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RESEARCH ARTICLE

Patient-Reported Needs Following a Referral for Colorectal Cancer Screening

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Introduction: Patient−physician communication about colorectal cancer screening can affect screening use, but discussions often lack information that patients need for informed decision making and seldom address personal preferences or barriers. To address this gap, a series of patient focus groups was conducted to guide the development of an online, interactive decision support program. This article presents findings on patient information needs and barriers to colorectal cancer screening after receiving a screening recommendation from a physician, and their perspectives on using electronic patient portals as platforms for health-related decision support.

Methods: Primary care patients with recent colonoscopy or stool testing orders were identified via the centralized data repository of a large Midwestern health system. Seven gender-stratified focus groups (N=45 participants) were convened between April and July 2016. Sessions were audio recorded, transcribed, coded, and analyzed for commonly expressed themes beginning in August 2016.

Results: Findings reveal a consistent need for simple and clear information on colorectal cancer screening. Participants desired step-by-step explanations of the colonoscopy procedure and information about bowel preparation options/alternatives. The desired level of additional information varied: some patients wanted to know about and act on test options, whereas others preferred following their physician-recommended testing path. Fears and concerns were prevalent, particularly about colonoscopy, and patients reported challenges getting these concerns and their informational needs addressed. Finally, they expressed consistent support for using the patient portal to gather additional information from their physician.

Conclusions: Patient portals may offer an opportunity to build sustainable programs for decision support and assistance that are integrated with clinic workflows and processes.

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INTRODUCTION

Several tests can effectively screen for colorectal cancer (CRC). Yet CRC is the second leading cause of U.S. cancer deaths and screening remains underutilized.[1,2] Although a physician recommendation for CRC screening is an important factor in screening use,[3–5] only 53% of insured patients who receive a recommendation undergo screening the following year.[6] Thus, for insured patients, the time period that exists between a physician recommendation and subsequent receipt of care is a potentially important touchpoint in the clinical process for CRC screening.

Patient–physician discussions about CRC screening frequently fall short of recommended approaches for preventive screening counseling,[7–9] lack information that patients need to make informed screening decisions, and seldom address patient preferences or barriers.[7,8,10,11] These communication gaps may have important implications, as patients who report having unanswered questions about CRC screening are less likely to be screened.[12] Developing strategies to engage and support patients once they have a physician recommendation is therefore critical to achieving the National Colorectal Cancer Roundtable's goal of 80% screened by 2018.[13]

When considered alongside known screening barriers, including time constraints during primary care (PC) office visits,[14] the above findings led this research team to develop a decision support program targeting patients after the receipt of a physician recommendation for CRC screening.[15] Intervention design was guided by the Health Belief Model,[16] Precaution Adoption Process Model,[17,18] Self-Determination Theory,[19,20] and Sheridan's[9] conceptualization of informed decision making (IDM) as the individual's "overall process of gathering relevant health information from both his/her clinician and from other clinical and nonclinical sources, with or without independent clarification of values." Although CRC screening–related IDM may begin during the patient–physician interaction, the patient may not reach a final decision at that point. Thus, opportunities to fulfill IDM elements also occur outside clinic visits.

Using data from focus groups, the authors identified IDM elements perceived as missing by patients, thus informing the development of an online program to address psychological and logistical barriers to screening. It is anticipated that (1) content could fill informational gaps in typical patient–provider office visit conversations, and (2) unique opportunities presented by electronic health record (EHR)–embedded patient portals could be leveraged to extend decision support beyond the walls of traditional office visits. The study consisted of focus groups with PC patients who had recently received a physician recommendation for CRC screening, to better understand patients' post-recommendation perspectives on the content and delivery of CRC screening information, experiences using electronic patient portals, and preferences around using the portal to extend patient–physician office-based information exchange and decision-making support.

