

Systematic Review and Meta-study Synthesis of Qualitative Studies Evaluating Facilitators and Barriers to Participation in Colorectal Cancer Screening

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Abstract

Screening reduces the incidence, morbidity, and mortality of colorectal cancer, yet participation tends to be low. We undertook a systematic review and meta-study synthesis of qualitative studies to identify facilitators and barriers to colorectal cancer screening participation. We searched major bibliographic databases for records published in all languages from inception to February 2015. Included primary studies that elicited views and perceptions towards colorectal cancer screening were appraised for relevance and quality. We used a two-stage synthesis to create an interpretation of colorectal cancer screening decisions grounded in primary studies; a thematic analysis to group themes and systematically compare studies and a meta-synthesis to generate an expanded theory of colorectal cancer screening participation.

Ninety-four studies were included. The decision to participate in colorectal cancer screening depended on an individual's awareness of colorectal cancer screening. Awareness affected views of cancer, attitudes towards colorectal cancer screening modalities, and motivation for screening. Factors mediating awareness included public education to address misconceptions, primary care physician efforts to recommend screening, and the influence of friends and family. Specific barriers to participation in populations with lower participation rates included language barriers, logistical challenges to attending screening tests, and cultural beliefs. This study identifies key barriers, facilitators, and mediators to colorectal cancer screening participation. *Cancer Epidemiol Biomarkers Prev*; 25(6); 907–17. ©2016 AACR.

Introduction

Colorectal cancer is a major health problem throughout the world (1). Colorectal cancer is the second most common cause of cancer-related death in the United States (2), Canada (3), and United Kingdom (4, 5). In 2014, an estimated 136,830 new colorectal cancer cases and 50,310 colorectal cancer deaths occurred in the United States (2) and 21,300 new colorectal cancer cases and 8,600 colorectal cancer deaths occurred in Canada (3). Screening for colorectal cancer can reduce the burden of the disease, yet participation in colorectal cancer screening is generally low (6, 7) and tends to be lower among ethnic minor-

ities (8–11), individuals of low socioeconomic status (SES; refs. 8, 12–14), and may vary by gender (13–16). It is important to understand why certain individuals get screened while others do not, the system and social factors affecting the decision to participate, and aspects of screening that are valued and culturally acceptable.

Numerous qualitative studies have investigated perceptions and experiences with colorectal cancer screening participation (17–20). These studies have identified factors that affect screening decisions, as well as barriers and facilitators of colorectal cancer screening in a variety of settings. However, no systematic review has been conducted to capture the breadth and depth of this literature. A greater conceptual understanding of these factors is needed to direct the development of interventions aimed at improving overall colorectal cancer screening participation rates and reducing inequities in participation. We therefore designed our study to systematically review the qualitative literature and explore factors that determine the decision to participate in colorectal cancer screening. We also explored factors influencing screening in groups with previously reported low colorectal cancer screening participation (ethnic minorities, patients with low SES) and in men and women.

Materials and Methods

The methods for this systematic review have been published (21) and are summarized briefly. The reporting of our review was guided by the ENTREQ criteria (22).

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Note: Supplementary data for this article are available at Cancer Epidemiology, Biomarkers & Prevention Online (<http://cebp.aacrjournals.org/>).

PROSPERO registration: This review is registered in PROSPERO (registration number: CRD42013005025 available at www.crd.york.ac.uk/PROSPERO).

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doi: 10.1158/1055-9965.EPI-15-0990

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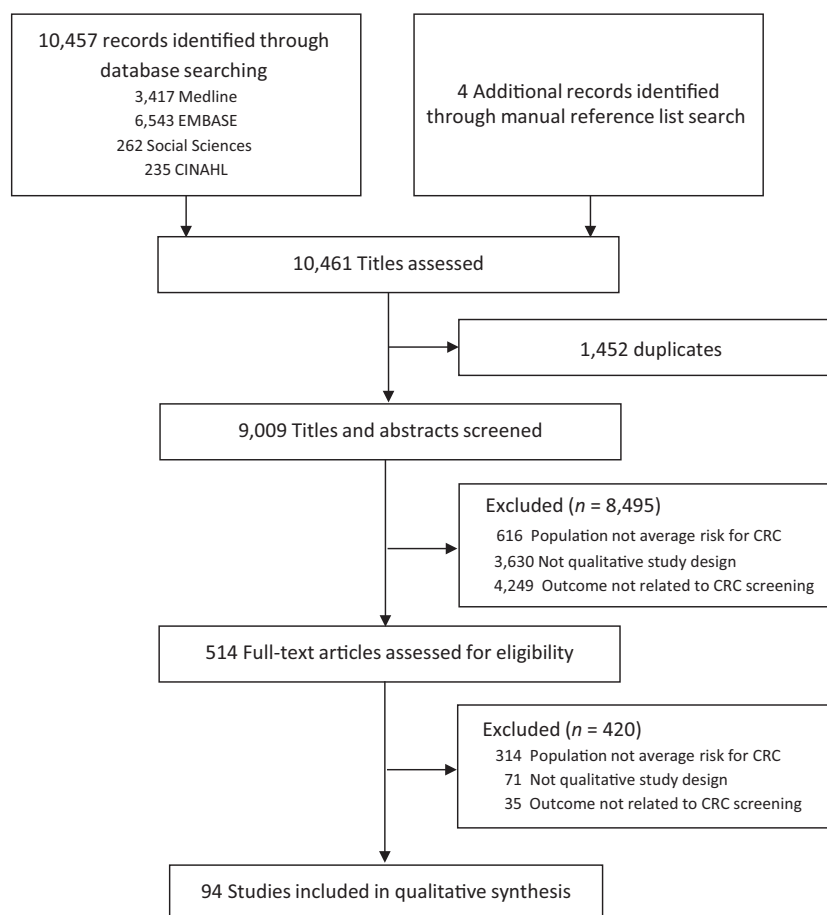


Figure 1.
Study selection PRISMA flow chart.

