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Original Research Article

Community level barriers for cervical cancer screening in marginalized population

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ABSTRACT

Background: In India, cervical cancer is the second common cause of cancer deaths among women of reproductive age, with 469 million Indian women at risk. High risk human papillomavirus genotypes mainly 16 and 18 account of cervical cancer. The burden of cervical cancer can be reduced by regular screening of human papillomavirus (HPV). There is no specific national program for cervical cancer screening. Eligible women have limited knowledge of screening and also limited access to preventive screenings.
Methods: The study was conducted in the slum areas of Ahmedabad city in Gujarat. 1088 women between 30-45 years of age were recruited in the study and 536 women consented to give cervical samples for DNA based HPV testing. We collected information regarding knowledge and practice for cervical cancer and HPV along with demographic data.
Results: Lack of knowledge and practices around cervical cancer and screening among community women was found. There is a lack of awareness about the importance of preventive healthcare and near absence of evidence-based practices. Sociodemographic characteristics are important predictors of participation in the screening program.
Conclusions: In the Indian context, HPV testing is a cost-effective option to prevent cervical cancer. The burden of cervical cancer is incredibly high. With increased ability to accurately detect, population level HPV testing would reduce the burden of cervical cancer and the ultimate cost per person would be minimal, due to the country's large population. There is a need to develop policy to ensure participation of women in the HPV based cervical cancer screening programs.

Keywords: Attitude, Cervical cancer, HPV, India, Knowledge, Urban slums

INTRODUCTION

Cervical cancer (CC) is the fourth most frequent cancer in women worldwide.[1] In 2012 there were an estimated 445,000 new cases and approximately 270,000 deaths from cervical cancer, more than 85% of which occurred in low and middle-income countries.[1] In the developed world, CC cases are on the decline; but the disease remains a heavy burden on much of the developing world, where resources are limited and the risk is 35% greater.[2] In India, CC is the second most common cause of cancer deaths among women of reproductive age, with 469 million Indian women at risk.[3] According to 2010 IHME estimates, the cumulative probability of incidence for Indian women is 1.9, the second highest in South Asia.[2] The WHO estimates that the annual burden of new cases in India will increase to almost 225,000 by 2025 without widespread screening and prevention efforts.[4] Currently, in low resource settings such as India, the structure to diagnose and treat CC in its early stages is not available. Cervical cancer is often identified in the later stages or when treatment is simply inaccessible, contributing to the high number of related deaths.

Nearly all cervical cancer cases can be attributed to human papillomavirus (HPV) infection, and 70% of cases

are caused by two HPV types (16 and 18).[1,5] Despite the strong link between HPV and cervical cancer, few studies have been conducted to assess the feasibility of HPV testing in India or the prevalence of HPV across India, including Gujarat.[6] Prevalence of high-risk types among the screening population in a study in Andhra Pradesh was approximately 10%.[7] Another study conducted in Odisha found an overall prevalence of HPV infection to be 60.33%.[8] Without knowing the prevalence of HPV throughout India, it is difficult to justify the need for widespread cervical cancer screening via HPV testing.

Despite the far too high number of CC related deaths in India, no organized cervical cancer screening program currently exists. In most cases, CC can be prevented through the early detection and treatment of abnormal cell changes that occur in the years before cervical cancer develops.[9-11] Burden of CC can be prevented through systematic, population-based screening, which has been successful in many high-income countries with the resources to support such programs.[12-14] However, what has worked in many developed countries (widespread cytology-based screening) need not necessarily work in low and middle-income countries with financial and resource constraints.[15,16]

The objectives of current study were; to understand the knowledge/awareness and practices of the community, to understand the predictors of cervical cancer screening, and to assess the acceptance of the HPV test in the community.

METHODS

Study design and setting

A community based cross-sectional study was carried out from August 2018 to October 2019. This study was conducted in the slum areas of Ahmedabad city in Gujarat. We selected two wards Behrampura from South and Vasna from West zone for the study. Both these wards were chosen based on population size and redevelopment of basic services. The population of Behrampura and Vasna are 81 thousand and 123 thousand respectively.[17] Local officials were contacted to finalize the wards.

Government officials were consulted to obtain permission for the study. An informed written consent of all participants was taken prior to study. If a participant could not read or write, the consent was read out and thumb impression was taken on the consent form.

Study population and data collection

For the study, the target population was married women between the ages of 30 and 45 years with no known history of cervical cancer. Women with known cervical cancer at the time of the survey were excluded from the survey. In-depth interviews were conducted to assess the feasibility and acceptance of the HPV testing method, the knowledge and attitudes of cervical cancer among the women.