METHODS

Study Sample

A large, integrated health system serving southeastern Michigan was the collaborating site. PC physicians within the health system tend to recommend colonoscopy for CRC screening.[21,22] The health system has used EpicCare EHR software and its associated patient portal, MyChart, since December 2012. Portal adoption rates across the health system's PC clinics average 32.7% (SD=12.4%, range, 6.8%–64.9%),[23] comparable to mean rates reported across national/regional health systems[24] and in a national survey,[25] although the clinics' adoption rates vary. Study-eligible patients were identified via the health system's centralized data repository, which includes EHR, administrative, and clinical data. The sample was drawn from the intervention's target population and eligibility criteria were the same. Individuals were considered eligible if they (1) were aged 50–75 years, (2) had adopted portal technology as defined by having an activated portal account (regardless of frequency of use), and (3) had received a physician referral for screening colonoscopy or an order for stool testing (fecal occult blood test [FOBT] or fecal immunochemical test [FIT]) in the previous 6 months. Individuals with an EHR-documented CRC risk factor (i.e., personal/family history of CRC or bowel disease, such as Crohn's Disease or ulcerative colitis) were excluded.

A total of 2,216 women and 1,639 men were identified as eligible. Study introduction letters (*n*=521) were mailed via the U.S. Postal Service starting with recent referrals and working backwards in three waves until recruitment was complete. Research personnel called patients to confirm eligibility and schedule participation. Of the 235 reached by phone (286 were called but not reached), 9 were ineligible (i.e., were high risk or did not confirm their recent order), 169 refused participation, 57 agreed to participate (37 women, 20 men), and N=45 attended a group (28 women, 17 men) between April and July 2016.

Measures

The semi-structured moderator's guide included open-ended questions and probes (available from the authors). Extraneous probes were eliminated after the first two groups to fit the 2-hour timeframe. Questions were designed to elicit (1) patient narratives about their recent experience obtaining a physician recommendation for CRC screening, (2) information needs and barriers to screening following receipt of the recommendation, (3) perspectives on using an electronic patient portal for health-related decision support (both general and CRC screening–specific), and (4) reactions to sample program content/messaging. Sessions were audio recorded and transcribed verbatim.

Focus groups were gender stratified and experienced moderators were gender matched. A gender-matched co-facilitator handled paperwork, operated the audio recorder, served as timekeeper, and distributed incentives post-discussion. Participants self-reported sociodemographic information via a structured questionnaire before discussions commenced. Each participant received $50.00. All participants signed informed consent forms and the health system IRB reviewed and approved the study.

Analysis

Beginning in August 2016, de-identified transcripts were imported into Dedoose, version 7.0.23, an online qualitative analysis program. Using a combination of a priori codes and inductive codes emerging from participant comments, the research team developed a codebook focusing on the key topics of elicitation, specifically information needs, reasons for screening, barriers to screening, perceptions of the patient portal, and reactions to sample program content/messaging. Transcripts were coded by using the constant comparative method.[26] Five team members participated in coding; each transcript was coded by one pair of analysts. To ensure inter-rater consistency, each pair compared their coding and resolved discrepancies through meetings and discussion. The fifth team member oversaw the coding process and served as arbiter in case of any unresolvable discrepancies. Coded segments were then sorted by category and analyzed for commonly expressed themes.

RESULTS

Table 1 describes the focus group participants (N=45). Per study inclusion criteria, all participants had received a physician recommendation for CRC screening within the previous 6 months and had an activated portal account. Discussions lasted 87 minutes on average (SD=10.8, range, 74–106 minutes), and included three to 11 participants each. The following section summarizes findings in three thematic areas that arose from discussions: information seeking, fears and concerns, and portal use and acceptability. Related example quotes are presented thematically in Tables 2–4.

Table 2 contains quotes related to information seeking, arranged by subtheme. Participants across groups acknowledged the significant limits of face-to-face consultations with doctors and expressed challenges to getting questions answered during office visits. They attributed these challenges both to physicians' time constraints and difficulty thinking of questions in the moment, remarking that important questions often occurred to them afterwards. On the other hand, participants in one of the men's groups emphasized that men are particularly reluctant to ask for clarification about CRC screening because of discomfort or embarrassment.