Search strategy and selection criteria

We searched MEDLINE, EMBASE, CINAHL, and PsycINFO for studies published in any language from inception to February 2015. A search strategy was developed using a combination of "colon/rectal/colorectal cancer," "screening," and "participation" medical subject headings and text words (Supplementary Table S1). A validated qualitative search strategy filter was used to optimize search results to include qualitative studies (23–26). Qualitative and mixed-methods studies (with a qualitative component) were considered relevant if they investigated perceptions of participation in colorectal cancer screening. Two reviewers independently applied eligibility criteria to identify potentially relevant articles. At each level of screening, disagreements were resolved by discussion. Figure 1 shows the process study selection according to the PRISMA guidelines (27).

Data extraction

Using a standardized, pilot-tested form, two reviewers independently extracted data on study characteristics (authors, year of publication, country of conduct), study population (sample size, gender, age, ethnicity, SES); and the determinants of colorectal cancer screening participation (with corresponding exemplary quotes) categorized by gender, SES, and ethnicity, if available. Quality of included studies was assessed independently by the two reviewers using the Critical Appraisal Skills Programme (CASP) tool (28) and classified as meeting at least 8 of 10 criteria,

4 to 7 criteria, or less than 3 criteria according to the process described by Brennan and colleagues (29). Disagreements were resolved through discussion among reviewers and a third reviewer settled discrepancies.

Data analysis and synthesis

Consistent with the meta-study methodology (30), we used a two-stage synthesis of the data to create an interpretation of colorectal cancer screening decisions grounded in the primary studies.

Stage I comprised data analysis according to the three major steps of the meta-study review method. First, we performed meta-data analysis, which is an interpretive analysis of research findings from primary studies as reported by study authors. This involved using thematic analysis to group themes according to identified facilitators and barriers, and to systematically compare studies for similarities and differences across themes (31). Second, we used meta-method to clarify how the quality of included studies influenced the interpretation of findings. For example, information on study quality enhanced our understanding of the credibility and trustworthiness of the evidence, which was then used to strengthen our interpretations. Finally, we used meta-theory to examine how the use of theory in the primary studies influenced our interpretation of findings. When reported, we identified the specific theoretical frameworks (e.g., the Health Belief Model; ref. 32) considered by study authors.

Stage 2 involved meta-synthesis, a more in-depth process of data synthesis aimed at generating an expanded interpretation of colorectal cancer screening participation decisions grounded in primary studies and from triangulation of findings from the three steps in stage I. More specifically, we generated an interpretation by integrating the influence of the study authors' interpretation of the data (i.e., meta-data), the quality of studies (meta-method), and the theoretical frameworks or perspectives underpinning research reports (meta-theory).

Results

We identified 10,457 citations and screened 9,009 unique titles and abstracts for eligibility. Of these, we screened 514 articles in full text, and 94 articles were included in the analysis (Fig. 1). All studies, but one (33), were published between 2000 and 2014. Study methods included in-depth interviews ($n = 48$), focus groups ($n = 37$), and a combination of the two ($n = 4$), or telephone/paper surveys with a qualitative component ($n = 5$). Study characteristics are summarized in Supplementary Table S2. Most studies were conducted in United States ($n = 61$); the remainder in the United Kingdom ($n = 11$), Australia ($n = 6$), Canada ($n = 5$), New Zealand ($n = 3$), Spain ($n = 3$); and one each in China, France, Israel, Singapore, and Taiwan. The majority of studies included White Americans ($n = 33$), some were restricted to ethnic groups, including African Americans ($n = 9$) and Hispanic/Latino Americans ($n = 6$), while the rest included a mix of individuals. Populations were described as having high ($n = 3$), middle ($n = 3$), low ($n = 24$), and mixed ($n = 22$) SES, while some studies did not report SES status of participants ($n = 42$).

Results of meta-data analysis

Our findings revealed several themes across facilitator and barrier factors. Facilitators of colorectal cancer screening were individuals' awareness of colorectal cancer screening and its purpose, having positive attitude towards colorectal cancer screening tests, and the motivation to get screened; the converse of these were barriers to colorectal cancer screening (Table 1). Factors that influenced barriers or facilitators were termed modifying factors. Public education, primary care physician (PCP) recommendation/approach, and friends and family promoted colorectal cancer screening. While most factors were relevant to all population groups, we also found barriers that were specific to certain ethnic minorities, lower SES populations, and gender. The specific facilitator and barrier factors are described below.

Facilitators of colorectal cancer screening participation. *Awareness of appropriate colorectal cancer screening and its purpose* Studies showed that individuals who were aware of appropriate colorectal cancer screening (34–36) and the indication for screening (i.e., when to start screening, screening test options, and periodicity; refs. 34, 37–40) were more supportive of screening and tended to be screened. They demonstrated an understanding that the purpose of colorectal cancer screening was to detect a potential problem early, and believed that it would be beneficial to find cancer early because of better treatment prospects (31, 36).

