PEDAGOGY IN HEALTH PROMOTION

Original Research

Pedagogy in Health Promotion: The Scholarship of Teaching and Learning
2017, Vol. 3(1S) 81S–87S

DOI: 10.1177/2373379917698673
journals.sagepub.com/home/php
SAGE

Cervical Cancer Attitudes and Knowledge in Somali Refugees in Nebraska

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Abstract

The state of Nebraska has a growing number of refugees with diverse backgrounds and health needs. To address these needs, a collaborative project was developed by the local performance site of the Midwestern Public Health Training Center at the University of Nebraska Medical Center, College of Public Health, and the Nebraska Department of Health and Human Services, Division of Public Health, Office of Women's and Men's Health. The purpose of this 2-year project is to improve the quality of services offered by the Office of Women's and Men's Health by assessing risk, knowledge, and preventive screening practices in refugee populations and provide recommendations to increase cancer-screening rates. The focus of the project was on cervical cancer prevention of Somali women refugees in Nebraska. In Year 1 of the project (2015-2016), a Refugee Screening Collaborative was created to provide input and recommendations throughout the project; focus groups and a literature review were completed to explore the knowledge, attitudes, and beliefs of cervical cancer screening and human papillomavirus vaccine among refugees and health care providers; and recommendations were made for the development and implementation of curricula and interventions that address the unique cultural and literacy needs of the population. This project demonstrates the importance of the Public Health Training Center program for building mutually beneficial partnerships between academia and practice.

Keywords

refugee health, cervical caner, minority health, focus groups

Introduction

Colleges of public health are responsible for assuring that students have the knowledge, skills, and abilities to be competent public health practitioners. Achieving this goal requires opportunities for students to participate in practice-based teaching and learning. Practice-based teaching is a learning collaborative among faculty, practitioners, and students. When successful, students build skills of critical thinking, implementation, collaboration, and translation of theory/science into practice. Practice-based teaching differs from traditional public health education in several ways. Practice-based teaching focuses on activities that are mutually beneficial to both academic and practice communities, involves community engagement, and requires scholarly service to assure the conditions in which all people can be healthy (Association of Schools and Programs of Public Health, 2004). One way for students to experience practice-based teaching is through participation in research projects. The goal of practice-based research for public health is to develop new knowledge that can be translated into evidence-based strategies used by practitioners. It is much more than simply doing research in a practical setting; practice-based research requires a trusting and mutually beneficial partnership that will inform and improve health outcomes in a defined community (Association of Schools of Public Health, Council of Public Health Practice Coordinators, 2006). Providing this type of training gives students the opportunity to build important skills, create and sustain partnerships, translate data into action, and work with diverse networks and coalitions.

One way for students to be involved in practice-based research is through regional Public Health Training Centers. One of the legislative mandates of the Health Resources and Services Administration Public Health

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Training Center Program is that the Centers must involve faculty members and students in collaborative projects with practitioners to enhance public health services to medically underserved communities. These types of projects build academic and practice partnerships and focus on priorities that affect the community. Additionally, students and faculty members gain practical experience, while practitioners gain research experience. A collaborative project was developed between the Local Performance Site at the University of Nebraska Medical Center (UNMC), part of the Region VII (Midwestern) Public Health Training Center and the Nebraska Department of Health and Human Services (DHHS), Division of Public Health, Office of Women's and Men's Health. The project included UNMC College of Public Health faculty from the departments of epidemiology and health promotion, a PhD student in the department of epidemiology, and several practitioners from the Nebraska DHHS, Division of Public Health. The focus of the project was on the prevention of cervical cancer in Somali women refugees in Nebraska.

Background of Collaborative Project

In 2015, the Nebraska DHHS, Division of Public Health, Office of Women's and Men's Health approached the Region VII (Midwestern) Public Health Training Center, Nebraska Local Performance Site at the UNMC, College of Public Health, about collaborating on a project to assess Somali women's knowledge, attitudes, and beliefs regarding cervical cancer and cervical cancer screening. Two faculty members, a student, and DHHS practitioners came together to establish the Refugee Cervical Cancer Preventative Screening Collaborative.