Across groups, participants strongly expressed a need to know exactly what to expect from screening, particularly colonoscopy. Many participants asked specifically for a detailed, step-by-step explanation of the colonoscopy procedure and its required bowel preparation ("prep") or endorsed the need for simple and clear explanations. Others voiced a desire to speak with someone who had been through screening personally or reported that such a conversation had served as important motivation.

Table 1. Sample Characteristics (N=45)

Variable	*n* (%)
Age, mean (range), years	58.2 (50–71)
Gender	
Men	17 (37.8)
Women	28 (62.2)
Race	
White or Caucasian	21 (46.7)
Black or African American	18 (40.0)
Other	6 (13.3)
Highest level of education	
Less than high school	0 (0.0)
Grades 9–11 (Some high school)	2 (4.4)
Grade 12 or GED (High school graduate)	5 (11.1)
College, 1–3 years (Some college/ technical school)	16 (35.6)
College, 4 years or more (College graduate)	22 (48.9)
Hours of Internet use per week	
0–4	9 (20.0)
5–9	16 (35.6)
10–20	10 (22.2)
>20	10 (22.2)
Comfort level with Internet	
Extremely comfortable	22 (48.9)
Quite a bit comfortable	16 (35.6)
Somewhat comfortable	6 (13.3)
A little bit comfortable	1 (2.2)
Not at all comfortable	0 (0.0)
CRC screening history[a]	
Ever had a stool test	17 (37.8)
Ever had a colonoscopy or sigmoidoscopy	39 (86.7)
Neither stool test nor colonoscopy/ sigmoidoscopy	6 (13.3)
CRC screening test intentions	
I don't plan on getting tested	0 (0.0)
I'm not sure if I plan on getting tested or not	8 (17.8)
I plan on getting tested within the next 6 months	9 (20.0)
I plan to get tested but more than 6 months from now	24 (53.3)
Not answered	4 (8.9)

[a]Response categories for CRC screening history are not mutually exclusive.
CRC, colorectal cancer.

Table 2. Information-Seeking Subthemes and Exemplar Quotes[a]

