



Published in final edited form as:

J Immigr Minor Health. 2009 August ; 11(4): 319–325. doi:10.1007/s10903-008-9126-6.

Colon Cancer Knowledge and Attitudes in an Immigrant Haitian Community

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Abstract

Objective—To qualitatively evaluate the views of Haitian immigrants on cancer and the influence of cultural and socio-ecological factors on cancer screening behavior.

Methods—Six focus groups, consisting of 4–10 individuals each, were conducted among Haitian adults at average risk for colorectal cancer. The interviews were conducted in Haitian Creole and featured questions that addressed beliefs and attitudes about general health, access to health care, colon cancer, and screening practices.

Results—The focus groups provided insight into the health service utilization patterns in the Haitian community, as well as the factors driving them including language and the pattern of accessing healthcare only for emergencies.

Conclusions—Many misconceptions regarding cancer and its development were evident in the discussions. However participants were willing to follow the recommendations of a physician. This highlighted the importance in this community of disseminating information at every opportunity about preventative care, including colorectal cancer screening.

Keywords

Colon cancer screening; Immigrant; Knowledge; Attitudes; Focus group

Introduction

Colorectal cancer (CRC) is the second leading cause of cancer-related death in the United States (U.S.) and the third most commonly diagnosed malignancy for both men and women [1]. Compared to other ethnic groups, African Americans have been reported to have the highest rates of advanced neoplasia in the proximal colon [2], and the highest age-adjusted

incidence rates and death rates for colorectal cancer [1]. The stage of CRC at diagnosis is also the most advanced for African Americans compared with all other ethnicities [1]. Individuals from places in the Caribbean such as Haiti may similarly be at increased risk for CRC.

Although CRC can be prevented through screening, it is underutilized in the U.S., despite the availability of effective testing methods [3]. Blacks and Hispanics have lower rates of CRC screening compared to Caucasians [4]. The barriers to cancer screening are multifactorial and include socioeconomic status [5], knowledge, and beliefs about health and disease [6]. The National Health Interview Survey revealed that the use of CRC screening was particularly low among those respondents without insurance, those with no usual source of health care, and those who reported no doctor's visits the preceding year [7]. Acceptance of screening practices may depend not only on the availability of services, but also on the belief that one is susceptible to the illness [8]. These factors may also influence screening rates among immigrant populations such as Haitians.

Haiti remains one of the poorest countries in the Western hemisphere [9]. Its political unrest further intensifies the poverty that drives health outcomes such as infectious disease epidemics and the risk of cancer development [10, 11]. Haitians make up one of the largest immigrant groups in the U.S. from the Caribbean. According to the 2000 census, there were 420,000 foreign born individuals from Haiti living in the U.S. [12]. In 2003 Haitians made up the third largest group of documented Caribbean immigrants entering the United States [13]. The contribution from the undocumented pool of immigrants is unknown but is suspected to be substantial [14]. Aside from Florida, the largest concentration of Haitians is currently in New York City, in particular in the borough of Brooklyn [15].

As a group, Haitians face potential linguistic, cultural, and economic barriers to cancer screening. A recent focus group study comparing five immigrant communities found that Haitians had the lowest percentage of insured individuals, contributing to access barriers [16]. Factors that have been found to be associated with health coverage status include, gender, citizenship, family income, as well as length of U.S. residence [17]. The extent to which these factors influence the knowledge and attitudes towards CRC screening in this community is unclear.

The aims of this study were: (1) to evaluate knowledge and attitudes about CRC, and CRC screening in the Haitian community and (2) to evaluate the cultural and socio-ecological factors influencing screening acceptance.

Methods

Given the limited existing data regarding colorectal cancer among Haitians, this study used focus group methodology to begin to develop a knowledge base on colorectal cancer screening in the Haitian community. Prior to the implementation of the study, the protocol was reviewed and approved by the New York University School of Medicine Institutional Review Board.

Setting and Study Population

Fliers were used to advertise the study in community centers, churches, and salons located in Brooklyn, with a predominantly Haitian clientele of diverse socioeconomic status. Information was also disseminated via a Haitian radio station that broadcasts to the New York metropolitan area with programs in French and Haitian Creole. Potential study candidates took the first step and initiated contact with a study coordinator, using a telephone number provided on the fliers and in the radio ads. The coordinator screened

candidates for eligibility and provided suitable individuals with further details on the focus group. Eligible participants were defined as adults age 40 or older of Haitian descent, able to understand and speak Haitian Creole, and living in a New York City neighborhood during the study period of January 1st 2005 to August 30th 2005.

