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KNOWLEDGE, ATTITUDES, AND BARRIERS TO SCREENING FOR CERVICAL CANCER AMONG WOMEN IN INDIA: A REVIEW

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Abstract – *Early detection and treatment via screening can prevent up to 80% of cervical cancers in developed countries, where efficient screening programs are in place. In developing countries, however, there is limited access to effective, wide scale screening, leading to increased deaths due to cervical cancer. Despite sufficient evidence supporting the use of screening as an effective intervention, there are still few large-scale screening programs being implemented in India. This systematic review examined the current literature on knowledge and attitudes regarding cervical cancer and barriers to screening for cervical cancer among women in India. Consistent themes were found throughout the literature – the story is the same not only in India but throughout the developing world. In urban and rural areas alike, most women have heard of cervical cancer, yet there is a shockingly low uptake of screening for cervical cancer. This low uptake of cervical cancer screening can be attributed to a number of factors, as demonstrated by the literature, including low level of knowledge and awareness, low level of perceived risk, stigma associated with cancer, fear of cancer, cost, and familial obligations. India has urgent need to develop health system capacity to ensure efficient cervical cancer screening program and community level efforts to improve knowledge about cervical cancer and screening programs. This effort would help save thousands of young women and their families from a great calamity.*

KEYWORDS: *Cervical cancer, India, Cancer screening.*

INTRODUCTION

Cervical cancer is the fourth most frequent cancer in women worldwide, according to the World Health Organization[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]. Unfortunately, not much progress has been made over the past few decades. According to the Institute for Health Metrics and Evaluation (IHME), the ratio of women dying compared to new cases was almost the same in 2010 as it was in 1980[2]. While cervical cancer cases are declining in the developed world, they pose a heavy burden on developing countries, where the risk of developing cervical cancer is 35% greater compared to developed countries[2].

The majority of cervical cancer cases are caused by HPV infection, 70% of which are caused by two HPV types (16 and 18)[1]. The prevalence of HPV 16 and/or HPV 18 is 5.0% among Indian women with normal cytology and 83.2% among women with cervical cancer[2]. There are currently two HPV vaccines, protecting against HPV types 16 and 18[1]. These vaccines are effective prior to HPV exposure and cannot treat HPV infections[1]. While HPV vaccination is an important supplemental element in addressing the cervical cancer burden, it does not take the place of screening.

Early detection and treatment via screening can prevent up to 80% of cervical cancers in developed countries, where efficient screening programs are in place[1]. In developing countries, however, there is limited access to effective, wide scale screening,

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leading to increased deaths due to cervical cancer[1]. Despite sufficient evidence supporting the use of screening as an effective intervention, there are still very few large-scale screening programs being implemented in India[3].

MATERIALS AND METHODS

Data Sources

The literature search was conducted in June and July of 2018, using the following databases: PubMed, Google Scholar, Embase, and CINAHL. The following terms and keywords were used: 'cervical cancer,' 'India,' 'South Asia,' 'knowledge,' 'attitudes,' 'screening,' 'vaccine,' 'barriers to cervical cancer screening.' Literature published between 2006 and 2018 was reviewed.

Study Selection

Inclusion criteria for articles included: relevance to topic; qualitative and quantitative studies considered; peer reviewed; based in India or another South Asian country. Exclusion criteria included studies conducted in high-income, developed countries.

Types of Studies

Only articles written in the English language were included. Multiple types of studies and reviews were considered and potentially included (including but not limited to semi-randomized control trials, cross-sectional studies, and systematic reviews).

RESULTS

Current Situation in India

In India cervical cancer is the leading cause of cancer mortality and the second most common cause of cancer deaths among women of reproductive age, with 469.1 million Indian women at risk of the disease[1]. According to 2010 IHME estimates, the cumulative probability of incidence for Indian women is 1.9, the second highest in South Asia (Afghanistan has the highest at 3.3)[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[3].

Currently, no national cervical cancer screening program exists in India. Capacity for Pap smear cytology is available at select laboratories in urban areas, but the quality varies significantly[4]. The concept of routine screening for asymptomatic women is almost non-existent among Indian populations. Women are generally advised to get a Pap smear if they present with symptoms[4]. In 2005 national screening guidelines were developed (MOHFW and WHO), recommending that all women aged 30-59 be screened using VIA and that a two-tier system be set up to perform screenings at PHCs and further testing at district hospitals[4]. However, dissemination of the guidelines was poor and little to no action was taken further. Generally, at the primary and secondary level of the public health system, there is limited capacity and limited infrastructure to perform screening or manage screen-positive women. In 2012 a new program for the control of all major non-communicable diseases was introduced, which allocated specific funds for cancer control through a community-oriented approach[4]. Operational guidelines were developed to recommend cervical cancer screening for women but issues in implementation remained[4].

While there is no national screening program, some state governments have taken the initiative. The Tamil Nadu Health Systems Project, established in 2005, is a breast and cervical cancer screening program in the state of Tamil Nadu[5,6]. The government of Tamil Nadu contracted a Technology Company to develop a data collection and management system to allow for unique patient identifiers, data collection, and management of records[5].