Positive attitudes towards colorectal cancer screening tests Studies indicated that previous experience with screening influenced attitudes towards subsequent colorectal cancer screening tests. Many people were willing to repeat the test and also expressed

preferences for one test over another (31). Some thought that FOBT was a convenient, non-invasive, non-painful test that can be done "in the privacy of your own home" (41). Others thought colonoscopy was a more thorough test compared with FOBT and some preferred colonoscopy over flexible sigmoidoscopy: "I would like to have the colonoscopy instead of just the flex sigmoidoscopy because there could be problems further on in there. . . . If I was going to go through with this process, I think the colonoscopy is probably the most complete test" (42).

Motivation for screening Several studies reported that individuals participated in colorectal cancer screening to provide a sense of relief and peace of mind that they did not have the disease: (10, 17, 34, 38, 42–54) "Put your mind at ease that you're not affected by whatever they are screening for" (54). Other motivating factors were maintaining and being proactive about their health to live longer: (10, 55–57) "This is all related to being very conscious of the age that I'm at. . . . therefore you just need to be cognizant of that and take preventative steps to ensure that your longevity continues" (57). Having a close individual affected by colorectal cancer was a key driver for colorectal cancer screening (13, 52, 55, 58–62) as this increased a sense of vulnerability and the value of early detection. This was particularly true if the close individual survived because of early detection through screening.

Spouses were an instrumental motivator for screening; several studies found wives influenced and convinced their husbands to complete the test (13, 31, 34, 57, 58, 61–66). Some participants attributed their knowledge of colorectal cancer and colorectal cancer screening to friends, family, and partners (11, 16, 31, 35–37, 39, 40, 44, 46, 47, 51, 52, 58, 66–74). Friends or family members who experienced colorectal cancer and their suffering motivated individuals to be screened: "Believe me . . . you would not want to go through what Michael went through. Believe me you would not want to do it" (35). In contrast, some reported that their friend or family member's account of a negative experience with screening dissuaded them from having the test (20, 31, 45, 61, 70, 75–77). In addition, those who witnessed family and friends die of colorectal cancer or other cancers were less likely to see a benefit to screening: "I know people who found out they had cancer and they died in 2 months" (36).

Barriers to colorectal cancer screening participation. *Lack of awareness of colorectal cancer screening and poor understanding of its purpose* Studies revealed that many individuals did not have great awareness of colorectal cancer, including colorectal cancer prevalence and mortality, how colorectal cancer develops, and how it can be prevented. There was a lack of awareness of colorectal cancer screening modalities, the risks and benefits of screening, and the impact of screening on colorectal cancer mortality. With little knowledge about colorectal cancer, many people were not screened and some concluded that colorectal cancer is "not that important, or [I] would have heard about it" (9, 10, 13, 17–20, 31, 34, 36, 38, 41–48, 54, 55, 60, 63, 65–67, 69, 70, 78–85). In most studies, the main barrier to screening was poor understanding of its goals, and the perception that screening was necessary only when symptoms develop.

Negative views of cancer Findings indicated that fear and fatalism were common views that impede participation in colorectal cancer screening. Fear occurred at different levels: (i) fear of cancer: "nobody whispers about a stroke like they do [about] cancer. . . . nobody

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Table 1. Themes, according to facilitators and barriers, associated with participation in colorectal cancer screening, with exemplary quotes