A refugee is a person who has been forced to flee his or her country because of persecution, war, or violence (UN Refugee Agency, n.d.). The United States has a long history of providing protection and assistance to refugees. In the aftermath of World War II, the United States resettled Europeans displaced from the war. Throughout the Cold War period, refugees from Southeast Asia, people fleeing from the former Soviet Union, and Cubans resettled to the United States in large numbers. In response to the massive waves of refugees coming to the United States in the 1970s from Vietnam and Cambodia, the Refugee Act of 1980 was passed, establishing the Federal Refugee Resettlement Program. The passing of the Patriot Act in 2001 ultimately resulted in a decrease in the number of refugees; however, in 2004, the number of refugees from Somalia increased (Igielnik, 2016).

Following the collapse of the Somali government in 1991 and the ensuing civil war and humanitarian crisis, many Somalis began to flee the country. Between 1990 and 2015, the total number of people born in Somalia but living outside the country more than doubled from 850,000 to 2 million. The Somali refugee situation is in its third decade; a third generation of refugees is being born in exile (Connor, 2016).

The state of Nebraska has a growing and diverse refugee community. According to resettlement data from the Bureau of Population, Refugees, and Migration, a total of 9,433 refugees were newly resettled to Nebraska between 2002 and 2015. The top 10 countries of origin were Burma, Bhutan, Sudan, Iraq, Somalia, Vietnam, Bosnia and Herzegovina, Ukraine, and Cuba (Refugee Procession Center, 2016). Of the 5,429 refugees resettled in the past 5 years (2010-2015) 3,998 or 74% resettled in Omaha and 1,267 or 23% resettled in Lincoln (Refugee Procession Center, 2016). However, these statistics are for refugees who directly resettled in Nebraska and do not include individuals who moved from other states. The latter group is often referred to as "secondary migrants." Because there is no centralized system for tracking refugees moving from one state to another, it is difficult to estimate the overall number of refugees currently living in any given state.

Somali refugees have found living in Nebraska to be suitable, with abundant work opportunities and low cost of living. Many Somali refugees work in the state's meatpacking plants (Corcoran, 2010). The main location for primary resettlement is urban Omaha or Lincoln; however, a substantial number of Somalis have resettled outside the metro area (Refugee Procession Center, 2016). For instance, Lexington has a population of approximately 10,000 of which 2,500 are Somali (Corcoran, 2010). Somalis comprise the largest ethnic group in Somalia and are organized into clans (Lewis, 2009). In addition, there are non-Somali ethnic groups living in Somalia, including Bantus. Both Somalis and Somali Bantus have been resettled in Nebraska and other states in the United States. It is believed that the two ethnicities have distinct health needs, as the Somali Bantu are generally less educated and are thought to be marginalized in Somalia (Stephen, 2002). In Nebraska, each has its own separate community centers and mosques.

In recent years, cervical cancer mortality and morbidity decreased in the developing world due to screening and the human papillomavirus (HPV) vaccine. However, many women in the developing world still suffer from high rates of cervical cancer. The countries of Nepal, Burma, Bhutan, Sudan, and Somalia see women at high risk of cervical cancer. Refugees originating from these countries could carry higher risks of cervical cancer (World Health Organization, 2014). Moreover, a nationwide HPV vaccine program is not available in any of the countries except Bhutan, which initiated the vaccination program in 2010 (World Health Organization, 2014).

While the cervical cancer screening rate of non–U.S.-born individuals remains lower than that of the individuals born in the United States, cervical cancer screening behavior changes with increased duration of stay in the United States (Tsui, Saraiya, Thompson, Dey, & Richardson, 2007). A study found a significant increase in adherence to cervical cancer screening in women who lived over 25% of their life in the United States compared with those who did not (Tsui et al., 2007). Recognizing that cervical cancer disparities affect refugee women in Nebraska, the collaborative project established three primary goals: (a) convene and facilitate a refugee preventive screening steering collaborative, (b) utilize refugee data to identify populations with a higher risk of cervical cancer who may benefit from increasing cervical cancer screening and HPV vaccine uptake, and (c) develop and conduct focus groups and other assessment tools to gather information from refugee populations.

Method

Refugee Screening Collaborative

The project leads followed the principles and process of community engagement by first establishing a clear purpose of the effort and the population. The second step was to become knowledgeable about the community's culture, norms, values, trends, history, perceptions, and power structures (Mogos, 2011). Thus, the Refugee Screening Collaborative Committee (RSCC) was established, comprising indiduals with experience in refugee health issues from the state health department, local health care facilities, and a university.

