Perspectives on colorectal cancer screening: a focus group study

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Abstract

Objective To assess attitudes and acceptability of Ontario consumers and doctors towards colorectal screening with faecal occult blood testing (FOBT) and colonoscopy.

Design, setting and participants Focus groups with gender-specific samples of the population, high-risk gastroenterology patients and family doctors.

Method Semi-structured interview guides used by facilitator to lead groups through knowledge of risk factors and prevention of colorectal cancer, the screening modalities, requirements for implementing screening programmes, barriers to screening and preferences towards screening.

Main findings There were low levels of knowledge about colorectal cancer and its prevention in the general population. FOBT was an acceptable screening modality, but considerable education about its use and benefits would be necessary to implement a screening programme. Colonoscopy was not perceived to be a good choice for a primary screen in the general population. The high-risk group supported use of FOBT in the general population and emphasized the need for education. The doctors were more reluctant about screening, requesting clear guidelines. They also identified the time and resources that would be required if a screening programme were initiated.

Conclusion While colorectal screening is acceptable in this sample, information and decision aids are required to enable consumers and providers to make effective decisions. Implementation of colorectal screening programmes requires substantial educational efforts for both consumers and doctors.

Background

Clinical trial evidence now firmly establishes the effectiveness of colorectal screening with faecal occult blood testing (FOBT) in reducing mortality.[1] Many organizations support colorectal screening.[2–6] Many jurisdictions are planning, or already have implemented, colorectal screening programmes. Recent evidence, as well as economic models, supports the use of colonoscopy

as a primary screening modality.[7,8] This may accelerate the push for colorectal screening programmes.

Despite the strong randomized trial evidence for screening for colorectal cancer, there remains considerable discussion regarding the effectiveness of screening interventions, selection of interventions and screening intervals, and the costs and resource requirements for screening.[9–11] Furthermore, there is perceived to be considerable resistance to colorectal screening among the public and doctors, at least in part based on the nature of the screening interventions. While there has been considerable work conducted regarding knowledge, attitudes and beliefs of these groups towards cancer screening and prevention, the majority of it has examined breast and cervical screening.[12] Recently, some surveys have been conducted regarding prevalence of colorectal screening in the population,[13] although little has been published on consumer knowledge, attitudes and beliefs towards this intervention. Dolan and Frisina[14] conducted a pilot study to examine the effectiveness of the analytic hierarchy process as a technique for assisting decision-making about colorectal screening. While they did demonstrate improvements in decision-making process, the intervention did not influence actual screening plans. In a focus group study, Davis *et al.*[15] showed the important role of health literacy as a factor in colorectal cancer screening decisions in low-income and low-education populations.

Implementation of a colorectal screening programme will require behaviour change on the part of both consumers and doctors. Individual perceptions and attitudes are a major factor in health decisions.[16] In order to plan for colorectal screening programmes, it is essential that there be a clearer understanding of consumer perceptions and attitudes regarding their acceptability. As family doctors will be key players in the implementation of colorectal screening programmes an understanding of their perspectives is also crucial.

This report describes the results of focus groups conducted on behalf of Cancer Care Ontario to assist with preparation of a proposal for a colorectal screening programme. The objective of this study was to obtain information on the understanding of colorectal cancer incidence and risk factors, and its prevention by consumers and doctors. This information is needed to assist with making decisions about implementation of such programmes and to provide guidance on the educational activities that would be required. The major research question was to ascertain consumer and doctor attitudes towards two screening modalities, FOBT and colonoscopy.

Methods

A qualitative approach, with purposive sampling of focus groups, was taken. A total of eight focus groups were conducted, with a target of approximately 10 individuals per group. There were two general population groups in Ontario in each of Toronto (large multicultural urban area with a population of over 3 000 000) and Kitchener (a mid-sized town with a surrounding rural area with a population of over 444 000). In each setting, one group was composed of men and the other of women. Eligibility criteria were: (i) age ≥50 years, (ii) no personal or family history of colorectal disease or cancer, and (iii) the ability to read and understand English. There was also a family doctor group in each setting. The doctors were sampled from the Canadian Medical Directory and included all doctors in unrestricted family or general practice. Two other groups, one male and the other female, were drawn from a gastroenterology practice at a Toronto teaching hospital. This included individuals with a personal or family history of colorectal disease. Those unable to read or understand English were excluded. While this high-risk group is not representative of the general population that would be eligible for a screening programme, they were selected to provide a group of patients with substantial experience with colorectal screening modalities.