Theme	Factor	Exemplary quote
Facilitators		
Awareness	Appropriate awareness of CRC screening and purpose of screening are pre-requisites for CRC screening participation (9–11, 13, 31, 34–40, 52, 57, 60, 67, 68, 75, 78, 80, 87, 106, 108)	<i>"If the cancer was found at the first stage, of course, the cancer will be cured more easily than the cancer found at the third or fourth stage. . . So when the doctor asked me to have a [FOBT], I did it right away" (11)</i>
Positive attitudes towards CRC screening tests	Positive attitudes and preferences for CRC screening test (13, 18, 31, 34, 35, 37, 38, 40–42, 46, 56, 57, 63, 66, 77, 80, 82, 83, 85, 88, 89, 93, 95, 106, 124–126)	<i>"At least [its] not painful. . . it's in privacy of your own home" (41)</i>
Motivation for screening	Desire to stay healthy and peace of mind (10, 19, 36, 48, 54–57, 68, 73, 80, 86, 88, 90)	<i>"Put your mind at ease that you're not effected by whatever they are screening for" (54).</i>
	Having a close individual affected by CRC (10, 13, 52, 54, 55, 58–62, 74, 75, 121)	<i>"If somebody you know has suffered with whatever then it makes you think 'should I be tested for this, should I do that?' (58)</i>
	Spouse as motivators (13, 31, 34, 57, 58, 61–66)	<i>"Well simply that wives frequently provide guidance in these matters to their husbands." (61)</i>
Barriers		
Lack of awareness	Lack of awareness of CRC screening (9, 10, 13, 16–18, 20, 31, 34, 36–38, 40–44, 47–50, 63, 65, 69, 71, 72, 78–80, 82, 83, 90, 107)	<i>"I have never heard of colorectal cancer screening. I was never recommended to do it and nobody has ever told me it's available. If I had known that there are various methods of colorectal cancer screening, I would you have gone for it or at least find out more about it" (82)</i>
	Symptom-driven testing (11, 13, 17, 18, 31, 36–38, 41, 44, 46, 48, 53–56, 58, 59, 62, 68, 71, 74, 75, 77, 78, 80, 82, 84, 86, 90, 97, 98, 100, 102)	<i>"Nothing wrong with me. Why should I do that [screening test]?" (102)</i>
Negative views of cancer	Fear of cancer, screening results and treatment (10, 11, 13, 17, 31, 34–36, 41, 42, 44–46, 48–50, 52–58, 60, 65, 68–70, 74, 75, 77, 82–87, 90, 93, 96, 106, 121, 127–129)	<i>". . . you are afraid that the doctor is going to tell you that you have cancer, so a lot of times you don't go because you are scared" (49)</i>
	Cancer is fatal and no screening can stop it (9, 10, 31, 34, 36, 38, 45–47, 49, 52, 53, 55, 58, 63, 65, 68, 72, 74, 82, 83, 87, 98, 108, 127)	<i>"When I hear about cancer, the first thing I think is death" (53)</i>
Negative attitudes towards CRC screening tests	Negative attitudes towards CRC screening tests (12, 17, 18, 31, 38, 40–42, 45–48, 50, 52, 55, 66, 68–71, 73–75, 82, 84, 86, 88, 90, 102, 105–107, 124, 126)	<i>"I think they're [colonoscopy, flexible sigmoidoscopy], you know, invasive and physically unpleasant" (40)</i>
	Embarrassment (13, 33, 41, 42, 44, 45, 48, 49, 54, 55, 58, 60, 63, 65, 67, 72, 73, 80, 105, 124, 127)	<i>"I think what happens is that it is something intimate and embarrassing. – Ashamed. – More intimate than a pap smear or mammography" (13)</i>
	Questioning efficacy of the test (9, 18, 19, 31, 34, 41, 42, 49, 56, 72, 82, 88, 89)	<i>"[Every] six months you go see your doctor and he said you got no cancer, next six month you see your doctor he says you are going to die. . ." (56)</i>
Lack of motivation	Other health concerns deterred from seeking screening (13, 18, 35, 36, 43, 45, 50, 55, 56, 90, 91)	<i>"I don't think too much about [CRC risk]. . . I worry more, I think, that I might get it [cancer] in the breast than anywhere else. Cause I've had lumps there" (90)</i>
	Competing life demands deterred from seeking screening (13, 17, 20, 36, 39, 43, 45, 47, 48, 50, 54, 60, 82)	<i>"I've been busy with work and looking after the family. When I go home, I'm so tired I can't take out extra time to go down to the hospital. And the queue's really long in hospital, right?" (82)</i>
	Scheduling challenges (34, 50, 70, 76, 85, 86, 92, 93)	<i>"It was more of a scheduling problem with the endoscopy clinic" (86)</i>
Cultural, gender, socioeconomic	Natural remedies conquer CRC (11, 54, 59, 68, 69)	<i>"Back home we have a lot of good home remedies. These remedies can cure most anything. I have a good remedy for stomach aches. Whenever I get a cold I boil 'ti bonm' and drink it hot and right away my stomach feels better" (69)</i>
	Ethnic food protect from CRC (18, 53, 59, 60)	<i>"We are different because our diet is predominantly fibre-based. . . so maybe there isn't [CRC] a lot in our community" (80)</i>
	Wellness visits are not part of the culture (13, 63, 69, 72, 73, 84)	<i>"In our culture we don't do these kinds of tests unless vital" (73)</i>
	CRC screening tests are offensive to masculinity and manhood (13, 16, 31, 36, 40, 44, 45, 57, 64, 65, 79–81, 95, 127)	<i>"a threat to masculinity: "an attack on your armour" (80)</i>
	Females perceived CRC as a male disease (31, 33, 34, 36, 65, 80, 90, 105–107)	<i>"I thought it [CRC] was a man's disease" (106)</i>
	Taking time off was not possible (17, 42, 63, 66, 84, 86, 96)	<i>"The time when the office or hospital is operant is not a good time for me. I work during the weekday and cannot get a day off" (96)</i>
	Transportation and finding an escort was a challenge (36, 84, 85, 88, 92, 96)	<i>"We do not have cars or a second car, and there is no public transportation in our area so it is not as easy to go see the doctor." (85)</i>
	Low health literacy (11, 18, 31, 36, 38, 40, 45, 46, 63, 71, 89, 93, 106)	<i>"Then we go into as to the polyps and the lumps and so forth and it seems to be oriented a little more for some of us familiar with this type of, well with these names and so forth. . ." (71)</i>
	Language barriers (9–11, 49, 72, 80, 92, 97, 99)	<i>"[Providers from another clinic] just told us to take [the FOBT instructions] back and read it ourselves. . . You know Chinese—we don't understand English that much. So I just threw it aside. . . I did not do it because I don't quite understand" (11)</i>

Abbreviation: CRC, colorectal cancer.

wants to talk about it because. . . everybody is afraid of it [cancer]" (65); (ii) fear of a potential diagnosis as a result of screening: "The fear of knowing. That sounds crazy, but that's reality. It's the fear of not wanting to know that I have cancer" (86); and (iii) fear of suffering following the diagnosis: "It is better to die than to live and suffer" and "Death is the easiest thing, it is the simplest thing, what comes before death is frightening" (87). Fatalism was another common barrier to screening participation: (31, 53) "I believe that. . . God decides everything. . . I do not believe in prevention. Death is already predetermined. It's just that I don't know when it will be" (53).