During the initial meeting, the project leads provided background information about the project and solicited input from the committee. RSCC members examined cervical cancer incidence and mortality rates as well as cervical cancer screening rates, and determined that refugees from Somalia, Sudan, South Sudan, Burma, and Bhutan had a higher risk of developing cervical cancer. Because cervical cancer incidence and mortality rates in Somalia are the highest among these groups and limited outreach had been done with the Somali community, the RSCC recommended conducting a needs assessment with Somali women. The RSCC also reviewed the proposed protocol and interview guides for the focus groups.

Focus Groups

RSCC supported the use of focus groups to assess the knowledge, attitudes, and beliefs of cervical cancer screening and HPV vaccine among the target population. Focus groups have proven to be successful in assessing social concerns and consequences (Green & Kreuter, 2005). Three focus groups and one individual interview were conducted using the procedures recommended by Krueger and Casey (2002) and Rubin and Rubin (2005). Focus group questions were tailored to each target population. For the first two focus groups of health providers and community stakeholders, questions focused on Somali culture, perceived barriers to cervical cancer screening, and difficulties faced by health providers interacting with Somali women in clinical settings. These two focus groups were developed and conducted in English. The third focus group, targeting Somali women, focused on knowledge and attitudes toward cervical cancer and barriers to cervical cancer screening. This focus group was facilitated in the Somali language by two bilingual women recruited from the Omaha Somali community. The questions were developed in English and translated into Somali by the facilitators.

The first focus group comprised stakeholders and community outreach specialists. The session lasted approximately two hours and was attended by four individuals: an obstetrics and gynecology physician, a faculty member, a community outreach specialist, and a community health educator, all of whom work closely with various refugee communities in Omaha, including Somalis. The second focus group was conducted with health care workers at a primary care clinic where refugee health screenings are administered. The session lasted approximately 1 hour and was attended by eight health care professionals: a nurse, a physician, four residents, and an administrator.

The third focus group, with women from the Somali community, was held at the Somali Community Center. The session lasted approximately 2 hours and was attended by 14 Somali women, including both married and single women. To gain information about issues affecting the Somali population in rural communities, stakeholders in Lexington were also interviewed. Face-to-face and phone interviews were conducted with a public health researcher and information was gained via email from an obstetrics and gynecology physician and the CEO of a rural hospital.

Analysis

All three focus groups were audio-recorded and transcribed, and one of the researchers took detailed notes during the sessions. Transcription and translation of the third focus group was performed by the two Somali facilitators. The responses of each of the questions were coded into concepts, themes, and events primarily using a local theory approach to develop a rich understanding of the local context. The purpose of this approach is to understand what is really happening and discover facts about a situation in an effort to build a general theory

(Willis, Jost, & Nilakanta, 2007). The first stage of the analysis was recognition, in which an attempt was made to identify the concepts, themes, events, and markers of the responses to each question. The next step was to clarify what was meant by each of the concepts and themes, which were identified by a brief label (code). These labels were then identified throughout the text of the responses where the themes or concepts were visible. Once the data were coded, matrices were developed to identify patterns, comparisons, trends and inconsistencies. The themes and patterns were used to assist in determining the knowledge, attitudes, and beliefs of cervical cancer screening and HPV vaccine among refugees (Maxwell, 2005). Because the project was for quality improvement purposes, it was determined that institutional review board approval was not necessary.

Results

In general, results of the focus groups indicated that Somali women have a limited understanding of cervical cancer screening and the HPV vaccine. Health care providers and public health educators indicated that most Somali women they encounter lack the basic knowledge of human anatomy needed to understand the purpose of the procedures like the Pap smear. While health care providers reported there is no difference in knowledge level by age group, younger participants of the Somali focus group demonstrated knowledge of cervical cancer, including prevention methods.

Both health providers and the Somali community members reported that pregnant women are more likely to get a Pap smear. For example, two women in the focus group reported undergoing a Pap smear when they were pregnant. Additionally, Somali women discussed cultural beliefs surrounding virginity and reported that virgin women should not undergo a Pap smear. One young woman reported that she was asked by her physician to undergo a Pap smear, but she refused because she believes she cannot get cervical cancer if she is a virgin.

