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Abstract (Document Summary)

The purpose of this study was to describe barriers to colorectal cancer (CRC) screening among a low income, urban sample. Participants were active members, or dependents, of a health care workers' union the New York City metropolitan area. The sample comprised 60 men and women of various ethnicity. A panel design was used with telephone contacts for up to 6 months. Data were collected during each telephone interaction regarding barriers associated with receipt of CRC screening. The majority of the barriers were based on influences of significant others and social environment, time constraints, other health problems, stress, and crisis.

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Keywords

Cancer, Health services, Urban communities

Abstract

The purpose of this study was to describe barriers to colorectal cancer (CRC) screening among a low income, urban sample. Participants were active members, or dependents, of a health care workers' union the New York City metropolitan area. The sample comprised 60 men and women of various ethnicity. A panel design was used with telephone contacts for up to 6 months. Data were collected during each telephone interaction regarding barriers associated with receipt of CRC screening. The majority of the barriers were based on influences of significant others and social environment, time constraints, other health problems, stress, and crisis.

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Introduction

Even though colorectal cancer (CRC) is largely preventable (Mandelson et al., 1999), it is the second leading cause of all cancer deaths in the USA (Landis et al., 2000) causing more than 50,000 deaths annually (Greenlee et al., 2001) with a

disproportionate number of these deaths occurring among African Americans (US Department of Health and Human Services, 2001). Several risk factors have been identified, such as age over 50 (US Preventive Services Task Force, 2002), family history (Schoen et al., 2002), Western diet style (Slattery, 2000; Giovannucci and Willett, 1994), and physical inactivity (Giovannucci, 2002), but early detection and treatment represent the best strategies for reducing CRC morbidity and mortality (US Preventive Services Task Force, 2002; Mandelson et al., 1999).

Early detection can be achieved with the fecal occult blood test (FOBT) (which has been shown to reduce population-wide mortality), flexible sigmoidoscopy, colonoscopy, and double contrast barium enema (Mandel et al., 1993). The US Preventive Services Task Force (USPSTF) recommends that all individuals 50 years of age or older receive CRC screening (US Preventive Services Task Force, 2002). This recommendation was based on the potential public health benefits (Pignone et al., 2002). Some of the strongest evidence supporting the value of CRC screening was derived from the Minnesota Colon Cancer Control Study (Mandel et al., 1993), as well as data collected in the UK (Hardcastle et al., 1996), and Denmark (Kronborg et al., 1996). In addition, a variety of studies have demonstrated that CRC screening is cost effective, with incremental cost effectiveness ratios being dramatically affected by rates of participation in screening (Frazier et al., 2002; Khandker et al., 2000; Sonnenberg et al., 2002).

Unfortunately, participation in CRC screening in the USA is quite low, with just fewer than 20 percent reporting an FOBT in the past year, and just over 30 percent reporting a proctoscopy/sigmoidoscopy in the preceding five years (US Preventive Services Task Force, 2002; MMWR, 1999). Participation in CRC screening is especially low for those with lower levels of education and income (Hoffman-Goetz et al., 1998; Jemal et al., 2003), those with no health care insurance (MMWR, 1999), and older black Americans (Hoffman-Goetz et al., 1998; Jemal et al., 2003).

There have been a number of studies to improve understanding about the correlates and predictors of participation in CRC screening, (Brenes and Paskett, 2000; Lewis and Jensen, 1996; Maxwell et al., 2000; Kremers et al., 2000; Beeker et al., 2000; Myers et al., 1994; Thomas and Clarke, 1998a, b; Schoen et al., 2002; Zack et al., 2001; Mandelson et al., 2000; Collett et al., 2000; Sarna and Chang, 2000; Chavel-Chapelon et al., 1999; Shapiro et al., 2001; Schwartzman et al., 2000; Box et al., 1984; Weitzman et al., 2001; Wender, 2002) which, collectively yield somewhat equivocal results. Lower levels of income and education are consistently associated with lower participation in CRC screening (Hoffman-Gotes et al., 1998; MMWR, 1999) while physician recommendations (Chavel-Chapelon et al., 1999; Brenes and Paskett, 2000) and family history of CRC appear to be associated with higher participation in CRC screening (Schoen et al., 2002). There are at least two major gaps in the published research reported to date. First, few of these studies have been conducted in a low income, minority population, which is at risk for CRC mortality. Second, there is a paucity of research using repeated interpersonal interviews, which might not only allow for establishing rapport with the respondent, but also providing multiple opportunities for probing to elicit personal and environmental impediments to CRC screening.