A research laboratory with the ability to conduct polymerase chain reaction was finalized for outsourcing testing of the samples. A standard operating procedure for the detection of HPV DNA from cervical samples was developed to standardize the process. A training of medical officers, field health workers, and staff nurses was conducted. The primary investigator, a trained obstetrician, conducted these trainings, which included the purpose of the study, general information regarding CC, and skill-based training on the sample collection process.

Research staff collected the house listings from local NGO and Government workers of the selected wards to inquire about eligible women in the area. On the designated screening day, eligible women were called and screened using the HPV DNA based testing method. Following the screenings, questionnaires were given to the women. The questionnaires included the following information; sociodemographic information (age, education, earning, poverty, diet, and family history), history of reproductive and sexual health (use of OCP/IUD, parity info, etc.), knowledge and practice of cervical cancer screening and vaccine, and experience of the screening procedure. The questionnaires were developed at the outset of the study and translated into the local language, Gujarati. The database for the data collection was prepared in the open data kit (ODK) application on a tablet.

Samples were regularly collected and sent to the research laboratory for testing. Positive samples were further tested for the type of HPV to assess the vulnerability to cervical cancer. Women testing positive were counselled and connected with the appropriate healthcare provider for follow-up. Quantitative data was analyzed for descriptive and logistic regression using IBM SPSS 25.0.

RESULTS

Sociodemographic characteristics

The study was conducted with analytic sample of 1088 women between ages 30-45 years of age residing in urban slums. (Table 1) describes sociodemographic information of the sample. Majority of women were Hindu, more than half belonged to other backward castes (OBC) and lived in joint family. More than 80% of women lived in their own homes and had access to own toilets. A large number of women belonged to households with monthly income of less than 215 USD and main income source was daily wages.

As seen in (Table 2), many of the participants were of less than 40 years of age and more than 80% women had less than 10 years of formal education. Among the

respondents, one third of the women had sexual debut before 17 years of age and more than 60% women had 3 or more pregnancies. Almost all women had first birth before age of 24 years and less than half of the women were using some contraceptive methods. Overall women were housewives by profession.

Table 1: Socio-demographic information.

Indicators (n=1088)	Frequency	%
Religion		
Hindu	1081	99.4
Others	7	0.6
Caste		
SC	418	38.5
OBC	577	53.0
ST/General	93	8.5
Type of family		
Joint	653	60.0
Nuclear	435	40.0
Type of house		
Kutcha/kutcha-pucca	531	48.8
Pucca	557	51.2
Own house	904	83.1
Type of toilet facility		
Own Flush toilet	914	84.0
Shared/ public flush toilet; own pit toilet	158	14.5
Shared/public pit toilet/no access to toilet	16	1.5
Main source of income		
Daily wage	796	73.2
Salaried (monthly wage)	292	26.8
Monthly income (in USD@70 INR)		
Less than 143	364	33.5
143 to 214	450	41.4
More than 215	274	25.1

Awareness among community women

Knowledge and practice about cervical cancer and screening was low among community women. Majority of the participants were not knowledgeable about HPV or cervical cancer, its symptoms, or that it could be prevented through screening. Nearly all of the women had never undergone cervical cancer screening. For example, less than 36% knew about HPV and cervical cancer. Likewise, knowledge about pap test and HPV vaccine was less than 5%.

During the interviews, lack of community mobilization and misinformation among the community were frequently cited as barriers to getting more women screened. Many women are unaware of the importance of preventive healthcare and do not understand the need to visit a clinic if they aren't experiencing any symptoms. Many expressed fear of pain and positive result during the screening test.

Table 2: Background information of women.

Indicators (n=1088)	Frequency	%
Respondent's age (years)		
< 30	136	12.5
≥30 to ≤35	430	39.5
>35 to ≤40	262	24.1
>40	260	23.9
Education		
Illiterate	453	41.6
1 to 10 years	539	49.5
>11 years	96	8.9
More than one marriage	50	4.7
Age at sexual debut (years)		
≤17	354	32.5
>17 to ≤24	680	62.5
>24	55	5.0
Number of pregnancy		
≤1	129	11.9
2	210	19.3
≥3	749	68.8
Age at first birth (years), N=1050		
≤17	129	12.3
>17 to ≤24	816	77.7
>24	105	10.0
Using contraceptive method	518	47.6

Predictors of undergoing screening

In current study, women who underwent screening were different from women who did not undergo screening with respect to current age, age at sexual debut, and age at first birth as seen in the (Table 3). Older women were more likely to undergo the tests compared to young women. Women who had sexual debut at later age were more likely to undergo testing compared to early age sexual initiation. Women who did not undergo screening were more likely to belong to schedule caste.