Subthemes	Exemplar quotes
Challenges in getting questions answered during office visits	
Time constraints	• Moderator (W): You said a little bit earlier that you just didn't want [your physician] to talk to you about it, so you didn't ask extra questions. Participant 1F (W): Well, I would have asked her, but she was so—you know how doctors are kind of—sometime they can get a little pushy and you'd be like, 'Okay, fine. Okay, fine.' But the moment you get ready to ask a question, they answer real fast and they move to something else really quick. [Agreement from other participants] Participant 1F (W): You'd be like, 'Okay, I'm taking up too much of your time right now.' So I'll call —I'll get it from the nurse or whatever and you just keep moving" (Group 1, women) • Participant 4E (M): The doctors are over-booked to where, okay, you have an appointment. You get there on time and you've got 20 minutes to wait to see the doctor after your appointment and then he's got like 5 minutes to see you and stuff like this because they're so harried [. . .] So unless there is some specific questions that you ask the doctor, to be, 'Okay, what's going on with this? What's going on with that?' you may not get the information you need from the doctor (Group 4, men)
Questions arise later	• Participant 3E (M): And I think Participant 3C (M), I agree with you 100% because depending on what your doctor tells you, a lot of times [. . .] you get in a fog and you don't hear everything they say because you're like, 'Oh, my gosh. What is going on here?' And so you get home and it's like, 'Okay, what did they say?' (Group 3, men) • Participant 7F (W): Yeah, because often you just can't think of everything and you have that first question they answer and you haven't had time to really process what they answered, and then as you're driving home, you're like, 'Well, what about that?' (Group 7, women)
What to expect and how to prepare for testing	
Clarifying colonoscopy process and preparation	• Participant 5A (W): Tell me about my colonoscopy. Tell me what you're going to do, tell me what I have to do to prepare, tell me do I have to be there early, tell me the fact that I need somebody to be there with me, tell me that 'wear comfortable clothes' and 'don't eat for X amount of hours.' Tell me all that stuff. Participant 5B (W): Mm-hm, step-by-step. 'This is what is going to happen [. . .] This is what I should expect' [. . .] Because this is a fear-inducing exam for many people I am sure, and I think the more you know about it and the more education you have—and all those little things, too, 'Wear comfy clothes' and da-da-da, 'somebody has to come with you to drive you and stay there with you.' All that helps you understand it and accept it and prepare in advance. (Group 5, women) • Participant 4E (M): For somebody going through it the first time, they need to be given as much information that says, 'Okay, this is what's going to happen. The prep is going to taste like garbage. It's going to—no food, whatever, (and so on and so forth).' But the more information that you're able to give that person coming into it the first time, I think you're prepping them a lot better than just saying, 'Oh, okay, you're going to make an appointment for a colonoscopy. Take this stuff. Don't eat anything.' [. . .] a lot of people don't have the information about the anatomy of what is going to happen. Where is it going, how is it going to be done, and so on. (Group 4, men)
Need for simple and clear explanations	• Participant 2B (W): Any procedure is intimidating to someone. You're a doctor, so you're familiar with these terms. Because I have had doctors who start saying terms to you that you don't understand. So I said, 'Okay, could you break it down in layman terms?' And they're looking at you like you don't understand. 'Well, that's what I pay you for!' (Group 2, women) • Participant 7B (W): Sometimes when you go on [the patient portal], I don't know about everybody else, but myself, I have to hit Google and start looking up, 'What does this mean? What does this mean?' when they put the results on there and are using all of these medical terms. Participant 7A (W): Thirty-letter words, mm-hm. Participant 7B (W): Yes, and I have to continuously look this up. I appreciate a better explanation: 'If we find this, then the next procedure is a biopsy. If we find this, then the next procedure is this'. (Group 7, women)
Talking to or hearing from others who have been through screening	• Participant 7C (W): Yeah, or at least talk to someone who's been through [a colonoscopy] and they could tell me exactly what to expect. Participant 7G (W): Have a mentor. [Agreement from other participants] Participant 7C (W): Right, you can get gross with, but I just want to know what to expect and how to prepare. (Group 7, women)

(continued on next page)

Table 2. Information-Seeking Subthemes and Exemplar Quotes[a] (*continued*)

