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Understanding cancer screening service utilization by Somali men in Minnesota

Barrett Sewali^{2,1}, Rebekah Pratt¹, Ekland Abdiwahab^{2,1}, Saeed Fahia⁶, Kathleen Thiede Call^{2,3,5}, and Kolawole S. Okuyemi^{2,3,4,1}

²Program in Health Disparities Research, University of Minnesota, Minneapolis, MN

³Center for Health Equity, University of Minnesota, Minneapolis, MN

⁴Masonic Cancer Center, University of Minnesota, Minneapolis, MN

⁵Division of Health Policy and Management, School of Public Health, University of Minnesota, Minneapolis, MN

⁶Confederation of Somali Community in Minnesota, Minneapolis, MN

BACKGROUND

Despite compelling evidence that cancer screening leads to early detection and treatment [1, 2], not all racial and ethnic groups in the United States (U.S.) use or have equal access to cancer screening services [3–5]. Being foreign born or a recent immigrant strongly predicts low use of screening services [6–10]. Somali immigrants are a relatively new population in the U.S., and most reside in Minnesota [11–13].

Cancer-screening disparities in the U.S. have been well documented; with factors such as race, ethnicity, and socioeconomic status contributing to these disparities [14–21]. However, these disparities have not been categorically broken down into specific immigrant groups. Available data from the American Cancer Society shows, cancer incidence, mortality and screening rates are categorized and reported under five races; Non-Hispanic Whites, African Americans (AA's), Asian American or Pacific Islander American Indian or Alaska Native and Hispanic Latino [22]. It is evident that the AA's disproportionately have higher mortality rates compared to all other races [22]. To our knowledge, there are no available data on the Somali immigrant population in the U.S; these data are only presented at the broader race and ethnicity levels [23].

However, some geographic or population specific U.S. based studies have examined barriers and facilitators to cancer screening among Somali women [24–26]. Some of the barriers reported by Somali women included; reported include fear of cancer, embarrassment, lack of insurance, no transportation, and limited English proficiency [24–26]. One Study conducted in Minnesota, showed that Somali women are less likely to undergo Pap testing compared to

¹Corresponding author: Barrett Sewali, Department of Family Medicine and Community Health, 717 Delaware St. SE. Ste. 166, Minneapolis, MN 55414, Phone: 612-625-4912, Fax: 612-626-6782, sewal026@umn.edu.

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other African immigrant women [27]. Another study by Morrison et al. in Minnesota, using patient's electronic medical records showed significantly lower completion rates of cancer screening among Somali male and female patients compared to non-Somali patients in a primary care practice in Rochester [28].

Existing research on cancer screening in the Somali immigrant population is fairly limited to women's breast and cervical cancer screening. To address this limitation we conducted a qualitative study to explore men's perspectives surrounding use of cancer screening services. Our exploration of factors that promote or hinder uptake of preventive healthcare services for Somali men is guided by the health belief model (HBM). Past studies that have used the HBM to demonstrate that individuals who perceive being at high risk of getting cancer are more likely to screen and the lower the perception of risk the less likely they are to screen [29, 30].

METHODS

This work was a result of a partnership between the University of Minnesota and a Somali community-based organization; the Confederation of Somali Community in Minnesota (CSCM). We conducted 20 key informant (KI) interviews followed by 8 focus groups (FG) interviews. Each participant was compensated \$30 for their time. The study was approved and monitored by the University of Minnesota Institutional Review Board.

Procedures (refer to Figure 2)

Training of Community Health Workers and Development of the KI interview guide—Two community health workers (CHW's) affiliated with CSCM were assigned to the project and were trained on interview methodology and the research protocol over several meetings with a member of the university research team (BS).

The key informant moderator's guide was developed over several meetings held with our research team with guidance from the community partner on the cultural appropriateness of the questions (for details see Table 2). The interview guide included semi-structured and open-ended questions. The community partner translated all study materials into Somali language. Interviews were conducted in participants preferred language.

Recruitment and Enrollment; KI interviews—CHW's approached potential key informant participants in the community and explained the purpose of the study. If the participant was willing to participate, an appointment was made to obtain informed consent and to conduct the interview. The CHW's undertook recruitment by word of mouth. Individuals recruited included Somali males, 18 years of age and older. The twenty individuals enrolled included leaders of community organizations, healthcare professionals, religious leaders and opinion leaders (well respected elderly community members). These men were selected because they were knowledgeable regarding the health beliefs of the Somali community.

Conducting of KI interviews—The one-on-one interviews were conducted between March and May of 2013. Interviews were conducted at a Somali community center. The interviews lasted for approximately 60 minutes.

