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## Knowledge, Attitudes, and Practices for Cervical Cancer Screening Among the Bhutanese Refugee Community in Omaha, Nebraska

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### Abstract

Cervical cancer is the second most common cause of cancer mortality among women with the vast majority of patients in developing countries. Bhutanese refugees in the United States are from South Central Asia, the 4th leading region of the world for cervical cancer incidence. Over the past few years, Bhutanese refugees have increased significantly in Nebraska. This study evaluates current knowledge of cervical cancer and screening practices among the Bhutanese refugee women in Omaha, Nebraska. The study aimed to investigate cervical cancer and screening knowledge and perceptions about the susceptibility and severity of cervical cancer and perceived benefits and barriers to screening. Self-administered questionnaires and focus groups based on the Health Belief Model were conducted among 42 healthy women from the Bhutanese refugee community in Omaha. The study revealed a significant lack of knowledge in this community regarding cervical cancer and screening practices, with only 22.2 % reporting ever hearing of a Pap test and 13.9 % reporting ever having one. Only 33.3 % of women were in agreement with their own perceived susceptibility to cervical cancer. Women who reported ever hearing about the Pap test tended to believe more strongly about curability of the disease if discovered early than women who never heard about the test (71.4 vs. 45.0 %, for the two groups, respectively).

Refugee populations in the United States are in need for tailored cancer education programs especially when being resettled from countries with high risk for cancer.

## Keywords

Bhutanese; Screening; Cervical cancer; Nebraska

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## Introduction

According to the latest United Nations Refugee statistics, there were 10.4 million refugees globally in 2013 [16]. In 2012, over 58,000 refugees resettled in the United States [16].

Refugees from Bhutan have a complicated history. Many of their ancestors migrated to Southern Bhutan from Nepal in the late 1800s in search of better farming. They lived there securely for many decades, while maintaining Nepalese culture, language and religion. However, in the 1980s, the ruling authorities became threatened by the growing population and imposed policies restricting participation in traditional cultural practices [5]. After years of failed negotiation attempts by Nepal and Bhutan, resettlement procedures began, with first arrivals to the United States in 2008 [16].

The United States agreed to resettle at least 60,000 of over 100,000 Bhutanese refugees [5]. Through 2012, Nebraska resettled over 800 since the beginning of the resettlement agreement with the United States Office of Resettlement [16]. This community continues to expand in Omaha with estimates of up to 2,000 individuals as of December, 2013. According to the Centers for Disease Control's Refugee Health Profiles, 60 % of the Bhutanese refugees who have resettled in the United States are between the ages of 15–44, 15 % are 45–64, 5 % are over 65, and the rest are under 15 years old with a fairly equal gender distribution [2]. Health research with Bhutanese refugee communities has primarily focused on mental health, particularly depression and post-traumatic stress disorder [3, 10, 14]. Very little is documented regarding cervical cancer or its prevention among Bhutanese refugee communities in the United States although these refugees come from high cervical cancer risk incidence and mortality regions [17]. In 2008, South Central Asia was the 4th leading region for cervical cancer incidences, and presents also with high mortality [8]. This study aimed to assess knowledge, attitudes, and practices for cervical cancer and its screening modalities among a group of the Bhutanese refugee women in Omaha, Nebraska.

## Methods

The need for this study originated from discussions with leaders in the Bhutanese community in Omaha. Input from the community and service organizations working with Bhutanese refugees helped in identifying female community members who assisted in the study design, methods, and development and refinement of the study tools and instruments. Two female Bhutanese community partners were identified to assist in maximizing participation from the diverse religious demographic backgrounds of the community.

The primary constructs of the Health Belief Model (HBM) were utilized in this study. The HBM has been a proven framework for explaining current health behaviors and prediction of health outcomes [7]. Constructs include perceived susceptibility and severity of the disease and perceived barriers and benefits [7]. In relation to cervical cancer, questions were developed as such: how susceptible a woman feels she is to getting cervical cancer (*perceived susceptibility*), how serious she sees cervical cancer (*perceived severity*), how valuable will acting on change (*prevention*) for cervical cancer be (*perceived benefits*), and what are the influential factors that keep a woman from acting on a health behavior (*perceived barriers*).

Two methods were utilized for further examination into knowledge, barriers, and beliefs surrounding cervical cancer and screening practices in this refugee population, electronic tablet survey and focus groups. Pilot testing with five Bhutanese women was completed to ensure cultural competency and effective communication of information. As a result, one question regarding English language ability was omitted as the formatting and accuracy was found confusing to participants. Women in the age group of 19–60 years old were included in the study. Older women were invited to take part in the study in order to motivate younger women to participate as well. Previously, other groups have validated and utilized survey tools based on the HBM for breast and cervical cancer research with diverse ethnic communities [1, 4, 6]. Questions based on the HBM constructs utilized in this survey were formulated to address the following research questions:

To what degree are Bhutanese refugee women aware of cervical cancer and the Pap test? and are they seeking Pap tests?