Subthemes	Exemplar quotes
	• Participant 4D (M): You need to introduce [information] to people who are getting ready to have [a colonoscopy] because they have a lot of apprehensions that are concerned about the invasion and potentially pain, which there is none whatsoever, but a lot of people still think there is. And maybe that's why they're not having this test. And then when I talk to 'em, I tell 'em how straightforward it is, how pain-free it is, how I played nine holes of golf the same day. Literally. (Group 4, men) • Participant 6D (M): I waited and then I had my wife, she had [a colonoscopy]. And she went through with flying colors and said, 'It was so easy.' [. . .] I said, 'All right, I'll do it now because now I feel more comfortable and more satisfied of what to expect.' And it wasn't as scary as all of the stories I have heard or been told over the years. (Group 6, men)
Colonoscopy prep options	• Participant 2B (W): Because it wasn't in the information they provided to me. You read it, what to do, the liquid diet, but they never said, 'Okay, if you're having problems, if you can't keep this down, you do have an option for other prep liquids or whatever.' (Group 2, women) • Participant 7G (W): I wish they would give you more options for the prep and not just say, 'this is what you have to have.' [Agreement from other participants] Participant 7F (W): Because everybody is different and you might clean out better doing one thing versus another. (Group 7, women)
CRC testing options	
Lack of information on testing alternatives	• Participant 2B (W): I have never even heard of the FIT test. I have never—I was never given the option. (Group 2, women) • Participant 3A (M): So really [colonoscopy and stool blood tests] are not equal, even though they are presented as being equal, they don't seem to be equal because one can miss something critical [. . .] that the other one can find out. (Group 3, men) • Participant 5A (W): I mean the FIT test, it didn't even occur to me that there was something else besides the colonoscopy. I mean way back when, I remember my dad doing something. I don't know when, or why, or but that was completely out of my vision. Colonoscopy. That's what you do. [Agreement from other participants] Participant 5C (W): I had never heard about FIT. (Group 5, women)
Prefer to learn about CRC testing options	• Participant 2A (W): I think I would need to get a lot more information [on CRC testing options]. I mean you've given us two tests and if I was leaning toward—I would ask [the doctor] why he felt I needed the colonoscopy. And if he had valid points, then he is the one with the medical degree. But I would give 'em my concerns as well. So I would need to discuss it with the doctor. (Group 2, women) • Participant 5C (W): Definitely I would go and look for information [on CRC testing options]. Once I understand what's happening with myself, I think that I can get control of that. [. . .] I need to understand what's happening. I would, yeah, definitely go and ask. (Group 5, women) • Participant 6D (M): It is nice to know if you have your options. I was not presented that. I didn't know either/or. Like I said, my doctor just said, 'You need to get a colonoscopy and just get it scheduled'. (Group 6, men)
Trust physician's decision about CRC test choice	• Participant 1F (W) [discussing whether patients should receive information on alternative screening tests available]: But then doesn't [seeing information on both tests] open it up for too many questions? I mean if your doctor comes in and if you trust your doctor and if he says, 'This is the test I want,' why do you want to even go into a second test? That makes no sense to me. If my doctor comes in and say, 'This is the test I want you to have,' why would I even want to look up all this information on another test that's similar or closer or whatever? [. . .] Why do you need to understand the difference of the other one? (Group 1, women) • Participant 4G (M): Yeah, I said before, I trust my doctor. He's never mentioned anything about the FIT test to me. At my last colonoscopy they found one polyp and it was fine. He said, 'I won't do anything for 10 years.' I am a diabetic so I have to go every three months for a full checkup anyway with him so whatever the recommendation is, I pretty much go with what he says. (Group 4, men)

[a] Instead of pseudonyms, participants are labeled by their focus group number (1–7) followed by their participant number (A, B, C. . .). Participant gender is denoted by (M), man or (W), woman.

CRC, colorectal cancer.

Bowel preparation was described as "horrible" and a significant barrier to screening follow-through. Many participants emphasized that providers did not adequately convey information about existing alternatives and wanted to be offered a selection of prep products or suggestions to alleviate the process. Indeed, participants in several groups shared strategies amongst themselves for improving the experience.

Another common informational need reported by participants concerned test alternatives to colonoscopy, and their relative advantages and disadvantages. Many had never heard of stool tests (FIT or FOBT), whereas others

Table 3. Fears and Concerns Subthemes and Exemplar Quotes

Subthemes	Exemplar quotes
Fear, anxiety, embarrassment surrounding colonoscopy procedure and/or prep	• Participant 4A (M): I don't want to go through it again [. . .] I don't like hospitals and I am terrified of needles. I am really terrified of needles when they give you the IV and that. My dad had a heart attack and my brother, he passed away and I seen all those needles in him and stuff like that and it just terrifies me to see it. So I just like 'psht, I'm out'. (Group 4, men) • Participant 1F (W): Well, all I have ever heard is that it's invasive and I was like, 'Okay, I don't know if I want to do that.' (Group 1, women) • Participant 2D (W): You have to have somebody to drive you and I was just so embarrassed. My girlfriend had came and I was just so embarrassed that that happened [vomiting before the colonoscopy]. (Group 2, women)
Do not want to hear bad news	• Participant 7E (W): I'm still the type of person that I don't want to find out something wrong with me. I'm still at the leery part. (Group 7, women) • Participant 5B (W): There's the fear of finding something that you don't want to find and you'd rather just not know. (Group 5, women) • Participant 6B (M): I wasn't apprehensive with the procedure. More the results (laughs). So I delayed it for a little time and then I had a follow-up visit and I said, 'Oh, shoot, I'd better get it done.' (Group 6, men)
Loved one or acquaintance experienced complications	• Participant 7B (W): My biggest concern [about getting a colonoscopy] was a couple of years ago, my aunt had it and somehow she got punctured and she had to go to the hospital like back and forth more than once. And it took a [while] for her to recover from it. (Group 7, women) • Participant 6A (M): Actually, what I had been told when it was time for me to get one, a coworker of mine had just had one because of other problems. He actually had a tear. He tore his colon, so I was very apprehensive about having it done. As it turned out, he had diverticulitis pretty badly and that's what complicated his colonoscopy. But so initially when they told me, I waited six months until my wife had it done. And she went through it okay, and so then I went ahead and got it done. (Group 6, men)