Surprisingly, more proportion of women who did not undergo screening were more likely to be from households that had lower monthly income and from nuclear households. Remarkably, beyond certain monthly income the likely hood decreased.

Acceptance of DNA based HPV testing as screening for cervical cancer

About the experience of screening in the study, all women reported that privacy was maintained during examination and examination was carried out by a woman doctor or staff nurse. Still, about 72% indicated that they felt embarrassed during examination and 19% said they felt discomfort during examination. Almost all

indicated the process was explained to them, would undergo further testing if needed and would recommend the test to others.

Table 3: Predictors of undergoing screening test.

Independent variables		Screening done (N=536) %	Screening not done (N=552) %	Odds ratio	p value
Respondent's age		-		1.030#	0.006*
Age at sexual debut		-		1.145#	0.000*
Education of women		-		1.013#	0.400
Caste	SC	29	48		
	OBC	57	49	0.161	0.000*
	ST/general	14	3	0.305	0.000*
Type of family	Joint	65	55	1.370	0.015*
	Nuclear	35	45		
Monthly income of house (in USD@70 INR)	<143	40	27		
	143 to 214	41	42	2.597	0.000*
	>215	19	31	1.681	0.001*

Used as continuous variable in regression analysis, *p<0.01.

DISCUSSION

Assessing the current level of knowledge and attitudes toward HPV, cervical cancer, and screening among Indian women and men is important in determining areas for improvement. Addressing the gaps in knowledge and the overall lack of awareness of cervical cancer identified is a critical first step towards earlier detection and fewer deaths. Awareness campaigns accompanied by state-wide and National level screening efforts are necessary to address the heavy burden of this disease in India. Simultaneously, the capacity of health systems across urban and rural India must also be built up in order to sufficiently and effectively screen and treat the women.

In our study the knowledge and understanding of cervical cancer and HPV is woefully low. Other studies from India and other countries have found the level of cervical cancer screening is directly related to knowledge and understanding of the cancer.[18-21]

While cytology-based screening using pap smears have been effective in most developed countries, such methods are not feasible in low and middle-income countries due to lack of infrastructure and trained personnel. Visual inspection with acetic acid is the commonly used method in such resource-poor settings, due to low cost and feasibility among limited resources. While HPV testing is a more high-tech and costly solution, its high sensitivity allows for a screening interval of up to 10 years for screen-negative women.[22]

In current study, compared to women belonging to schedule caste, women from OBC and general/ST were more likely undergo HPV screening. When considering family type, odds of HPV screening performed was higher in joint family compared to nuclear family.

Similarly, HPV screening done was higher in women who were using family planning method than those who were not using any family planning method. As age at sexual debut is increased, chances of getting HPV screening performed also increases. As income of family increased, the chances of getting screening performed became less. These findings indicate that marginalized vulnerable women are more likely not to undergo screening; hence there is a need to develop policy to ensure participation of these women in the screening programs. Most primary and community health centres in India have the capacity to perform cervical cancer screening tests, if only the healthcare providers were provided more training opportunities and the community was mobilized to seek such screening services. Severe lack of knowledge regarding cervical cancer, risk factors, screening, and treatment found among most community women highlights the need for increased education and community mobilization from community health workers.

In addition to developing national screening guidelines, the underlying health systems and community barriers must also be addressed in order to effectively reach all vulnerable and at-risk women. Community awareness can be improved through existing schemes through which house to house visits are already being conducted. Effective implementation of a population-based screening program necessitates a need for increased training and capacity of healthcare providers at all levels, including medical officers and district health officers.

Limitations

The cross-sectional nature of the study and inclusion of only urban slums make findings not generalizable. Despite these limitations, this is one of few studies

carried out at the population level and unique in ensuring those who needed follow up after screening were tied up with a free/subsidized care by a regional cancer centre.

CONCLUSION

Despite the WHO's recommendation against the use of HPV testing in low resource settings, we believe that in the Indian context, HPV testing is the most cost-effective option to prevent cervical cancer related deaths. Due to the country's large population, the burden of cervical cancer is incredibly high. With its increased interval time and ability to accurately detect more pre-cancers and cancers, population level HPV testing would greatly reduce the burden of cervical cancer and the ultimate cost per person would be minimal.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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