Negative attitudes towards colorectal cancer screening modalities Many individuals held negative attitudes towards colorectal cancer screening modalities and avoided screening due to the undesirable nature of the tests. When asked why they do not undergo a FOBT, people indicated that "dealing with a dirty part of the body" (9), storing the kit for several days, and posting samples of fecal materials, were all threats to hygiene and represented social taboos. The main reasons for not participating in colonoscopy were the need for bowel preparation, the pain and discomfort associated with the procedure, and the risk of perforation (31). Screening in general was also avoided because of embarrassment due to the area of the body under investigation and having "zero dignity in the procedure" (42). Some people questioned the efficacy of colorectal cancer screening especially after witnessing rapidly growing cancers in friends and family (9, 18, 19, 31, 34, 41, 42, 49, 56, 72, 82, 88, 89): "[every] six months you go see your doctor and he said you got no cancer, next six month you see your doctor [now] he says you are going to die" (56).

Lack of motivation for screening Several studies showed that individuals perceive colorectal cancer screening as less important in the context of other life obligations and priorities including other health concerns (13, 18, 35, 36, 43, 45, 46, 50, 55, 56, 59, 90, 91), and competing life demands (being a caregiver, work commitments; refs. 13, 17, 20, 39, 43, 45, 47, 48, 50, 54, 60, 82) "I think most people feel they don't have time. . . They are more concerned with family, their jobs, whatever" (54). People found booking a colonoscopy appointment that fit into their schedule a challenge (34, 50, 76, 85, 86, 92–94).

Cultural and gender barriers Culture-specific barriers to colorectal cancer screening included beliefs that natural remedies could prevent cancer (43, 51, 55, 67, 69, 73), and that screening habits are not part of their culture (13, 63, 69, 72, 73, 84). Certain ethnic minorities including Indian, African-Caribbean, and Chinese-American people considered their ethnic diet sufficient to protect against colorectal cancer (31). Latino and African-American men reacted strongly to the idea of a colonoscopy. Because of the anatomical area, having a colonoscopy was perceived as a threat to masculinity (16, 31, 36, 40, 44, 45, 55, 64, 65, 79, 80, 95): "Probing around in my rectum. . . [is] treading on my masculinity" (31). Some women believed colorectal cancer was a male disease (31).

Socioeconomic barriers The need to take time off from work to have a colonoscopy was a barrier. As providers for their family, many low SES individuals were concerned about losing income and preferred to sacrifice their health for the well-being of their families (17, 42, 63, 83, 84, 96). Transportation and finding someone to take them home after the procedure were challenges (36, 50, 55, 70, 77, 84, 85, 88, 92, 96, 97). In addition, poor health literacy among people with low SES (11, 16, 19, 31, 33, 42, 52, 58, 69, 70, 90, 98) made it difficult to understand medical terms such as "colon" or "rectum" or "percentage" (31). Furthermore, language barriers, particularly among non-English-speaking participants, made following physician instructions about sample collection challenging and prevented some from completing the test (9–11, 49, 72, 80, 85, 92, 98–100).

Modifying factors. There were several modifying factors influencing facilitators and barriers (Table 2). Public education helped promote colorectal cancer screening by increasing awareness about colorectal cancer and colorectal cancer screening modalities, clarifying misperceptions around the need for screening when asymptomatic, and addressing unrealistic fear of cancer (83): ". . . when people are educated, then that takes away the fear because they have an understanding of things. . . and the more things are spoken to, people, I mean as long as it stays a mystery, then the fear factor is going to be real high." Public education also made colorectal cancer a more socially acceptable topic: "Just as the mention of 'breast cancer' or 'prostate' once made people squeamish. . . so will

Table 2. Modifiers of facilitators and barriers associated with participation in colorectal cancer screening, with exemplary quotes

	Modifiers	Exemplary quote
Facilitators	Public education raises awareness and addresses misconceptions and unrealistic fears (10, 18, 31, 37, 65, 86)	"The more it's in the media, the more socially acceptable it is to talk about it [CRC]" (31)
	PCP recommendation motivate individuals to get screened (10, 11, 18, 19, 31, 34, 36–38, 43, 54–56, 60, 65, 68, 71, 75, 121)	"If my doctor says to. . . I'd go ahead and have one done." (34)
	Interpersonal communication with PCP (12, 48, 63, 69, 78, 81, 90, 97, 108, 124)	"Talking to the patient in the language the patient can understand. . . that's the key." (81)
	Friends, family, and partners are important source of information and emotional support (18, 38, 49, 61, 81, 128)	"If she [spouse] says, 'Ah, I'm not going to do it', I say, 'Ah, neither am I', but if she says, 'I'm going to do it', I say, 'Ah, me too'" (13)
Barriers	Little public education about CRC compared with other cancers (13, 17, 19, 31, 43–45, 59, 64, 65, 69, 80, 85, 99, 101, 102, 107)	"I couldn't tell you what could cause colon cancer because they don't talk much about this subject. Talk about other types of cancer is more common" (44)
	Lack of physician's recommendation and approach was a powerful deterrent for CRC screening participation (9, 16, 18, 20, 31, 33, 36, 42, 45, 52, 59, 65, 70, 84, 90, 92, 99, 130)	"My doctor never said anything to me about it. If he wanted me to have it, wouldn't he say something?" (65)
	Friends, family, and kin accounts of a negative experience (31, 45, 60, 61, 70, 75–77) (36)	"I know people who found out they had cancer and they died in 2 months" (36)
	PCP inadequate explanation (47, 67, 81, 90, 104, 126, 131)	"You can go all high falutin' [sic] and talk about prostate-specific antigens, and if the patient doesn't understand what that means, he's going to get frightened." (81)

Abbreviations: CRC, colorectal cancer; PCP, primary care physician.