were unsure why or how these tests are performed. Some participants viewed them as extra "insurance" between colonoscopies, whereas others emphasized the importance of informing patients that stool testing benefits do not match those of colonoscopy.

Participants overall reported a desire to understand their physician's rationale for recommending one CRC screening test over another. However, across groups they were relatively evenly divided in their preference to either be offered a choice of test or trust the test recommended by their physician. The former wanted to gather information on each test before making an informed decision, whereas the latter group was comfortable relying on their physician's recommendation.

In addition to the information needs reported above, participants voiced important cognitive and emotional barriers to screening. They expressed fear, anxiety, and embarrassment surrounding the colonoscopy prep and procedure, specifically related to its perceived invasiveness, associated pain, and need for anesthesia and needles. Some wanted to avoid hearing bad news or discovering something was wrong. Several participants talked about complications experienced by loved ones or acquaintances during or after colonoscopy; after witnessing those complications they now hesitated to undergo colonoscopy themselves. Table 3 provides quotes by subtheme.

Table 4 presents quotes related to portal use and acceptability by subtheme. Participants were first asked about their general use, experience, and opinions of the health system's patient portal, followed by CRC screening–specific questions. All had activated portal accounts. Participants overall voiced support for the portal as an alternative information channel to supplement the information gained from in-person clinical interactions, both in general and specific to CRC screening. They were quite positive about the portal, reporting that it was fast, responsive, and easy to navigate once learned. They used it to schedule appointments, view test results, pay bills, message providers, and request prescription refills. The perceived advantages generally exceeded expectations: the opportunity to ask follow-up questions after appointments, access additional information and resources, and avoid voicemail or "phone tag". For many participants, the portal represented a new, promising way to interact with providers. Many reported receiving appointment scheduling reminders through the portal but were uncertain whether they provided enough motivation to pursue screening. Most agreed that the reminders were somewhat helpful, although some participants reported ignoring non-urgent communications.

Overall participants were positive and enthusiastic about using the portal for general or CRC-specific decision support; at the same time, they also endorsed the