This study was conducted as part of the Healthy Colon Project, a randomized trial to compare the effectiveness of two strategies for promoting CRC screening, standard print communication vs tailored telephone education (TTE). The intent was to identify and describe barriers to screening among a low income, minority population.

Methodology

This is a qualitative descriptive study based on data collected during the process of providing TTE about CRC screening as part of The Healthy Colon Project.

Subjects and sample

The setting for the study was the New York metropolitan area. All the participants were employees of a large healthcare workers union or their dependents, with over 250,000 active or retired members. The majority of members held lower income occupations, with the median annual salary in 2002 at about 30,000 dollars. Over 80 percent were African American or Hispanic American. CRC screening is 100 percent reimbursable for all members.

The inclusion criteria were: aged 52-65 years; no documentation of FOBT in the preceding two years, flexible sigmoidoscopy in the preceding five years, colonoscopy in the preceding ten years, or double-contrast barium enema in the past ten years; ability to identify a primary care provider; access to a telephone; and consent to participate. Exclusion criteria included documentation of CRC, gastrointestinal disease, or intention to leave the region within the ensuing year. Only participants randomized to TTE group were eligible for this study.

Non-probability purposive sampling was used. As of September 2002, over 200 participants completed the TTE and served as the sample pool. The sampling strategy was to select some individuals who did and some that did not report actively seeking and receiving CRC screening during the six month intervention period. A second factor was to include cases that illustrated a particular barrier or facilitating factor. A third factor was to include cases that were considered unique or important. Finally, an effort was made to include cases at different points during the two-year study period to capture various historical events (e.g. September 11, 2001). The sampling strategy was subjective in that the researchers selected cases that were particularly illustrative, unique, interesting, or important. This sampling approach was used to help ensure that a wide range of barriers was identified and described. Since the intent of the study was to generate hypotheses, the sampling

strategy was intended to capture as many barriers as possible.

The sample size was based on including only participants who had completed the Healthy Colon Project by October 1, 2002 and including participants to reflect the range of barriers and facilitating factors. An initial sample of 37 cases was selected based on the criteria specified above. Then, considering the sampling criteria the remaining cases were reviewed and assessed to determine how many and which additional cases would contribute to further understanding. Based on this, 23 additional cases were identified and described, yielding a total of 60 cases.

Intervention

The intervention involved multiple telephone conversations between the health educator and participant over a six-month period. The initial call followed a loosely structured outline and contained selected factual information, tailored to the perceived needs of the participant (their stage of readiness to change, their knowledge, screening test preference, access to resources, skills, and social support). The goal was to elicit a verbal commitment to complete a CRC screening test. If a verbal commitment was offered, follow-up contacts reinforced this commitment and addressed barriers along the way. If a verbal commitment was not offered, subsequent calls addressed barriers to making such a commitment. Overall, we sought an informal and conversational tone.

The nature of the intervention varied for each participant and was determined by the factors outlined above as well as by other individual characteristics of participants (e.g. talkativeness). The participant guided the flow of conversation and the topic was allowed to drift away from cancer and cancer screening. There was an emphasis on creating a caring and trusting relationship between the health educator and participant.

Measurements

Measurements used for this study were written notes taken by the health educator (CHB) during and after each telephone interaction. During these interactions an effort was made to gain some of the same information from all participants in order to provide context and for comparative purposes. The comparative data included, but were not limited to, the following: extent of familiarity with CRC screening tests and guidelines, test preference and rationale, and particular barriers to CRC screening. Questions concerning participants' familiarity with CRC screening tests and guidelines were asked to determine if participants had misconceptions that would impede their motivation to be screened. Questions related to test preference and rationale were asked to identify CRC screening options that were likely to present the fewest barriers for the respective individual. In most cases the barriers were identified through probing to elicit factors related to insufficient motivation to be screened or, if the participant was motivated, impediments to acting on that motivation. The nature and extent of each interaction was described with particular attention to the barriers that were operative for each person.

Data analysis

In the description phase, the hand written notes were reviewed for each participant and the nature of the TTE interaction was described. Common information for each case provided context for comparison, including age and sex, extent of familiarity with CRC screening tests and guidelines, test preference and rationale (if applicable), and barriers to CRC screening. At the conclusion of the description section for each case, a summary was included in an attempt to draw insights and inferences. Finally, all the cases were reviewed and categories representing the different kinds of barriers encountered were formulated, which yielded eight categories.