All the groups, except those from the gastrointestinal (GI) clinic, were recruited through the assistance of a market research firm. Staff from the firm contacted potential subjects, based on

telephone directory listings, and introduced the topic. The research team provided a script for this purpose, which included informing potential subjects that this work was being undertaken for the provincial cancer agency. Members of the general public were reimbursed US$40 plus expenses and the doctors were provided an honorarium of US$150. The focus groups were carried out by the research team in rooms provided by the market research firm. This provided an opportunity for investigators to observe the groups behind a two-way mirror.

The group from the GI clinic was recruited through review of clinic records. Potential subjects were sent a letter of invitation, which included the study co-ordinator's telephone number. Individuals who contacted the study co-ordinator were then included in the study. The majority of these subjects had a history of polypectomy, while a few had a family history of colorectal cancer. These groups were conducted at a community church near the hospital.

A trained interviewer facilitated all groups. Prior to commencement of the focus groups, the study team developed an interview guide that covered the key objectives of the study. As it was anticipated that many participants would not have knowledge about colorectal cancer or screening, summary materials were prepared to describe the epidemiology of colorectal cancer and to inform subjects about the screening interventions. Furthermore, an FOBT kit (Hemoccult II, Beckman Coulter Inc, Fullerton, CA, USA) was obtained for demonstration at the focus groups, as were pictures of a colonoscope.

Each group commenced with subjects completing a consent form. There was then a discussion about colorectal cancer and its prevention, following which the materials about colorectal cancer were presented and further reactions were elicited by the interviewer. Group participants were asked about their current awareness of colorectal cancer screening practices. For the general population groups, the interviewer then introduced information about how the screening tests are conducted. All groups discussed their reactions to the two screening approaches. Statistical information related to screening was provided for each of the screening tests, and the interviewer facilitated a discussion about the relative merits of the tests. At the end of the public groups, brochures on cancer prevention were made available for those seeking further information.

The groups were audiotaped. The interviewer reviewed each tape and extracted key themes along with pertinent quotations. Thematic analysis was conducted to identify areas of common concern. A member of the research team reviewed the tapes independently to identify the key themes. The research team regularly reviewed the thematic analysis as the study progressed. A theme is characterized as shared by the 'majority' or 'most' members of a group when at least half expressed the thought. 'Few' is characterized as a theme shared by one or two individuals in a group, while 'some' is more than a few but not the majority.

The study was approved by the Institutional Ethics Review Board at Sunnybrook and Women's College Health Sciences Centre.

Results

Table 1 provides the key features of each group. There were 41 general population subjects (18 from the GI clinic) and 15 doctors.

General population groups

The general population groups displayed little knowledge of the risk factors for bowel cancer. A few individuals named diet as a risk factor. Several individuals in the female groups mentioned heredity as a risk factor. There was little to no knowledge of the course of disease. The groups did not know what the prevalence or incidence of colorectal cancer was or how it ranked compared with other cancers, such as breast or prostate cancer.

The general population groups had little knowledge of how colorectal cancer could be prevented or of the specific screening tests. The knowledge of the tests was either self acquired, or acquired through personal experience, a family member or a close friend.

Table 1 Characteristics of focus groups

Characteristics	Females		Males	
	Toronto ($n = 11$)	Kitchener ($n = 11$)	Toronto ($n = 9$)	Kitchener ($n = 10$)
General population groups				
Age (mean, years)	61.1	60.8	63.6	61.2
Main activity				
Working (paid or volunteer)	6	4	5	3
Homemaker	1	2	4	0
Retired or partly retired	2	3	0	6
Unable to work or looking for work	2	2	0	1
Highest level schooling				
No formal schooling	0	0	0	0
Primary school	0	1	0	0
Secondary school	4	6	2	4
College programme	1	2	2	1
University degree	6	2	5	5
Ever had cancer?	2	3	2	1
Member of family had cancer	9	9	7	4
Ever had one of screening tests	3	3	4	3
Missing	1	0	0	0
If yes, test types				
Faecal occult blood	1	3	3	2
Barium enema	2	3	2	2
Sigmoidoscopy	1	0	1	0
Colonoscopy	1	2	3	1