Table 4. Portal Use and Acceptability Subthemes and Exemplar Quotes

Subthemes	Exemplar quotes
Support for using the portal for physician communication	• Participant 4C (M): What I like about [the patient portal] is—in the old days, you'd call up on the phone and you'd talk to a person. But now everything is so automated that all you get is a computer prompt. So it's a lot better to be able to use the email. And they're very good about getting back to you. I mean it's within a matter of 3 to 4 hours you'll get a reply or an answer to your question on [the patient portal]. So yeah, I'm very pleased. And the test results. I had the results from my colonoscopy. I had it done like at 8:00 in the morning. And I had 'em the next morning when I opened up my email account. (Group 4, men) • Participant 1F (W): You could talk to anybody and the doctors actually respond back. That's why I like [the patient portal]. (Group 1, women) • Participant 7D (W): You think of stuff [later]. And that's one thing I like about [the patient portal] that you can send your doctor an email—and they get to that person, or you have some concerns because sometimes like in before, like say 10 years ago, you'd leave the doctor's office and you'd be like, 'I've got all these questions and I don't know how to get them answered.' Well, now with technology, with [the patient portal], you can send that person—I have gotten answers from the doctor very quickly that I had had on something. [Agreement from other participants] Participant 7F (W): So yeah, the [patient portal] is great for that. I like that interaction. (Group 7, women)
Importance of connection and interaction with clinic	• Participant 4E (M): It goes back to the doctor–patient relationship. If after a certain amount of time, like I said, the patient doesn't respond to scheduling a colonoscopy, then I think it needs to go back to the doctor and the doctor or his staff needs to make contact with 'em and get that individual back into the office so they can discuss it and see if they can't clear up any apprehensions or questions that the person may have. Participant 4D (M): It's just getting back to the doctor–patient relationship. If you're getting this information from [the patient portal] and you're not responding to it, you've got to get the doctor involved or his staff so that they can communicate to you the relevance of these tests so you can get 'em done. Yeah, this [program] is good. It's just that it's another tool but you have to get the doctor and the staff involved so they can communicate to you on how relevant or how significant it is to have a colonoscopy or whatever test that you need or are required at a certain time. (Group 4, men) • Participant 3E (M): With technology today, you can make it personalized without having the physician have to do any time at all. It could be programmed in there, 'Hey, ___, it's been five years since your last colonoscopy. And because you're 55 years old, it would behoove you to get (da-da-da).' [Agreement from other participants] Participant 3F (M): It could be just a form that's already done, but it sounds like it's personalized directly to me and all it did was go in and pick up information out of my personal chart. Pick up my name, pick up my age, that kinda thing. And, 'Dr. ___ made a personal message' and she probably didn't even write it, but I would think it was cool. (Group 3, men)

importance of face-to-face interactions with doctors for motivating patient follow-through with recommended testing. For example, a prominent topic in one of the men's groups was the importance of talking with one's physician about the need for screening; these participants felt that patient–provider communication was most influential. Thus, participants across groups emphasized that their physicians, nurses, and clinic should be the primary source of information and guidance about CRC screening.

DISCUSSION

Discussions among PC patients with a recent physician recommendation for CRC screening revealed a consistent need for better access to understandable information. Participants desired detailed, step-by-step explanations of the colonoscopy procedure, more information on alternatives and options for colonoscopy preparation, and simple, clear information on CRC screening overall. The desired level of additional information varied: some patients wanted to know about testing options not mentioned by their doctor, whereas others preferred not to disrupt their physician-recommended testing path. Patients also reported numerous fears and concerns, particularly about colonoscopy, and challenges in getting these concerns and their informational needs addressed. Finally, participants expressed consistent support for using the patient portal to gather additional information from their physician.

Peterson and colleagues[3] note that a provider recommendation for CRC screening is "necessary but not sufficient for optimal adherence to cancer screening guidelines," pointing to the importance of discussion content and quality (e.g., Lafata et al.[7]). The prevalence of informational needs in this sample has significant implications, given that CRC screening rates are lower among those who have unanswered questions or desire more information, and higher among those who have discussed CRC screening modalities with their physician.[12] In one study examining CRC screening discussions in PC, although nearly all visits included a discussion, they frequently lacked information about topics rated "important" by patients, such as testing pros and cons.[10] Furthermore, the questions that patients did ask were often unrelated to topics originally rated as important.

Findings also underscore the high level of fears and concerns in this sample. Barriers align with those identified in previous studies,[4] such as the mixed-methods study by Jones and colleagues[27] on CRC screening barriers. Top barriers included several types of fear (e.g., of procedure itself, potential complications, abnormal results, and anesthesia), apprehension about bowel preparation, embarrassment, invasiveness, and pain/discomfort.[27] Similarly, fears of cancer or delayed detection, abnormal results, and testing complications were prevalent in a recent study by Woolf et al.[28] A systematic review concluded that patients who receive insufficient information from their physician about test-related pain and discomfort were less likely to undergo repeat screening.[4]

On the other hand, participants expressed consistent, optimistic support for using the patient portal as a source of additional information from their physician, noting that it facilitates asking questions and improves the timeliness of answers. Connectivity to one's doctor remains important, as even patients who ultimately decide to be screened still desire the ability to speak to their physicians about next steps.[28] In addition to the need for maintaining clinical connection, participants' responses reflect a desire for alternative channels to getting questions answered, a finding that holds promise for technological, portal-based solutions. This aligns with the broader role for health information technology envisioned by the Federal Health Information Technology Strategic Plan 2015−2020.[29]

