Journal of Community Health (2018) 43:929–936
https://doi.org/10.1007/s10900-018-0507-z

ORIGINAL PAPER

Cancer Community Education in Somali Refugees in Nebraska

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Published online: 18 April 2018

Abstract
Nebraska has one of the highest numbers of refugees per capita in the U.S. A high number of Somalis have resettled in Nebraska due to job opportunities and the low cost of living. In this paper, we report the process and the results of a cervical and breast cancer education program for Somali women conducted through a collaboration among public health, academia, and community entities. The curriculum was built to be suitable for the literacy level and cultural values of this community. Topics include female reproductive anatomy; breast and cervical cancer knowledge and screening; hepatitis C and liver cancer; and preparing for a health screening visit. Two community members trained as lay health workers conducted a pilot and an actual education session. The 2-day education program was attended by 52 women. Qualitative data showed the intervention to be promising for this and other African refugee populations.

Keywords Refugee · Cancer · Education · Health disparities · Cancer prevention and screening

Introduction

According to the Pew Research Center's analysis of data from the U.S. State Department's Refugee Processing Center and the U.S. Census Bureau, 76 refugees were resettled per 100,000 Nebraskans in the fiscal year 2016 [1]. Among all U.S. states, Nebraska resettled the highest number of refugees per capita. Between 2002 and 2015, approximately 10,000 refugees were newly resettled to Nebraska. The top 10 countries of origin were Burma, Bhutan, Sudan, Iraq, Somalia, Vietnam, Bosnia and Herzegovina, Ukraine, and Cuba [2]. A growing Somali community has developed in Nebraska due to the abundant work opportunities and low cost of living [3]. According to resettlement data from the Bureau of Population, Refugees, and Migration, 555 Somali refugees were directly resettled to Nebraska during the period of 2004–2015 [2]. During the same period, 2255 Somali-born persons received permanent resident status in Nebraska [4]. These statistics do not include secondary migrants who moved to Nebraska after receiving their permanent resident status in other states. According to refugee resettlement agencies and refugee community leaders, there are approximately 20,000 Muslim immigrants in Nebraska, including people from Somalia.

In Somalia and in other African countries, chronic diseases, (including cancer) are emerging public health problems. In Africa and many developing countries, cancers related to infectious diseases are much more common than in developed countries. In Somalia and South Sudan, cervical cancer incidence rates are 5–6 times higher and the mortality rate is 8–10 times higher than the US [5]. Lack of screening services are attributed to these high rates [6]. Breast cancer, which was once uncommon in developing countries, is now rapidly rising in Africa, in part because of a higher prevalence of reproductive risk factors, obesity, and better detection methods [6]. Although breast cancer incidence rates are lower in Somalia and South Sudan compared to the U.S., it is important to note that breast cancer mortality rates are much higher in these countries compared to the U.S., somewhat replicating patterns in black and white Americans [5, 7].

An analysis of data from the Health Information National Trends (HINTS) survey, a national survey of cancer information, showed that foreign-born persons are less likely to

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seek cancer information, less likely to have somebody else look for cancer information for them, and less trusting of some sources of health information compared to U.S.-born persons [8]. In an interview study of Somali and Somali Bantu women in Rochester, New York, only 26% understood the term "cancer." About 53% of participants recognized the terms, "Pap test," "GYN check-up," or "pelvic exam"; no Bantu women knew these terms [9]. With the exception of four respondents who had been in the U.S. for 5 years or longer, participants indicated that they would not go to see the doctor unless they were sick [9]. In a survey study of Somali and other African immigrants in Minnesota, only 61 and 52% of age-eligible women had ever been screened for breast and cervical cancer, respectively [10]. Another study examined medical records from primary care clinics in Minnesota. Mammogram and Pap smear use was lower among Somali patients compared to non-Somali patients (mammogram in the past year: 15.4 vs. 48.5%; Pap smear in the past 3 years: 48.8 vs. 69.1%) [11].