Data collection for KI interviews—During the interview sessions, one of the CHW's meticulously took notes that were later summarized at the end of the session and read back to the participant to verify if they represented his views. All the interviews were audio recorded during the session. All audio transcripts were hand transcribed by a University Somali born research assistant (EA) who was part of the study team.

KI data Analysis—All the transcripts were entered into the QSR NVivo 10 software and shared with the coders. Our multidisciplinary team used grounded theory, thematic approach to conduct the analysis [21]. One university member (BS) conducted the majority of the coding. The analysis process identified emergent themes and subthemes based on transcripts. As new themes and subthemes emerged in each interview, they were noted. With each subsequent interview, some divergent themes and subthemes were introduced in the subsequent interviews. Themes and subthemes were then grouped, and analyzed to gain an overall understanding of participant's views surrounding cancer screening. The coder and a qualitative expert (RP) met regularly to review the themes and ensure consistency with the transcripts.

Development of FG guide—The focus group guide was developed following the analysis of the key informant interview data thus allowing for further depth and clarification of themes that emerged from the individual interviews (for details see Table 3).

Recruitment Of FG participants—*Focus groups* were conducted between June and September 2013. A total of forty four individuals took part in a series of 8 focus groups. Individuals recruited for the focus groups included Somali males 18 years and above. Participants who took part in the KI interviews were not eligible to participate in the FG interviews. Men were purposively recruited who would fit these four categories (1) 18 – 49 years with < 5 years of residence in the U.S, (2) 18 – 49 years with > 5 years of residence, (3) 50 years and older with < 5 years of residence and (4) 50 years and older with > 5 years of residence. These homogeneous groupings were intended to ensure men's comfort sharing their attitudes and opinions.

Enrollment of for FG interviews—CHW's approached potential FG participants in the community and explained the purpose of the study. If the participant was willing to participate, an appointment (date and time) was made with 5–6 FG participants to meet and conduct the focus group. Informed consent was obtained on the day of the interview and the session was conducted thereafter.

FG data Analysis—The team used similar data and analysis methods as those used for the key informant interviews.

RESULTS

Six main themes emerged in the analysis, these were; 1) religious influence on cancer screening, 2) fear surrounding screening, 3) beliefs about a cancer diagnosis, 4) attitudes towards screening, 5) knowledge of cancer screening, and 6) barriers to cancer screening. As illustrated in figure 1 we present an analysis of how these themes relate to key components of the health belief model.

Participants

A total of sixty four adult Somali-born men living in the Minneapolis or Saint Paul area agreed to participate in the study (20 key informants and 44 focus group participants across 8 groups). Fifty six percent (36) of the participants were 50 years and older, with 72% (46) were married; A more detailed description of the demographic profile of participants is shown in Table 1.

Emerging Themes

1) Religious influence on cancer screening: Most participants described a belief among Somali men that getting cancer is God's will, and one has no control over God's will. Many participants indicated that if one was a faithful Muslim, he would be protected from getting cancer. Participants further indicated that good health was awarded to a person by God. Many participants believe that as an individual, one cannot prevent illness, it's only God that can protect them from illness. Despite the belief in God's will participants indicated that their faith encourages them to seek and live a healthy life style.

Prophet Muhammad himself used a doctor. He's the one who revealed the Quran. No one said leave the Quran, we use the Quran but we go first to the one who knows. (Key informant #019) Luckily God has not given it to me; the cases are few in Muslims. Cancer is rare in the Muslim population. God protects those who are truly faithful Muslims. (Key informant #011)

The participants in our study emphasized religious venues as places that might contribute to the awareness and acceptance of the preventive health services.

2) Fear surrounding cancer screening: The fear of being diagnosed with cancer following a screening test was a major concern for all participants. Few participants indicated that they would rather know they had cancer in order to do something about it before it's too late. Most men indicated that they would rather live without knowing because finding out would only cause more fear and anxiety, which would in turn exacerbate the problem.

The issue has become a taboo. Our people like to believe that if you don't know something it's okay. If you hide cancer it will not bring about a problem. (Focus group #007)

Cancer is a disease that all participants associated with a loss of hope, fear and death. Many participants in both key informant interviews and focus group discussions shared stories of people they knew that died from cancer and that the disappointment of knowing would only make the cancer worse.

Like this gentleman said, when someone finds out they have cancer they get disappointed, they give up, they leave the community and get ready for death. (Focus group #006)

3) Beliefs towards cancer screening: Most participants believed that cancer was most common in white populations and less so among Africans. Most participants understood cancer screening as a test an individual takes only after they fall ill. Often, participants shared their view that Somalis will not take prescribed medications or visit a healthcare provider if they do not feel sick; a practice which is at odds with the concept of preventive care. Some participants described how it was not logical for them to go ahead and screen for something they don't know they have.