Focus Groups

Six focus groups, each consisting of 4–10 participants, were conducted with asymptomatic individuals with no personal or family history of CRC. Three of the average risk focus groups included only men while the other three groups were conducted only for women. All focus groups were conducted in Haitian Creole by the first author or his trained study coordinator, at a Haitian community center that provides services such as day care, after school programs, English as a second language classes, and vocational courses. Informed consent was obtained from the participants immediately prior to the start of the sessions. Each group was reassured that identifying information would not be shared with any agency. The focus groups lasted at least one and one half hours, followed a semi-structured format, and were audio-taped with the permission of the participants. The elements of the focus group interviews are detailed in Table 1. All participants were encouraged to make a comment on every issue raised. At the end of the session, each individual received \$25 for participating.

Analysis of the Focus Group Data

The focus group recordings were reviewed in Haitian Creole, then interpreted and transcribed in English. Inductive analysis techniques were used requiring that patterns, themes, and categories of analysis come from the data. Using an iterative process, a coding scheme was developed [18] from the evaluation of the data and used to code the transcripts. The act of coding allowed for careful analysis of the salient issues discussed in the focus groups and enabled the identification of specific themes and the narrative for particular subtopics. Descriptive statistics (means, medians, frequency distributions) were used to characterize study participants. Statistical analysis was performed using SPSS software version 13.0 for Windows (SPSS Inc., Chicago, IL) and a two-tailed P -value of <0.05 was considered statistically significant. SPSS was also used to analyze the codes generated from the transcripts to assess for interrater reliability.

Results

Focus Group Participant Demographics

A total of 45 average risk individuals participated in the 6 focus groups. Table 2 summarizes their sociodemographic characteristics. The participants had a median age of 55 years (IQR 47–65) for the men and 49 years (IQR 46–64) for the women. Compared to 50% of the men, only 35% of the women have been in the U.S. for more than 5 years. The men were significantly more likely to be employed full time compared to the women (56% vs. 19%, $P = 0.027$). While 28% of men had no health insurance, it was 41% for women. Notably, only 47% of all individuals reporting full-time employment had employer-sponsored insurance. There was also no significant difference in the number of years of formal schooling between the male and female groups (median 4 years, IQR 1–7).

Focus Group Findings

Access to Health Care—Most of the participants said that they can find a doctor if they need one, by going to the nearest free clinic or public hospital emergency room. However there was concern that without insurance it may not be possible to get quality care. It was

generally agreed that undocumented immigrants are reluctant to seek health care, especially in facilities that request a social security number.

- For Haitians [the biggest problem] is insurance, and not having their [legal immigration status] papers.
- When I was in Haiti I consulted a doctor frequently, but while I've been here I have not done so. Insurance is the problem because doctors here are very expensive.
- People who are not here legally will not go to the hospital unless it is an emergency. Some Haitians are very afraid especially if they are asked for social security number, you know we do not like to write or give our information to the authorities.

Although the groups were aware of the availability of health care at public hospitals, they placed more value on having a single source of primary care with whom they can develop a relationship. Choosing the “right” physician is considered to be a very important decision because there is great trust placed in that person and recommendations from that individual are usually followed closely. When presented with a choice, the decision on which doctor to use is often dependent on whether the individual is of Haitian descent, was referred by a friend or family, or has been in practice for what is perceived to be a long time. The female groups expressed a preference for a Haitian female physician.

- I will only go to a doctor based on referrals. I also look at the doctor's directory and look for Haitian doctors. My doctor is F.M.; I picked him because he has the same name as my brother. I thought that was a good sign.