There is a dearth of research on interventions to increase the knowledge and uptake of cancer screening among refugees, especially African refugees. Applying an intervention proven to be effective for other underserved populations may be a sensible approach. For example, an evidenced-based intervention, such as the Lay Health Worker model is promising [12, 13]. Lay health workers are community members who do not necessarily have a medical certification but have received training enabling them to provide health services and health promotion to their community [13]. A report from the Cochrane Database for Systematic Reviews that reviewed over forty-three studies concluded that lay health workers can effectively promote healthy behaviors in minorities [12].

In late 2015, Nebraska's Breast and Cervical Cancer Early Detection Program ("Every Woman Matters") reached out to the faculty at the University of Nebraska Medical Center (UNMC) to initiate a project to increase the awareness and the use of breast and cervical cancer screening among refugees. We used a logic model to plan and pilot a lay health worker based cancer education program specifically tailored toward Somali women. In this paper, we will describe our process of developing educational materials and the results of the pilot education program.

Methods

Logic Model and Timeline Development

We used a logic model to organize the intervention (Fig. 1). Our long-term goal is to reduce cancer disparities among refugees. The project goal was to increase the rates of breast and cervical cancer screening among refugees. We assumed that after women complete the educational sessions they will have increased levels of understanding of cancer screening and will be better prepared to undergo cervical and breast cancer screening procedures. Every intervention requires an investment of resources. As shown in Fig. 1 "Inputs", the resources used for this project include funding through the Breast and Cervical Cancer Early Detection Program (BCCEDP), partnerships introduced by BCCEDP, the expertise of steering committee members and UNMC faculty, and existing resources on cancer prevention and control. Figure 1 also shows "Activities" and associated "Outputs" and "Outcomes." We developed a timeline for the 1.5-year project period to map the activities in detail (Table 1). This project received an exemption status from the UNMC's IRB for being a quality control intervention instead of human research. For this reason, informed consent was not collected from intervention participants.

Year 1 Activities

The process and findings from the needs assessment conducted in Year 1 have been described in detail elsewhere [14]. During the first 6-month project period, we spent about 2 months preparing for the needs assessment. Individuals who closely worked with refugee women were invited to join a steering committee, resulting in a committee with representatives from a wide range of organizations and backgrounds, (health care providers, the state refugee program personnel, refugee resettlement agency personnel, and university faculty). We discussed the findings from the literature review and environmental scan with the steering committee members. The Somali community was chosen as a priority population because Somalia has one of the highest incidence of cervical cancer and there had been limited outreach done in Nebraska with women from Somalia. Although there are other Nebraskan communities with many Somali people, the city of Omaha was chosen as the focus of this outreach because a steering committee member who worked as a refugee outreach specialist had contacts with the Omaha Somali community.

Focus groups were implemented to obtain input from Somali women and individuals who worked closely with Somali women. We prepared a protocol and questions for the focus groups and initiated communication with the Somali community in Omaha. The focus groups helped to identify barriers to receiving cervical and breast cancer screening, knowledge and interest level about cancer education, and their preferred mode of education (i.e., group education).

Year 2 Activities

The first part of Year 2 was spent preparing educational materials and establishing a partnership with the Somali