Results

Demographics

Of the 226 participants randomized to receive the telephone intervention, only seven refused to participate or withdrew at some stage of the process. The mean age was 57.5, and the range was 52.1-65.3. Seventy per cent were female. Two-thirds were married. More than half had not completed high school and only 10 percent had completed college. About one-quarter reported a household income of less than \$30,000 per year while about half reported a household income of between \$30,000 and \$50,000 per year. Almost all (95 percent) worked full-time. The majority (62 percent) were African American, 15 percent were white, and the remaining participants were Hispanic, Asian, or other.

The seven categories outlined below represent a variety of factors that appeared to be barriers to obtaining CRC screening.

Role of primary care provider (PCP)

There was a reported lack of support for CRC screening from some PCPs. In some cases, this was extreme, while in others it was more benign. Examples of these extremes are depicted in the following quotes of two participants, AA and [BU](#). AA stated that he had "great confidence in his doctor and if he did not recommend it, he would not do it." Conversely, in a conversation with [BU](#) about her doctor, she stated, "he doesn't even want to help me do something good."

The experience of many individuals indicates that physicians are perceived as a trusted source of health information and

they can have a very powerful influence on their patient's behavior. For example, numerous participants who stated a preference for an FOBT were willing to receive a colonoscopy based on their physician's recommendation. The reported support of physicians in this study varied greatly. Some were reportedly very cooperative when the participant requested an FOBT kit, and were willing to mail the kit to the participant. Others required the participant to schedule and attend an office visit. Some reportedly did while others reportedly did not have FOBT kits available in their office. When we mailed the kit to those offices without kits, some of them forwarded the kit to their patient in a timely way, and were grateful for our assistance. Others were much less cooperative.

Time constraints

The individuals participating in this study appeared to have extremely busy lives. Not only did the majority have full-time work responsibilities, but many also had a second job. A common report was that the participants could not get time off from work, or had to cancel appointments as the result of conflicts at work. In fact, some participants attempted to get FOBT kits from the hospital in which they worked to save time going to their PCP. Others were responsible for caring for their own children or grandchildren. Some participants were the primary caretakers of ill family members, and reported, "not having time to think about their own health" and that "I am too busy right now." The following description extracted from the researcher's notes reflects time constraints which were experienced by many, "She (BH) is a person who is very busy, not only because of her own full-time work responsibilities, but because she is caring for her daughter's children while her daughter goes to work."

It appeared that short-term time factors also had an influence on participants' willingness to contemplate and act on CRC screening. The most consistent examples of this were during holiday times. For example, during Thanksgiving, Christmas, Easter, Labor Day, and Memorial Day, the participants were generally preoccupied with preparations for the holiday and were less likely to make verbal commitments related to CRC screening. This became so apparent that during some holiday periods, intervention calls were suspended. Another aspect of short-term time factors was more idiosyncratic toward the individual participant. There were some times when the participant was much less willing to contemplate or act on CRC screening. For example, if they were exceptionally busy, attending to other personal health issues, dealing with personal or family crisis, or factors affecting the accessibility and availability of health care services (e.g. physician on vacation, long waiting time for appointment).

Health problems

Many individuals experience a range of other health problems. Some of these were chronic diseases such as diabetes requiring on going care and others were more acute conditions necessitating short-term acute care. For example, AS told the educator that she was having "horrible complications" with her knee. She wanted to be called back in 1 year, when she predicted she would be able to do "other health things." In some cases, the acute problems were quite serious and some even required surgery. These other health problems were said to interfere with screening for many of the participants. In some cases participants chose to actively seek out CRC screening even though they were experiencing other health problems, although many others did not.

Stress and crisis

Many of the participants reported dealing with many stressful life events. These included, but were not limited to, the death of loved ones, taking care of friends or family members who were ill, difficult work situations, and financial instability. AC stated, "I will not be able to participate in the project any longer because I am overcome with grief and dealing with it is my main priority." BJ was not able to complete the intervention because she was moving in with her ill father to take care of him. A good deal of time in the intervention process was devoted to listening to participants "vent" about these issues. These events and circumstances were significant barriers to participants practicing a preventive behavior.

The effect of September 11, 2001 was an extreme example of stress and crisis, and had a dramatic effect on the lives of virtually all of the participants. AI told me that the events at the World Trade Center really took a toll on his mind. When I spoke with AR, she told me that the tragedy at the World Trade Center "put her over the edge." AV exclaimed, "This (WTC tragedy) made my life go haywire!" This is an example of how a catastrophic event can affect a particular intervention research project. It seemed clear that participants with an intervention window encompassing the World Trade Center catastrophe faced unique circumstances. Some participants were reluctant to leave their house except for essential reasons. Others wanted to discuss the events extensively rather than discuss CRC or CRC screening. Certain participants were overwhelmed by personal grief and loss, and could not contemplate CRC screening in the immediate future.

