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Unwillingness to participate in colorectal cancer screening: Examining fears, attitudes, and medical mistrust in an ethnically diverse sample of adults 50 years and older

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Abstract

Purpose—Identify the influence of medical mistrust, fears, attitudes, and sociodemographic characteristics on unwillingness to participate in colorectal cancer (CRC) screening.

Design—Cross-sectional disproportionally allocated, stratified, random-digit dial telephone questionnaire of non-institutionalized households.

Setting—New York City, NY; Baltimore, MD; San Juan, Puerto Rico.

Subjects—Ethnically diverse sample of 454 adults 50 years of age.

Measures—Health status, cancer screening effectiveness, psychosocial factors (i.e., perceptions of pain, fear, trust), and CRC screening intentions using the Cancer Screening Questionnaire which addresses a range of issues related to willingness of minorities to participate in cancer screening.

Analysis—Multivariate logistic regression was used to model the probability of reporting unwillingness to participate in CRC screening.

Results—Fear of embarrassment during screening (OR = 10.72; 95% CI: 2.15–53.39), fear of getting AIDS (OR = 8.75; 95% CI: 2.48–30.86), fear that exam might be painful (OR=3.43; 95% CI: 1.03–11.35), and older age (OR = 1.10; 95% CI: 1.04 – 1.17) were positively associated with unwillingness to participate in CRC screening. Fear of developing cancer (OR = 0.12; 95% CI: 0.03 – 0.57) and medical mistrust (OR =0.19; 95% CI: 0.06 – 0.60) were negatively associated with unwillingness to screen.

Conclusions—Findings suggest that CRC health initiatives should focus on increasing knowledge; addressing fears, mistrust, normalize CRC screening as a beneficial preventive practice; and increase focus on older adults.

Keywords

Colorectal Cancer; Screening; Fear; Trust; Prevention and Control

Introduction

Colorectal cancer (CRC) incidence and mortality has declined significantly over the past 20 years, but remains the third most common cancer in the United States (US) and the second leading cause of cancer death.^{1–3} In 2010, it was estimated that 142,570 new cases of CRC were diagnosed in the US and 51,370 died from the disease.⁴ The American Cancer Society (ACS) recommends routine CRC screening starting at age 50 for average risk individuals.⁵ Evidence suggests that 90% of CRC incidence and 60% of deaths can be prevented through recommended screenings and follow-up of abnormal test results.^{6, 7} Despite the advantages of screening, 38% of adults aged 50 and older have never had a sigmoidoscopy/colonoscopy and 79% have never had a fecal occult blood test (FOBT).⁸ The lack of screening utilization poses a significant challenge to reducing and ultimately eliminating CRC incidence and mortality.⁷

Barriers to CRC screening are complex and involve individual, community, and system level factors.⁹ Research suggests that limited knowledge, health care access and delivery, doctor recommendation, sociodemographic factors such as age and income, and psychosocial factors contribute to whether an individual participates in CRC screening.^{9–11} Therefore, it is important to target these factors in health promotion and policy initiatives if continued reduction in CRC incidence and mortality is to be realized. Modifiable psychosocial factors such as fear, perceptions of pain and embarrassment, and medical mistrust have been found to correlate with CRC screening.^{11–14} Fear and anxiety concerning the procedural aspects of CRC screening has been widely implicated as a screening barrier across racial and ethnic groups.^{11–13} Medical mistrust has also been linked to screening participation.^{14–17} Medical mistrust is a cultural construct, that in general, has historical relevance and is deeply rooted in minority populations.¹⁸ However, a recent study by Bussey-Jones and colleagues found that after controlling for trust, racial differences in willingness to participate in blood donation was no longer observed.¹⁹ This finding may suggest that identifying and addressing trust, regardless of race, has important implications for participation in health programs and interacting with the health care system across groups. CRC screening barriers and facilitators have been studied extensively.^{12–14, 20, 21} However, there is a paucity of research examining psychosocial factors such as medical mistrust and fear across racial/ethnic groups.²² Such an examination will determine the need for targeted CRC interventions or if interventions can be developed for diverse populations.