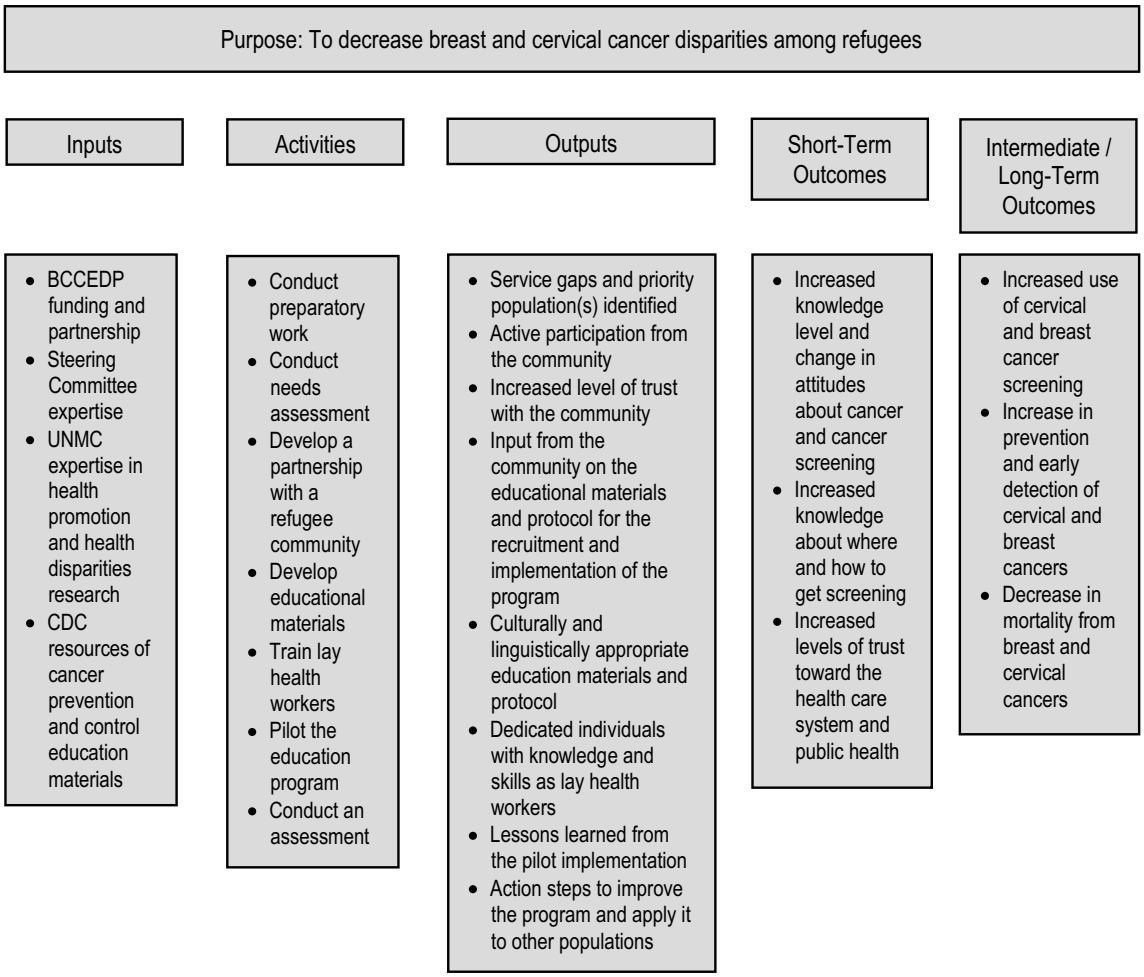

Fig. 1 Logic model used to design intervention. The model maps the inputs and activities that contribute to the intervention, as well as the expected outputs, short-term outcomes, and intermediate/long-term outcomes

community to plan and implement the education program. We designed a group-level primary intervention based on the Health Belief Model. The model theorizes that people's beliefs about their risk for a disease, and their perception of benefits to prevent it, directly influence their willingness to act [15].The second part of Year 2 was used to train lay health workers, pilot and implement education sessions, and obtain feedback from participants.

Curriculum Topics and Information Sources

Curriculum topics include the basics of reproductive anatomy, cancer, and cervical and breast cancer screening (Table 2). Cancer related information and screening guidelines were obtained from the Centers for Disease Prevention and Control and the American Cancer Society [16, 17]. We also reviewed the educational material for Somali refugees available through the Ethno-med website [18].