Many of the participants felt that their lack of proficiency with the English language was a significant barrier to health care access:

- If I consult a doctor and he speaks my mother's tongue, I feel at ease. I would not want to have someone else there during my conversation with the doctor. If the doctor speaks my language, it is just simpler to tell him 'I couldn't sleep last night' and have him ask right away, 'why, what's wrong' it is just better.
- [A Haitian doctor] understands everything you are saying and you understand everything he is saying. 90% of Haitians will choose to go see a Haitian doctor.
- “Lakay se Lakay [Home is home]” which means if you have a Haitian doctor you feel at home.
- You know what I mean when I say that a Haitian doctor will tell you how to take the medication. “Take 2 pills 3 times per day” may not be enough of an instruction for some Haitians. A Haitian doctor may tell you to “take 2 pills at 10 am, at 2 pm and at 6 pm.”

Haitian physicians were also felt to spend more time with Haitian patients. Some participants elaborated further that although both French and Creole are spoken in Haiti, the latter is the language spoken by all Haitians while the former requires formal education. The preference therefore was for a physician who speaks Creole. Many described having to bring family members or friends along with them to interpret if they did not see a Creole speaking doctor, causing those individuals to miss a day of work or of school.

- If I need to see a doctor and the only person to help me is someone who speaks French, I will take it. But if there is a choice, I will always take the Creole speaker.
- This doctor office doesn't have English, Creole translator. Therefore I am unable to speak about some of the things that I feel. Language is a big barrier for me.

Fear was brought up by many of the participants as yet another aspect that limits access to health care. Many expressed that they simply do not want to know whether there is something wrong with them.

- Fear is the first problem...they might find something wrong with your body.
- They [Haitians] are afraid and they tend to develop other health related problems once they have learned of one health problem.
- Going for the general check-up is not the problem, it's the result.

Attitudes and Beliefs about Primary Care—There was a recurring theme about going to a doctor only when there is an obvious reason to do so. However, those individuals with health insurance were much more likely to have a primary care doctor that they saw with some regularity.

- I go to the hospital only when I am pregnant.
- I will not go to a doctor unless I feel sick. Why should I spend my money if I don't feel sick?
- I know that I'm supposed to, but I don't have a primary doctor [because of] negligence. Also I don't want to think about getting older.

Knowledge about Cancer in General—There were many strong opinions about the cause of cancer in general. A central focus was on the relationship of cancer to food, although other possible etiologies were also discussed.

- I heard if you eat a lot of beef you can get cancer.
- Too much preservatives in canned foods, prepared foods, like those you buy at the grocery store. That can give you cancer. Also if you don't clean your food properly before cooking them.
- Expired food and too much rum can cause cancer.
- Reheating your food in the microwave. The X-ray is not good for you and may cause cancer.
- I think smoking, if you work too hard and don't eat well.
- Taking too much medication in general can cause you to have cancer.
- My mother used to tell me if a key on a doorknob hit you on your breast it can give you cancer.
- A mother whose baby bites her while breastfeeding. In the future the mother will develop cancer.

Knowledge about Colon Cancer—The majority of the participants did not know where, or what, the colon was. After a brief explanation was given using an anatomy model, some of the participants thought that it was possible to have cancer in the colon, and others offered these thoughts:

- It is impossible to have cancer of the colon, because I believe that smoking and drinking cause cancer.
- I don't think it is possible to get colon cancer. I have never heard of it. I have heard of other cancers.

Those who knew about colon cancer thought the causes centered on food. The possible etiologies offered included bad digestion if food lingers in the intestine, using a microwave oven, constipation, poor bowel hygiene, family history, and anal intercourse. Bowel cleansing was agreed upon as a way of maintaining or re-establishing health. There was a minority of individuals who thought colon cancer could be caused by someone putting a curse on you.

- I believe that undigested food can cause cancer.
- I think it is necessary to cleanse your system, to make sure to fight colon cancer.
- People who eat their nails or any type of food that's not natural for their body.
- Germs and microbes also can cause colon cancer.
- People who do not go to the bathroom regularly and those who do not have a normal bowel movement.

The groups were asked to offer some thoughts about who is at risk for colon cancer and they invoked God as well as homosexuality among other things.

- Smokers and drinkers are at risk.
- If you are 40 and are not a healthy eater.
- God does not create us all equal. There are people who have more of a chance to get cancer.
- Homosexual men are at risk for colon cancer.