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publicity about colorectal cancer make it easier to say "rectum" and "colon" (31). In fact, some studies indicated the lack of public education and awareness of colorectal cancer contributed to the deficiencies in knowledge about colorectal cancer screening (31): "I think most people...don't know too much about colorectal cancer...for females, they are more concerned about breast cancer...men...prostate...but colorectal cancer is seldom mentioned...they're not put on the same level of awareness and concern" (59).

PCPs also influenced colorectal cancer screening participation both positively and negatively. PCPs who addressed the importance of asymptomatic screening helped individuals understand and value the purpose of screening (31), but many studies found PCPs did not frequently recommend colorectal cancer screening (17, 49, 50, 52, 58, 61, 62, 67, 68, 70, 76, 86, 96, 97, 101, 102): "I would have been more encouraged to do the screening if I have been talked to by my GP" (18). Studies that explored the way PCPs communicate colorectal cancer screening recommendations found patients who received inadequate information about the pain and discomfort associated with endoscopy did not participate in repeat screening (51, 80, 81) and those who received inadequate FOBT instruction did not complete the test (97, 103).

Results of the meta-method analysis

Guided by the CASP tool for quality assessment of qualitative studies, the mean quality score for 94 included studies was 8 out of 10 (range 3–10), 75 (80%) of which met at least 8 out of 10 of the CASP criteria, 17 met 4 to 7 criteria, and 2 met less than 3 criteria (Supplementary Table S3). Our meta-method exploration helped our understanding of the credibility and trustworthiness of the evidence, and facilitated our interpretation of findings. For example, 65% of included studies meeting most (at least 8 of 10) CASP criteria identified awareness as a barrier or facilitator to colorectal cancer screening participation compared with 50% of studies meeting few (3 or less) CASP criteria.

As part of the meta-method analysis, we critically examined the research design, data collection process, and analytical methods used in the included studies; most showed coherence between the research question, methods, analytic strategy, and presentation of results. The majority of studies (92.5%) used appropriate qualitative research designs for their research questions; and 87.2% of studies appropriately addressed the sampling strategy and details of study participants, enhancing transferability of findings to similar populations. We also found that studies sufficiently described the data collection process (95.7%) and analysis (71.3%). Finally, most studies (94.7%) provided a clear statement of findings with verbatim quotes representing participant views, increasing the credibility of findings. However, only 35.1% of studies provided sufficient information on the effect of the researcher on data interpretation to enable an assessment of the extent to which findings were grounded in the data vs. biased by the researchers' interpretations.

Results of the meta-theory analysis

We examined included studies that used a theoretical model or framework to guide their investigation and assessed how this may have influenced the choice of data collection and interpretation. We found that 41 studies (44%) report using a theoretical model, primarily the Health Belief Model (32) ($n = 15$) or the PRECEDE-PROCEED model (ref. 94; $n = 6$; Table 1). The remaining 53 studies did not explicitly use a theoretical model to guide their investigation, but most (59%) indicated that their research ques-

tions and interview guide were informed by known determinants of colorectal cancer screening from the literature. Nine studies used grounded theory as an analytic method to generate themes (18, 36, 50, 54, 59, 74, 104–106).

