviewed at a Patient Advisory meeting, consisting of two individuals who had colonoscopy in the past, and who provided additional insights into the findings and interpretations. Although the overall coding scheme was not altered, the input of the Advisory Group was helpful in making decisions about issues to emphasize in finalizing the results. This included, for example, the importance of communication and relationships with the endoscopy team.

FINDINGS
We report the findings below as they related to the three stages of the colonoscopy process: bowel preparation, the colonoscopy procedure and communication of results. Findings are supported by quotes identified by participants’ code number and sex.

Bowel Preparation
The health region was initiating a centralized colonoscopy booking system at the time of the study; so, many participants received bowel preparation instructions by mail directly from that system. Some participants were booked directly through the endoscopist’s office and received instructions unique to that physician; even after the institution of the central booking system, some physicians (some consistently; others on a patient case by case basis) have continued to use their own instructions solely or in addition to those provided by the central booking system.

The majority of the participants understood the importance of bowel preparation to ensure that the endoscopist can adequately see the condition of the colon and avoid a repeat procedure required when the view is obstructed. When asked whether they had any difficulty following the instructions for the bowel preparation, only one-third indicated that the bowel preparation instructions were clear. Two-thirds of the participants reported that the instruction sheets were either a mix of clear and confusing information (50.0%) or solely confusing information (16.6%). In terms of clear information, the most frequently noted positive aspects of the instructions were the visual content. Several participants commented that they appreciated the pictures of what their bowel movements should look like at the end of the preparation (clear liquid with no solid particles). In terms of confusing information, many participants were overwhelmed by the volume of information. Some had to review the information several times by ‘reading and re-reading’ to fully understand what they were supposed to do. Some participants reviewed the instructions with a spouse or family member who had experienced a previous colonoscopy or who worked in health care to be sure they were understanding what was expected.

I sort of had to read ‘em [the instructions] a second or third time, whatever, to go back, ok, am I doing this right? Just to make sure. On the day before. And then the day of, too, … I had to go back and just double-check. (Participant 4, male)

Some participants were unsure how to proceed because they had more than one set instructions. For example, some had instructions for both day before and split-dose preparation on the same information sheet, others had another set of instructions from a previous colonoscopy, and some noted that there were different instructions on the laxative package than those on the information sheet. One participant said:

Even though some of the instructions contradict with the labels of the [laxative], but I still followed this thing [the doctor’s instructions] because, see, if I'd compared it between the other one is, is giving another instruction. (Participant 21, male)

In addition, some participants received conflicting advice from family or friends while others found different information on the internet. Participants also identified some specific areas for which they wanted more clarity. These areas were primarily related to food and drink intake, for example, whether vitamins were considered ‘medications’, and understanding what clear fluids were allowed.

Whether this was a first colonoscopy seemed to make a difference; 10 of the 12 participants who had prepared for their first colonoscopy prior to the interview, mentioned areas of lack of clarity in the instructions. Half of those participants who were preparing for a repeat colonoscopy also found parts of the instructions confusing.

We also examined the differences between participants who had the quality of their bowel preparation rated by the endoscopist as inadequate or poor (n = 10) as compared with those rated as good or excellent (n = 14). We noted that, of the 10 participants with inadequate or poor bowel prep, 33% found the instructions confusing and 33% found them a mix of clear and confusing. Of all participants who reported that the instructions were clear, only 50% had good or excellent bowel preparation.

Interestingly, four of the five participants from rural or northern communities had a poor or inadequate bowel preparation, yet all reported that they found the instructions clear.

Some participants wanted information on topics that were not addressed. For example, one participant indicated that knowing beforehand that they would need to wake very early when taking the split-dose regime for an early colonoscopy, would be helpful.
Just to prepare the individual that prior to that appointment, you actually have to be up, you know, 5 hours before. (Participant 16, female)

Many participants sought additional information and received support related to the bowel preparation instructions. Sources of information and support included family and friends, a contact at the endoscopist’s office or at a phone number listed on the bowel preparation instruction sheet, primary care provider, pharmacist and the internet. Participants were asked whether they would access a website with additional colonoscopy information. Most indicated that they would be interested in this, but a small number indicated that they did not have internet access or did not use the internet.

There were variations in experiences with bowel preparation. Most participants found the process very unpleasant but managed to complete it. Some participants mentioned wanting to do a good job with the preparation to avoid having a repeat colonoscopy. A few participants were unable to finish the dose because they found taking the laxative too difficult because of the volume, taste and/or texture.

