

Barriers and innovative interventions for early detection of cervical cancer

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Abstract

Cervical cancer has decreased significantly over the past 30 years in some countries. However, it remains among the leading causes of cancer deaths in low-income, and racial/ethnic minority women. Cervical cancer prevention technologies are not always available. Laboratories are often not well equipped to use them. HPV information has not been widely disseminated. WHO guidelines, and US and Latin American data provide context for strategies on effective interventions to reduce cervical cancer disparities. Systemic, personal and cultural barriers, combined with decision-making guidelines, and impactful messaging can accelerate reductions in cervical cancer health inequities in the Americas.

Keywords: uterine cervical cancer;

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Resumen

El cáncer cervicouterino ha disminuido significativamente en los últimos 30 años, pero sigue siendo una de las principales causas de muerte entre mujeres de bajos recursos y minorías raciales/étnicas. Las tecnologías preventivas del cáncer cervicouterino no están siempre disponibles y los laboratorios no están siempre bien equipados para utilizarlas. La información sobre el VPH no ha sido difundida ampliamente. La OMS y datos de EEUU y Latinoamérica ofrecen estrategias para reducir el cáncer cervicouterino. El entendimiento de las barreras sistémicas, personales y culturales, dentro de un marco de toma de decisiones, y mensajes innovadores puede reducir las barreras asociadas con el cáncer cervicouterino en las Américas.

Palabras clave: cáncer de cuello uterino.

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Even though cervical cancer rates have significantly decreased over the last 30 years, largely due to screening and treatment in the Americas,^{1,2} the lack of resources (including laboratory analysis and advanced diagnostics and technologies)^{3,4} and of a health system structure able to sustain programs requiring regular screenings has impacted screening rates and early detection.^{3,4} In Latin America and the US, low educational levels, illiteracy within the adult population,^{1,2} and personal and cultural barriers^{5,6} have also been linked as contributors to cancer-related inequities. Innovative ways to promote healthy behaviors, increase access, quality and coverage of interventions for the prevention and control of cervical cancer are urgently needed. However, information regarding new technologies, optimal ways to make decisions on the choice of the most adequate screening for specific environments, and data regarding beliefs, attitudes, and behaviors have not always been combined in the development of innovative interventions to reduce cancer-related inequities.

The objective of this paper is to describe different types of barriers to cervical cancer screening and propose strategies for innovative interventions. Strategies include utilizing guidelines from the World Health Organization for cervical cancer screening, combined with data regarding barriers from the US and Latin America, for a more comprehensive understanding of what is needed. We propose the use of innovative, culture- and language-specific messaging and storytelling to improve cancer prevention and control in the Americas.

Discussion

Decision making regarding technological advances in cervical cancer prevention to reduce disparities. New technologies⁵⁻⁷ that provide alternatives to current screening and precancer treatment and which may help decision-makers to reach women at risk more effectively are available. These include HPV DNA testing, RNA-protein testing, visual inspection with acetic acid (VIA), high-resolution micro-endoscopy, and handheld digital colposcopy, among others.^{3,5-7} However, acceptability, costs, and infrastructural requirements and complexities challenge their use, creating barriers to their sustained implementation throughout the Americas.

The World Health Organization's (WHO)^{7,3} Decision-Making Flowchart for program managers could be a useful tool for the ministries of health and health departments to make adequate decisions regarding the viability of screening programs for specific populations. The WHO^{3,7} provides program managers with a decision tree that may be useful in making choices between alternative screening, triage, and treatment options that

are most appropriate to their populations, situation, context, environment, and resources.⁶ Key elements to consider in decision-making include: acceptability of the program to providers and patients, adoption, appropriateness, reach, feasibility, fidelity, incremental implementation costs, penetration, and sustainability. Other key elements to consider include whether the screening test is amenable to a single visit and to self-sampling by women, the percentage of precancer missed in a single visit, the percentage with a positive test, the percentage that actually have precancer, the percentage of treatment that was unnecessary (overtreatment), the human resources required, the time until tests results are available, and the approximate costs of the test.^{3,7}

However, addressing systemic problems through strategic decision-making will not completely resolve the barriers to low screening and lack of early detection of cervical cancer in vulnerable population groups. Understanding of knowledge gaps, attitudes, beliefs, and educational and cultural barriers is also needed.

The role of barriers related to knowledge, attitudes, and beliefs in reducing disparities: Common misconceptions exist in connection to the lack of cervical cancer screenings in Latin America and among low-income Latinas in the United States.^{4,6,8} Attitudes of women in Mexico⁹ and Panama¹⁰ include not thinking it was important, being a virgin, not having a sexual partner, being too young, and being asymptomatic.^{2,6,8} Other barriers deal with socioeconomic status and education, and lack of access to screening and follow up.⁹⁻¹¹ Barriers tend to be similar in Latin America and in the U.S. among women of low socioeconomic status.^{2,5,12,13} When asked to define cervical cancer, women in Guatemala referred to it as "cancer of the womb".² These Guatemalan women were not able to define or describe cervical cancer accurately.² In another study from Argentina,¹⁴ even after getting screened for cervical cancer, women did not know the meaning of an abnormal Pap smear result. This resulted in women not returning for follow-up screenings or treatment, thereby contributing to high cervical cancer rates in Argentina.¹⁴

Lack of education leading to feelings of embarrassment in relation to cervical cancer screening and vaccination is also a common barrier that keeps women away from regular screenings.¹⁵ Research has found negative psychosocial reactions that surround Pap test utilization, including shame, fear, and pain.^{6,8,16,9} The stigma of cervical cancer and its association with sexually transmitted infections (STIs) further limits screening and vaccination.^{14,15} Latin American women^{8,17} expressed discomfort at talking about HPV and STIs. In a rural group in Chile, women expressed that sexual contact and STIs were taboo subjects to talk about. In Trinidad &

Tobago, women were worried about the stigma of HPV as an STI. In both countries, STIs were associated with an active sexual life, which led to the belief that women did not need to seek screening when not sexually active.

