Patient Attitudes and Issues in Colon Cancer Screening

Dayna S. Early, MD, and Darrell M. Gray II, MD

Abstract

Colorectal cancer (CRC) is the third leading cause of cancer death in the United States, and is largely preventable by CRC screening (CRCS). Participation in CRCS, however, is much lower than participation in other forms of preventive care. Many reasons for low rates of participation have been identified, and can be generally divided into provider- and patient-specific issues. Lack of a provider recommendation is a well-established and widely reported patient barrier to CRCS. Numerous patient-specific issues have been identified, ranging from fear of CRCS test results to lack of knowledge about individual risk for CRC and inadequate resources to complete CRCS. This article discusses the impact of patient attitudes and issues toward CRCS, with particular attention to modifiable psychosocial factors, the importance of patient preferences for one CRCS test over another, knowledge of CRC risk, and the impact of educational tools on patient compliance with CRCS. (J Natl Compr Canc Netw 2014;12:673–678)

Despite the proven efficacy of CRCS, rates of use by average-risk individuals remain low, particularly compared with screening for other cancers. This limited use may be because of low rates of delivery (screening is not recommended/offered) or use (screening is recommended/offered but not chosen by the patient), or both.

Patient attitudes toward CRCS affect participation in screening tests, and patients report a wide range of barriers to its use (Table 1), including lack of provider recommendation, lack of resources (eg, insurance coverage, transportation), fear (of screening tests or test findings), embarrassment, and worry about being diagnosed with cancer. Understanding these attitudes may help improve use of this important preventive measure.

Patient Knowledge

Uptake of CRCS is largely influenced by individuals’ perception of personal CRC risk, the risk/benefit ratio of undergoing a screening test, levels of trust (in providers and provider recommendations), and fear or worry related to the CRCS test itself and/or the results.

How patients perceive their risk for CRC can have a significant impact on their health behavior, including efforts to seek out information about CRC, and willingness to comply with a CRCS recommendation. Perceived risk can be influenced by several issues, with family history of CRC being the most widely studied.

From Washington University in St. Louis, St. Louis, Missouri. Submitted June 19, 2013; accepted for publication December 4, 2013. The authors have disclosed that they have no financial interests, arrangements, affiliations, or commercial interests with the manufacturers of any products discussed in this article or their competitors.

Correspondence: Dayna S. Early, MD, Washington University in St. Louis, 660 South Euclid Avenue, Campus Box 8124, St. Louis, MO 63110. E-mail: dearly@dom.wustl.edu

© JNCCN—Journal of the National Comprehensive Cancer Network | Volume 12 Number 5 | May 2014
style factors that increase CRC risk (diabetes, smoking, obesity) influenced participation in CRCS in a large primary care practice. Their study found that high-risk participants (personal history of inflammatory bowel disease, colon polyps, or CRC, or family history of CRC) were more likely to be up-to-date with CRCS, and more likely to adhere to a physician recommendation for CRCS compared with average-risk individuals. Patients with lifestyle factors associated with increased risk of CRC were actually less likely to have participated in CRCS.

Risk factors for CRC are generally well-known by providers, but individuals may underestimate or overestimate their risk, and perceived risk can influence behaviors associated with CRCS. Although national guidelines incorporate personal and family history of colorectal polyps and CRC into screening and surveillance recommendations, studies have shown that patients have poor recall of this information, limiting its usefulness.18–20 If individuals consider themselves average or low risk for CRC, they may not seek out information about CRCS or pursue conversations about CRCS with their providers. However, individuals who underestimate their risk for CRC may change their behavior if they are provided information about their CRC risk. Wang et al21 used a Web-based tool developed by the CDC that allows participants to assess familial risk for several conditions, including CRC, and provides personalized prevention messages based on risk. Subjects in this study were randomized to receive either personalized information about disease risk, or standard (not personalized) information about screening in general. The investigators found that individuals who underestimated their risk for CRC were more likely than controls to change their perceived risk to be congruent with actual risk if they received the intervention (personalized risk assessment through the CDC tool). Yim et al22 also assessed the effect of perceived risk, but in a much different patient population. Their study included patients who had recently undergone screening colonoscopy, and assessed subjects’ perception of whether the colonoscopy had reduced their chance of dying from CRC. The authors found that subjects were significantly more likely to believe that colonoscopy had reduced their risk of death from CRC if they had a family history of CRC, a personal history of colon polyps, or had undergone their first colonoscopy.