Policy

Government commitment is essential to tackling any public health issue and addressing the problem on a population level. In recent years, the National Cancer Control Program (NCRP) has focused on national level efforts and currently maintains two cancer registries: population-based and hospital-based[7]. But there is still a need to strengthen the existing cancer registries in India to better monitor cervical cancer rates and trends[8].

In 2010, the Indian government launched the National Program for the Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS)[5]. NPCDCS began in 100 districts and was expanded to 468 districts in 2012. The goal of NPCDCS is to set up NCD clinics at the district and CHC levels to enable opportunistic screening for common non-communicable diseases. A few years later, in 2016, a screening program was launched to specifically address breast, oral, and cervical cancer, and operational guidelines were developed concurrently: "Operational Guidelines for the Prevention, Screening,

and Control of Common Non-Communicable Diseases: Hypertension, Diabetes and Common Cancers (Oral, Breast, Cervix)"[5,9]. These guidelines aim to integrate screening and early detection of non-communicable diseases into the standard of care available at local health centers. These guidelines focus on six main areas: (1) the organization of referral and treatment services, (2) human resource requirements, (3) training strategy, (4) community engagement, (5) program monitoring, and (6) financing.

Health System Issues

A necessary component to any population-based screening program is an effective health system. Competent health personnel, organizational resources and capacity, and coordinated service delivery are essential building blocks of an effective screening system[5]. Yet, many low- and middle- income countries face infrastructure related challenges, including inequitable service delivery, low adoption of recommendations, limited number of trained experts, and lack of financing. In a country as unique as India, where the healthcare system is especially complex and quality can vary significantly from state to state, a nationwide screening program can be difficult to implement.

India's health system is a mix of both public and private providers, with most of the private providers residing in urban areas. Public healthcare in India is a multi-tiered system comprised of sub-centers, primary health centers, community health centers, and district hospitals. Sub-centers reach the most rural of communities and are staffed primarily by auxiliary nurse midwives and female health workers. Primary health centers (PHC) deal in both prevention and promotion and are staffed my medical officers, paramedical staff, and community level health workers. Community health centers are staffed by four medical specialists supported by paramedical and other staff. With more beds, surgical abilities, x-rays, and lab facilities, community health centers often receive referrals from PHCs. District hospitals are able to provide round-the-clock support and services for emergency obstetric and newborn care as well as other medical emergencies[10].

Health coverage and quality of care in India is fragmented, with significant inequalities between states, socioeconomic groups, castes, and rural and urban areas. In recent years, India has taken steps towards improving and monitoring quality of healthcare. Launched in 2008, the Health Management Information System monitors health programs with data from district reports by facility. The Indian Council of Medical Research (ICMR) also maintains registries for a number of diseases. Despite recent improvements, implementation of quality healthcare remains an issue. The Indian government lacks a single, coherent approach to addressing standardized guidelines for health services across the country[11].

Community Level Issues

Another major barrier to cervical cancer screening is the lack of knowledge and awareness of the community about prevention and treatment of cervical cancer and HPV. Much of the literature highlighted a gap between knowledge of cervical cancer and actual uptake of screening among community women. While many women have heard of cervical cancer, fewer are aware of its symptoms, and far fewer have undergone any type of screening. Yet, many women expressed a willingness to undergo screening despite the low uptake. Many researchers came to similar conclusions, highlighting the need for increased health education around cervical cancer and the importance of screening among both urban and rural women in India.

Narayana et al[12] conducted a cross-sectional hospital-based survey of women attending the Obstetrics and Gynecology Department of a secondary care referral hospital in Andhra Pradesh. Among the 403 women who completed the survey, 74.6% had heard about cervical cancer, 64.2% had some knowledge about signs and symptoms, and 62.8% had knowledge of cervical cancer risk factors. Most participants believed that early screening and HPV vaccination could prevent cervical cancer; yet, the majority of the women (86.6%) had never been screened. Many researchers had similar findings. In other studies, a strikingly lower level of knowledge of cervical cancer was found.

In a cross-sectional study among women at a primary health center in Tamil Nadu, the majority of participants were aware of cervical cancer (75.42%) and many believed that they were at risk (50.58%)[13]. However, only 31% had undergone a Pap smear, but 69.96% of those unscreened were willing to undergo it. Bansal et al[14] found similar results in a study of women of reproductive age who presented to the outpatient department of a hospital in Bhopal. Of the 400 respondents, 65.5% had heard of cervical cancer, only 9.5% had ever undergone a screening test, but 76.25% favored positively to the idea of screening. In Kerala, among 809 women interviewed, three-fourths were aware that cervical cancer can be detected through early screening, yet a mere 6.9% had actually undergone any sort of screening test[15].