Study Purpose

The purpose of this study was to identify psychosocial and sociodemographic factors associated with unwillingness to undergo CRC screening among a diverse sample of adults 50 years and older. We attempt to determine which psychosocial factors are associated with unwillingness to participate in CRC screening so that such factors can be targeted in health promotion/education efforts to reduce fears and increase screening efficacy. We hypothesized that perceived cancer screening effectiveness, fear, medical mistrust, and socioeconomic status are associated with unwillingness to participate in CRC screening.

Methods

Design

This cross-sectional study employed a disproportionally allocated, stratified, random-digit-dial telephone questionnaire of non-institutionalized adults (≥ 18 years of age) living in New York City, NY; Baltimore, MD; and San Juan, Puerto Rico. An international opinion research cooperation (Marco International, Inc.) was contracted to administer the random-

digit-dial questionnaire using a computer-assisted telephone interviewing (CATI) system. The questionnaire was designed to assess factors associated with willingness of minorities to undergo cancer screenings. The data collection protocol was similar to that of the Behavioral Risk Factor Surveillance System (BRFSS).²³ A 10-attempt dialing protocol, in which up to 10 contact attempts were made unless a final disposition was obtained during an earlier attempt, was employed. A final disposition was attained when either: 1) the respondent completed the interview; 2) the telephone number was found to be invalid; 3) 10 attempts were reached; or 4) the respondent refused participation. A more detailed explanation of the study design, as well as justifications of methodological decisions, is described elsewhere.^{24, 25} The study was approved by the University of Puerto Rico and New York University (NYU) Institutional Review Boards.

Sample

Baltimore, New York, and Puerto Rico were selected as recruitment cities to ensure a wide geographic and racial/ethnic representation which included equal representation of Whites, AAs, and Hispanics. Each of the three cities were sampled independently, with a target number of 900 completed questionnaires overall, with specific race/ethnic group targets within each city: 300 AAs (150 in New York City, 150 in Baltimore); 300 Puerto-Rican Hispanics (150 in San Juan, 150 in New York City); and 300 Whites (150 in New York City, 150 in Baltimore). The initial sample allocation across strata (within city) was based on expected yields computed using exchange incidence data.

A total of 1,148 respondents completed the questionnaire. Response rates for Puerto Rico, Baltimore, and New York were 58%, 51%, and 45%, respectively with an overall completion rate of 82.6%. This study includes data on 454 respondents, a subsample of the total sample meeting the following inclusion criteria: 50 years or older, had an unrestricted land-line telephone; English or Spanish speaking; and self-identified as AA, Hispanic, or White.

Measures

The study instrument, the Cancer Screening Questionnaire (CSQ) comprised 60 questions that assessed willingness to participate in cancer screenings. The CSQ was adapted from a previously validated questionnaire, the Tuskegee Legacy Project Questionnaire²⁶, which was designed to assess willingness to participate in biomedical research. The questionnaire was developed by a multi-disciplinary, multi-university research team within the NYU Oral Cancer Research on Adolescent and Adult Health Promotion (RAAHP) Center, a National Institute of Dental and Craniofacial Research (NIDCR) National Institutes of Health (NIH) Oral Health Disparities Center. English and Spanish versions of the questionnaire were developed and administered per respondent preference. The Spanish version of the questionnaire was pilot-tested for comprehension of English-to-Spanish translation in San Juan, Puerto Rico. The questionnaire was administered by trained interviewers who received extensive training over several days on the CATI program, interview protocol, interviewing techniques including role-playing, and hands-on calling experience. Development, administration, and other study decisions regarding the questionnaire is described in-depth in previous publications.^{24, 26, 27}

Dependent variable—Respondents were asked, “*How likely are you to have a cancer screening exam if the screening were for colon cancer?*” Responses were measured on a 5-point Likert scale ranging from 1=“very unlikely” to 5=“very likely”. As we were interested in understanding factors associated with unwillingness to screen, as opposed to the degree of unwillingness, the five categories were dichotomized to model 1=“unwillingness” versus 0=“willingness” to participate in CRC screening.