Psychosocial Factors
Psychosocial factors may reduce compliance with CRCS. Patients report psychosocial factors such as fear (of tests or test results), embarrassment, and mistrust of the health care system, and these factors have been shown to impact willingness to participate in CRCS. For example, Bynum et al23 studied an ethnically diverse group of subjects older than 50 years and found that fear of acquiring AIDS from CRCS and fear of pain and embarrassment during a CRCS test were associated with an unwillingness to participate in CRCS, although mistrust of medical personnel was not. Through work with focus groups, James et al24 found that fear of cancer treatment, fatalism, and lack of confidence in CRCS tests were additional psychosocial factors that may affect compliance with CRCS. Yet findings have conflicted regarding whether fear or worry about having CRC discovered during screening influences compliance, with some studies showing an increase in compliance and others not.25

Increasing patient knowledge about CRCS and educating patients about their personal CRC risk can help improve participation in CRCS programs. Additionally, understanding the impact of psychosocial factors provides an opportunity to improve CRCS compliance through increasing patient knowledge.

### Table 1 Patient Barriers to CRCS

<table>
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<th>Psychosocial</th>
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<tr>
<td>Medical mistrust</td>
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<tr>
<td>Worry, fear, or embarrassment (of cancer, CRCS test, and/or CRCS test findings)</td>
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<th>Socioeconomic</th>
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<td>Low education</td>
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<td>Low income/unemployed</td>
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<td>Uninsured/underinsured</td>
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<tr>
<th>Geographic</th>
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<tr>
<td>Poor access to care (etc, lack of transportation, availability of providers and screening tests)</td>
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<th>Knowledge</th>
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<tr>
<td>Low health literacy</td>
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<td>False perception of CRC risk and CRCS test risk/benefit</td>
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<th>Patient–Provider Relationship</th>
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<tr>
<td>Lack of provider recommendation</td>
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<tr>
<td>No shared decision-making</td>
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Abbreviations: CRC, colorectal cancer; CRCS, colorectal cancer screening.
Patient Preference

Many features of CRCS tests can be considered when choosing a screening program, including test accuracy, amount of colon examined by the test, complication rate of the test, cost to the patient, discomfort associated with the test, frequency of testing, whether follow-up testing is needed, place of service, level of scientific evidence supporting the test, type of preparation needed for the test, amount of time the test takes, and whether sedation is needed. In view of the unique features of each CRCS test, many patients have preferences for one test over another, and this preference may impact their willingness to undergo CRCS.

National recommendations for CRCS of average-risk individuals differ from those for many other cancers, in that CRCS can be performed using several different modalities, each with its own advantages and disadvantages. Current options for CRCS include annual FOBT or FIT, FS every 5 years, annual FOBT plus FS every 5 years, or colonoscopy every 10 years. Stool samples for FOBT and FIT are collected in the patient's home, and testing cards are returned to the provider for development. This approach is low-cost, low-risk, and painless, but is primarily a cancer detection test, rather than a cancer prevention test, because most polyps do not produce occult blood loss and therefore will not be detected. FS is performed in a doctor's office or hospital outpatient department, and therefore requires a greater time commitment from the patient than FOBT/FIT. Most procedures are performed with patients unsedated, and therefore pain and discomfort may occur, but patients are not restricted in terms of diet or activity after the procedure is complete. FS is very effective for identifying and removing polyps in the distal colon, but only examines approximately one-fourth to one-third of the colon, and is therefore insensitive for proximal colon lesions. Because of its limitations, some clinicians have opined that FS is comparable to performing a mammogram on one breast, and consider it incomplete screening. Colonoscopy requires colonic cleansing with a potent laxative before the test and, because sedation is typically administered, requires restrictions on activity after the procedure. A distinct advantage of colonoscopy is that colon polyps are identified and removed at the time of the procedure, making it an effective cancer prevention test. Colonoscopy is more expensive than FOBT, FIT, and FS, but less expensive than computed tomography colonography (CTC), and carries a risk of complications of approximately 1 in 350. Colonoscopy is recommended for patients with positive FOBT or FIT results, and for patients with a polyp identified on FS. CTC is not currently covered by Medicare for routine CRCS. A CTC examination requires colonic lavage but not sedation. The main disadvantage of CTC is that when polyps are identified, the patient must then undergo colonoscopy to remove them.