If God did not give you a disease then don't wish it upon yourself. (Key informant #011)

4) Attitudes towards cancer screening: Most participants agreed that cancer is a deadly disease; however, they did not feel they were susceptible to getting cancer and thus had no reason to screen. Several participants had a positive attitude about screening and indicated that neither their religion nor culture forbids screening for cancer. Some shared a view that their health insurance card has a finite amount of money on it and they prefer to save that resource for emergency situations. Participants felt that even with health insurance, they were not willing to use it as there is a lack of trust with the healthcare system.

People are deeply suspicious about the doctors, so, they don't know anything about cancer; they tend to think doctors are there to milk their health insurance card to get some money from the insurances. (Key informant #003)

5) Barriers to screening: The men indicated that fear of cancer coupled with embarrassment of the screening test are some of the reasons they did not want to screen. Some participants also indicated difficulties with communication with the healthcare system due to their limited English proficiency. The fear of friends and family abandoning one who is sick is a major barrier to seeking cancer screening services for Somali men. Being discovered as someone with cancer could lead to being ostracized.

Another man may not see it that way. He may see it forget cancer even if he has a cold he might be afraid of being ostracized by the community and that is the reason he might not even go the doctor. (Key informant #012)

The concern for privacy impacted the use of medical interpreters. Participants indicated that the privacy of their health information was undermined, given that they had to use interpreters to communicate with health providers. Interpreters are members of this relatively small community in which most people know one another directly or indirectly. They worried that news about cancer would not remain private.

6) Knowledge surrounding cancer screening: Health prevention was described as a fairly new concept for Somali men, with many saying they had become familiar with health prevention only after they migrated to the U.S. Screening was described primarily as a treatment procedure as opposed to an investigative procedure.

The cancer screening I have heard about is the primary treatment or screening or some other body which gets swollen. (Key informant #008)

The participants indicated that many men in their community might not screen because they are not convinced that one should check for a disease without any symptoms. They indicated that they needed to know more about cancer and cancer screening in order to make a decision to screen. Few participants indicated that they were aware that cancer screening provides opportunities for early and timely diagnosis and treatment.

DISCUSSION

We used the Health Belief Model, (as illustrated in figure 1) to make sense of the cancer screening barriers reported by Somali men. Using the model provided us with insight about individual perceptions of cancer and cancer screening. Overall, our results indicate a general lack of knowledge among Somali men in this study on issues surrounding cancer screening. To our knowledge this is the first study that has discussed at length the barriers faced by Somali men in relation to use and access to cancer screening services. Several studies have addressed cancer screening barriers for Somali women [24–29].

The men had varying opinions with regard to being at risk of developing cancer, with most men indicating that they were less at risk because of their Islamic faith as compared to the non-Muslims. The participants' views about God's will and the encouragement from their faith to keep healthy are consistent with some studies that have shown that the Islamic faith compels individuals to take responsibility for their health by choosing healthy lifestyles. Our findings run contrary to several studies focusing on women's cancer screening behaviors that have shown religion in some instances acts as a barrier to the use of screening services for [Somali or Muslim] women [32, 38, 39]. We are inclined to conclude that religion potentially plays both positive and negative role in the men's perceptions of general health.

Studies that have addressed cancer-screening barriers in Somali women indicated that some of the perceived barriers were fear of cancer, embarrassment of the screening test, and limited English ability [24–26]; these barriers are similar to those reported by Somali men in this study. In addition to these perceived barriers, Somali men in our study stressed the fear of private health information being compromised by Somali interpreters; interpreters who are also members of their community. The fear of being stigmatized and ostracized by the community as a result of a cancer diagnosis is compounded by the lack of trust in the health system and interpreter mistrust. Future studies should explore ethical training of interpreters in order to improve screening behaviors within the Somali community.

Furthermore, Somali men did not perceive themselves to be at risk for developing cancer and considered the disease to be more frequent in the white population and in women. Most participants believed that cancer is an incurable disease and a diagnosis was considered to be a death sentence. This fear leads to the avoidance of the discussion of cancer in this community. Despite many of the men understanding the severity of cancer, they did not perceive their own vulnerability. This low perceived susceptibility is consistent with other studies [34, 35], where immigrants expressed the attitude that screening was unnecessary.

Somali women identified factors that would enable them utilize screening services, these included physician recommendations, lay health workers reminders, written materials, and media [36, 37]; men in this study referenced some of the same factors identified above. Given what we have learned from the Somali men, future interventions need to incorporate individual knowledge and perceptions surrounding cancer screening in order to increase the use of cancer-screening services.

