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Opportunities to Expand Colorectal Cancer Screening Participation

Crystale Purvis Cooper[1] and **Cynthia A. Gelb**[2]

[1]Soltera Center for Cancer Prevention and Control, Tucson, AZ 85704

[2]Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA 30341

Abstract

The Centers for Disease Control and Prevention's *Screen for Life: National Colorectal Cancer Action Campaign* has operated continuously since 1999 to promote colorectal cancer screening. The campaign's most recent formative research cycle was conducted in 2015, and included 16 focus groups in four U.S. cities with adults aged 50–75 years who had not received colorectal cancer screening as recommended. The most common reason for screening non-participation was aversion to some aspect of colonoscopy, such as preparation, the invasive nature of the test, or the possibility of complications. Other reasons for screening non-participation were absence of symptoms, lack of screening awareness/provider recommendation, and lack of family history. Screening promotion messages that resonated with participants included: multiple screening tests are available; colorectal cancer may not cause symptoms; screening should begin at age 50; and most cases of colorectal cancer occur in individuals with no family history of the disease. Efforts to increase colorectal cancer screening participation may be supported by disseminating messages that counter common concerns about screening. Raising awareness of the range of colorectal cancer screening options may be especially critical given that many unscreened individuals were unwilling to undergo a colonoscopy.

INTRODUCTION

Colorectal cancer is largely preventable through screening,[1] yet it remains the second leading cause of U.S. cancer death.[2] Among cancers that affect only women, colorectal cancer is the third most lethal after lung and breast cancers.[2] Only 58.9% of women and 56.7% of men aged 50–75 years in the United States have been screened with a recommended modality[3]: colonoscopy every 10 years, annual high-sensitivity fecal occult blood test (FOBT), or sigmoidoscopy every five years in combination with FOBT every three years.[4]

Corresponding author: Cynthia A. Gelb, Centers for Disease Control and Prevention, Division of Cancer Prevention and Control, 3719 North Peachtree, MS: F75, Chamblee Building 107, Room 4262, Chamblee, GA 30341, Phone: 770-488-4708, Fax: 770-488-3040, cgelb@cdc.gov.

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"80% by 2018" is a goal to increase colorectal cancer screening to 80% of eligible adults by 2018 issued by the National Colorectal Roundtable, an organization cofounded by the Centers for Disease Control and Prevention (CDC) and the American Cancer Society.[5] To promote colorectal cancer screening among the at-risk population, CDC implemented the *Screen for Life: National Colorectal Cancer Action Campaign (*www.cdc.gov/screenforlife*),* which has operated continuously and year-round since 1999.[6] The campaign's most recent formative research cycle investigated reasons for screening non-participation among individuals who were not up-to-date with screening, as well as messages and creative approaches to promote screening.

METHODS

During September and October 2015, CDC conducted 16 focus groups in four U.S. cities—four groups each in New York City (n=36), Chicago (n=34), Los Angeles (n=35), and Miami (n=34) (N=139). Each focus group included 7–9 participants and lasted approximately two hours.

The cities where focus groups were held were selected based on their geographic diversity, the racial/ethnic diversity of their residents, and the availability of reliable and experienced focus group facilities. Participants were recruited using public information (e.g., telephone listings) and venues (e.g., city parks), as well as proprietary sources (e.g., lists maintained by focus group facilities). Participants were limited to adults aged 50–75 years who had never been diagnosed with colorectal cancer or polyps and had not been screened as recommended (no colonoscopy within the last 10 years; no FOBT within the last year; and no sigmoidoscopy within the last five years in combination with FOBT within the last three years). Recruiters evaluated participants' eligibility based on self-reported data obtained using a brief screening questionnaire. Participants included a diverse mix of individuals (Table 1).

The focus groups were facilitated by a professional moderator who followed a semi-structured discussion guide. At the beginning of each focus group, participants were asked what they knew about colorectal cancer. If the topics of risk factors and recommended screening tests did not come up organically, the moderator raised these topics to investigate general colorectal cancer knowledge among participants. The moderator also asked participants if they had been screened for colorectal cancer and then why they were not up-to-date with screening. After this, participants were shown creative concepts for video public service announcements. These were formatted as animatics, a series of drawings edited together on video, along with a soundtrack of the script read by non-professional actors. Prior to showing the creative concept prototypes, the focus group moderator explained their unfinished nature and emphasized that any concept, if produced, would flow seamlessly, and would include live, professional actors, not drawings.

In total, 11 concepts were tested; however, no more than seven were tested in any city (Table 2). The order in which concepts were shown was varied in every focus group to counter the potential for order effects.[7] All focus groups were monitored by at least two on-site

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observers. Additional observers watched the focus groups remotely via online streaming video.

All observers recorded detailed notes. After each city, the lead investigator prepared a summary of results, which was then shared with other observers to reach consensus on the findings.