	Female ($n = 9$)	Male ($n = 9$)
Gastrointestinal patient focus group		
Age (years)		
30–39	0	1
40–49	2	0
50–59	2	0
60–69	4	4
70–79	1	4
Main activity		
Working (paid or volunteer)	4	3
Homemaker	0	0
Looking for work	0	0
Retired or partly retired	4	5
Unable to work because of physical problems	1	1
Other	0	0
Highest level schooling		
No formal schooling	0	0
Primary school	0	0
Secondary school	3	4
College programme	4	1
University degree	2	4
Care of gastroenterologist		
<3 years	3	2
3–5 years 11 months	2	2
≥ 6 years	4	4
Missing	0	1

Table 1 (Continued)

Characteristics	Female ($n = 9$)	Male ($n = 9$)
Faecal occult blood test		
Ever faecal occult blood test	3	3
Number of faecal occult blood tests in past 5 years		
0	2	1
1	0	2
2	1	0
Barium enema		
Ever barium enema	4	4
Number of barium enema in past 5 years		
0	1	0
1	1	2
2	2	0
4	0	1
Missing	0	1
Sigmoidoscopy		
Ever sigmoidoscopy	5	3
Number of sigmoidoscopy in past 5 years		
0	1	0
1	4	0
2	0	1
6	0	1
Missing	0	1
Colonoscopy		
Ever colonoscopy	9	9
Number of colonoscopy in past 5 years		
1	5	1
2–4	3	6
≥5	1	1
Missing	0	1

Doctor focus groups	Toronto ($n = 8$)	Kitchener ($n = 7$)
Gender		
Female	4	2
Male	4	5
Age (years)		
30–39	3	1
40–49	3	1
50–59	1	3
60–69	1	0
70–79	0	1
Missing	0	1
Years in active practice		
>5	0	1
5–9	1	0
10–19	4	1
20–29	2	4
30–39	1	1
College of family doctors certificant?		
Yes	5	2
Completed family medicine residency?		
Yes	3	3

Table 1 (Continued)

Characteristics	Toronto ($n = 8$)	Kitchener ($n = 7$)
Practice type		
Solo	3	4
Group	5	2
Clinic (multispecialty)	0	0
Other	0	1

Group practices ranged from two to eight doctors.

Only a few participants had taken the FOBT. The initial reaction from the majority of subjects was, they felt that the test was acceptable. In particular, the participants felt that they would be willing to have the test for prevention purposes.

> At least [its] not painful…it's in privacy of your own home. (Toronto, women general population)

The primary resistance to FOBT was not due to the characteristics of the test itself. Rather, these focused around the cost implications of the test, whether it would be covered by health insurance and whether taxes would have to be raised for a screening programme.

> I think it is good idea but are we willing to have our taxes raised a little bit to pay for this? (Toronto, men general population)

There was also concern about the mechanics of the test – how often it would have to be carried out, and whether three separate specimens were actually required. It was clear that considerable education would be required around how to do the test, and how to handle specimens.

Some subjects noted that they would be less inclined to do the test if they had no symptoms and that younger people (e.g. those in their thirties) may be more likely to object to it. It was also noted that embarrassment might hinder some, and fear of cancers may be an issue for others. There was also concern expressed by a few individuals about possible insurance implications, if a test was positive. Some individuals also questioned the test's accuracy.

The groups identified that a screening programme would have to provide considerable information about colorectal cancer, such as describing its symptoms. While they had many good ideas about how to promote a programme, it was noted that the most important motivation for testing would be recommendation by their family doctor.

Within the general population group, there was very limited previous experience with colonoscopy. Information about what the test involved had to be presented prior to eliciting perceptions from the groups. Generally it was not perceived to be a test that would be acceptable for screening. Most participants indicated that they would only be willing to go for the test, if they had symptoms. However, those individuals who did have experience with the test tended to be more willing to accept it. Concerns that were raised about colonoscopy included those around its risks ('piercing') and pain that may be associated with the intervention.