Implications

The findings from this study indicate that a community-based, culturally tailored intervention may be effective at increasing screening rates in the Somali population. Increasing awareness of cancer types, symptoms, causes, tests, and treatment may help quell fears associated with poor-outcomes and may increase cancer screen among men. As indicated by the participants, it may be particularly important to utilize the Mosque to disseminate cancer related information. This may be effective because the Mosque already acts as a vector for non-health related information and the community has already established trust with those in charge of the Mosques. Similar methods have already been shown to be effective in other minority populations (e.g., church-based interventions in the African American population) [40, 41].

Limitations

This research has several limitations. It is possible that discrepancies in translations from Somali to English could have inadvertently changed the meanings of some comments made by participants. We did not ask participants whether they had ever screened for cancer prior to study. The small sample size and participants not being selected at random limits the generalizability of our findings. Despite these limitations, this study raises a number of important issues that have implications for advancing knowledge to increase screening in this population.

CONCLUSIONS

To our knowledge, this is the first study to assess knowledge, attitudes and beliefs surrounding cancer screening in Somali men in the U.S. Our study highlights potential areas of opportunity to engage religious leaders in future efforts to improve cancer screening uptake in the Somali population.

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FIGURE 1.
Themes described utilizing the Health Belief Model's key components:

FIGURE 2.
STUDY FLOW DIAGRAM

* No overlapping participants

TABLE 1

Demographic characteristics of 64 study participants

Demographic Factors		Key Informants	Focus groups informants
		Community leaders	Community members
		(n=20)	(n=44)
Age (years)	18 – 49	4 (20%)	24 (55%)
	50	16 (80%)	20 (45%)
Marital status	Married	17 (85%)	29 (66%)
	Divorced/Separated	2 (10%)	6 (14%)
	Widowed	1 (5%)	9 (20%)
Health insurance	No health insurance	7 (35%)	7 (16%)
	With health insurance	13 (65%)	37 (84%)
Number of years in MN	5	5 (25%)	24 (50%)
	> 5	15 (75%)	24 (50%)
Highest grade level	High School or GED	15 (75%)	34 (77%)
	< High School or GED	5 (25%)	10 (23%)
Residence	Inner City/Urban	17 (85%)	32 (73%)
	Rural	3 (15%)	15 (27%)
Monthly Income	\$1200 / month	12 (60%)	Not asked
	>\$1200 – \$1799 / month	8 (40%)	Not asked
Screened for Cancer	Yes	Not asked	12 (27%)
	No	Not asked	20 (45%)
	No response	Not asked	12 (27%)

TABLE 2

Summary guide for Key informant interviews with community leaders

Knowledge of cancer screening	
1)	What is your understanding of cancer or if someone asked you what cancer is; what would be your response?
2)	What do you think are some of the causes of cancer in general?
To assess the attitudes of Somali men about cancer prevention.	
3)	Some cancers can be screened for even before they happen! Do you agree or disagree with this information?
To assess the beliefs of Somali men about cancer prevention.	
4)	Do you believe that some cancers can be detected and diagnosed early?
5)	Who gets cancer and why do you think they may get it?
To determine the potential role of men in promoting cancer screening among Somali immigrant women.	
6)	What role do Somali men play when it comes to general cancer screening for their families?
7)	Do you know who would finally make the health decisions in a family?
Barriers to cancer screening and possible solutions:	
8)	Now I'd like us to list all of the reasons your community might not utilize cancer screening services.
To understand ways to improve cancer screening practices among Somali immigrant populations.	
9)	Can you suggest ways we can improve utilization of cancer screening services among your community.

TABLE 3

Summary guide for focus groups community members

1	What roles do men in your community have in regards to healthcare decisions for themselves and their families? (Considering the changing roles in the U.S)
2	In your own opinions how do we utilize these roles to encourage cancer screening for men, their families and the community at large?
3	How has migration and the changing family roles influenced your general health and that of the community? (You can give both positive and negative implications of this change on your health and the health of the community in general)
4	How should we involve men in efforts to increase cancer screening utilization?
5	What do you view or look at as opportunities or strengths as men in your community when it comes to seeking preventive healthcare services?
6	How do we build on these opportunities or strengths to increase cancer screening for men in your community?
7	What are the barriers or challenges that men face when it comes to accessing healthcare services?
8	Can you suggest ways we can address these barriers or challenges that you face?
9	Religion might influence the way some people make health decisions.
	✓ What are your views about this?
	✓ How do we use religion to promote cancer screening in the community?
10	If you had an opportunity to design a program that would encourage men in your community to screen for cancer what would you do or what would this program look like?