

Cervical cancer screening in Nepal: ethical considerations

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Abstract: Cervical cancer is the leading cause of cancer deaths for women worldwide. Cervical screening and early treatment can help to prevent cervical cancers. Cervical screening programs in Nepal are often associated with a number of socioeconomic, cultural, and ethical challenges. This paper discusses some central ethical challenges in providing cervical cancer screening in the Nepalese context and culture. It is necessary to address these challenges for successful implementation of such screening programs.

Keywords: public health screening, ethics, women, South Asia

Background

Cervical cancer is one of the most prevalent cancers affecting women globally. The worldwide incidence of cervical cancer is approximately 510,000 new cases annually, with approximately 288,000 deaths.¹ More than 85% of these deaths are reported in low and middle income countries.² The World Health Organization estimates that a crude incidence rate of cervical cancer in Nepal is 24.2 per 100,000 women per year, with 3,504 new cases diagnosed every year and 1,872 deaths.³ The incidence rate of cervical cancer in the neighboring country, India, is reported to be the highest in South Central Asia, with an age-standardized incidence rate of 30.7 per 100,000 and an age-standardized mortality rate of 17.4 per 100,000.⁴ High cervical cancer incidence has also been reported in Eastern and Western Africa, South America, and Middle Africa.⁵

The introduction of different screening techniques for cervical cancer has led to a significant reduction in morbidity and mortality from the disease. Screening techniques vary with test characteristics, feasibility, and economic considerations. Various screening techniques have been introduced for early detection of cervical cancer in Nepal. For instance, Papanicolaou smear screening (cervical cytology) has been reported to be a good method for detecting early cervical cancer.⁶ Although the Papanicolaou test has been used as a primary method of screening in Nepal, feasibility of its introduction among the general population is often questioned due to restrictions in the present infrastructure and a lack of human and financial resources.⁶⁻⁸ The human papilloma virus (HPV) test has been used for identifying high-risk HPV in women's cervixes and gives highly sensitive test results.⁹ However, the high cost associated with HPV testing has affected its use in Nepal and other low resource settings.¹⁰ More recently, visual inspection after acetic acid application (VIA) has been found to be a most promising alternative screening test in Nepal, given that it is convenient, affordable,

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and accurate.^{11–13} Cervical screening has been associated with a number of socioeconomic, cultural, and ethical challenges in Nepal, including social inequalities, violation of autonomy, affordability, and acceptability, as well as insufficient and inefficient health care resources.^{14,15} It is necessary to address these challenges for successful implementation of screening programs and ultimately to have an enduring effect on the health of women.

Policy context and challenges for Nepal

The coverage rates for cervical cancer screening services is very low (2.4%) in Nepal.³ The low coverage may be related to a variety of factors, including socioeconomic and cultural barriers. Studies have documented poverty, lack of information, fear of promiscuity among teenagers, myths, and lack of support from husbands and families as major obstacles to screening.¹⁶ For instance, asymptomatic women are unconcerned with screening.^{17,18} Due to lack of routine screening, women from poor communities often seek care only when they develop symptoms, often at an advanced stage of the cancer. Sherpa highlighted a lack of knowledge regarding the preventive role of screening, lack of time available, and permission from husbands to go for cervical cancer screening as obstacles to screening in Nepal.⁷ Moreover, lack of privacy during screening, embarrassment among women, and low importance given to women's health issues have also been cited as factors contributing to the reluctance of women to access cervical cancer screening services in low income countries.⁴

The 2010 national guideline for cervical cancer screening in Nepal has prioritized prevention of cervical cancer through screening and has emphasized using the VIA approach for cervical cancer screening.¹⁹ The guideline has highlighted the need for integration of cervical cancer screening programs and prevention through national health policy and reproductive health programs. The integration of cervical cancer screening with regular health services could potentially increase the uptake of screening services. It has underlined the pre- and post- screening counseling to women and their family members which may support informed consent and increase service utilization. The provision of cervical cancer screening through static service sites, as well as mobile clinics, may improve access to services for people living in rural and remote areas, contributing to equal access to the service. The policy has identified primary health care centers as the starting point of screening, since they are distributed all over the country, and also emphasized the

referral system. Although we moved from Papanicolaou to VIA, the same set of problems persist. While the government made a commitment to reduce cervical cancer by introduction of a commendable screening program, there are still challenges to the implementation of cervical screening policy. Important considerations that need to be taken into account are the lack of discussion about various issues with respect to rights of clients on equal treatment, respecting their privacy, and the right to appropriate treatment, which have not been sufficiently explored.

This paper discusses some central ethical challenges in providing cervical cancer screening in the Nepalese culture and context. These challenges are analyzed using the basic principles of public health ethics.

Ethical issues

Cervical cancer screening programs are often associated with ethical dilemmas. Various ethical challenges may be associated while conducting the VIA test. These may include issues of informed consent and privacy of information, issues regarding challenges of inequalities and access to screening services, along with concerns about benefits and harms of screening. With limited health care resources and competing health care needs, it is very difficult to fund screening programs in low resource settings like Nepal, and this may lead to low and unequal uptake of cervical screening by various subgroups of the population. For successful implementation of the screening program, it is essential to deal with these issues.