The majority of subjects chose faecal occult blood when asked which test they would prefer for screening. They largely felt that colonoscopy should be used in those with a history of disease or those who have a positive FOBT.

GI patient groups (increased risk groups)

Among the gastroenterology clinic subjects, there was a much clearer understanding of what bowel cancer was and how it could be prevented.

Women expressed more confidence in their understanding of cancer prevention than men. They were more interested in their health, and educated with regard to pap smears and breast examinations. They noted that they often had care-giving roles for children and aged parents. They also noted that women talk to each other about health more than men – they compare notes and educate each other.

Some members of these groups had personal experience with the FOBT. They noted that they usually had minimal instructions given when they had the test. Most of these subjects proceeded directly to colonoscopy. Those who had had FOBT did not feel it was objectionable and felt that it was easy to perform. They did feel that it should be part of a regular physical examination for the general population. However, they noted that for many individuals some motivation would be required to get people to take it (e.g. family history or family pressure).

The GI patients felt that the onus to promote screening should be with the doctor who should increase awareness of colorectal cancer, stress prevention and explain the test in detail. They felt that education of doctors was important and the way it was done should be standardized across the doctors.

Even after presentation of the test statistics for FOBT, most felt that the test was still worth taking given that it was easy and non-invasive. A few individuals did not realize the value of the test after discussion of its effectiveness.

> So it's somewhat of a waste of time then. (male GI patients)

> So that's 50% more than you would catch. (male GI patients)

Most of the individuals in the GI patient groups had minimal problems with colonoscopy. They felt that there was minimal discomfort with the procedure. The preparation was of greater concern, as it was felt to lead to considerable nausea and fatigue. The subjects noted that it was important for doctors to be sensitive to individual patient needs such as pain tolerance and the reaction to the preparation.

In terms of offering colonoscopy for the general population as a screening test, the male group speculated that there might be some resistance among those with no symptoms. They felt that a trusting relationship with a doctor would be essential to getting people to take the test. Those with such a relationship could be expected to be more compliant. The women felt that those without symptoms would not be likely to comply because of the invasive nature of the procedure. They noted that the test did have significant risks. There were a few who felt that it would be reasonable to offer colonoscopy every 10 years.

Most of the GI patients recommended FOBT as the screening strategy and felt it would be easier to implement. A few felt that because colonoscopy was more thorough it would be more acceptable to the public. They felt that if a doctor explained the features of both in detail then people would choose colonoscopy. They did agree that the initial reaction to colonoscopy would be negative, given how invasive it is, particularly among those without a strong incentive to be tested (e.g. family history, bowel disease, symptoms).

> If we set aside our personal experiences and how everyone is comfortable with colonoscopy I gotta believe that if you said to somebody who is 50 years old you can use that for three days once a year and it has this statistical probability of identifying that you got it or you can have a colonoscopy and you describe the preparation you know the whole you know 24 hour experience um I gotta believe that the vast majority of people are gonna go home with a hat (faecal occult) and I'm not 50 I don't know but that's my guess. (male GI patients)

Family doctor groups

When asked about which cancer screening tests they commonly used, the doctors described a broad range. They expressed concern about the information that was available on cancer screening and the apparent variability between guidelines. In particular, they felt that the guidelines varied by source. They also expressed concern that they changed frequently and that the multiple sources differed. They noted that the guidelines were not concise enough to be useful.

> Difficult to know what are the criteria for screening. Where do these criteria come from, who publishes them, who transmits them…I wish I had some formal criteria for one example, colorectal. (Toronto, family doctors)

They felt that the factors that related to whether or not they did screening tests included (i) a patient's family history and age, (ii) their own training, (iii) their knowledge about the

prevalence of illness and the effectiveness of the test, (iv) pressure from the patient, (v) the cost to the patient and (vi) guidelines.

Few doctors were routinely performing colorectal screening and the majority were skeptical with regard to evidence of its potential benefit. Many of the doctors equated screening with surveillance. That is, they referred to regular follow-up in individuals with a family history of colorectal cancer, or patients with a history of bowel disease, as screening. They also noted that they used 'screening tests' when there were symptoms, such as a change in bowel habits, anaemia, rectal bleeding or abdominal pain.