Is there significant relationship to/between:

- Having ever heard of a Pap test and having ever had one?
- Having had a Pap test and perceived susceptibility to cervical cancer among Bhutanese refugee women? or perceived severity to cervical cancer?
- Background demographics and health practices (education, literacy, religion, age, etc.) that affect the outcome of having ever heard of or have had a Pap test?

What are reasons, if any, given by this cohort as perceived barriers to going for a Pap test?

Survey and focus group questions were translated from English to Nepali and back translated to English for content preservation and assurance. Questions regarding cervical cancer screening were limited to the Pap test, as the gold standard in the United States and other developed countries. In low-resource international settings, visual inspection with acetic acid (VIA) is the most common method for identifying abnormal cervical lesions [11]. However, as the ultimate goal is increased knowledge of cervical cancer and prevention under the practices currently available to refugee women in the U.S., it was important to present information in this study based on the Pap test not VIA. The following text describes in more detail the methodological process for development and implementation of the survey and focus groups.

### Electronic Tablet Survey (n = 42)

This survey was implemented via digital media (iPad®) to allow for multi-lingual, multi-media, real-time interactive capability to accommodate language or literacy barriers and to reduce potential reporting bias that may occur with an interpreter. Questions were developed with cultural considerations and community expert guidance. The first 14 questions were either demographic (duration of living in United States, education, literacy, age, marital status, and religion) or relating to health practices (pregnancy, pregnancy prevention, previous screening behaviors, awareness of a Pap test). Traditional demographic questions were utilized to assess characteristics that might impact knowledge and beliefs. Further questions were asked based on inquiry of secondary migration to Nebraska from other states and information relating to settling in original states or Nebraska.

Respondents were asked if they had ever heard of a Pap test, with a brief explanation. If “yes” was chosen, the follow up question was about ever receiving a Pap test. If the answer was “no” to hearing of a Pap test, then the demographic questions were concluded. Respondents then transitioned to the remaining 20 questions.

The next 20 questions were based on the HBM for perceived susceptibility and severity of cervical cancer and perceived barriers and benefits of screening. The final question was about identifying the community interest and readiness for potentially incorporating community health workers in future cancer education. These questions were measured on a 5 point Likert scale, scored from 1 (“strongly disagree”) to 5 (“strongly agree”), 3 was neutral and also utilized if a women indicated verbally or nonverbally that she did not know how to respond. Surveys were administered at multiple community venues and residences where Bhutanese refugee women were able to participate.

Women were each approached only once for participation. Varying times and places were chosen under community partners’ guidance in order to maximize opportunities most appropriate and conducive to the women’s schedules and to capture a representative sample from the community. As a result, refusal was rare and nonparticipation was usually due to limited time availability of the targeted study women. The survey moderator found that once women listened to the introduction video in their native language, the majority were willing to participate. The two community partners assisting with translation and community expertise also spread word throughout the community regarding the survey and that women would be approached for participation if they wished.

Survey data were collected via an encrypted online data storage center through the online survey tool. Once the survey was completed, data were imported into the SPSS statistical software for further analysis.

### Focus Groups (n = 27)

Two focus groups consisting of 12 and 15 women in the age group of 19–60 years were recruited through the two female community partners who were given instructions to invite women from varying backgrounds that would represent the larger and diverse community (age, religion, marital status, and number of years since resettling in the United States). The focus groups provided qualitative data to further explain responses of perceived barriers and

knowledge about cervical cancer, screening, and HPV vaccination. Each session lasted about 1.5 h and was led by a co-author (RJH) and 1–2 community facilitators. Dialogue was guided by pre-written questions regarding cervical cancer disease and prevention as well as the previously mentioned Health Belief constructs.

Two Nepali-speaking community partners served as moderator and translator during focus groups. Protocol for analyzing the focus groups incorporated a cut-and-paste method [13]. The reviewers individually read through each focus group results to identify sections that were relevant to the particular research questions. Based on the responses, themes were identified and classified. Themes, comments, and findings were analyzed from each focus group and compared between the two focus groups. Themes were then compared with findings identified in the survey results.