A number of researchers identified barriers as to why women are not going for screening, ranging from cost and perceived low level of risk to fear and misunderstanding. Nyblade et al[16] performed a qualitative exploration of cervical and breast cancer stigma in Karnataka, finding a consistent theme of stigma as the underlying barrier to prevention and treatment throughout their interviews. Stigma was frequently cited as a barrier to screening, early diagnosis, and seeking treatment. This stigma derived primarily from a fear of transmission of cancer, personal responsibility for having caused the cancer, and a fear of the inevitability of disability and death following a cancer diagnosis. Montgomery et al[17] found that cost and a low level of perceived risk were most frequently cited as potential barriers to cervical cancer screening and vaccination among women in Karnataka. 60% of the women in this study did not have health insurance and had to pay for medical visits out of pocket, and only 27% said that they can always afford to go to the doctor. Many women said the doctor's office is too far or that transportation is too expensive. Only 5% of the women interviewed had ever had a Pap smear. Basu et al[18] looked at the barriers to cervical cancer screening among two different groups of women in India: those who had purposefully opted out of screening and those who were willing but could not attend for various reasons. The main reasons for which women purposefully opted out of screening were reluctance to go through a test that could detect cancer and a lack of understanding of the need to visit a health professional despite a lack of symptoms. Women who were willing but could not go for screening faced other barriers, including family obligations and a lack of approval from their husbands.

Cervical Cancer in Other Low-Resource Settings

Similar to India, other developing countries are dealing with high numbers of cervical cancer cases and deaths but low screening coverage. Based on a 2008 analysis, coverage of cervical cancer screening is on average 19% in developing countries, compared to 63% in developed countries[19]. In Nigeria, Nwankwo et al[20] found that only 15.5% of respondents were aware that cervical cancer screening services were available and only 4.2% had ever undergone Pap testing. In Ghana, Ebu et al[21] found that, of the 392 female participants in their study, only three had even undergone Pap testing (0.8%) and 97.7% had never even heard of the Pap test. In Bangladesh, among 1113 urban and 924 rural women interviewed, 3.1% of urban women and 0.7% of rural women had ever undergone cervical cancer screening[22].

Comparison of Cervical Screening Program in India and Developed Countries

In India, current program indicates that there is a lack of exclusive cervical cancer screening and it is a part of common cancer control program under the scheme of NPCDCS[23] whereas UK and Australia have a specific screening program for detection of cervical cancer[26,27] (Table 1). Cervical Cancer screening is the most successful disease prevention programs in developed world. However, developing countries are unsuccessful in attaining the same results[28]. In developed countries like UK and Australia cervix screening with Pap and HPV DNA testing is considered as a routine examination. Cytology based examinations are difficult to organize in screening programs in India due to absence of trained human resources and infrastructure at the grassroots level, logistics, quality assurance, repeat screening/testing and economic factors involved[28].

DISCUSSION

This systematic review examined the current literature on knowledge and attitudes regarding cervical cancer and barriers to screening for cervical cancer among women in India. Consistent themes were found throughout the literature – the story is the same not only in India but throughout the developing world. In urban and rural areas alike, most women have heard of cervical cancer, yet there is a shockingly low uptake of screening for cervical cancer. This low uptake of cervical cancer screening can be attributed to a number of factors, as demonstrated by the literature, including low level of knowledge and awareness, low level of perceived risk, stigma associated with cancer, fear of cancer, cost, and familial obligations.

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. Organized screening programs require the health system to monitor program participation, processes, and outcomes, along with referral pathways and follow ups[5]. The International Cancer Screening Network

TABLE 1. Cervical Cancer Screening Program Characteristics in India, UK, and Australia.

	Cervical Cancer Screening Program Characteristics		
	India	***UK***	***Australia***
Program	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)[23] ***Program Component*** • Setting up/strengthening of 20 State Cancer Institutes and 50 Tertiary Care Cancer Centers	National Health Service Cervical Screening Program[26]	National Cervical Screening Program[27]
Population	All women aged 30-65 years; Once in 5years	All eligible female & trans men with cervix	All women aged 25–74
Screening Test	• Visual inspection with acetic acid (VIA), • Magnified VIA (VIAM) visual inspection with Lugol's iodine[24] • Papanicolaou test[25] • HPV DNA testing[25]	HPV testing and Cervical cytology	5-yearly cervical screening with a primary HPV test with partial HPV genotyping and reflex liquid-based cytology triage

identified six essential elements of national cancer screening programs[5], which the Indian government and the governments of other low- and middle- income countries can take note of: (1) development of a clear screening policy, (2) recognition that screening is part of a continuum of care, not a stand-alone event, (3) strong infrastructure, (4) establishment of a monitoring and evaluation system, (5) a plan for community engagement, and (6) implementation of scientific evidence in health delivery settings.

CONCLUSIONS

India has urgent need to develop health system capacity to ensure efficient cervical cancer screening program and community level efforts to improve knowledge about cervical cancer and screening programs. These efforts would help save thousands of young women and their families from a great calamity.

Conflict of Interest:
The Authors declare that they have no conflict of interests.

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