Ethical principles

Public health ethics involve identification, analysis, and resolution of ethical problems arising in public health practice. Ethical principles to be followed in public health programs are expected mainly to maximize benefits and minimize unnecessary harms to participating individuals. Many ethical principles are employed in cancer screening, and it is believed that focusing on principle-based common morality can help to analyze and ethically justify problematic issues with regard to outcomes of a public health measure, considering the rights of individuals and groups and taking into account the characteristics of what constitutes a good society.²⁰ Four widely accepted principles that describe the ethical concerns of public health practice are autonomy, beneficence, nonmaleficence, and justice.²¹ Autonomy refers to the duty to respect persons and their rights of self-determination. Beneficence refers to the obligations to maximize possible benefits, whereas nonmaleficence refers to the duty to prevent

or do no harm. Justice refers to the duty to treat individuals fairly (right to equity).

Common ethical dilemmas in cervical cancer screening in Nepal

Ensuring informed consent

Respect for patient autonomy is the ethical principle that lies behind informed consent. Informed consent is almost a universal phenomenon in health care service. The basic requirements of informed consent are that the health care provider conveys the necessary information to the patient with regard to the nature of their illness and respects the patient's decision-making. It is ethically and legally permissible for patients with decision-making capacity to refuse unwanted medical treatment.

In the context of cervical cancer screening, informed consent demands provision of information about the individual's personal risk of developing cervical cancer, the benefits of a screening test, accuracy of the test, further provision of treatment if a positive result is detected on screening, as well as effective communication. Concerns about communication between service provider and patients during screening is evident in Nepal.²² It has been reported that nearly 50% of Nepalese patients are unable to understand informed consent properly due to illiteracy.²³ As a result of lack of information, women are unable to understand the screening test procedure and therefore may not be able to accept the test. It is the responsibility of the health care providers to give appropriate as well as complete information regarding the screening and treatment programs to the patients and family in the way that they can understand. This could promote acceptance and uptake of the newly launched VIA screening test in Nepal.

Woman's autonomy may be affected by various sociological challenges that exist in Nepalese society. Women have less power and autonomy than men in regard to making decisions about their own health care.²⁴ Women often have to consult their husbands before any treatment can be accepted.²⁵ Women's decision-making processes are often affected by their economic situation.²⁴ Women of high socioeconomic status in Nepal may pay close attention to the lesions detected early and may go for immediate treatment, but there may be barriers for women from deprived social strata because of lack of material resources, such as the cost of transport to the treatment center. For these reasons, people of low socioeconomic status may delay about knowing their disease status or delay treatment in the case they had health problems.²⁶ In these

circumstances, women's lack of autonomy regarding health care decision-making not only has the potential to affect their health, but also reduces their participation in screening programs.

Privacy of information

Another aspect related to autonomy is privacy of information. The cancer screening consultation is sensitive in nature and screening clinics should ensure privacy. It has been reported that lack of privacy for women is one of the important reasons behind nonattendance for screening in Nepal.²⁷ Further perceived barriers to screening include fear and shame, especially in a situation when there is unnecessary exposure of the private parts in the presence of male health care providers.^{28,29} This may negatively affect trust in women and their participation in screening may be affected. Women who chose cervical screening in Peru, Kenya, Mexico, and South Africa felt that providers should take time to converse with them, answer questions, explain procedures, and give encouragement during the screening procedure.³⁰ Women need to feel confident that the privacy of their results is maintained.³¹ Indeed, Ghimere et al reported a lack of privacy and confidentiality at government hospitals in Nepal, highlighting the lack of this essential component in the provision of health care.³² The notion of limited privacy extends beyond Nepal, with women in Nigeria also highlighting this as their main reason for nonparticipation in cervical cancer screening programs.³³ Like other screening tests, the VIA test has to be performed with an intimate examination. It is essential that the health care provider gains the trust of the woman, addresses her concerns, and initiates a meaningful dialog with her to ensure consent. Sex preferences of attending medical personnel may also affect attendance. Intensive and appropriate training of health care providers would help to develop an emotional connection with regard to the issues of patient privacy and patients' rights to control information.³⁴ Further, the national guideline should highlight policies that govern patient privacy.

Benefits of screening

The benefits of implementing a VIA screening program in all the primary health care centers of Nepal are obvious. These may include early treatment for cancer, prevention of cervical cancer, alleviation of suffering, and being accessible to women. In addition, the test has minimal complications, produces instant results, and health care providers, after intensive training and supervision, can safely provide testing and treatment in primary care settings.³⁴ In low resource

settings, screening with the VIA test has been considered to be the most feasible and practical approach for early detection of cervical cancer, and is the most effective in, for instance, reducing the burden of disease at an affordable cost.^{35–37} Ethically, providing VIA as an alternative to other high-cost screening programs for prevention of cervical cancer in a low resource setting is a significant and reasonable act of beneficence.