Attitudes and Beliefs about Colon Cancer Screening—There was mixed knowledge about whether or not it was possible to be screened for colon cancer. Many people had never heard of colonoscopy. The majority of the screening age participants who had undergone CRC screening only had the fecal occult blood test, while a few had colonoscopy. People stated that they would be more comfortable with the fecal occult blood test (FOBT). Reasons cited included the fact that the FOBT could be done at home, and fears that the colonoscopy could kill you because it was like an operation. A few of the male participants agreed with the comment that compared with other tests, colonoscopy was the one they would least likely agree to undergo:

- Of the tests colonoscopy is the better one, but honestly as a Haitian man, I don't like the idea of having that test.
- I have an appointment to do the stool [test] next month, I don't know about the colonoscopy.
- I will think about it.

There was general agreement in the group that they would follow any recommendation of a doctor to do a particular screening test for colon cancer. Many eligible participants had not undergone screening because their doctors never talked to them about it. When they were asked what would help them to have a colon cancer screening, these thoughts were offered:

- I will do whatever test my doctor tells me to do.
- Have someone, a doctor...explain what it is and how it will help us.
- The problem with some doctors is that they are always in a rush and do not recommend the test that we should be taking for our age to prevent health problems.

Several of the participants themselves or people they knew had blood in their stool but did not get it evaluated, either out of fear, lack of insurance, not knowing that blood in the stool could signal something bad, or embarrassment. There was the belief among some that home remedies such as “ti bonm” (peppermint leaves) can cure anything, including blood in the stool.

- As most of you know, back home we have a lot of good home remedies. These remedies can cure most anything. I have a good remedy for stomach aches. Whenever I get a cold I boil ‘ti bonm’ and drank it hot and right away my stomach feels better.”

One participant offered this rationale for getting screened for cancer, in general, and CRC in particular

- This banana on the table looks good on the outside. But you don’t know if it is good until you peel it.

Discussion

The number of immigrants (documented and undocumented) living in the U.S. is approximately 35 million [19]. Between 1990 and 2000 the number of immigrants in NYC grew by 135% [19]. The non-Hispanic Caribbean region accounted for 24% of the City’s immigrants, with Haiti being one of the top ten largest sources of foreign-born individuals [19]. Given that the average age for an immigrant was 39 years in 2000, a large segment of this population will be entering CRC screening age over the next decade. It is of importance to consider the factors that may influence colon cancer screening patterns.

A comparison of data from 49 states and the District of Columbia participating in the Behavioral Risk Factor Surveillance System (BFRSS) surveys, revealed that the proportion of respondents who have had a lower endoscopy increased from 45.2% in 2002 to 50.6% in 2004 [20]. Despite this increase, there remain approximately 41.8 million average-risk adults in the U.S. aged 50 years or older who have not been screened for colorectal cancer [21]. In NYC adults age 50 or older, the subgroups least likely to undergo screening were the poor and the uninsured [5]. Furthermore, colonoscopy was less frequently reported by non-Hispanic blacks [5]. As in many other immigrant groups, the rate of colorectal cancer screening in Haitians has not been well defined.

In this study we sought to evaluate the knowledge and attitudes about colorectal cancer in a New York City immigrant Haitian community. The focus groups provided insight into the health service utilization patterns in the community, as well as the factors driving them. This sort of information from focus groups can help identify appropriate cultural metaphors that can be used to support CRC screening. There was a general sense that the forum provided a rare opportunity to speak and to be heard and the participants were eager to provide information that might help the community.

Although most individuals felt that they could find a doctor if they needed one, several other factors affecting access to health care were raised. The concern about the cost of healthcare in the absence of insurance was a shared reality for many of the participants. Rather than being able to develop a relationship with a primary care physician, many in the community rely on the emergency rooms for routine health maintenance access and have few “safety nets” available for long-term care. Those individuals who are undocumented often prefer not to seek help from conventional health care systems unless it is an absolute emergency. Instead they rely on home remedies such as teas and ointment rubs.

Yet another issue that influences access to health care is language. While all Haitian immigrants speak Creole, only those with a formal education are also proficient in both French and English. Because there is no official written version of Creole, it remains mainly a verbal form of communication, with nuances and verbiage that do not lend themselves well to translation. Although there have been attempts to develop a written form of Creole, most Haitians cannot read or write it. As such, the immigrant Haitian community is uniquely dependent on the oral tradition as a way of obtaining and of disseminating information. This may also explain the importance, noted by the focus group, of having physicians to whom they can relate linguistically.

