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Primary care patients' understanding of colorectal cancer screening

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Abstract

Purpose: To determine the current level of awareness and understanding about colorectal cancer (CRC) and colorectal cancer screening (CRCS) among primary care patients in order to develop interventions to educate patients about options for CRCS, help them identify CRCS preferences and make informed choices about CRCS options. *Methods:* During the spring of 2001 and 2003, two sets of focus groups with primary care patients were conducted at a large multi-specialty group practice in Houston, Texas. *Results:* Participants (n = 42) in both sets of focus groups had low knowledge about CRC and expressed fear and embarrassment about CRC and CRCS. Attitudes towards the fecal occult blood test (FOBT) were mixed, with some participants considering it difficult to finish and others preferring the privacy it afforded. Some participants initially failed to recognize the difference between sigmoidoscopy (SIG) and colonoscopy (COL), and several endoscopy-specific barriers were identified such as fear of pain, embarrassment/humiliation, and dislike or fear of test preparation. Some participants felt that endoscopy was likely to be more effective than FOBT, and others clearly preferred COL to SIG. System-specific barriers to endoscopy (e.g. difficulty scheduling appointments and insurance coverage) were also identified. We found little change in the barriers reported by primary care patients, despite a two-year difference between focus groups. Participants also provided suggestions for improving CRCS including telephone, letters and/or email reminders from the clinic, videotapes and websites. *Conclusions:* Future interventions focused on improving informed decision-making by educating primary care patients about the risks and benefits of specific test options and about the importance of early detection of CRC could prove to be effective for increasing CRCS.

Keywords: Colorectal cancer; Screening; Informed decision-making; Focus groups; Primary care clinics; Colorectal cancer screening guidelines; Group characteristics; Test-specific concerns; Knowledge barriers; Fear of cancer; Humiliation

1. Introduction

Colorectal cancer (CRC) is the third most common cancer and the second leading cause of cancer deaths among men and women 50 years of age and older in the US. In 2005, an estimated 147,290 people will be diagnosed with CRC and 57,100 will die from it [1,2]. Studies show that regular screening with the fecal occult blood test (FOBT) or flexible sigmoidoscopy (SIG) can lead to earlier detection and lowered mortality from CRC [3–6]. Two additional CRC screening modalities, colonoscopy (COL) and double contrast barium enema (DCBE) have been shown to be effective methods for polyp detection, and removal of pre-cancerous polyps lowers mortality from CRC [7–9]. Although the 5-year survival rate for CRC exceeds 90% when diagnosed at an early stage, screening rates using any of the recommended modalities remain low in the US Behavioral Risk Factor Surveillance System (BRFSS) data for persons 50 years of age and over show that in 2001 23.9% of those surveyed had

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had a FOBT in the preceding year compared to 20.6% in 1999 [10,11]. In 2001, 38.9% had had a SIG in the preceding five years compared to 33.6% in 1999 [10,11].

One possible reason for continually low rates of colorectal cancer screening (CRCS) is the patient's limited understanding of barriers to CRCS. One way to obtain such information is by qualitative research methods such as focus groups. Focus groups can provide rich descriptive information about a phenomenon [12–14] and are appropriate when little is known about the target behavior, as is the case for CRCS. The few qualitative research studies of CRCS using focus groups report that most participants were poorly informed about CRC, its risk factors, and CRCS [15–20]. Barriers to CRCS from previous focus group studies included lack of public awareness of CRC and the need for screening, questionable efficacy of screening tests [18,21], fear of positive test results [18], fear of pain and death from CRC [16,21], embarrassment about CRCS [22], lack of physician recommendation for CRCS [16], inconsistent provider recommendations [19,21], the cost of CRCS, and lack of insurance coverage [22]. A few studies have identified CRCS test-specific barriers [17,19,21,22].

Qualitative studies have been useful in identifying some CRCS barriers; however, there is a need to update and expand these initial findings. Studies to date collected CRCS information at one point in time, and most data were collected in 2000 or before. In addition, there are no data on changes over time in perceived barriers among the same patient population. Existing studies were not conducted among primary care patients in settings where they had access to both preventive and diagnostic care. Perhaps most importantly, prior focus group studies were conducted shortly after the first set of CRCS guidelines were publicized in 1997 [23]. Although the test options have remained relatively consistent, new guidelines have been published by several groups including the American Cancer Society [24,25], and the American Gastroenterological Association (AGA) [26]. The expansion of the guidelines coupled with their complexity has necessitated that medical care organizations stress the importance of informed decision making (IDM) for CRCS. In fact, the 2003 AGA guidelines specifically state, "[Men and women] should be offered options for screening, with information about the advantages and disadvantages associated with each approach, and should be given the opportunity to apply their own preferences in selecting how they should be screened" [26]. The Task Force on Community Preventive Services [27] provides a definition of IDM that provides a useful context for our study (verbatim excerpt from p. 68):

> "The review team defined IDM as occurring when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time."

It follows that compliance with recommended procedures, such as CRCS, would increase if the above definition of IDM was applied. Patients who understand the importance of screening and are truly informed of the pros and cons of screening options, are in a position to make a screening choice consistent with their preferences. As highlighted in a recent article by Meissner et al., 2004 [28], screening information can be delivered by physicians, or more realistically, through interventions such as brochures, videotapes and even websites. Given that CRCS is currently delivered in the context of primary care, more information is needed about potential facilitators and barriers to IDM related to CRCS from the perspective of primary care patients. It is important to understand whether or not patients believe they have made an informed choice regarding CRCS, and what specific aspects of IDM relating to CRCS can or should be improved from the patients' perspective. Such information can be used to guide the development of interventions to increase IDM about CRCS in primary care.

This paper reports the findings from two sets of focus groups, conducted with patients at a large multi-specialty medical organization at two points of time (2001 and 2003), since new guidelines for CRCS were disseminated. Both sets of focus groups were held to determine the current level of awareness and understanding about CRC and CRCS in patient populations in order to develop interventions to educate patients about options for CRCS and to help them make informed screening choices.

2. Methods

2.1. Study setting

During the spring of 2001 and 2003, two series of focus groups were held at Kelsey-Seybold Clinic (KSC), the largest multi-speciality group practice in Houston, Texas. (Hereafter, the series of focus groups conducted in 2001 are referred to as FG1; the 2003 series of focus groups as FG2.) KSC serves an ethnically diverse population of over 300,000 patients at 21 primary care clinics located in Houston and the surrounding geographic area. Regarding insurance, 42% of patients at KSC are enrolled in capitated plans, 47% in preferred provider plans, 8% in Medicare or Medicaid, and 3% are fee-for-service patients. Since 2001, the multidisciplinary Colorectal Cancer Screening Guidelines Committee at KSC has promoted CRCS guidelines by developing and distributing patient education brochures on CRCS and by increasing physician awareness of CRCS through quality improvement presentations.