## Results

Table 1 describes seven initial demographic questions and Table 2 outlines reproductive profile, knowledge, and practices regarding cervical screening. In this cohort, the majority of participants were married, between the ages of 35–54, arrived to Nebraska as the first state of resettlement. Most women (74 %) reported having come to the United States within the last 2 years. About half the participants (47.6 %) reported arriving to the United States within the last year, with the exception of the sample of women who had reported having heard of a Pap test who resettled in the United States for more than a year. A little over half the participants (54.8 %) had primary school or less education and the rest of participants were able to read in their native language.

Only 22.2 % of the study participants reported having ever heard of a Pap test, with 13.9 % reporting ever having one. Five of the eight women, who reported ever hearing of a Pap test, reported ever receiving one. Women who received a Pap test reported having their most recent Pap test within the last 2 years (100 %). Over half (57.1 %) of those reporting having heard of a Pap test were between 25 and 34 years, with 71 % of them had completed more than primary school education and 85.7 % identified themselves as Christians (85.7 %).

Three-fourths of the women surveyed reported ever having a pregnancy. Almost half the study participants reported having pregnancy prevention or visiting a doctor's office in the United States, aside from the initial health screening required at resettlement. Reporting having a Pap test was associated in 85.7 % of responses with utilizing a method of pregnancy prevention and with having been to a doctor's office. This seems logical as a Pap test is performed at a doctor's visit and often precedes methods of pregnancy prevention.

### Health Belief Model Survey Results

Frequencies with percentages (Table 3) were also generated for the 20 HBM questions, and the study participants' responding to these questions were assessed with having had a Pap test. A neutral response was the most frequent response category for the entire group in nearly all of the statements. Agreement ('strongly agree' and 'agree') for perceived susceptibility measures were between 0 and 33.3 % for both the general group and for those reporting having had a Pap test. Perceived seriousness of cervical cancer was more frequent

among those reporting ever having had a Pap test, with the belief cervical cancer would make a woman's life very difficult (57.1 %) being the most frequent among the group. Perceived seriousness ranged from 33.3 to 40.7 % for the general responses and 42.9–57.1 % of those reporting having ever having had a Pap test. Perceived benefits reports were slightly higher than both susceptibility and seriousness, especially with the group having had a Pap test (Table 3). Of those who reported ever having a Pap test, 57.1 % reported the 'Pap test can find cervical changes before they become cancer' compared to 48.1 % of the entire group (Table 3). Perceived barriers were otherwise reported low, except that 'the Pap test is painful' as reported by those who had ever had a Pap test (85.7 %) compared with 40.7 % of the complete group.

The final question for this section was assessing the community's belief regarding the implementation of a community health workers' (CHW) program. Overwhelmingly, those who have had a Pap test (100 %) felt they would prefer more information about cervical cancer and screening from someone who is trained from their own community and can speak their language. The majority of the study participants (70.4 %) reported agreement with the importance of CHWs in education about screening and prevention of cervical cancer.

### Focus Group Analysis

**Construct of Health**—The construct of 'health' was determined from the two questions: 'What does health mean to you?' and 'What or who do you think controls one's health and illness?' Health was defined as having something of precious value, being neat and clean, taking care of yourself inside and out, and being free from various health conditions such as pain and high blood pressure. Women in both focus groups all agreed 'self' was in control of their health. Some women reported that if their health required a visit to a physician, then the doctor also participates in their health. Interestingly, husbands or significant others were not identified in this portion of the group as being important responsible parties in their individual health. However, later on in the focus group the women indicated the importance of involving partners in decisions that impact their health.

**Knowledge of Cervical Cancer**—The major themes identified here with regard to knowledge of cervical cancer were stated as "nobody knows about cervical cancer in our community", having multiple sexual partners, and various states of health. For both focus groups, the majority of the women reported that they had never heard of cervical cancer and felt that it was not something that occurred in their community. There were few reports about awareness of cancer but none about cervical cancer. The women also reported not having knowledge about HPV. Various poor states of health were included in the discussion about cervical cancer, including the statement "good blood circulating around your body," might have an effect on your health. Weakness in general due to other health conditions such as heart disease and diabetes were identified as potential contributors to cervical cancer. Finally, a few participants mentioned that multiple sexual partners, not using protection during sexual intercourse and virus transfer through the male partner increase susceptibility to cervical cancer.

**Knowledge of Prevention**—The construct of prevention was not present among women who participated in the study. During the translation process, prevention was frequently expressed as treatment. Subsequently, the answers related more to potential treatment, cures, or symptoms. Interventions included surgery or medication to “itchy inner parts”, use of contraceptives, and to keeping clothes clean. Due to language barriers, during the focus groups, the moderator was not able to identify that treatment was being substituted when prevention was the intended message. There was an overall lack of education of the Pap test and HPV vaccination.