The Colonoscopy Procedure
Participants reported a variety of worries going into the procedure: not knowing what to expect, wondering whether or not they would have sedation, wondering whether the procedure would be painful, fear of choking during a concomitant upper gastrointestinal endoscopy, apprehension about whether they would have a bowel movement on the examination table and concern about experiencing flatulence after the procedure. However, for many, the primary worry was about the results of the test. One participant said:

I was nervous, scared. I was just thinking how this thing will work out for me, and I was hoping that they won’t find anything. I was hoping and praying that everything will turn out good. … one of my sisters has cancer. … It kept popping in my head. But I was told not to worry about that. (Participant 25, female)

For one participant who had had multiple colonoscopies, the focus of her worries had changed over time:

I used to be scared of the procedure, the IV the procedure … cried my whole way there. Now I’m scared of the results. So my whole focus has changed. … For me, it causes a lot of anxiety because of what it could mean. (Participant 7, female)

Some participants who had worries prior to the colonoscopy, felt the procedure went better than they had expected in the end. Other participants were less positive about the procedure. Six participants provided a negative assessment of their colonoscopy related to pain when the intravenous was inserted \( n = 2 \), pain, discomfort or cramping during the procedure \( n = 4 \) or nausea or vomiting after the procedure \( n = 2 \), with some participants reporting more than one source of discomfort.

Participants spoke positively about, and the importance of, their interactions with staff during the time they were in the endoscopy suite. Nurses had a crucial role to play in setting the tone when they interacted with participants in the pre-op area. Their efforts to provide comfort were noticed and appreciated by participants.

The nurses there were fantastic. They … provided information and I wasn’t really anxious so I was okay. But I know that there were other patients that were and they were good about trying to ease their anxiety. (Participant 16, female)

Participants also commented on the importance of a positive atmosphere in the endoscopy suite. The collegiality between nurses and doctors, and the use of humour to attenuate tension seemed to make the process easier as illustrated by the following two quotes.

I felt comfortable the whole time. I was never anxious … and just the atmosphere was quite lovely too. They were all very cheery … which was kind of nice. (Participant 14, female)

Everybody I dealt with was pleasant, professional, … they all had a … sense of humour. Even the doc himself had a few chuckles when we were talking, … we had a little bit of joking back and forth. (Participant 17, male)

Communication of Results
Participants reported a range of experiences about the type of information they received and how they received the information after the procedure. They hoped for direct and clear communication about the results of the colonoscopy and recommendations for follow-up. Half of the participants said they received a typed report with pictures immediately after the procedure, which they appreciated. Three out of the six endoscopy units in the health care region in the time of the study had the ability to generate such reports.

The doctor gave me a preliminary report; typed, and pictures and it was actually really good. And just what he found or didn’t find, was very good. And then he said all we have to do is wait for the biopsy results … we’ll mail you a letter when we want you to come in, if we want you to come in, and go from there. So I knew all about what was going to happen. (Participant 22, female)

Two other participants received a pamphlet at discharge with hand-written notes from the doctor. One participant was bothered by the inability to read the hand-written notes.
Participants, who were not given the results immediately after the procedure, stated that they wanted to know when and how they could receive the information, and it was important that the timeframe be followed. For one participant, not receiving the results within the timeframe given by the endoscopist caused distress.

(After the test, the endoscopist) wrote on a piece of paper that they removed the polyp and that they would be sending it to pathology … and that the office will get back to me in 2 to 3 weeks … If (the doctor) would have said … ‘you’ll hear from us whenever,’ I wouldn’t have worried about it but when they give you a timeframe and then that timeframe comes and goes … you know, it’s been almost 6 weeks. (Participant 11, female).

In addition to test results, participants also identified other information they would have appreciated after the procedure such as whether loose stools should be expected. Other participants were interested in knowing the quality of their bowel preparation so they could make adjustments next time they had a colonoscopy. This was particularly important for those who had frequent tests.

Even a grade from the doctor at the end like … if they could say, ‘hey, good job on the scope this time, keep that up.’ Then I’d know what to repeat. (Participant 10, female)

**DISCUSSION**

Patients have a central role in colonoscopy procedures. Adequate bowel preparation increases the likelihood of completing the colonoscopy and detecting polyps (7). The results of this study support findings from other research that bowel preparation can be a significant burden for some patients (7,8). Although some patients manage, others experience considerable challenges. Previous research has suggested that people living with multiple chronic health conditions can experience unique worries about colonoscopy and challenges preparing for the procedure (9). Many participants in our study found the bowel preparation instructions challenging and sought clarification and additional information from other sources to increase or confirm their understanding. Factors that contributed to the clarity of the instructions were simple consistent messages and visuals. People with low literacy in the language of the instructions, and with limited supports from others may have particular difficulty in following instructions (10). Other factors, including age, sex and the type of preparation are associated with how patients’ experience the burden of bowel preparation (7). Results from our study emphasize the unmet need of improving communication with patients both before and after the procedures.