RESULTS

Colorectal Cancer Screening Awareness

Many participants indicated that they had received a colorectal cancer screening recommendation from their health care provider (Table 2), with colonoscopy being the only test recommended to most participants. Accordingly, several participants in every focus group said that colonoscopy was a screening test for colorectal cancer. FOBT was mentioned by participants in half of the focus groups. No participants mentioned flexible sigmoidoscopy as a screening test. A few participants mistakenly believed that the digital rectal exam and upper endoscopy screened for colorectal cancer. In most focus groups, participants mentioned that screening should begin at age 50. Colorectal cancer risk factors mentioned by participants included family history, diet, and age. Participants in every city mentioned the term “polyps” before it was introduced by the moderator or the materials tested.

Reasons for Screening Non-Participation

The most common reason participants gave for not getting screened for colorectal cancer was an aversion to some aspect of colonoscopy, such as preparation, the invasive nature of the test, or the possibility of complications. Many colonoscopy-resistant participants lacked awareness of alternative screening options, and those who were familiar with other screening tests generally believed that colonoscopy was the only worthwhile test. Other participants indicated that they had not been screened because they did not know that they should be, or because no health care provider had recommended it to them. Many participants also indicated that they did not feel that screening was necessary because they had no symptoms and were in good health. Some believed they did not need to be screened because they had no family history of colorectal cancer. A few participants indicated that the costs and logistics (e.g. taking time off from work) associated with colonoscopy prevented them from being screened. Several participants were reluctant to see a health care provider under any circumstance, and a few indicated that they would prefer to die of cancer without it ever being diagnosed. Finally, a few participants attributed their lack of screening to general procrastination and laziness.

Messages that Resonated

When asked what messages presented in the creative concepts were compelling, participants most often mentioned the availability of several screening options. The existence of screening alternatives to colonoscopy was new information to most participants and generated a great deal of interest. Other messages frequently mentioned by participants as compelling were: screening should begin at age 50; colorectal cancer is the second leading

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cancer killer; colorectal cancer may not cause symptoms; most colorectal cancers occur in individuals with no family history of the disease; and colorectal cancer can be prevented through screening.

Creative Elements that Resonated

Several types of appeals were tested, including informational (straightforward, first-person presentations), metaphorical (appeals involving analogies, such as comparing caring for one's body to taking care of home maintenance), and role modeling with a positive outcome (someone was screened and precancerous polyps were found and removed as a result). Some of the creative concepts featured just one individual making a direct appeal, while others featured a diverse cast; and some focused on the family as a reason to get tested.

Straightforward, informational appeals were preferred in every focus group. Concepts that mentioned the importance of being screened so that one could live to enjoy his or her family were also very well received. Concepts with a sad tone, such as those mentioning someone dying from colorectal cancer, were polarizing with participants reacting either very positively or very negatively. Conversely, broad appeal was achieved by concepts in which individuals were screened and precancerous polyps or cancer were caught in time. Participants also responded favorably to concepts that featured racially and ethnically diverse men and women who role modeled being screened.

DISCUSSION

Efforts to increase colorectal cancer screening rates may be supported by the dissemination of screening information in a straightforward, direct manner, which was overwhelmingly preferred by focus group participants. Messages that particularly resonated with participants countered common reasons for screening non-participation (Table 3).

In contrast to previous research conducted by CDC's *Screen for Life* campaign in which most participants knew little about colorectal cancer and the need for screening,[9] most participants in the present study were aware that they should be screened, and many had received a colonoscopy referral from their health care provider. In addition, participants in the majority of focus groups were largely familiar with the risk factors of colorectal cancer, and many knew that screening should begin at age 50. This reflects an important shift in consumer knowledge and perceptions about colorectal cancer and screening.

Raising awareness of the range of colorectal cancer screening options may be a critical component of screening promotion efforts. Colonoscopy was at the center of an impasse to screening for many participants in the present study. Concerns about the preparation, invasiveness, and possible complications of colonoscopy were abundant, and many participants were resistant to having the procedure. Colonoscopy was the most familiar screening option and was usually the only test that participants said that their health care provider had recommended. This result is consistent with national screening data; colonoscopy is the screening strategy used almost exclusively in the United States.[8] Participants were enthusiastic and intrigued to learn there are screening options other than colonoscopy. While FOBT offers a non-invasive screening option, familiarity with FOBT

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was relatively low, and it was rarely offered to participants by their health care provider. In every focus group, several participants expressed an interest in learning more about screening options and said they would ask their health care provider about undergoing a screening test other than colonoscopy.

The design of the present study does not support gender-specific analyses, as focus groups included both men and women and were not stratified by gender. However, women's reasons for non-participation in colorectal cancer screening reported in prior studies[10–14]—lack of awareness, lack of provider recommendation, test invasiveness, fear of pain or discomfort, aversion to preparation for endoscopic procedures, low perceived risk, embarrassment, fear of complications, fear of test result, cost, and inconvenience—are consistent with the results of the present study.

Increasing screening participation in the United States may depend in large part on raising awareness that colonoscopy is not synonymous with colorectal cancer screening. Mass communication strategies and provider-patient communication can work in tandem to disseminate this message. Providers should offer patients the range of recommended screening options and should recommend colorectal cancer screening opportunistically, when patients visit for any reason.