> I don't usually screen the patients unless they give me a reason for it. I don't think of bowel cancer as such unless, as I say, they are anaemic or a change in bowel habits. (Toronto, family doctors)

All but one doctor felt that FOBT had severe limitations and they did not use it for screening in asymptomatic adults over the age of 50. Many stated that they did not use the test even when there was suspected bleeding, preferring to refer directly to a surgeon or gastroenterologist or to obtain a barium enema.

The doctors noted that they rarely described the procedure for the FOBT to the patients directly, leaving it to the lab or nurse. They noted that there were directions on the package. Some did occasionally give information about diet, and use of aspirin and anti-inflammatories. They perceived that they rarely got questions or comments about the test from their patients.

The main reasons for concern about the FOBT as a screening test was its low yield, high false positive and false negative rates and technical problems. These included unclear instructions about how to carry out the test, what are the samples involved (e.g. separate days or separate specimens?), difficulty in getting patients to adhere to dietary restrictions and in getting specimens returned in a timely manner.

Colonoscopy tended to be used for monitoring patients with family history or bowel disease or in those with symptoms. The doctors did not use it for screening in asymptomatic adults. They noted that they did not usually make the decisions about use of colonoscopy. They felt their role was to refer a patient to a surgeon or gastroenterologist who would make the decision and inform the patient. Thus they rarely discussed what the test involved with their patients. They also usually left the follow-up to the specialist. They perceived that compliance with colonoscopy tended to be high, as the patients were motivated. It was noted that patient's reaction to the test varied with the specialist and with the results of the test.

None of the doctors participating used sigmoidoscopy in their offices. They did not refer patients for screening with this test. Again, they left the decision about using the test in symptomatic patients to the specialist. They did not feel that compliance issues differed between colonoscopy and sigmoidoscopy and felt that many patients did not know which one they had had.

When asked about choice of screening regimen the doctors had mixed views. They felt they needed more information on the effectiveness and costs of the tests. While some believed that higher compliance would be obtained with FOBT, others preferred colonoscopy because it was more effective.

Discussion

Focus groups with members of the general population, and individuals attending a GI surveillance clinic, suggest that FOBT would be acceptable as a screening modality to the general population. Colonoscopy would be acceptable to some, and even preferred by a few. However, in order for any screening approach to be successful, extensive education would be required about colorectal cancer, its causes and prevention, how it presents and its treatment. Each screening and follow-up modality would have to be carefully presented. Instructions about the tests and their preparation would have to be carefully tailored to a wide range of educational and cultural groups. A multifaceted educational campaign involving many health-care stakeholders would be required to ensure success.

Consistent with other screening tests, the population clearly expects to get the message about colorectal screening from their doctors. Yet, many doctors expressed concern about the time required to support a screening programme. They were also the most skeptical group about the likely benefit of any colorectal screening approach. These issues will have to be addressed proactively as screening programmes are introduced. Our findings reinforce the importance of shared decision-making between providers and consumers. Decision aids to support doctors in their discussions with patients could be valuable, given the need to balance potential risks and benefits, and the different perspectives on test quality and acceptability that were expressed.

These focus groups were conducted in order to help inform the Ontario Expert Panel on Colorectal Screening. They are not necessarily representative of the views of the general population or of family doctors. Sampling was limited to a few areas of the province. In particular, time and resources did not provide the opportunity to examine perspectives in the north or in remote rural areas. It will be important to gather knowledge, attitudes and beliefs about colorectal screening from population-based surveys prior to full implementation of screening programmes. Pilot studies of colorectal screening programmes should assess the acceptability of different screening modalities for the population. Finally, successful implementation of colorectal screening programmes will require well-designed public and doctor education strategies.

Conclusion

The study results suggest that colorectal screening with FOBT would be acceptable to consumers in this Ontario sample. Doctors are less enthusiastic about colorectal screening in general. The results clearly demonstrate the importance of developing a sound education and decision support programme for both groups. Screening programmes will also need to ensure that appropriate mechanisms are in place to ensure that doctors who take part in recruiting patients for screening receive adequate support.

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