Fear

The topic of fear was a recurrent one in many of the interactions. Some people openly verbalized their fear about CRC and some of the CRC screening procedures (i.e. the colonoscopy). BA, e.g. stated, "The idea of any testing makes me nervous." AU explained that she recently had a total hysterectomy, and as a result, frequently experienced severe pain. Despite the fact that the FOBT is painless, she admitted to being scared of testing. Another example was AE, who told me that she was frightened because both her mother and father died from CRC. She said that she never wanted to get tested because she

was so afraid that she too would have CRC. Fear was also experienced by BN, who stated, "I do not want to go to the appointment alone." Other individuals did not openly verbalize their fears. Still others did not mention anything about fear until several conversations, and then indicated they had a great deal of fear.

Some participants acknowledged their fear and cope with it through a rationale that if there was a problem, screening would help identify it early when treatment would be most effective. Others seemed paralyzed by their fear and could not overcome it to the point of participating in screening; still others were so afraid of unintended side effects of the colonoscopy that they chose not to have one.

Role of friends and family

For some participants, it did not appear that friends or family members played a strong role in their decision to receive or not receive CRC screening, but for other participants, these social referents appeared to be a key determinant of their behavior. An example of a negative influence was the case of BZ, whose friend had a colonoscopy resulting in a perforated colon. For this BZ, who had hemorrhoids, an FOBT was not a viable screening option and, based on his friend's experience, he was not willing to have a colonoscopy. Friends also contributed to providing inaccurate information such as the case of BC who reported that she did not need to participate in CRC screening since her friend told her that only those who smoke are at risk. This participant believed strongly that her friend cared about her and would never steer her wrong. Another participant would not consider any course of action without first checking with and then following the advice of his spouse. Friends and family members also assisted participants with logistical issues such as scheduling an appointment and providing transportation and accompaniment. An example of this was the participant BK who stated, "I even convinced my 61-year-old husband to get a colonoscopy." In the case of BE, the main reason for her motivation to get screened for CRC was because she wanted to feel "empowered" to help her friends and family get tested.

Sponsor and source of communication

For most of the participants, the sponsoring organization appeared to be perceived as a very credible organization and legitimized the educational process, at least initially. When most of the participants learned that the call was coming from an individual representing the sponsoring organization, this appeared to predispose them to be at least somewhat less skeptical than they might have otherwise been. For example, BM explained that the basis for his decision to make a verbal commitment was that "his people (his union)" were encouraging it.

There were, however, exceptions, and in some cases the negative reaction was so extreme that it compromised the participant's willingness to participate in the program at all. For example, CE described her unresolved billing issues with the organization, and explained that they were going to court. She declared that she was "fed up" with the organization, and therefore, did not want to participate in their program, but overall, the sponsoring organization seemed very well perceived and this worked in the favor of the educational process.

Some participants did not value their relationship with the researcher/educator, e.g. AQ, whose final words to me were, "Don't call me again! My doctor did not give the test to me, so why should I listen to you?" BY, on the other hand appeared to highly value his relationship with the researcher/educator. He stated, "I wouldn't have done this if you didn't call. I am sure there are many others who could benefit from your encouragement." The combined influence of the sponsoring organization and the relationship between the educator and the participant also may have played a role in the success of the project. In the best case scenario, the sponsoring organization was highly regarded and the participant appreciated and valued their relationship with the educator. In some instances, albeit rare, the sponsoring organization was not well regarded, nor was the educator. There were also instances where the participant had some issue with the sponsoring organization, but valued and appreciated the relationship with the educator. The relative importance of these factors and their influence on the participant's behavior needs further study.

Discussion

The majority of the barriers were based on influences of significant others and social environment, time constraints, other health problems, fear, stress, and crisis.

The findings from this study indicating the importance of PCPs support for CRC screening. This is consistent with other studies (Brenes and Paskett, 2000; Lewis and Jensen, 1996; Myers et al., 1994; Thomas and Clarke, 1998a,b; Myers et al., 1990; Hoogewerf et al., 1990; Kelly and Shank, 1992). Research is needed to improve understanding about PCP's opinions and perspectives about CRC screening. While there are physicians who are more or less supportive of CRC screening and other standards of care, what happens in an office setting is the result, at least in part, of the interaction between the patient and the doctor. Research concerning interactions between physicians and patients had been reviewed by Feldman and Christensen (Feldman and Christensen, 1997). There is a need for additional understanding concerning the interaction or negotiation that takes place between physicians and patients.