The above findings are relevant to the development of the decision support program in several key ways. First, it is clear that any program must address common fears and concerns about CRC screening, particularly colonoscopy. Second, informational solutions should not be one-size-fits-all. For example, discussions surrounding patients' desired level of information about CRC test choice revealed a diversity of opinion; roughly half wanted information on both stool tests and colonoscopy, whereas the other half trusted their physicians' expertise and rationale for recommending one particular test over another. This split supports the notion of personalization, or offering users the ability to seek additional information only if desired—a program should be tailorable to individuals' informational and decision-making preferences. Because it may feel paralyzing to some individuals to be presented with a large amount of information or too many choices,[30,31] the team's design approach has been to encourage users to follow their physician's recommendation, if willing, while offering the option to gain more detailed information on either test. Third, because it is well recognized that targeting levels of knowledge and awareness is not likely to affect screening uptake without accounting for broader social−structural factors, the program facilitates access via mailed stool testing kits, online colonoscopy scheduling, and direct messaging with providers.[15]

Current strategies to increase adherence to preventive healthcare services, such as CRC screening, generally fall into two categories: (1) "low-touch," low-cost strategies, such as e-mail reminder systems or mailings of stool cards; or (2) "high-touch," high-cost patient navigation services. Although the former have the benefit of being relatively inexpensive, they often overlook significant segments of the population.[32] As underscored by participants in this study, reminders alone are generally insufficient to move many people forward with screening. On the other hand, high-touch approaches often do increase CRC testing (and other service use) but are expensive and thus not realistic for widespread use in today's healthcare market. For these study participants, who were all insured members of one integrated health system with activated portal accounts, logistical barriers did not seem to substantially impede screening, so an approach like patient navigation may be "overkill" and unnecessarily costly. It remains unknown whether adherence to physician-recommended CRC screening can be facilitated by a program more interactive and personalized than a simple mailed reminder but lacking in human personalization; this will be tested by the team's ongoing clinical trial (#NCT02798224).

Limitations

Findings should be interpreted with study limitations in mind. First, recruiting male participants proved difficult; four men's groups were initially planned but only three could be filled. Similarly, a proposed stratification of groups by screening intention proved infeasible because all participants reported either planning to be screened eventually or being unsure; none planned to decline testing. Second, groups were not stratified by other variables, such as ethnicity, portal use characteristics, or income, so inferences cannot be drawn for specific segments of the population. Third, as with any study there is potential for selection bias; although participants belonged to the intervention target population, they may have been more likely to be information seekers, or curious about and willing to undergo CRC screening. On the other hand, even these motivated patients had significant concerns, unanswered questions, and screening barriers as indicated by their intention to screen (18% were unsure and more than half planned to get tested more than 6 months later). This makes them a relevant intervention audience, and findings may even underestimate the typical patient's information and other needs. All participants likewise belonged to one health system. Collectively these may limit the ability to generalize findings; however, discussion topics were broadly applicable and addressed common barriers faced by general PC populations. Similarly, this study was limited to insured patients who had adopted portal technology (as indicated by an activated account), which may limit generalizability to different clinical contexts, patient populations, or health concerns. Future research with non-adopters on the acceptability of conveying health information through the portal will help to elucidate additional challenges.

CONCLUSIONS

Both informational needs and cognitive/emotional barriers to screening were expressed at high levels by study participants. Responses varied regarding desired level of additional information about testing options. An ongoing challenge lies in identifying platforms for building sustainable, practice-integrated tools that offer interactive, personalized information while addressing common fears and concerns. Overcoming this challenge is imperative if the field of preventive medicine is to make substantive, rather than incremental, improvements in its ability to engage and support patients in important healthcare decisions, such as whether and how to undergo CRC screening.

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