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Discussing Cancer: Communication with African Americans

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Abstract

Regular screening for colorectal cancer (CRC) facilitates earlier detection, lowers mortality, and may reduce incidence through detection and removal of pre-cancerous polyps. Optimizing health professional delivery of CRC screening information and recommendations can assist in reducing CRC disparity in the African American community. This paper presents qualitative data on African Americans' attitudes about health professional CRC communications based on the analysis of focus groups (N=79). Using a social-ecological framework, colorectal cancer and professional communication themes are examined to offer four general and nine cancer specific theoretically based and culturally appropriate strategies for improving health professional cancer communication with African Americans.

Keywords

Diagnosis at an early, localized stage of colorectal cancer (CRC) is important for long-term survival. Regular screening with fecal occult blood testing (FOBT), sigmoidoscopy (SIG) or colonoscopy (COL) facilitates earlier detection of CRC, lowers mortality and may reduce incidence through early detection and removal of pre-cancerous polyps (ACS, 2012; Jemal, Siegel, Ward & Xu, 2010; USPSTF, 2008). Most screening guidelines recommend that for those at average risk, screening should begin at age 50 (ACS, 2012; USPSTF, 2008). When diagnosed at an early stage, CRC 5-year survival is 90.3%, however only 39.5% of CRC

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patients are diagnosed at this stage (Howlader, Noone, Krapcho, Garshell, Neyman, Altekruse, Kosary, et al., 2013).

Despite progress made in reducing the burden of cancer in the U.S., disparities persist in how cancer affects different racial and ethnic groups (Jemal, Siegel, Ward, Hao, Xu & Thun, 2009). While African Americans exhibit lower 5-year survival rates for all combined cancers, disparity is particularly evident in CRC (Jemal, Siegel, Ward & Xu, 2010). Death rates from CRC account for a quarter of the overall cancer disparity between African American women and White women and 11% of the cancer disparity between African American men and White men (ACS, 2007a). This disparity may be partially attributable to differences in African Americans' screening utilization, which has been linked to later stage CRC diagnosis among African Americans (ACS, 2007b; Jackson-Thompson, Ahmed & German, 2006); thus, establishing the need for CRC prevention efforts in the African American community.

Patients who lack information are likely to have misconceptions about cancer prevention and screening, which can have an adverse effect on their adherence to cancer screening recommendations (Denberg, Wong & Beattie, 2005). Primary care physicians and other health professionals have a vital role to play in the process of increasing screening rates. Patients seeking cancer information, including African Americans, often perceive physicians and other health professionals as the most credible sources of heath and cancer information (Hesse, Nelson, Kreps, et al., 2005). Previous research has indicated that one of the most common reasons for obtaining a screening test is physician recommendation (Gilbert & Kanarek, 2005; Katz, James, Pignone, 2004). Less is known about the impact of recommendations by other health professionals including physician assistants, nurse practitioners, nurses, health social workers and health educators. However, limited data suggest the potential for including a variety of health professionals in CRC education and screening promotion efforts (Kelley, Daly, Anthony, et al., 2002).

A number of factors seem to influence health communication between patient and health professionals, including education, race/ethnicity, length of interaction, first vs. repeat visits, presence of a companion, and the medical issue. Social cognitive theory suggests that the success of communication to promote healthy behaviors is based on the ability to improve knowledge of the health effects of behavior change, create positive outcome expectations, emphasize resources that assist in behavior, address factors that are barriers to the desired behavior, and establish short term goals such as the completion of screening Seligman, Wallace, DeWalt, et al., 2007). Culturally appropriate cancer communication can assist in addressing general educational needs and in achieving communication objectives based on social cognitive theory (Guidry & Walker, 2002).

Beisecker & Beisecker (1990) noted that doctors typically transmitted more medical information to patients who appeared to desire that information. However, patient behavior related to the desire for medical information is easily misunderstood and/or overlooked. Katz, et al. (2004) found that patients who viewed health professional communications positively were more knowledgeable and more likely to complete CRC screening than those who viewed patient-health professional communications negatively (Katz, et al., 2004).

Given the CRC profile of African Americans, there is clearly a need to improve screening utilization. Optimizing health professional delivery of CRC information and screening recommendations is a reasonable strategy for increasing CRC screening use; thus, this article describes African American attitudes on health professional - patient communication about cancer, particularly CRC and offers theoretically based and culturally appropriate strategies for improving communication with African Americans.

Methods

Focus Groups

Researchers used focus group methodology in order to obtain rich information on attitudes and experiences that could be used to develop ideas for programs and interventions (Morgan, 1997). Gender specific focus group interviews captured participants' attitudes on: 1) cancer knowledge and attitudes in the African American community; 2) how health professional communications about cancer and CRC are perceived and experienced by African Americans; and 3) how to use these findings to develop health professional communication tips and strategies to encourage CRC screening and colon health in the African American community. The moderator guide included items such as: "Tell me about your interactions with people in the healthcare system." Because the focus groups were also used to inform CRC prevention materials, the discussions were later guided to cancer topics. Participants were asked broad, open-ended questions and encouraged to include personal stories or anecdotes regardless of whether they perceived those experiences as positive or negative.