Health care providers are expected not to cause harm, and have an obligation to help their patients. The goal of public health should be to promote the welfare of patients, and health providers should possess skills and knowledge that enable them to assist others. The success of any health care practice relies on the professional behavior of the attending health care professional. However, health care providers will always encounter ethical issues and these need to be carefully addressed with all patients. Previous studies have identified challenges to the health care provider–patient relationship as including fear of malpractice and lack of knowledge, as well as the shortage of skilled health workers while screening for cervical cancer.³⁸ It is therefore essential for health care providers to be appropriately trained and qualified so that they deliver the sensitive care required when women choose to attend for cervical screening.³¹

Risks of screening

In addition to beneficence, it is important to be aware that an organized screening program not only achieves a net health benefit for a community, but can also result in adverse outcomes. VIA screening, like all public health screening, can have false-positive results.³⁹ A false-positive result means that women without the disease are incorrectly identified as being at risk, and subsequently undergo follow-up testing that may be uncomfortable, expensive, and, in some cases, potentially harmful, and some may even receive unnecessary treatment. The patient and their family may suffer from psychological consequences, such as distress and anxiety.⁴⁰ Generally, the better the test and the training of the people administering and interpreting the test, the lower the risk of a false-positive result. At this stage, the health care provider must consider his or her duty not to harm the patient and weigh the psychological risks of inviting the patient for screening against the physical risks of not doing so. In this case, the risks of generating psychological damage seem comparatively great and the chance of doing good seems comparatively small. Perhaps one way to establish a balance is to ensure that the benefit of screening is maximized and the risk is minimized. One of the crucial ways of reducing anxiety is to ensure that

before, during, and after the screening process the patient is fully informed and thus involved in the decision-making process; also, the potential concerns of women need to be addressed in a respectful way. It is therefore ethically imperative that the health care provider performing the VIA test attend to these details.

A further inherent risk of screening is the occurrence of false-negative results. This epidemiological term refers to people being tested and wrongly identified as without risk, but in reality living with an increased risk of a disease. Such a result can give false reassurance. Under the principle of nonmaleficence (doing no harm), it is important to reduce the chance of this happening. In public health terms, false-positives and false-negatives are related to the quality of the test, referred to as the sensitivity and specificity of the test.⁴¹

The acceptability of screening may be limited by personal beliefs, fatalism, or fear. Women may fear that a cervical cancer diagnosis would bring them shame, blame, and even abandonment by their husbands and families, so some may prefer not to know because of their fear of a positive result.^{4,42} Further, women in Nepal's patriarchal society may fear the stigma associated with a test result; for example, they may worry about male partners suspecting them of having a sexually transmitted infection. Stigma, as defined by Goffman, involves rejection of an individual with an attribute that is deeply discredited by society as a result of the attribute.⁴³ Developing culturally appropriate messages and educational materials and identifying effective factors may help to encourage women to participate in cervical cancer screening and may decrease the stigma of treatment. Obviously, such health promotion messages also need to be aimed at men to help reduce the stigma experienced by women. In addition, the significant issues associated with stigma need careful consideration while developing cervical cancer screening for Nepalese women. In the case of VIA inspection, access to information (benefits and risks) can motivate both patients and their families to be proactive in health care decision-making.

Social inequalities

Cervical cancer and other sexually transmitted infections can occur in people regardless of age, sex and other factors. Since most of the disparities in disease burden are rooted in inequitable access to health care, it would be against the principle of justice to provide health care to one group and hold back health care from another group because of bias to do with age, sex or other factors.⁴⁴ Justice denotes fair and

equitable treatment, and the principle of justice implies that a screening program should be available to all who need it. A study revealed that the urban population in Nepal, with its high literacy rate and access to treatment, benefits more from screening programs (coverage 4.7%) than the rural population of Nepal (coverage 2%).³ It is the women from poor households, rural areas, and regions with low health care expenditure who are reported to have difficulty utilizing cervical cancer screening.^{45,46} Nygård et al found that nonattendance for cervical screening was associated with economic barriers.⁴⁷ Based on all these facts, VIA screening is likely to create health disparities because there are still issues regarding how poor, underserved, and hard-to-reach women access this service. For justice to be served, the screening service should be made available at a reduced cost to those who are in need, irrespective of place of residence and economic status.

Conclusion

Cervical cancer is an important public health problem in low income countries, where over 85% of the global deaths occur annually. Cervical screening and early treatment are vital to help prevent cervical cancers. Cervical screening may possess several ethical challenges that need to be addressed through careful analysis and consultation with involvement of the populations affected. A cost analysis of the most effective method of screening, in conjunction with acceptance of that method for a given population, is an essential component of cervical screening delivery in low income countries. The VIA test, being simple, accurate, and cost-effective, can help to decrease the persistent gap in health care access in Nepal. This requires a strong foundation before its introduction at the community level. There should be provision of adequate screening information regarding privacy and the rights of clients to equal treatment, as well as an accessible and affordable service. Barriers need to be identified in the early phase so that the necessary steps can be taken towards addressing them. If ethical issues are addressed, screening for cervical cancer has the potential to improve the health of our nation in terms of higher rates of detection of cervical cancer, and will become a significant achievement in public health in low resource settings.

Disclosure

The authors report no conflicts of interest in this work.

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