Independent variables—To assess psychosocial barriers to cancer screening respondents were asked “*There are lots of things that might make people not want to participate in cancer screening exams. How much would the following interfere with your taking part in a cancer screening exam:*” fear of getting AIDS; fear of results not being private or confidential; fear about how the disease would upset my family; fear of hearing that you might have cancer; feeling that you are very unlikely to get cancer; lack of trust in medical people; fear that it might be painful; and fear of being embarrassed in the cancer screening exam. Respondents were asked to respond to the nine psychosocial items on a 5-point Likert response scale, 1=“not at all” to 5=“totally”. Because we were interested in understanding factors contributing any influence to CRC screening versus factors contributing no influence, the five response categories were collapsed into two, 1=“interferes” versus 0=“not at all interferes”. Health status (excellent, good, fair/poor), cancer screening effectiveness (all/most of the time, some of the time, occasionally/rarely), ever having had a cancer screening exam (yes/no), age, race, gender, education, and income level were also assessed as independent variables. The income category of “don’t know/refused” (n = 59; 13.0%) was included in the analysis to reduce bias and to retain a larger sample of people within the 50 and older age group.²⁸

Analysis

Frequency distributions and means of sociodemographic variables were computed to show the characteristic distribution of the sample. Unadjusted bivariate chi-square tests were calculated to examine associations between categorical sociodemographic variables (i.e., race, education, income) and unwillingness to participate in CRC screening. ANOVA was performed to examine an association between age and unwillingness to participate in CRC screening. Multivariate logistic regression was used to model the probability of reporting unwillingness to participate in CRC screening. The logistic regression analysis, using proc survey logistic procedure, accounted for the multistage sampling techniques used in the random-digit-dial telephone questionnaire and adjusted for age, race, gender, education, income level, and city. We adjusted for city to account for any geographical differences between the recruitment sites and to reduce bias (data not shown). Odds ratios (ORs) with 95% confidence intervals (CIs) were produced. SAS version 9.1 (SAS Institute Inc. Cary, North Carolina) was used for data analyses and a level of $p < 0.05$ was deemed statistically significant.

Results

Table 1 shows the distribution of demographic characteristics of the 454 respondents. The mean age of respondents was 63 ± 9.9 . The largest proportion of respondents were female (66.7%), White (45.2%), high school graduates (46.5%), and had an annual income of < \$20,000 (33.7%).

Fifteen percent (n=69) of respondents indicated unwillingness to participate in CRC screening. While females (16.3%), AAs (17.2%), those with less than a high school education (17.2%), and those with an annual income of < \$20,000 were more unwilling to participate in CRC screening (Figure 1). However, these differences were not statistically significant.

The model convergence criterion for logistic regression was satisfied and likelihood ratio test indicated a good fit for the model. The multivariate logistic regression analysis modeled the probability of being unwilling to participate in CRC screening. Table 2 shows the ORs and 95% CIs of associations of unwillingness to participate in CRC screening with each variable adjusted for all the other variables in the model. Reporting fear of embarrassment during screening exam (OR = 10.72; 95% CI: 2.15–53.39), fear of getting AIDS (OR = 8.75;

95% CI: 2.48–30.86), and fear that the screening might be painful (OR=3.43; 95% CI: 1.03–11.35) were positively associated with unwillingness to screen for CRC. Reporting medical mistrust (OR =0.19; 95% CI: 0.06–0.60) and fear of developing cancer (OR = 0.12; 95% CI: 0.03–0.57) were negatively associated with unwillingness to screen. Age was the only sociodemographic variable associated with unwillingness to participate in CRC screening, when included in the full model. The odds for being unwilling to participate in CRC increases by about 10% for every one year increase in age (OR = 1.10; 95% CI: 1.04–1.17).

Discussion

This study explored factors associated with unwillingness to participate in CRC screening among an ethnically diverse sample of adults 50 years and older. Overall, unwillingness to participate in CRC screening was low. This is a promising finding given the effectiveness of cancer screenings in detecting abnormalities and preventing cancer.⁴ However, the promise of preventing cancer is only realized when intent translates into action whereby individuals are screened at intervals as recommended by evidence-base and follow-up on abnormal test results. This study attempted to uncover attitudes and beliefs associated with unwillingness to screen as such factors can be addressed and modified through intervention.