This study was originally approved by the Saint Louis University Institutional Review Board and also by the Washington University in St. Louis Institutional Review Board. All participants received a detailed explanation of the study before providing signed consent.

Participants

Focus groups of men (n=12 groups) and women (n=8 groups) were held separately and included 3 to 8 participants each. A total of 79 participants volunteered (43 men, 36 women) and were included in the study. More male groups were conducted than female groups because the literature contains less information about African American men on this topic (Deshpande, Thompson Sanders, Vaughn & Kreuter, 2009). Participants had a mean age of 50 and a majority of participants (80%) had not obtained a college degree. The largest proportion of participants had a household income of less than $10,000 (40%), with over 70% having a household income below $30,000. Participants received a twenty-dollar gift certificate for their participation. Detailed demographic characteristics are provided in Table 1.

Procedures

All focus groups in this study were moderated by an African American researcher experienced in qualitative methods and analyses. Focus groups were held in a mid-western metropolitan area and lasted roughly 90 minutes. Eligible participants were recruited from churches, community centers, government facilities and local businesses such as drug stores,

department stores, salons and a thrift store. Three approaches were used to recruit participants. First, the research staff visited each of these locations to personally invite community members to participate. Next, local community members working with the research team identified potential participants who were then contacted by the project staff. Finally, flyers were posted at these community venues encouraging interested and eligible adults to contact the project staff. Focus groups were carried out in churches, libraries, an university conference room, and the Neighborhood Voice, a mobile van used for research activities. Focus groups were audio recorded and professionally transcribed.

Coding and Analysis

Coding guides were developed by an interdisciplinary team of researchers from public health, psychology and anthropology. We used a consensus coding procedure (Morgan, 1997) and worked in three-person coding and analysis teams. Members of the team coded the focus group transcripts individually, identifying text units that described: interactions with the healthcare system, anecdotes about live events, class, disparities, race, trust, distrust, or reason for disparities. Coders then met with other members of their team to reach a consensus on the codes. Each code was discussed during a consensus meeting, so no code was included in the final analysis that had not been agreed upon by all coders. If there was difficulty reaching a coding decision within the group, the project Principal Investigator made the final decision.

Transcripts were downloaded into Atlas TI® (Muhr, 2002) and after consensus coding was complete, agreed upon codes were entered into the Atlas transcript file. Text units were then grouped by codes and all groupings were analyzed for themes. Participant comments were included in this study when they were coded with a healthcare interaction, healthcare system or professional, health behavior or information code likely to produce comments on patient health professional relationships and communication.

All of the text blocks meeting these coding criteria were printed from Atlas TI and reviewed independently by a member of the research team to verify that the text section should be included in this analysis. A researcher then categorically assigned reactions on health care interaction, colon cancer, colon cancer screening and related health information as positive, negative, and neutral. Codes were keyed into an Excel spreadsheet to permit quantification of themes, related experiences, concerns, and preferences. Researchers then met to reach consensus on which sections should be included and analyzed the text for themes. These themes were used to develop effective communication strategies related to increasing CRC screening among African American adults.

Results

Colorectal Cancer Themes

The participants in these focus groups reported a lack of information about cancer, including CRC. Over 60% of men and 57.1% of women expressed a need for cancer information. What information was known had been generated through experience and transmitted intergenerationally. Thus, myths such as "if you cut on a cancer it will spread" were

repeated by focus group participants. Participants discussed cancer as a disease that has only recently been emphasized and discussed in the African American community. Participants were not convinced that you could prevent cancer, but agreed that there were ways to reduce cancer and CRC risks.

Participants were unfamiliar with the term "colorectal" and typically referred to the cancer as "colon" cancer (approximately 70%). One female participant referred to CRC as a male disease and was unaware that it affected women. Among men discussions of SIG and COL generated discussions that focused on violations of their masculinity.

> "… more black men do … I've met quite a few, so I can honestly say, including myself, do not like the idea of that rectal exam."

Participants were generally unaware of CRC signs and symptoms, preventive strategies, or screening options. Participants did not recognize the names of screening strategies, the appropriate age to obtain a screening test, or what the procedures entailed. Participants, particularly men, confused a FOBT and the digital rectal exam, which is not a CRC screening option. Fears of pain and tearing were voiced in response to SIG and COL screening options. Participants considered pride/machismo as major barriers to CRC exams of any kind among men.