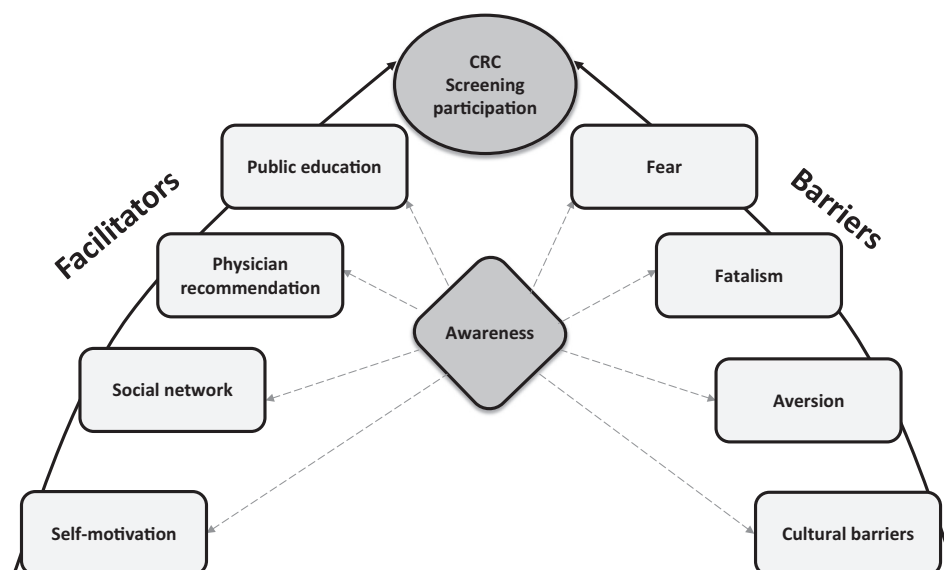
Results of the meta-synthesis

We identified a number of barriers and facilitators influencing the decision to participate in colorectal cancer screening. We propose an interpretive framework capturing the main facilitators and barriers to colorectal cancer screening participation decisions and strategies that influence them. This conceptual framework is grounded in the primary studies included in this review and based on the triangulation of findings from the three steps in stage I. We found that awareness is a requisite concept for colorectal cancer screening decisions as it is integrated in overcoming other structural and motivational barriers related to screening (Fig. 2). We found that individuals with the most knowledge of colorectal cancer screening were supportive of screening while those with the least knowledge were less supportive and tended not to be screened. Lack of awareness is also partly responsible for negative views of cancer and the unrealistic fear and fatalistic views of colorectal cancer, while appropriate awareness led to positive views and attitudes, creating motivation for individuals to participate in screening, despite perceptions of undesirable nature of screening tests. Individuals who had previous experience with colorectal cancer screening tests or were appropriately informed about the benefits and risks of the test held positive attitudes towards colorectal cancer screening. In contrast, those who were poorly informed often held negative attitudes towards screening modalities. Cultural beliefs, socioeconomic status, health literacy, and language barriers were the major factors influencing the decision to participate in colorectal cancer screening among certain population groups with lower participation. Strategies that influenced these barriers and facilitators included public education, PCP efforts to educate and recommend screening, and influential friends and family.

Discussion

Our systematic review found a large, high quality qualitative literature evaluating barriers and facilitators to colorectal cancer screening participation from the perspective of the potential participants. To our knowledge, this is the first systematic review of qualitative studies relevant to the general screening population, and findings should be of interest to PCPs, public health officials, colorectal cancer screening programs, and oncologists providing colorectal cancer care. Our research suggests that while there are some barriers and facilitators to colorectal cancer screening common across various settings, there are also specific barriers affecting colorectal cancer screening participation in ethnic minority and male groups. Importantly, our meta-study synthesis of 94 qualitative studies revealed that a requisite factor influencing the decision to participate in colorectal cancer screening is "awareness", including awareness of colorectal cancer as a disease; the etiology and progression of colorectal cancer; colorectal cancer screening modalities and their risks and benefits; the need to screen in the asymptomatic state; and the role of screening in prevention of colorectal cancer incidence, morbidity, and mortality. Our analysis revealed awareness to be a requisite concept relating to participation in colorectal cancer screening as it was integral in overcoming other reported structural and motivational

Figure 2.
A novel conceptual framework of factors influencing the decision to participate in colorectal cancer screening.



barriers to screening. Participants' lack of awareness of colorectal cancer was frequently reported among included studies (9–11, 13, 16–18, 20, 31, 34, 36–38, 40–44, 46–50, 53–56, 58, 59, 62, 63, 65, 68, 69, 71, 72, 74, 75, 77–80, 82–84, 86, 90, 97, 98, 100, 102, 107), and influenced their views of colorectal cancer as well as their attitude and motivation to participate in colorectal cancer screening—those who were poorly informed often held negative attitudes towards screening and were less likely to participate. Conversely, a sufficient level of awareness was a key enabler for individual decision-making (9–11, 13, 31, 34–40, 52, 57, 60, 67, 68, 75, 78, 80, 87, 106, 108). This is a concordant finding with a previous systematic review of 19 articles examining patient barriers to colonoscopy among African-Americans (109).

The requisite role of awareness has been identified in quantitative literature examining factors associated with colorectal cancer screening. In a recent study, evaluating decision-making in over 900 individuals invited to colorectal cancer screening as part of a randomized trial, while 81% of individuals who participated in screening had sufficient knowledge to make an informed choice about colorectal cancer screening, only 12% of those who did not participate had sufficient knowledge to make an informed decision (103). Similarly in a population-based survey of over 1,600 individuals in the United Kingdom, there was a strong relationship between knowledge and intention to undergo screening – those with greater knowledge about colorectal cancer had a positive attitude toward screening and expressed a stronger intent to undergo screening (110). This relationship was found to be modified by attitudes towards colorectal cancer (110); increased knowledge had a positive impact on attitudes which then resulted in a stronger intent for screening, a finding concordant with the results of our meta-synthesis. In U.S.-based studies, a relationship between education level and participation in colorectal cancer screening has been found consistently, even after controlling for other important determinants such as access to care and SES (111, 112). The relationship between educational level and participation is generally considered a proxy for health literacy and knowledge about colorectal cancer and screening, although the data supporting the relationship between health literacy and attitudes towards colorectal cancer screening is unclear in the literature (113).

Despite the requisite role of awareness, designing interventions to improve colorectal cancer screening participation by targeting awareness has proven challenging. The use of "small media" including educational booklets, videos, and advanced notification of invitation letters has been found to have an impact on colorectal cancer screening uptake (114, 115), although the effect is modest and not demonstrated in all studies (111). The influence of mass media campaigns on awareness and screening uptake is difficult to assess; although some research supports the role of mass media and community interventions in improving screening participation, the evidence is inconsistent (116–119). It is likely that although improving awareness is a precondition to enhancing colorectal cancer screening participation, addressing structural and motivational barriers may be essential to raising participation rates once awareness has been established (111, 115).