Health care providers indicated that Somali women did not attend the well woman clinic for their Pap smear and often refuse a Pap smear when offered by the physician. Somali women reported that the main reason they refuse a Pap smear is because of their lack of awareness of the importance of the procedure in preventing cancer. In addition, Somali women mentioned that medical translators do not deliver the complete or correct information provided by the health care professional.

Multiple barriers were identified by both health care providers and community members, including the presence of male physicians and interpreters, the lack of time in the clinic, and the language barrier (Table 1). Somali women reported that they feel shy about revealing their private parts to a male provider and a male translator. Somali women expressed their concern about the translation services provided by the health clinics and reported that many translators were not qualified, lacked a general understanding of medical terminology, and did not relay correct information to the patients (Table 2). Solutions suggested by the health providers and the community members included community education, cultural education for health care providers, and improving interpretation and translation service quality (Table 3).

Table 1. Barriers Identified From Focus Group Data.

Personal barriers/cervical cancer knowledge
Somali women have very poor understanding of cervical cancer regardless of age
General knowledge of human anatomy is lacking among Somali female patients
Somali women believe that Pap smear is part of their antenatal examination not routine screening
Cultural barriers
Somali women do not come to the well woman clinic (for Pap smear) because they are not used to go to a clinic/hospital unless they are sick
Poor understanding of the concept of prevention among Somali residents
Many Somali women refuse Pap smear when offered by providers
Male health care providers
Health system barriers
Male health care providers
Language barrier
Male interpreter
Lack of clinic time

Discussion

Barriers for Somali women to cervical cancer screening are summarized by three themes: health system barriers, cultural barriers, and personal barriers. These results are consistent with similar studies conducted in other states (Abdullahi, Copping, Kessel, Luck, & Bonell, 2009; Ghebre et al., 2015; Morrison, Flynn, Weaver, & Wieland, 2013).

Navigation of the health care system in the United States can be challenging for refugees. Moreover, the complexity of health insurance and medical appointments can become overwhelming to persons who are not used to accessing health care unless they are sick (Abdullahi et al., 2009). Both Somali women and health providers reported that the language barrier is the single most important barrier for the Pap smear and other screening services. The Intergovernmental Organization for Migration estimated that only 5% of Somali refugees are proficient in English (Capps et al., 2015; Carroll et al., 2007).

Table 2. Common Feedback/Comments From Focus Group Participants.

Clinical providers: Younger Somali women are knowledgeable about cervical cancer.
Clinical providers: It is an assumption of providers that Somali women do not ask questions or engage because they do not feel comfortable questioning people of authority.
Clinical providers: Providers have a concern about interpreters relaying accurate information. It is perceived that information is being lost during translation from doctor, to translator, to patient.
Clinical providers: Perception that there is a lack of understanding of the importance of cervical cancer screening.
Somali community members: Less than five of the focus group participants indicated that they had ever had a Pap smear. Two of the participants indicated that they had one because they were pregnant. It was perceived that a Pap smear was a required procedure when someone is pregnant.
Somali community members: One young Somali woman reported that a provider offered her a Pap smear but she refused because she is single.
Somali community members: A number of participants indicated that they did not feel comfortable having a Pap spear because they are shy to undress in front of a doctor, especially male doctors.
Somali community members: Community members have a concern about confidentiality when the interpreter is from the same community as they are.

Table 3. Recommendations and Solutions.

Community education (instead of or in addition to one-on-one provider–patient education)
Train community members to be navigators
Provider education/training about refugee culture and health issues and about female genital mutilation
Improve interpreting and translation service quality
Ethnic specific outreach/education (especially for Bantus)

In this study, Somali women discussed the concept of virginity and reported that virgin women should not undergo a Pap smear procedure. Similarly, other studies showed that single women undergoing the procedure would be frowned on by the Somali community because it would be thought that they were sexually active outside of marriage (Ghebre et al., 2015). Results from the community focus group showed that the conservative culture of the Somali community leads many women to be shy and hesitant if asked to undress by a male health provider. A study examining adherence to cervical cancer screening showed that male providers tested less than 25% of Somali women who underwent cervical cancer screening (Morrison et al., 2013). Although the Muslim religion does not prevent women from undergoing testing by a male practitioner, many Somali women do not prefer it (Ghebre et al., 2015).