Professional Communication Themes

All comments related to healthcare interactions were dichotomized into negative or positive and were found to be overwhelmingly negative (See Table 2). Among men, 63.7% characterized patient-health professional interactions and 61.5% characterized patient-health care system interactions in this manner; women's responses to these interactions followed a similar negative pattern, 71.9% and 60% respectively. Likewise, 66.7% of men and 91.7% of women described their reactions to cancer communication from health professionals in negative terms. The most prevalent and striking negative theme was the characterization of health professional communication as being dismissive/rushed, 69.2% of males and 78.1% of females, rather than caring/respectful.

Male "They don't take any time. You know, I sit there and I tell him something and he don't think it's important. ….he doesn't answer my question,… It's like he's making me feel like either he doesn't respect me…"

Female: "I mean, one doctor I had, I mean, I hated this man. He was a specialist but he didn't know how to talk to you…. He didn't make me feel like he was concerned about me at all."

The focus group discussions permitted the formulation of the interaction characteristics that led to these complaints. Feelings of mistrust and expectations of negative interactions were primed by historical issues (the Tuskegee experiments), but also related to prior experience. When interactions with health professionals were abrupt and impersonal, participants perceived the professional involved as uncaring. In this scenario feelings of mistrust were exacerbated. Many participants also attributed the impersonal behavior to biased attitudes. While race was a factor, participants reported feeling that many negative interactions with

the healthcare system stemmed from insurance coverage. They believed that if you had insurance you were treated well; if you did not, you were treated abruptly, or poorly.

Male: "I didn't have Medicaid one time and I went to the doctor. I stayed around and I waited and waited at the hospital…I sat there and waited because I didn't have no insurance. I finally got seen. But they didn't give me much attention…"

Female: "Now, if you don't have insurance, they kicking you straight to the curb, yes they are. They don't pay no attention to you."

A sense of health professional and system respect, care and concern began with the initiation of the visit and included the responses and behavior of all personnel in the environment. Focus group participants reported that they noted issues as simple as time spent waiting and examination and interaction time when deciding how to evaluate health professionals and their time with them. These participants often felt that their waiting times were longer and examination times shorter than Whites.

Patients reported the greatest concern with healthcare professional interactions when they believed that they were posing appropriate questions and did not receive what they viewed as a response, or felt that the response was dismissive. Some participants reported receiving information that assumed they had no or too little knowledge. One participant reported that when she asked questions of her physician the response she received was "when had "she" become a doctor." The reverse also occurred and patients received information that included medical terminology that made comprehension difficult. Participants seemed most annoyed when they perceived health professionals as too busy to answer questions and disinterested in them as individuals.

> "Nurses from the time I have been in the hospital, …now a days it's just a job. It use to be more than just a job to people. It use to be their career, something they put their heart in…you don't get that same effect… There is no concern anymore."

Focus group participants expected professionals to ask questions about their symptoms, experience with medications, and understanding of the information provided. When there was a failure to do this, there was disappointment and greater mistrust. Participants discussed the professionals' ability to provide an accurate or appropriate treatment and assistance without the information they believed that they could provide with appropriate questions and opportunity. Participants also expressed resentment when they were not told what was to be done for or to them. Under these circumstances, focus group participants seemed less likely to adhere to recommendations.

> "… I'm just mad at the doctor… Why come you can't tell me what all you did to me? They tell me they can't give that information out. Why not? …, what did you do? I want to know. "

Qualitative data also allow us to discuss and provide examples of interactions that promote trust and willingness to engage in screening. Participants reported more trust and satisfaction with health professionals who seemed less rushed, more willing to answer questions, and who asked about them as individuals.

> "I go back because I like the doctor. She takes time. ...But for other medical reasons
> I go to her, because we have a rapport there and she talks to me…"

These efforts assisted them in overcoming their expectations of poor and biased treatment. Participants expected direct recommendations for all necessary screenings, tests, and treatments. However, they wanted professionals to offer these in a respectful manner that included explanations, the opportunity to discuss options, and assistance locating strategies to manage costs when appropriate. When health education materials were offered, focus groups participants expressed a preference for race and ethnic specific information. Likewise, they appreciated acknowledgments of their faith and spirituality and efforts to use these as coping strategies. Focus group participants also appreciated health recommendations that were framed positively and avoided the appearance that the professional believed that they were always right or knew best.

Discussion

The findings from this qualitative work are consistent with themes noted in other studies. Consistent with other research (Denberg, et al., 2005; Katz, et al., 2004; Seligman, et al., 2007) there was a strong sentiment that cancer and CRC education and information were needed in the African American community. While physician recommendations were expected and desired for appropriate screening (Gilbert, 2005), mistrust and perceptions of bias affect screening adherence.