Module Development

Educational modules were developed in the form of PowerPoint slides, speaker notes, interactive parts, and pre- and post-tests. The PowerPoint slides and the pre/post tests are in English but the speaker's notes were translated to Somali. Each module consists of objectives, five to six slides of educational content and images, interactive exercises, and pre- and post-tests. The educational content includes a description of the cancer types, prevalence of cancer in Somalia compared to the US, risk factors, preventive strategies, and screening recommendations. The interactive exercises include role-play, myth versus truth exercises, and anatomy model presentations. A pre/post-test consisting of four to five questions was created to be distributed at the beginning and end of each module to test the knowledge gained. An artist was hired to make culturally themed slide designs, making the material more appealing to community members.

Table 1 Timeline of intervention creation and implementation

	Calendar year/month	Activities
Project year 1 (6 months)	2016 Jan–Feb	Preparatory work for needs assessment
		• Establish a steering committee
		• Conduct a literature review: (1) top 10 countries where refugees are from, (2) breast and cervical incidence and mortality rates in the top 10 countries, (3) cancer screening and HPV vaccination in the top 10 countries, (4) cancer screening and HPV vaccination use among US refugees, and (5) barriers and promotors of breast and cervical cancer screening
		• Conduct an environmental scan: (1) levels of outreach with different refugee communities in Nebraska, and (2) existing education materials for different refugee populations
		• Prepare for the needs assessment: (1) draft focus group questions and (2) draft focus group protocol
		• Implement a steering committee meeting: (1) reflection on the literature review and environmental scan findings, (2) identification of the priority populations, and (3) year 1 action steps and a timeline
		Initiation of partnership development with community
		• Identify points of contact based on input from the steering committee
		• Identify focus group facilitators
	2016 Mar–Jun	Needs assessment
		• Finalize the focus group questions and protocol
		• Conduct focus groups to obtain feedback from: (1) health care providers, (2) refugee resettlement/social work agencies, (3) public health, and (4) community members
		• Analyze the focus group data
		Dissemination
		• Disseminate the end-of-year report to the steering committee
		• Present at a conference and prepare a manuscript
Project Year 2 (12 months)	2016 Jul–Dec	Building partnership development with community
		• Make visits to the community center to meet with community leaders
		• Confirm the individuals to serve as lay health educators
		• Develop formal agreements with the community center and lay health educators
		Education material development
		• Search for existing cervical and breast cancer education materials
		• Outline the curriculum
		• Draft the modules
		• Implement a steering committee meeting: (1) obtain feedback on the topics and (2) obtain feedback on the draft modules
		• Obtain clinical input from a nurse practitioner who sees refugee patients
		• Obtain community input from the lay health educators
	2017 Jan–Jun	Train lay health worker
		• Implement a training session
		• Modify the curriculum based on the feedback obtained from the training session
		Pilot
		• Conduct a half-day pilot workshop
		• Finalize the curriculum based on the feedback from the pilot workshop
		Workshop
		• Conduct a 2-day workshop
		• Obtain feedback from the facilitators and participants
		Dissemination
		• Disseminate the end-of-year report to the steering committee
		• Prepare a manuscript

Table 2 Intervention curriculum, including module themes and topics covered

Module no. and title	Topics
1: What is cancer?	• What is cancer? • Different types of cancer • Cancer treatment options • Cancer screening
2: Reproductive anatomy basics	• Parts of female reproductive system • Functions of female reproductive system
3: Cervical cancer and screening	• What is cervical cancer? • What are the risk factors for cervical cancer? • Ways to prevent cervical cancer • Cervical cancer screening guidelines • What is the Pap test?
4: HPV vaccine	• What is the Human Papilloma Virus (HPV)? • What is the HPV vaccine? • Who should get the HPV vaccine? • Should I allow my daughter or son to take it?
5: Breast cancer and screening	• What is breast cancer? • What are the risk factors for breast cancer? • Ways to reduce your risk of breast cancer • Breast cancer screening guidelines • What is a mammogram? • Breast cancer treatment options
6: Hepatitis C and cancer	• Location and function of the liver • Causes of liver cancer • Signs and symptoms of liver cancer • Liver cancer prevention • Hepatitis C screening
7: Preparing for a doctor's visit	• Preparing for a doctor's visit • How to make your clinic visit successful • How to avoid common mistakes