Our study in Chile, Trinidad & Tobago of women's knowledge of cervical cancer^{8,17} revealed gaps in knowledge, attitudes, beliefs, and adequacy of health education materials on cervical cancer for use in the Americas. Knowledge-related findings in Chile revealed that, regardless of their socioeconomic status, geographic location, or education, women over 50 years of age had difficulty reading the fact sheets provided and gained little understanding from them. In contrast to Chile, literacy differences among Trinidad and Tobago participants were related to socioeconomic status, not age.

The main sources of information about HPV and cervical cancer in Chile and Trinidad and Tobago were television, radio, educational campaigns and direct contact with health providers,^{8,10} the same as for Latinas in the US.^{12,13,18} Gaps in knowledge included misunderstanding of the appropriate age for screening, the risk factors and the causes of cervical cancer.¹¹ While some women suggested that screening before age 30 would be of benefit to detect cancer early, others questioned the idea of limiting screening at an older age. Chile participants, in particular, were interested in learning about the scientific aspects of cervical cancer, while women in Trinidad and Tobago requested general facts about HPV and the vaccine, believing that women should be given the information only when needed.

Our LA study^{12,13} revealed higher morbidity and mortality rates for cervical cancer among the Hispanic population compared to other population groups, including non-Hispanic whites. The study was originally conducted among English speaking women and was followed by a similar study of 140 Spanish-speaking women of Mexican origin in Los Angeles. This study was conducted from June 1, 2015, to May 31, 2016. Women aged 25-45 years completed three waves of data (baseline, two weeks after the intervention, and six months later). This study corroborated some of the findings in Latin America, in particular, low levels of knowledge, limited access to health care services, and inadequate follow-up.^{12,13}

In our randomized controlled telephone trial, we also examined the effectiveness of two educational films (*Tamale Lesson* and *It's Time*).^{18,19} *Tamale Lesson* utilized storytelling to inform women about cervical cancer screening and HPV vaccination. The *It's Time* film utilized a fact-based non-narrative style to convey the same message. Findings revealed that, when women felt immersed in a storytelling film (*Tamale Lesson*), with a culturally appropriate narrative—a short person-

alized story about cervical cancer screening and HPV vaccination—a higher percentage of them made an appointment or went in for screening for cervical cancer than when they viewed a fact-based film.^{12,13,18} Being able to be immersed in the storyline of the narrative/storytelling allows women to identify with the characters and helps change their behaviors and attitudes. The *Tamale Lesson* film¹⁹ about cervical cancer screening and HPV vaccination increased the percentage of women being proactive in their preventive measures.

Conclusions

Reducing the barriers to early detection on cervical cancer and regular screening among Latinas in the US and high-risk women in the Americas requires a better understanding of the screening options and an analysis of the use of appropriate technologies. To maximize efficiency, decision-makers need to consider screening test performance data combined with an assessment of other health systems and personal and cultural barriers in order to make optimal decisions to improve screening for cervical cancer. Sometimes lower performing options (e.g., tests with lower sensitivity) may represent an optimum strategy if coverage is increased, compared to an option with better performance but lower coverage. However, selection and availability of testing are not enough to reduce the barriers to screening in the U.S. and Latin America. Consideration of personal, educational, cultural barriers and more effective learning styles is also needed to accelerate and sustain changes in screening over time. These considerations are important because the vaccine is not yet available for older women, although it is being considered for women aged 27-45 years. A combination of these strategies may prove optimal for purposes of intervention to reduce disparities.

In addition, especially among younger populations, we must consider, in addition to screening, which is the purpose of this paper, greater diffusion of the vaccine against the Human Papilloma Virus, if we truly are to reduce the burden of cervical cancer in the Americas. Without the widespread vaccinations of boys and girls and young women and men, it will be difficult to obtain the gains that the vaccine promises in Latin America and in many underserved communities in the US.

To reduce systemic barriers in screening, our analysis revealed the usefulness of the WHO guidelines for effective decision-making guidelines regarding screening and precancer treatment. Our Los Angeles and Latin American studies propose the use of tested, culturally and language grounded fact sheets and the widespread and effective use of storytelling as potential strategies to reduce personal and cultural barriers. Com-

binning these powerful tools proven to be effective could go a long way in the prevention and control of cervical cancer in the future, by increasing cancer screening and follow-up to treatment as indicated.

Lessons for the future

New technologies are not just limited to the use of new screening methods presented here, but also include new and emerging technologies that may be considered in the delivery of messaging both for increasing screening and/or to motivate individuals to become vaccinated against HPV. As many populations become more adept in the use of the Internet, smartphones, YouTube, Facebook, Instagram and Twitter, and these technologies reach a wider segment of the population, consideration of short vignettes and short messaging in text format, fact sheets that can be placed on websites, information sheets (infograms) that can be delivered electronically and in print, or short stories (webnovels, online photostories), and other materials that are culturally tuned to address perceived barriers may all provide innovative ways to address increased screenings. These innovative strategies could may provide a broader reach, resulting in a potentially higher impact on screening and on HPV vaccinations among vulnerable women in the US and Latin America.

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