The important contribution of this study was its ability to describe the interactions that stimulate mistrust, perceptions of bias and those that promote positive attitudes toward patient-health professional interactions. Because these attitudes and interactions influence adherence to screening and treatment recommendations, this information makes it possible to develop recommendations for more culturally appropriate communication by any health professional (Guidry, 1999). However, it is important to recognize the diversity of the African American community. Attitudes and beliefs, as well as socioeconomic status, varies among African Americans. Addressing the issues discussed in this paper without some understanding of this diversity risks anger and resentment due to possible stereotypes. For example, not all African Americans lack insurance or economic resources and it cannot be assumed that healthcare costs are of concern.

Based on the requirements of social cognitive theory (Seligman, et al., 2007) and focus group data specific to African Americans, the following general and CRC-specific health professional communication recommendations are offered. Each number refers to the social cognitive theory requirement as follows:

1. = ability to improve knowledge of the health effects of behavior change

2. = create positive outcome expectations

3. = emphasize resources that assist in behavior

4. = address factors that are barriers to the desired behavior

5. = establish short term goals such as the completion of screening

General

- Gain an understanding of why some African Americans may have negative feelings about the healthcare system even before walking in the door. SCT requirement 4

- Employ respect, an important component of positive patient-health professional interactions. Respect can be demonstrated through truly listening to what each patient has to say and acknowledging fears and concerns. SCT requirement 2 and 4

- Ask patients about family, personal stress, and how they cope; discuss ways to cope collaboratively. SCT requirement 3 and 4

- Be open to incorporating spirituality/religion as a coping strategy or source of support as the patient deals with fears or anxieties related to tests, diagnoses or health concerns. SCT requirement 3 and 4

Cancer

- Learn about cultural beliefs and attitudes like "cutting on cancer will make it spread", "CRC is a male disease", .and rectal exams as an affront to masculinity that influence attitudes and behaviors among community members. Professionals may need to provide information to counter these attitudes and beliefs. SCT requirement 1, 2 and 4

- Use the term "colon" cancer, and pair it with the term CRC, so that patients become familiar with the medical terminology. SCT requirement 1, 2 and

- Make explicit cancer screening recommendations, particularly for CRC when appropriate due to age or family history. SCT requirement 1, 2, 3, 4 and 5

- Assure that there are mechanisms to educate patients and carefully explain tests, test preparation, costs, pros and cons. Identify and share resources to make screening affordable or accessible. SCT requirement 1, 2, 3, 4, 5

- Patients need to believe that screening tests save lives. Explain in layman's terms that in the event that cancer is found, individuals can be treated immediately to increase chances of survival. SCT requirement 1, 2, 4, 5

- Discuss what happens after a positive screening (e.g. treatment options and assistance in obtaining needed services) and specific actions to take. SCT requirement 1, 2, 3, 4, 5

- The increased awareness of disparity and mistrust of the healthcare system may create concern about the treatments offered. Be prepared to highlight what you know about the efficacy of treatments, screening, medication, etc. for African Americans. Use non-technical language. SCT requirement 1, 4

- Use a positive frame: "These tests allow us to see if your colon is healthy." vs. "These tests allow us to screen for cancer." SCT requirement 2

Acknowledgements

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Table 1

Summary of Participant Demographics by Focus Group (N = 94)

	Evidential (N=49)	Socio-Cultural (N=45)
Age	51.3	49.8
	[39–71]	[36–67]
Male	48.9	49.3
Female	53.6	50.6
Income		
%		
< 10,000	41.2	38.6
10,000–19,999	20.6	13.6
20,000–29,999	17.6	13.6
30,000–39,999	8.8	6.8
40,000–49,999	5.9	6.8
50,000–59,999	2.9	4.5
60,000–69,999	0.0	4.5
70,000–79,999	0.0	2.3
80,000–89,999	0.0	4.5
90,000–99,999	2.9	0.0
>100,000	0.0	4.5
Education		
%		
< HS	2.9	0.0
Some HS	23.5	17.8
HS Grad/GED	17.6	26.7
Some College	38.2	33.3
College Grad	11.8	13.3
Some Graduate	5.9	8.9

() = Standard Deviation

[] = Range

Table 2

Focus group response categories by gender

Response categories	Males (n=58)	Females (n=36)
	%	%
Health care professional		
Positive	36.3	28.1
Negative	63.7	71.9
Healthcare system interaction		
Positive	38.5	40.0
Negative	61.5	60.0
Health professional communication		
Positive	0	0
Negative	100.0	100.0
Response to cancer communication		
Positive	33.3	8.3
Negative	66.7	91.7
Characterization of communication		
Caring/respectful (trust)	30.8	21.9
Dismissive/rushed (distrust)	69.2	78.1
Patient CRC terminology		
Colon	71.4	70.0
Rectal	28.6	10.0
Bowel	0	20.0
Concerns about CRC screening		
Positive	0	0
Negative	100.0	100.0
Expressed need for information		
Positive	33.3	42.9
Negative	66.7	57.1