Content and Cultural Review

After curriculum development, a content review was performed by a nurse practitioner who sees refugee patients at a community clinic. To ensure cultural appropriateness and comprehension, the modules were also reviewed by the two Somali lay health workers. It was clear after their review that the initial curriculum needed to be edited to be less clinical. Sections were also added to explain certain vocabulary, for example, virus and human cells. Some interactive activities such as "Myth vs. Truth" were also changed to be more in line with what is commonly known in the Somali community.

Evaluation

For all modules, an evaluation form was developed by the core research team. It was adapted from the University of Nebraska Medical Center's E-Learning program. The form uses 12 evaluation criteria: accuracy, appropriateness, clarity, readability, organization, flow of contents, literacy level, aesthetic, cultural appropriateness, resources, and usefulness. A scale of three was used for each criterion, with a high score of three (excellent) and a low score of 1 (poor). The focus group assessment forms were reviewed by the research group and changes were made to the curriculum as needed.

Lay Health Worker Education and Training

Two lay health workers have been involved from the curriculum designing stage, providing input on module content and literacy level. Both individuals were working on advanced degrees and have also worked as outreach specialists and interpreters for the Somali community. Because they already had considerable experience in educational settings, we focused their training on clinical content. They reviewed the educational materials before the training session and came with questions and suggestions for modification of the materials. We had a mock session with members from the research team, where they lay health workers facilitated selected modules so they could respond to potential questions from the audience.

Pilot

One week before the educational intervention, we conducted a pilot session with eight Somali women of various ages, ranging from early 20 s to over the age of 50. This half-day

long pilot took place at the Somali community center and included registration, practice sessions, and a wrap-up. The audience was engaged, asked questions, and gave suggestions to improve the materials and process. Notes were taken and the curriculum was revised according to their feedback.

Recruitment of Participants

Several weeks before the intervention, the lay health workers collaborated with the Somali Community Center leadership team to invite women within the Somali community to attend the intervention sessions. They went door to door, handing invitations written to women in Somali. Reminders were texted to participants a few days before the educational sessions. Transportation was also available for participants.

Educational Sessions

We conducted a 2-day educational intervention, with each session lasting 90 min plus a lunch and prayer break. Daycare was also provided at the intervention site. As per the advice of Somali community educators, ethnic food was served as a symbol of good hospitality and respect in the Somali culture. The sessions were conducted at the "Somali Community Service, Inc." Center, a community based organization that works to improve the health, safety, and productivity of the Somali community in Omaha [19]. It is equipped with a meeting area that can hold up to 70 people, an office, and a prayer room. The center was an ideal venue for the intervention as it is located in close proximity to the neighborhood in which many Somali families live. In addition, Somali community members are familiar with the space, as they use it to gather on the weekends, share food, and pray together. One focus group was done three weeks after the content and cultural review by community leaders. The focus group was conducted in English and Somali and was recorded.

Results

Five Somali women attended the focus group. Fifty-two people attended the educational session. The majority were of Somali ethnicity (94%) and between the ages of 31–40 years old (32%) (Table 3). Most participants were born in Somalia (94%) and had lived in the U.S. for less than two years (35%). The participants were from different literacy levels, with 21% having no formal schooling and (38%) having a middle school education. We used pencil and paper to obtain demographic information from each participant, including age, educational level, and the number of years in the U.S.

Overall, the intervention was perceived to be successful. Most women interviewed reported that they were invited to this intervention by the lay health workers or community leaders. They reported that the best way to recruit persons from the Somali community is word of mouth. They also mentioned two apartment complexes where most Somali community members live in and around and can be used to recruit or host future events.