To improve the quality of bowel preparation, efforts need to be made to identify patients who may experience increased burden, including those with multiple health conditions, low health literacy, living in rural or remote areas, or having fewer economic and social resources. The findings of this study suggest that additional work to improve educational resources may improve the experience of patients coming for colonoscopy (11). As an example, plain language principles (12,13) may be used to simplify written materials and make it more readable for patients. Step-by-step instructions with additional visual materials may be added to text to make instructions easier to follow. Video content describing (a) bowel preparation and (b) the experiences of people who have been through a colonoscopy, may provide a better understanding of the experience. Additional information for patients coming from remote locations may help them plan an approach to completing bowel preparation according to recommendations.

Translating updated materials into common languages used by patients may make preparation easier for patients (and their helpers) who do not speak the main language used in the endoscopy program. Based on the needs identified from the current study and our other recent studies (14,15), our team has recently launched a website, (http://mycolonoscopy.ca/, last Accessed April 3, 2019), to improve patient access to multimodal information about colonoscopy. Educational materials have been translated into multiple languages. The instructions underwent a review, revision and evaluation (16). Since the initiation of this study, the Winnipeg region, where most of the colonoscopies in Manitoba are performed, has rolled out a Central Intake system and patients now receive standardized bowel prep instructions through this system.

Telephone reminders (17) and patient navigators (18) may improve preparation quality for people with specific challenges. In addition, well developed information provided to patients while waiting for their colonoscopy can reduce their anxiety about the procedure (19,20). Ongoing collaboration between endoscopists and primary care providers is warranted to ensure that patients have the information and resources they need. Special attention should be paid to collaboration in rural and remote communities in which communication may be more challenging due to fewer primary care resources and geographic distance.

Participants in the current study reported having several worries prior to the procedure. Consistent with previous research, pain and embarrassment were concerns for some (21) and may be exacerbated for people with inflammatory bowel disease (8). Although some participants reported that the procedure went better than expected, others reported having a negative experience due to pain and physical discomfort. Studies that examined the effect of an education video shown prior to the colonoscopy have had positive results in reducing anxiety.
acknowledging and addressing common fears and concerns is important to improving patients’ experiences and promoting attendance at the procedure. Providing written and/or verbal information about the evidence for the low risk associated with colonoscopy, and methods to manage pain and discomfort, including details about sedation, could be helpful.

In our study, participants were generally positive about the experience with the nursing and physician attending staff. In the Global Rating Scale-Canada (GRS-C), dignity and the ability of patients to ask questions are important quality criteria and our findings in this regard are reassuring. Participants emphasized the importance of instilling confidence through positive interactions with the health care team. Efforts to comfort and reassure patients were appreciated, as was the use of humour. Von Wagner and colleagues also found that patients appreciated the use of humour and noted that patients felt the positive approaches used by staff were helpful in reducing embarrassment (21). Communication about the colonoscopy procedure, and interaction with, and trust in, the endoscopist (8), as well as, the personal manner of the endoscopist (24), and support staff (25) have all been shown to be highly valued by patients.

Communication about the results of the colonoscopy to participants in our study was dependent on the individual endoscopist. During the time period of the study, our health region had a policy that all patients should receive written information on findings on colonoscopy and be informed when and how they will receive final results on any pathological specimens obtained; however, there was no mechanism to enforce this policy. Overall, participants appreciated obtaining clear and timely reports of the colonoscopy findings, which was not always the case. These findings are consistent with other literature supporting patients’ desire for postprocedure communication (24–26). De Jonge and colleagues found that receiving a report before leaving the endoscopy unit increased patient’s willingness to return for another colonoscopy (27). Receiving verbal and written reports, as opposed to just verbal communication, can enhance patients’ understanding of the procedure and its implications (28). Obtaining feedback about the quality of bowel preparation may be particularly important for individuals who have repeat colonoscopies.