Not surprisingly, the physician-patient relationship appeared as a key component in learning about and accepting colon cancer screening. Similar to other immigrant communities [22], the community reports that if a physician or other health educator suggests cancer screening, the patient is likely to complete it. Physicians, therefore, must be vigilant recommending colorectal cancer screening to their patients.

The importance of disseminating information about how colorectal cancer screening can be lifesaving is highlighted by the fact that most of the participants noted that they would not visit a physician unless they felt that something was wrong. Furthermore, many misconceptions regarding cancer and its development were evident in the discussions.

The concept of “wellness visits” or “check-ups” has not been integrated into the fabric of the immigrant Haitian community. Many barriers remain to achieving this goal and implementing effective CRC screening programs. Materials, including audio, must be developed in the community’s language, addressing community knowledge, beliefs, and concerns. CRC screening payment strategies for those without insurance must be devised and publicized to both community members and the physicians who serve them. Interpreters must be made widely available. Finally, providers, who are seen as key for health intervention, should be educated on CRC and the community, and encouraged to refer at-risk patients for screening.

Acknowledgments

This work was funded by the Special Populations Network of the National Cancer Institute Grant # UA CA 86286-01. We thank the Flatbush Haitian Center, and Radio Tropicale for their support of this project.

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Table 1

Elements of focus group interviews

Element	Sample questions
Access to health care	<ul style="list-style-type: none"> • Where would you go to see a doctor if you needed to? • What is the biggest problem in getting a visit with a doctor? • Do you have health insurance? What type? • Do you have a primary doctor? Male or female?
Attitudes and beliefs about primary care	<ul style="list-style-type: none"> • How do you feel about going to the doctor? • How often do you see your doctor? • Do you go to the doctor when you are supposed to? Why or why not? • If you have a primary doctor, do you always understand your doctor? Does your doctor speak French or Creole? • If you do not have a primary doctor, what is the main reason why you do not have one? • Do you always understand your doctor? • Does your doctor speak French or Creole?
Knowledge about colon cancer	<ul style="list-style-type: none"> • What do you think causes colon cancer? • Who do you think is at risk for getting colon cancer? • Can colon cancer be prevented? If so, how? • Can colon cancer be cured? Why? Why not?
Attitudes and beliefs about colon cancer screening	<ul style="list-style-type: none"> • Are there tests that can be done to check for colon cancer? • What test would you be willing to do for colon cancer screening? • Have you ever been tested for colon cancer? When? Why? Why not? • In your opinion, what would help you to have colon cancer screening?

Table 2

Focus group demographics

	Average Risk (n = 45)	
	Male (n = 18)	Female (n = 27)
Age in years (range)	55 (41–77)	54 (41–83)
Years in the US <i>n</i> (%)		
< 1 year	2 (11)	3 (12)
1–3 years	5 (28)	10 (39)
4–5 years	2 (11)	4 (15)
6–10 years	1 (6)	4 (15)
> 10 years	8 (44)	5 (19)
Years of schooling <i>n</i> (%)		
< 1 year	2 (11)	2 (7)
1–3 years	0 (0)	7 (26)
4–5 years	2 (11)	0 (0)
6–8 years	5 (28)	10 (37)
9–12 years	6 (33)	8 (30)
Some university/college	2 (11)	0 (0)
Graduate school	1 (6)	0 (0)
Language spoken at home <i>n</i> (%)		
Creole only	11 (61)	20 (74)
English and Creole	7 (39)	7 (26)
Citizenship <i>n</i> (%)		
Naturalized US citizen	4 (24)	5 (19)
Permanent resident	10 (59)	14 (52)
Temporary immigrant status	1 (6)	5 (19)
Not documented	1 (25)	3 (11)
Employment status <i>n</i> (%)		
Full time	10 (56)	5 (19)
Part time	6 (33)	3 (11)
Temporary/short term	1 (6)	1 (4)
Unemployed	4 (22)	18 (67)
Health coverage <i>n</i> (%)		
None	5 (28)	11 (41)
Medicaid	6 (33)	14 (52)
Medicare	1 (6)	0 (0)
Employer-funded	6 (33)	2 (7)