One of the objectives of this synthesis was to gain a more in-depth understanding of the cultural and social barriers contributing to inequities in colorectal cancer screening participation. The impact of cultural beliefs, socioeconomic factors, and gender perceptions on individuals' decision to participate in colorectal cancer screening was evident in many studies including ethnic minorities, low income individuals, and women and men from various backgrounds. Our research found certain barriers were prominent in specific ethnic groups such as fear of cancer (10, 31, 44), the perception of screening as futile (42, 47, 88), and misconceptions about the role of natural remedies and diet in colorectal cancer development (11, 53, 54, 59) and its cure (10, 31, 55, 72). Similarly, for those with lower SES, structural and motivational barriers such as screening scheduling challenges, as well as getting time off to participate in screening, and finding transportation for testing were key barriers; in a recent review of 8 qualitative studies evaluating the under-use of colonoscopy screening in African Americans, such barriers are termed "competing factors" (109). The authors of this review highlight that it is critical to target such competing factors and reduce the logistical barriers to screening (in addition to improving awareness and attitudes) to have a meaningful impact on screening participation, a conclusion supported by our findings.

The role of the PCP is vital to addressing "competing factors". Consistent with the quantitative literature (6, 111, 120), we found that the PCP has a key role in addressing barriers and facilitators to screening participation. Our review provides further insights into the PCP practices that may have the most influence. For example, patients with low health literacy reported having difficulties understanding medical terms used during PCP recommendations, while others did not understand the content of the recommendation because of a language barrier or avoided encounters with PCPs unless there was an acute or chronic need. In many cases, PCPs did not recommend colorectal cancer screening to patients (65, 121), and when they did, the instructions provided were often insufficient (31, 47, 81). To enhance equitable colorectal cancer screening participation, PCPs should identify and address "competing factors" for their patients while providing customized culturally sensitive information that is appropriate for their level of education, language, and health literacy.

While 54% of included studies did not report using a theoretical model, 77% of included studies were guided by theory or known determinants of colorectal cancer screening from the literature. Qualitative scholars suggest that use of theory in qualitative research is not uniform and may be problematic. In a meta-synthesis of qualitative studies, Sandelowski and Barroso (2002; ref. 122) found that researchers tend to fit collected data to theory, hence limiting the exploratory aspect of qualitative research. Furthermore, much like in quantitative studies, many researchers often do not clearly articulate their theoretical framework yet they state that they based their research questions, sampling, interview guide, and interpretation on important concepts delineated in the literature. In our meta-study, most of the studies not using a theoretical model were informed by known determinants of colorectal cancer screening from the literature. The current review is advantageous for including studies informed by theory and also those more exploratory in nature.

Our systematic meta-study review has major strengths. First, the meta-study method was very useful for exploring factors that determine the decision to participate in colorectal cancer screening. Meta-study involves an interpretive constructivist approach whereby the deconstruction of the three meta-study processes (meta-data, meta-method, meta-theory) through "meta-synthesis" can provide comprehensive understandings. Indeed, our understanding of data from 94 qualitative studies allowed us to create a conceptual framework capturing several factors influencing colorectal cancer screening participation, which will help inform the development of future interventions and research to promote effective colorectal cancer screening practices. Second, our process for conducting the meta-study review was rigorous and systematic involving a multidisciplinary team who helped design and conduct the review. Our search did not impose any limitations on language, publication date, ethnic group perspective, and qualitative methods; and two reviewers independently selected articles for inclusion, abstracted data, assessed study quality, and synthesized and discussed data, increasing the credibility of findings. Third, the studies included a broad range of

participants in terms of geographic region, ethnicity and SES, and we considered participation in all screening modalities (e.g., FOBT, colonoscopy), which all enhances the transferability of our findings to different populations and settings.

Our meta-study review has some limitations. First, we completed an exhaustive search of the literature, but there is still a risk that we may have missed some studies, a potential limitation of all systematic reviews (30). However, we had an information science expert who developed and executed our search strategy to help mitigate this concern. Second, our interpretations may have been influenced by personal views of colorectal cancer and colorectal cancer screening participation. To minimize this potential bias, we attempted to stay truthful to the included studies, and continuously engaged in team discussions to interpret findings. Third, qualitative studies may be considered contextually bound and non-generalizable. However, as demonstrated by our study, synthesizing the qualitative literature can provide a wealth of information and identify findings consistent between studies and across populations and is thus supported by many researchers (123). While we summarized qualitative studies evaluating the perspective of the potential participant in screening, additional insights would be gained by examining qualitative research from the perspective of the provider and system.

Conclusion

A lack of awareness about colorectal cancer as a disease, its progression and the role of screening in mitigating the impact of the disease influences people's views of colorectal cancer and their attitude and motivation to participate in colorectal cancer screening. While educational interventions need to address awareness, pairing such education interventions with those targeting logistic, cultural and motivational barriers is most likely to result in equitable participation in colorectal cancer screening. Our meta-study review provides a conceptual framework to guide the development of future interventions and research aiming to improve participation rates, enhance informed decision-making and reduce inequities in participation in colorectal cancer screening.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

Acknowledgments

The authors thank Selina Tang for her assistance with the manuscript.

Grant Support

This research was supported through Cancer Care Ontario and Canadian Cancer Society Research Institute (700803) research awards.

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Received September 17, 2015; revised March 17, 2016; accepted March 31, 2016; published OnlineFirst April 13, 2016.

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Cancer Epidemiol Biomarkers Prev 2016;25:907-917. Published OnlineFirst April 13, 2016.

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