**Barriers to Prevention**—Barriers identified in these focus groups were related to limited or no knowledge regarding cervical cancer and its prevention. Other barriers included shyness, feelings of exposure and potential stigma for going to a health provider for a Pap test. Also, language, navigation of the complicated healthcare system, limited insurance coverage, and transportation to health appointments were other barriers. Although cost was identified as a barrier, some women reported that receiving a Pap test as a priority regardless of keeping them healthy. Trust in providers and interpreters were also important to the study participants. Women reported not feeling comfortable with male translators from their community.

**Culture**—Although there were no particular focus group questions in regard to culture, there were a few cultural-related themes that presented themselves throughout the focus groups. The one of primary consideration was the idea of trust. Women shared reports of inappropriate behavior, sexual assault, and abuse by male health providers in Nepal and India while living in refugee camps. Almost unanimously, the women reported preferring female doctors. Women also stated that in the United States there are cameras everywhere and wondered if there would be cause for concern of cameras in an exam room.

**Community Health Workers**—In a forward thinking approach for effective health education, the idea of CHWs was presented to participants by asking what prior experience the women had with CHWs, and about their preference of health education. Consistent with survey responses, the women all felt having someone who speaks their native language, from their community, and trained in health education topics was the preferable method of information transfer. Women did report wanting to still go to their physician for things beyond the scope of the CHWs. Participants indicated that their experience with CHWs in the refugee camps were primarily for family planning and STI prevention.

## Discussion

Through the HBM and assessment of knowledge and practices of women in this study, several interesting observations were identified. These observations included the lack of knowledge about cervical cancer and its screening, low rates of screening, and interest in community health workers as facilitators of cancer education and prevention.

First, there is significant lack of knowledge regarding cervical cancer, screening and prevention practices in this Bhutanese refugee group. This is consistent with the literature regarding foreign-born women compared with the general U.S. population [1, 9]. Women in

this group generally had an awareness regarding the general terms of cancer and STDs but very limited knowledge about cervical cancer and its appropriate screening. The majority of women in this study had never heard of cervical cancer or a Pap test. According to women in the focus groups, reproductive health and STD education were provided in the camps but findings of the study suggest that HPV and cervical cancer risk were not included in such camp education.

Research on prevention and health communication reveals significant disparities at times between health providers and patients from different cultural backgrounds [12]. There is significant data regarding the importance of providing culturally competent care. However, research focusing particularly on the construct of prevention within culture is limited.

Second, a small percentage surveyed in this group reported having ever heard of a Pap test, and even less reported ever having one. These were primarily young married women having been in the United States more than 1 year and with higher education levels compared to their peers who did not hear about the Pap test. Other studies with foreign-born populations concur with the results of this study in that most of the women in this cohort have never experienced cervical cancer screening [1, 15]. These findings also concur with the Centers for Disease Control and Prevention (CDC) research, where awareness of preventative healthcare is limited and many female Bhutanese refugees have never experienced cytological cancer screening and HPV testing [2].

Lastly, the idea of community health workers as health interventionists was well received by survey and focus group participants. CHWs could help significantly bridge gaps with education/prevention, and were identified as a viable option with this community. Communication, lack of knowledge, transportation, navigation of the health system, language and trust are among a few of the barriers identified in the focus groups for accessing cancer care and prevention services. The issue of trust is important for health education and particularly women's health, as it would be critical to consider previous experiences and assumptions when working to build trust and rapport. CHWs have the potential to bridge gaps in addressing health disparities in significantly underserved populations and can also provide opportunities to implement research into practice [18].

The greatest strength of this study was the support and guidance received from Bhutanese community members, leaders, and other organizations that support the refugee communities. The comparison of survey data with focus group information is consistent as well, which adds to the efficacy of our results. One limitation may be the Pap test is not the standard test for this region and questions regarding preventative screening in this survey were limited to the Pap test. However, beliefs and knowledge of cervical cancer itself, even aside from screening practices were low as outlined in the focus groups. Although not conclusive given the scope of this project, one might consider how education leads to ever hearing of a Pap test and increased rates of cervical cancer screening in this population. In other words, education leads to the intended health outcome of having a Pap test. This seemed to concur with focus group responses from women asking where they could go for a Pap test.



Resettlement brings many challenges and opportunities for refugees. Access to healthcare is a major concern and should be addressed. Language, transportation, education, finances, trust, and knowledge in particular are major limiting factors in navigating the system striving to achieve overall wellbeing and access health education and services. Often refugees are not even sure what to ask for, because there is a significant disparity in health education. As explored in this research, cervical cancer prevention falls in the disparate gap of health knowledge. Beliefs with lack of knowledge regarding severity, susceptibility to cervical cancer and barriers and benefits of screening are limited and warrant tailored and culturally appropriate cancer education interventions of this and other refugee and underserved communities in the United States.