The strongest association of unwillingness to participate in CRC screening was fear of embarrassment during the screening exam. This finding is consistent with other studies citing embarrassment as a barrier to screening.^{29–32} Fear of getting AIDS was the second strongest association of unwillingness to undergo CRC screening. This finding may be related to knowledge deficits, unfavorable beliefs and attitudes about CRC screening, and the perception that CRC screening exams are non-normative medical procedures.^{17, 31, 33, 34} Some studies suggests that CRC screening exams have a negative sexual connotation which may be related to the procedural aspect of rectum penetration and its perceived association with anal intercourse and men who have sex with men.^{17, 33} Fear of pain during the screening exam was also positively associated with unwillingness to screen which is consistent with the current literature.¹¹

Unexpectedly, both fear of developing cancer and medical mistrust were negatively associated with unwillingness to participate in CRC screening. For example, those reporting fear of developing cancer were less likely to report unwillingness to participate in screening. This finding suggests that fear of cancer development may facilitate readiness to participate in CRC screening. Fear as a predictor of participation in cancer screenings has been previously supported³⁵, while other studies have identified fear as a barrier to screening^{34, 36, 37} and having no association with screening.³⁸ Fear-based approaches to CRC screening promotion should be considered with caution. Research suggest that cancer fear and worry is often accompanied and exacerbated by other psychosocial impairments such as fear of death and fatalistic attitudes.³⁹ Medical mistrust was also negatively associated with unwillingness to undergo CRC screening. That is, those reporting medical mistrust were less likely to report unwillingness to screen. This finding is in contrast with other research outlining medical mistrust as a barrier to participation in preventive health programs.^{14, 40, 41} This finding warrants further investigation to elucidate the unexpected association between mistrust and CRC screening participation. Others studies have found that CRC screening was predicted by an individuals perceived susceptibility to CRC¹⁴ and having had a previous cancer screening exam.⁴² However in the current study, these factors were not associated with unwillingness to participate in CRC screening. It may be that psychosocial factors take precedent over perceptions of susceptibility and previous experiences with screening. In the current study, addressing and overcoming fears appear to be of greatest importance in efforts to reduce CRC screening barriers. Efforts to address psychosocial barriers to screening such as fear, should include specific communication on

the different types of CRC screening exams, the pros and cons of each exam, and the procedural aspects of the exam (prep time, etc). Ensuring that patients are fully informed about the screening procedure may reduce fear and anxiety, and address screening myths and misconceptions.

Age was the only one significant sociodemographic variable associated with unwillingness to participate in CRC screening. The logistic regression model showed that as age increased respondents were more likely to report unwillingness to participate in CRC screening. This finding may be related to decreased CRC risk perceptions among older adults and competing health issues and concerns.^{43–45} Inconsistent with other research, gender, race, education, and income were not significantly associated with CRC screening intentions.^{13, 17, 46–48} Previous research suggests that when factors such as trust are controlled for racial differences in interfacing with the health care system are less pronounced.^{16, 19, 49} These findings suggest that addressing psychosocial impairments across racial/ethnic groups has the potential to substantially improve screening rates.

Study Limitations

Limitations of this study are that individuals without land telephone lines were excluded; data were self-reported which may have introduced recall and reporting error; data were not collected on intentions to screen for specific tests such as fecal occult blood test or colonoscopy so the context of the findings should be interpreted accordingly; data on structural barriers to CRC screening (e.g., access, health insurance) were not collected; data on family history of cancer were not collected; and the cross-sectional design prohibits assessments of study measures across time-periods (i.e., shifts in CRC screening intentions, etc). Barriers to CRC screening between respondents living in Puerto Rico compared to those living in the US may be distinctly different. However, any differences were accounted for by adjusting for geographical location in the logistic model. Lastly, it is important to note that CRC screening recommendations vary by organization. Specifically, the American College of Gastroenterologists recommends that AAs begin CRC screening at age 45. However, the current study age inclusion was based on the ACS CRC screening age recommendation of 50 across racial and ethnic groups.