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Table 1

Participant characteristics (N=139)

Characteristic	n	%
Location		
New York City	36	25.9
Chicago	34	24.5
Los Angeles	35	25.2
Miami	34	24.5
Gender		
Male	68	48.9
Female	71	51.1
Age (years)		
50–54	46	33.1
55–59	47	33.8
60–64	31	22.3
65–75	15	10.8
Race/ethnicity		
Caucasian	59	42.4
African-American	49	35.3
Hispanic	21	15.1
Asian	10	7.2
Educational attainment		
< High school	0	0.0
High school	31	22.3
Some college	44	31.7
College degree	41	29.5
Advanced degree	23	16.5
Income		
$60K	74	53.2
>$60K	65	46.8
Employment		
Full-time	75	54.0
Part-time	33	23.7
None/retired	31	22.3
Health insurance		
Yes	117	84.2
No	22	15.8
Last routine check-up		

Characteristic	n	%
Within last year	99	71.2
2–3 years	26	18.7
4 years or longer	14	10.1

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Table 2

Colorectal cancer screening awareness, reasons for screening non-participation, and resonating screening promotion messages and creative elements

		Quote	Number of Focus Groups Which Mention				
			Chicago (4 focus groups)	New York City (4 focus groups)	Los Angeles (4 focus groups)	Miami (4 focus groups)	Total (16 focus groups)
Colorectal cancer screening awareness	Screening had been recommended by : health care provider	"Every year my doctor gives me a colonoscopy referral, and I tell her it is a waste of paper."	4	4	4	4	16
	Familiarity with colonoscopy	"Colonoscopy is the test you have to get."	4	4	3	4	15
	Familiarity with other screening options	"There are kits to test your stool."	3	1	3	1	8
	Risk factors	"People with it in their families have to get screened more often."	3	3	4	3	13
	Screening should begin at age 50	"This starts at 50—I am in that age group."	4	2	2	4	12
	Familiarity with term "polyp"	"I heard that polyps can be removed, so you don't get cancer."	1	1	1	3	6
Reasons for screening non-participation	Aversion to colonoscopy	"I am just not ready to get a colonoscopy." "The prep is supposed to be awful."	4	4	3	4	15
	Absence of symptoms	"I feel fine so I don't see the need."	4	3	2	3	12
	Lack of awareness in general or provider recommendation	"My doctor never told me to be screened."	1	3	4	0	8
	Lack of family history	"It is not an issue in my family."	1	3	4	0	8
	Cost concerns	"Right now I don't have insurance, so I won't be getting screened."	0	1	2	2	5
	Aversion to doctors	"I haven't seen a doctor in 14 years."	2	1	1	1	5
	Aversion to finding out cancer diagnosis	"I don't want to know if I have cancer."	0	2	1	0	3
	Logistics	"Taking off work is hard for me."	0	0	1	1	2
	General procrastination	"I keep putting it off. I guess I am just lazy."	0	1	0	0	1
Messages that resonated	Multiple screening tests are available	"I am appalled that my doctor never told me there is an alternate test. He just pushes the colonoscopy all the time."	4	4	3	4	15
	Screening should begin at age 50	"Starting screening at 50 caught my attention because I am over 50."	2	4	4	4	14

		Quote	Number of Focus Groups Which Mention				
			Chicago (4 focus groups)	**New York City (4 focus groups)**	**Los Angeles (4 focus groups)**	**Miami (4 focus groups)**	**Total (16 focus groups)**
	Colorectal cancer is the second leading cancer killer	"I was really surprised about it being the second leading killer."	2	3	3	4	12
	Colorectal cancer may not cause symptoms	"The no-symptom thing made me think."	4	3	2	2	11
	Most colorectal cancers occur in individuals with no family history of the disease	"I thought it mostly ran in families, so that was new information."	3	3	3	1	10
	Colorectal cancer is preventable through screening	"The part about it being preventable stood out."	2	3	2	2	9
Creative elements that resonated	Informational appeal	"It presented the information in a straightforward way with no distractions."	4	4	4	4	16
	Family theme	"The family element made me think of the special people in my own life."	3	4	4	4	15
	Positive outcome/tone	"There was no doom and gloom. I felt good at the end."	4	4	3	4	15
	Diverse cast	"There were men and women and people of different races. It showed that colon cancer affects everyone."	3	3	2	3	11
	Role modeling	"It showed people happy about getting screened. It made it think it is not that bad."	1	3	2	3	9

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Table 3

Colorectal cancer screening promotion messages that counter common screening concerns

Screening concerns	Counter message
Aversion to colonoscopy	Multiple screening tests are available.
Absence of symptoms	Colorectal cancer may not cause symptoms.
Lack of awareness in general or provider recommendation	Screening should begin at age 50.
Lack of family history	Most cases of colorectal cancer occur in individuals with no family history of the disease.