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**Table 1**

## Demographic characteristics of the study population

Characteristic		%
Years in the United States	n = 42	
<1	20	47.6
1–2	11	26.2
2–3	3	7.1
3–4	4	9.5
4+	3	7.1
Prefer not to answer	1	2.4
Was NE 1st resettlement state	n = 42	
Yes	36	85.7
No	4	9.5
Prefer not to answer	2	4.8
Education level	n = 42	
Primary	23	54.8
Secondary	8	19.1
University/college	6	14.3
Prefer not to answer	5	11.9
Literacy level (native language)	n = 42	
Read	19	45.2
Write	6	14.3
Speak fluently	17	40.5
Age	n = 37	
19–24	1	2.7
25–34	5	13.5
35–44	12	32.4
45–54	13	35.1
55–60	4	10.8
60+	1	2.7
Prefer not to answer	1	2.7
Marital status	n = 37	
Single (divorce/widow/separated)	6	16.2
Single (never been married)	4	10.8
Married	25	67.6
Prefer not to answer	2	5.4
Religion	n = 37	
Hindu	6	16.2
Buddhist	9	24.3
Shaman	2	5.4
Christianity	14	37.8
Other/none	3	8.1

Characteristic		%
Prefer not to answer	3	8.1

**Table 2**

Reproductive profiles, knowledge and practices of the study participants

Characteristic	n	%
Been to doctor in United States (not initial screening)	n =37	
Yes	18	48.7
No	16	43.2
Prefer not to answer	3	8.1
Practice method of pregnancy prevention	n =36	
Yes	16	44.4
No	16	44.4
Prefer not to answer	4	11.1
Ever had pregnancy	n =36	
Yes	27	75.0
No	6	16.7
Prefer not to answer	3	8.3
Ever heard of Pap test	n =36	
Yes	8	22.2
No	8	22.2
I don't know	18	50
Prefer not to answer	2	5.6
Ever received Pap test	n =8	
Yes	5	62.5
No	3	37.5
I don't know	0	0
Prefer not to answer	0	0
If yes, most recent Pap	n =5	
Within last year	3	60.0
Last 2 years	2	40.0
Last 3 years	0	0.0
Greater than 3 years	0	0.0
Prefer not to answer	0	0.0

**Table 3**

Frequency with percentages of agree/strongly agree of the Health Belief Model questions for study participant responses (n = 27), and those responding to ever had a Pap test (n = 7)

	Strongly/ agree; n = 27 (%)	Strongly/ agree; n = 7 (%)
<i>Perceived susceptibility</i>		
I am not at risk for cervical cancer	9 (33.3)	1 (14.3)
Cervical cancer only happens to women over 50	4 (14.8)	0 (0.0)
Young women are at risk for cervical cancer	5 (18.5)	0 (0.0)
<i>Perceived seriousness</i>		
Cervical cancer is not as serious as other types of cancer	9 (33.3)	3 (42.9)
Cervical cancer is easily cured	10 (37.0)	3 (42.9)
Having cervical cancer would make a woman's life very difficult	9 (33.3)	4 (57.1)
There are effective treatments for cervical cancer	11 (40.7)	3 (42.9)
<i>Perceived benefits</i>		
The Pap test can find cervical changes before they become cancer	13 (48.1)	4 (57.1)
It is important for a woman to have a Pap test so she will know if she is healthy	9 (33.3)	3 (42.9)
If cervical changes are found early, they are easily curable	14 (51.9)	5 (71.4)
<i>Perceived barriers</i>		
Only women who have had babies need a Pap test	8 (29.6)	1 (14.3)
Getting a Pap test would only make me worry	7 (25.9)	1 (14.3)
My partner (boyfriend/husband) would not want me to have a Pap test	5 (18.5)	0 (0.0)
If a young unmarried woman goes for a Pap smear, everyone will assume she is having sex	7 (25.9)	2 (28.6)
The Pap test is painful	11 (40.7)	6 (85.7)
I don't know where I could go if I wanted a Pap test	6 (23.0)	2 (28.6)
It is too expensive to have a Pap test	8 (29.6)	2 (28.6)
It is too embarrassing to have a Pap test	6 (22.2)	3 (42.9)
If a woman has not had sex, a Pap test will take away her virginity	8 (29.6)	2 (28.6)
Most young unmarried women that I know go to have Pap smears done	7 (25.9)	3 (42.9)