Time constraints were reported as a barrier by many respondents. This is consistent with the findings of a study conducted by Box et al. In a study measuring compliance in 2 General Practitioner practices, it was noted that time constraints were among the main reasons for not complying with CRC screening recommendations (Box et al., 1984). The amount of time

required for CRC screening was significant. For the individuals seeking an FOBT, many had to take the time to schedule and attend an office visit. For those completing a colonoscopy, extra time was needed for preparation before the procedure and time to recuperate after. The role of time factors was not mentioned in the published literature that was reviewed for this study, but it seems likely that such factors can and do have at least short-term effects. Of course, for some people, CRC screening may not have been too important, while for others the reported time constraints may have been a way of dealing with fear or reluctance to be screened.

Respondents clearly associated the issue of CRC with fear, which is perhaps to be expected. For an individual to participate in cancer screening, they must acknowledge that they may have cancer. Lantz et al. reported on several focus groups and highlighted that fear was prevalent among participants. They noted that their fear was directly associated with a fatalistic attitude toward cancer (Lantz et al., 1994). The topic of fear can be conceptualized as perceived susceptibility or risk. From this perspective, fear can be viewed as one of the primary constructs in the Health Belief Model. The role of perceived risk and pain associated with screening has been shown to be associated with screening in several studies (Brenes and Paskett, 2000; Lewis and Jensen, 1996; Wardle et al., 2000). Additional research is needed not only to clarify the extent of fear regarding this topic, but also the more and less constructive ways in which people deal with their fear, and the best ways to address fear in an educational intervention. In the past, some health education programs have intentionally evoked fear as a way to motivate an individual to practice a given behavior. While this may work in some cases, it is likely to be ineffective in others, since a common and effective strategy for dealing with fear is denial. Further, evoking fear is inconsistent with the philosophical and ethical approach on which the intervention in this project was based.

The results showed that for some participants, social referents appeared to be a key determinant of their behavior. The role of social referents has been discussed previously by others. This may include knowing somebody with CRC (Myers et al., 1990; Price, 1993; Hunter et al., 1991), or being encouraged by a family member (Myers et al., 1994). The role that significant others play should be assessed when attempting to tailor an intervention to a particular individual. Interventions may be more successful if they are directed to secondary audiences along with primary target audiences. The importance of the source of the message has also been well recognized. In the context of this study, two aspects of the communication source were the sponsoring organization and the educator. Both of these could serve as either positive or negative influences on the participant, and it is also possible that they had interaction effects.

Many theoretical frameworks from the social sciences recognize the role of social support and the influence of the social environment in shaping individual's health behaviors (Bandura, 1986; Ajzen and Fishbein, 1980). The majority of the barriers identified were not based on the participant's knowledge or beliefs, but rather influences of significant others and the social environment, such as the role of the Primary Care Provider, friends and family, the sponsor and source of health communications, and September 11, 2001.

Some of the factors mentioned concerned aspects of the individual's life that they seemed to have little control over, such as time constraints, other health problems, and stress and crisis. If these factors are barriers to preventive health actions, interventions directed at individuals can have only limited effectiveness. More effective interventions will require addressing secondary audiences and health and social issues that may not appear to be directly related to a specific topic.

In many cases, it appeared that the participant's motivation to receive CRC screening was more based upon the commitment they made to the educator and their desire to not let her down, than it was due to the participant's genuine desire to be screened based on health reasons. One of the main conclusions from this study is that rapport and trust between the participant and health educator is instrumental in assisting individuals to make informed decisions about health. It appears that the key to effective education is to establish good rapport with the intended audience. To the extent that participants sense that an educator has their best interest in mind and is willing to abandon their educational agenda and pay attention to what the participant most cares about at a given time may ultimately cultivate a good relationship between the educator and the participant. It is the quality of this interpersonal relationship that may be most important.

The implication is that we need to design and implement programs that are respectful of our audience and reflect genuine caring resulting in the development of rapport and trust. We need to use a tailored approach, which fits the nature and scope of content provided, and the kind of interaction, (e.g. patiently listening, offering information, offering social support) to the audience. Of course, the importance of a tailored, and caring approach to education is not new. Unfortunately, too often this approach seems to be more rhetoric than reality in contemporary education programs in general, and health education programs more specifically. To the extent that educators are willing to abandon their scripts and regimented approaches, to have as their main agenda to be helpful to others, whether or not is directly related to their educational agenda, and to relate to their audience as people, both the quality and effectiveness of the educational experience may be enhanced.

[Sidebar]

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