Pamphlets and communication materials in our health care region had been revamped just a few years prior to the current study, although the prior process used did not engage patients for their input. Our current study emphasizes the need to involve patients. We recommend the routine assessment of patient experiences to inform quality improvement efforts within endoscopy units. Patients can help identify areas and processes to improve patient outcomes and quality of care, which might be otherwise overlooked. Our findings suggest that quality indicators should include patients’ perspectives of the:

1. Clarity of bowel preparation instructions,
2. need for additional supports, not routinely provided, for bowel preparation and attending the colonoscopy appointment,
3. extent to which fears and concerns about the procedure are acknowledged and addressed,
4. extent to which patients had positive interactions with the endoscopy team,
5. extent to which the endoscopy team had positive interactions with each other,
6. experience of comfort during the procedure and sources of discomfort, and
7. timeliness and clarity of results and follow-up instructions, including feedback about the quality of the bowel prep.

The Canadian Association of Gastroenterology has adapted the GRS, a tool used to assess quality of services in endoscopy units in United Kingdom and developed GRS-Canada (GRS-C) to aid improvement of the quality of endoscopy services in Canada (4,29). Our study findings should be incorporated in the surveys conducted as part of GRS-C. GRS-C already identifies the need for annual patient satisfaction surveys that include the quality of patient information and feedback about aftercare. However, a specific questionnaire, which units are expected to administer, has not been identified. Our study provides information, which we believe is essential to be incorporated in surveys developed, adapted and used by the individual units. The use of interviews can also provide in-depth information and may be particularly important for patients who experience social, economic, health and geographic barriers to care.

Our study had limitations and strengths. One limitation was the potential for selection bias of the people who agreed to participate. We recruited participants from only six endoscopists potentially limiting the range of experiences. There may have been differences in experiences of first colonoscopy participants who were booked direct to procedure and those who had a prior visit with the endoscopist. However, we did not collect this information and analysis would have been limited due to the very small number of participants in this subset of the current sample. In addition, we did not inquire about communication of information on risks of colonoscopy.

A strength of this study was recruitment of a range of participants across demographic characteristics and geographic communities, enhancing the potential transferability of the findings. Both positive and negative experiences were shared, demonstrating that there did not appear to be a bias toward only those with experiences on one end of the spectrum (positive or negative). This qualitative study provided the opportunity to
CONCLUSION

This qualitative study contributes to deeper understanding about patients’ experiences with the process of having a colonoscopy. Using open-ended questions, we identified several issues of importance to participants that can be used to develop quality indicators (such as the clarity and patient understanding of the information provided before and after colonoscopy, patient comfort during the colonoscopy, anxiety level before colonoscopy) valued by patients. Participants appreciated having clear consistent messages about bowel preparation. Plain language messages should include information about potential risks and benefits of colonoscopy as well as ways to manage pain and discomfort during the procedure. Access to instructions for bowel preparation through various sources (written and visual) is important. Mechanisms to identify special challenges that some patients may experience and to provide additional support to these patients for navigating the colonoscopy procedure are recommended. During the procedure, positive and reassuring interactions with, and between, members of the health care team, in addition to management of physical pain and discomfort, are important. Finally, participants wanted clear and timely information about the results of their test, including, for some, the quality of their bowel preparation. Quality indicators that identify patient perspectives about their experiences with colonoscopy can promote high quality and efficient colonoscopy services for colorectal screening programs, diagnosis and clinical management of inflammatory bowel disease and assessment of gastrointestinal symptoms.

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Declarations

Ethics Approval: The study was approved by the Health Research Ethics Review Board at the University of Manitoba. Participants provided informed consent.

Competing Interests: Charles Bernstein has consulted to, or served on, advisory boards of Abbvie Canada, Shire Canada, Takeda Canada, Pfizer Canada, Janssen Canada, Ferring Canada, and Mylan Pharmaceuticals. In addition, he has received educational grants from Abbvie Canada, Janssen Canada, Shire Canada, Pfizer Canada and Takeda Canada. He has been speaker’s bureaus of Abbvie Canada, Shire Canada, Ferring Canada and Medtronic Canada. Harminder Singh has been on advisory board of Pendopharm, Ferring, Takeda and Merck Canada; received educational grant from Ferring and investigator initiated research funding from Merck Canada. The remaining authors declare that they have no competing interests.

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Authors’ Contributions: G.R. contributed to conceptualization of the project, data collection, analysis and interpretation, and was a major contributor to writing the manuscript. V.M. conducted interviews with participants and first cycle analysis of the data, and contributed to writing the manuscript. J.W. contributed to conceptualization of the project, data collection, analysis and interpretation, and was a contributor to writing the manuscript. C.W. conducted interviews with participants. Due to her untimely death, she did not contribute to the final manuscript. C.B., J.P. and K.W. contributed to conceptualization of the project and critically reviewed the final manuscript. H.S. was the principal investigator on the grant and contributed to the conceptualization of the project, data collection, analysis and interpretation and was contributor to writing the manuscript.

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