Several studies have shown that patients exhibit preferences for one CRCS test over another, and most patients can articulate reasons for their preference. Shokar et al, for example, queried a cohort of primary care patients about CRCS test preferences. The patients were given 13 test attributes to consider and rank, and were asked about CRCS test preference. Patient preferences were highest for test accuracy, amount of colon examined, strong scientific evidence for efficacy, and low risk of complications. Because no single test can satisfy all of these attributes, patients were asked to rank FOBT, FS, colonoscopy, and double-contrast barium enema (DCBE). Colonoscopy was preferred by most, followed by FS, FOBT, and DCBE. A similar study by Imaeda et al found that patients place importance on the sensitivity of the test, the risk of a complication, and the need for a second test. In this study, patients preferred colonoscopy, followed by colon capsule, CTC, FOBT, and FS. Ling et al showed that for patients who value test accuracy, colonoscopy was preferred by 62%, and for those who placed importance on a noninvasive test, FOBT was preferred by 76%. Another study by Wolf et al showed that patients prefer FOBT over colonoscopy primarily because it is convenient and noninvasive.

Patient acceptance of CRCS can be optimized through an understanding that CRCS is unique because different options are available and that patients have preferences regarding method. Patient preference has been shown to impact compliance with a CRCS recommendation. For example, Senore et al showed that when patients were offered screening with FS, approximately 35% participated. Those who did not participate in FS screening were then offered FIT screening, in which an additional 19% participated, suggesting that patient preferences for screening tests affect compliance. Inadomi et al studied...
the effect of patient preference on compliance by randomizing patients into 3 groups: those receiving a recommendation for colonoscopy, receiving a recommendation for FOBT, or undergoing their choice of FOBT or colonoscopy. Subject compliance with the test to which they were randomized was highest among those allowed to choose between FOBT and colonoscopy (69% vs 67% for FOBT and 38% for colonoscopy). Interestingly, nonwhite participants adhered more often to FOBT, whereas white participants adhered more often to colonoscopy.

Educating patients about CRCS test options and taking into account patient preferences is a strategy that may produce higher rates of CRCS use, and can be incorporated into primary care practices.

**Effect of Educational Tools**

A wide variety of educational tools have been studied with respect to their impact on compliance with a CRCS recommendation. Educational tools can be delivered in print, online, or by personal communication and should be tailored to the target patient population, taking into account barriers to CRCS, reading level, socioeconomic status, and access to resources.

From a provider standpoint, educational tools and interventions vary considerably in the investment required in terms of personnel time and resources needed to provide the education. For example, written educational materials require an initial investment for creation or acquisition, but can subsequently be reproduced as needed. Use of telephone reminders require either staff time to conduct or the use of automated technology, both of which may be cost prohibitive for some providers. In recent years, patient navigators have been incorporated into the educational toolbox. Patient navigators are trained health care personnel who can assist patients in overcoming barriers to screening (including but not limited to health literacy, mistrust, fear, transportation, and cost) and in navigating the sequence of events leading to a successful screening examination (eg, referral, scheduling, bowel preparation).

Patient navigation represents the education intervention that requires the most commitment in terms of personnel time and resources. For example, a patient navigator who is helping a patient perform FOBT or FIT testing will provide education about how to collect a sample for the test and apply it to the test card correctly, and may provide reminder phone calls to complete the test, or even make a home visit to collect the test. Furthermore, colonoscopy is a multistep process, and patient navigators may assist patients with numerous steps including scheduling the test, understanding the steps required for adequate bowel cleansing, arranging transportation to and from the colonoscopy, and identifying resources to pay for costs associated with the test.