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SO WHAT?: Implications for Health Promotion Practitioners and Researchers

Despite the promise of CRC screening in preventing and detecting cancer, a large proportion of the population remains unscreened. The literature shows that knowledge deficiencies, health care access, and psychosocial factors influence screening intentions and behaviors. This study adds to the paucity of research examining psychosocial influences on CRC screening such as pain, fear, and trust across racial and ethnic groups. The findings of this study suggest that CRC screening initiatives should focus on increasing knowledge; addressing fears and mistrust, and normalizing CRC screening as a beneficial preventive practice. As race and other sociodemographic characteristic were not significantly associated with CRC screening intentions, study findings may be generalizable across racial/ethnic groups. The promise of reducing and ultimately eliminating CRC incidence and mortality rests with the ability to promote widespread screening and follow-up of abnormal test results. This study provides valuable insight into the attitudes, beliefs, and behaviors related to CRC screening among an ethnically diverse sample of men and women which can aid in intervention efforts to reduce mortality.

Figure 1.

Percent of unwillingness to participate in colorectal cancer screening by sociodemographic characteristics among adults aged 50 and older

Table 1

Sociodemographic characteristics of participants 50 years and older

Characteristic	N	%
Age		
Mean $\pm$ SD [*] = 62.9 $\pm$ 9.9		
Range = 50–95 years old		
Gender		
Male	151	33.3
Female	303	66.7
Race		
African American	134	29.5
Hispanic	115	25.3
White	205	45.2
Education Level		
< High school	93	20.5
High school graduate	127	28.0
Some college	84	18.5
College graduate	93	20.5
> College graduate	53	11.7
Income Level		
< \$20,000	153	33.7
\$20–34,999	99	21.8
\$35–49,999	55	12.1
\$50–74,999	39	8.6
\$75,000	49	10.8

^{*} SD = standard deviation

Table 2

Multivariate logistic regression results for unwillingness to participate in colorectal cancer screening among adults 50 years and older

Variable	Odds Ratio (95% Confidence Interval)
Health Status	
Excellent	3.62 (0.93 – 14.13)
Good	1.27 (0.31 – 5.21)
Fair/poor (reference)	1.00
Cancer Screening Effectiveness in Detecting Cancer	
Always/most of the time (reference)	1.00
Some of the time	1.91 (0.64 – 5.66)
Occasionally/rarely	4.43 (0.45 – 43.50)
Ever Had a Cancer Screening	
Yes vs. No	1.91 (0.67 – 5.44)
Psychosocial Factors	
Fear of getting AIDS vs. Not at all	8.13 (2.57 – 25.71) *
Fear of being a guinea pig vs. Not at all	0.67 (0.20 – 2.21)
Fear results not being kept confidential vs. Not at all	0.59 (0.20 – 1.72)
Fear of how the disease would upset the family vs. Not at all	2.66 (0.74 – 9.52)
Fear of hearing you might have cancer vs. Not at all	0.19 (0.05 – 0.68) *
Feeling very unlikely to get cancer vs. Not at all	0.33 (0.09 – 1.16)
Lack of trust in medical people vs. Not at all	0.24 (0.09 – 0.70) *
Fear screening might be painful vs. Not at all	2.18 (0.74 – 6.44)
Fear of being embarrassed during screening vs. Not at all	8.81 (2.26 – 34.27) *
Gender	
Female vs. Male	1.37 (0.57 – 3.26)
Race	
Hispanic	0.67 (0.15 – 2.99)
African American	2.14 (0.73 – 6.28)
White (Reference)	1.00
Education	
< High school	0.90 (0.13 – 6.12)
High school graduate	5.32 (1.44 – 19.76) *
Some college	2.68 (0.67 – 10.69)
> College graduate	0.98 (0.17 – 5.69)
College graduate (Reference)	1.00
Income	
< \$20,000	0.44 (0.06 – 3.48)
\$20–34,999	0.71 (0.11 – 4.68)
\$35–49,999	1.90 (0.24 – 15.26)
\$50–74,999	0.92 (0.12 – 6.89)

Variable	Odds Ratio (95% Confidence Interval)
\$75,000 (Reference)	1.00
Age	1.08 (1.03 – 1.14) *

* Statistically significant at $p = 0.05$