When asked about training needs for health care providers, stakeholders reported the need for education about female genital mutilation (FGM). FGM, also known as female circumcision, is commonly practiced in Somalia (Abdullahi et al., 2009). A focus group study in Minneapolis found that many Somali women indicated that being circumcised prevented them from tolerating the pain of a pelvic exam (Ghebre et al., 2015). Another study reported that health care providers' reaction toward circumcision is a cause of embarrassment and a barrier to cervical cancer screening by Somali women (Abdullahi et al., 2009). Health providers reported a lack of knowledge about reproductive anatomy and knowledge about cervical cancer in Somali women attending their clinics. Several other studies also concluded that the level of cervical cancer knowledge and understanding is low among the Somali community (Abdullahi et al., 2009; Carroll et al., 2007; Ghebre et al., 2015).

Other themes that emerged included fear of cancer and mistrust in the health care system. Cancer is thought to be a death sentence and the topic of cancer is difficult to discuss in the Somali community (Ghebre et al., 2015). Thus, convincing healthy Somalis to undergo cancer screening can be challenging. Lack of trust in the health care providers is a major barrier to disease prevention and management in general. In Minneapolis, several Somali women expressed their lack of trust in their health provider and said that they do not follow the doctor's instruction unless reassured by community members (Ghebre et al., 2015).

This project proved to be an outstanding learning opportunity; establishing a professional relationship based on mutual trust between the community and the research team serves as a gateway to further collaboration and research. Now, there are clear outcomes and programs are being developed for the community members. The Nebraska DHHS Division of Public Health has clear recommendations and priorities, and the students and faculty gained practical experience that would not be possible from a textbook or lecture. Interacting with the Somali community provided insight into the literacy level and cultural norms in this community, and an understanding of the health needs of this community is of great value for future projects by the students and faculty. Experiences like these are essential to ensuring the preparation of the public health workforce.

Recommendations for Year 2

The extent of community outreach and provider education done in Nebraska is not well understood or

documented. Therefore, it is recommended that an environmental scan be conducted by collecting information from health departments and Federally Qualified Health Centers. Questions to be answered include the following: (a) What type of education materials about cervical cancer, Pap smear, and HPV vaccine have been developed for refugee populations? (b) What type of community outreach and education has been conducted with refugee populations about cervical cancer, Pap smear, and HPV vaccine? and (c) What type of education and training have been provided to health care providers to increase their understanding of refugee health and cultural issues? Data should be collected through surveys and key informant interviews.

It has been noted that the lack of education and training of health care providers is a serious issue across the United States and Canada, and many providers have expressed the desire to learn more about cultural and health issues affecting refugee patients. FGM, for example, is relatively common among refugees from Africa and some parts of Asia, and can be a source of embarrassment and fear among female patients.

In the second year of the project, educational modules for health care providers will be developed. The modules will include topics related to the following: (a) refugee resettlement trends and patterns, (b) major health issues affecting refugees, (c) general cultural issues, and (d) population-specific topics such as FGM. Materials will be investigated and adapted as appropriate, and input will be solicited from national and international experts, Nebraska providers working with refugees, and members of refugee communities. Educational activities may be conducted face-to-face and/or through distance education.

Limitations and Future Opportunities

The study was conducted with Somalis only; it did not include the Somali Bantu. Due to differences in cultures, it is possible that results would have been different for the Somali Bantu population. In order to develop truly culturally appropriate interventions, it is important to obtain input from this population as well. Thus, plans include additional focus groups and/or interviews in Lexington and other communities with a large concentration of Somali Bantu refugees. Another limitation is that only one student was involved in the project. In the future, it would be beneficial for more students to be involved in this type of practical experience.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Nebraska Local Performance Site is supported by a grant from the Health Resources & Services Administration through the University of Iowa, Grant UB6HP27879.

Supplement Issue Note

This article is part of a *Pedagogy in Health Promotion: The Scholarship of Teaching and Learning* supplement, "U.S. Public Health Learning Network: Innovative Competency-Based Training for the Public Health Workforce," which was supported by the Society for Public Health Education and the Region IV Public Health Training Center, Health Resources and Services Administration of the U.S. Department of Health and Human Services under Grant Number UB6HP27875, Affordable Care Act (ACA) Public Health Training Centers. The entire supplement issue is available open access for one year at http://journals.sagepub.com/toc/phpa/3/1_suppl.

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