In a pilot study that randomized low-income minorities to receive a CRCS recommendation with or without the assistance of a patient navigator, Christie et al reported that 54% of patients who had assistance completed a colonoscopy compared with 13% who had no assistance, and subjects who were assisted were overall very satisfied. Levy et al studied a combination of written educational tools and a telephone call aimed at increasing CRCS rates in the Iowa Research Network Practices. Patients in this study were randomized to receive written and DVD educational materials with a FIT, with or without a reminder telephone call. A significant overall increase was seen in subjects’ interest in CRCS, and the return rate of FIT reached nearly 50% in both groups, although the telephone call had no added benefit over the print and DVD materials in terms of return of FIT cards.

Other investigators have studied combined patient- and provider-focused interventions to increase uptake of CRCS. Ling et al examined the impact on CRCS uptake of a nontailored versus a tailored letter to 599 patients, and a nontailored versus an enhanced intervention for office and patient management in 10 primary care physicians’ offices. All letters to patients contained an invitation to participate in endoscopic CRCS, whereas the tailored letters also contained patient-specific information that would allow patients to judge their risk of CRCS. The office interventions all included educational meetings with physicians and staff about CRCS processes, whereas the enhanced interventions also included assistance in implementing office protocols for CRCS, and assistance to patients in overcoming barriers to CRCS. The enhanced office and patient management significantly increased uptake of CRCS, whereas the tailored patient letter did not show an advantage over the nontailored patient letter, underscoring the important role that primary
care providers play in promoting use of CRCS. In a study with a similar design, however, Sequist et al. found that a patient-focused intervention was more effective than a physician-focused intervention in increasing CRCS rates. This study involved 21,860 patients randomized to receive educational pamphlets along with instructions for performing FOBT or scheduling flexible sigmoidoscopy or colonoscopy, and 110 primary care physicians randomized to receive electronic reminders. Screening rates were significantly higher for patients who received the mailed information compared with controls, whereas the electronic physician reminders did not increase CRCS rates. Green et al. showed that a stepped up approach to interventions resulted in incremental increases in compliance with a CRCS recommendation. Compliance rates were 26% for usual care, 51% for those receiving an automated mailing, 58% for those receiving an automated mailing and telephone assistance, and 65% for those receiving an automated mailing, telephone assistance, and the support of a nurse navigator.

Printed material or online information can be provided to patients to increase their knowledge regarding CRCS test choices and can encourage shared decision-making with their provider. Any intervention to increase compliance with CRCS is generally more effective than none, and therefore providers can use the type of intervention that best suits their office resources and patient population (Table 2).

**Conclusions**

Participation in CRCS is largely influenced by patient risk perception, knowledge, psychosocial factors, screening test preference, and economic and geographic barriers. Addressing the modifiable barriers to CRCS may significantly improve uptake. No “one size fits all” educational tool has been proven to increase screening rates. Data suggest that interventions tailored to a target population may have benefit. Moreover, provider awareness of patient attitudes toward and barriers to CRCS is critical to increase uptake. Increased screening is necessary to fully realize its impact on reducing CRC mortality.

### References


### Table 2 Methods to Address Patient Attitudes and Issues Regarding CRCS

<table>
<thead>
<tr>
<th>Systems-Level Interventions</th>
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<tbody>
<tr>
<td>Reduce cost for screening tests</td>
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<tr>
<td>Improve access to a usual source of care</td>
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<tr>
<td>Establish screening services at the community level</td>
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<tr>
<th>Provider-Level Interventions</th>
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<tbody>
<tr>
<td>Discuss individual CRC risk and CRCS</td>
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<tr>
<td>Encourage patient choice of CRCS test</td>
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<tr>
<td>Improve patient knowledge of CRCS test attributes</td>
</tr>
<tr>
<td>Identify individual barriers to CRCS</td>
</tr>
</tbody>
</table>

Abbreviations: CRC, colorectal cancer; CRCS, colorectal cancer screening.


33. Imaeda A, Bender D, Fraenkel L. What is most important to patients when deciding about colorectal screening? J Gen Intern Med 2010;25:688–693.