Topics that resonated with the audience the most included cervical cancer screening and the high rate of cervical cancer in Somalia. Although none of the interviewees reported to her health provider for cancer screening after the sessions, they all expressed that the session motivated them to talk to their health provider about cancer screening. The literacy level of the educational material was thought to be appropriate to most women. One younger woman stated that she was familiar with most of the information provided, but it was interesting to hear it in her local language. Somali women mostly liked that the education was done in their language and at their community center.

Table 3 Demographics of study participants

Characteristics	Number	Percentage
Age		
13–20	4	8.7
21–30	15	32.6
31–40	15	32.6
41–49	4	8.7
50–64	7	15.2
65+	1	2.2
Ethnicity		
Somali	43	93.5
Somali Bantu	2	4.4
Other	1	2.2
Place of birth		
USA	1	4.4
Somalia	40	88.9
Kenya	2	4.4
Other	1	2.2%
Years living in the USA		
2 years or less	16	34.8
3–5 years	7	15.2
5–10 years	12	26.1
10+ years	11	23.9
Schooling		
No schooling	10	21.3
1–3 years	6	12.8
4–6 years	0	0.0
Middle school	18	38.3
High school	10	21.3
Some college	3	6.4

Discussion

The Somali community is a family oriented, hardworking community. Both men and women contribute financially to the family. Religious and cultural values play an important role in the lives of community members. Community members live in close proximity to each other and commonly share rides to work and school. Newcomers often follow the footsteps of the previously settled members in all aspects of their American lives. Educational backgrounds vary between people, ranging from very low literacy level to college graduates, with the majority being in between. Many Somali women speak very little English, even when they have lived many years in the U.S. Younger generations who came to the U.S. as children or teenagers take the responsibility of interpreting to other community members and thus can make ideal health educators and navigators.

This intervention was the first of its kind in Nebraska. It provided challenges and lessons that can be emphasized or avoided in future interventions. First, community partnerships and lay health workers from the community were the key to the success of this intervention. Second, recruitment through word of mouth is a successful way of inviting community members to participate. Third, the Somali community is very family oriented and offering childcare as part of the community intervention is important for its success. Fourth, having a meal helped to attract and encourage participants to continue the sessions and also was a symbol of hospitality and respect to the community. Fifth, successful teaching methods that resonated with the community were role-play that resembled common conversations between women in the Somali community.

In general, the community members and the lay health workers expressed their satisfaction with the sessions. In addition, community members indicated that this intervention showed that the Somali community center could be used in many different ways and inspired them to utilize it for other educational purposes. This indicates a larger and longer-term impact of this intervention beyond cancer health education.

In this intervention we also faced some challenges that we hope to avoid in the future. One example is that the Somali and Somali-Bantu are two different communities although both come from Somalia and speak the same language. This intervention was done in the Somali community center and although both groups were invited to the sessions, very few Bantu members attended. This illustrates the importance of tailoring the program for each community using their own community members and public spaces. Another challenge was in the evaluation aspect. Because we were not able to use the Audience Response System (ARS) due to technical issues, we used paper and pencil pre- and post-test forms. This was not the ideal way to collect information from this group because some women did not read or write English. In the future, we should use ARS so that the participants only have to choose an appropriate number (option) they see on the screen read by the instructor.

The use of a logic model was helpful in guiding the team to plan and implement activities to develop and pilot this educational program. Although some of the team members had a prior experience working with the Somali population in Nebraska, it still took approximately 1.5 years to develop a culturally and linguistically appropriate education program. Because of a high level of interest among the community leadership and lay health educators, we were able to recruit a large number of women for the pilot. However, we encountered some challenges with conducting evaluation activities due to technical issues and time constrains. Our future efforts will include an assessment of changes in both knowledge and actual screening behavior. We plan to collaborate with primary care and ObGyn providers in the community to enhance the connection between Somali women eligible to receive screening with the health care system.

Acknowledgements We would like to thank the members of the Omaha Sudanese community, the steering committee members, and other partners who helped with the project.

Funding This project was supported by funds provided by the Nebraska Department of Health and Human Services, Division of Public Health, Women's and Men's Health Programs.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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