Barriers and innovative interventions for early detection of cervical cancer

Lourdes Baezconde-Garbanati, MPH, PhD,(1-3) Irene Agurto, MD, PhD,(4) Patti E Gravitt, MS, PhD,(5) Silvana Luciani, MHSc,(4) Sheila Murphy, PhD,(6) Carol Ochoa, MPH,(2) Katia Gallegos, MSc, PhD,(2,7) Rosa Barahona, BA,(1-3) Yaneth L Rodriguez, MPH,(2,3)

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: cervix cancer uterine; disease prevention

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; prevención de enfermedades

Received on: March 3, 2019 • Accepted on: June 19, 2019
Corresponding author: PhD. Lourdes Baezconde-Garbanati. Norris Comprehensive Cancer Center, Keck School of Medicine, University of Southern California. Soto Street 2001, Room 302N 90033 Los Angeles, California, USA. E-mail: Baezcond@usc.edu
Even though cervical cancer rates have significantly decreased over the last 30 years, largely due to screening and treatment in the Americas, the lack of resources (including laboratory analysis and advanced diagnostics and technologies) and of a health system structure able to sustain programs requiring regular screenings has impacted screening rates and early detection. In Latin America and the US, low educational levels, illiteracy within the adult population, and personal and cultural barriers 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

This essay helps inform decision making regarding technological advances in cervical cancer prevention to reduce disparities. New technologies 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. 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) 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 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. 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.

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. Attitudes of women in Mexico and Panama for not getting screened on time include not thinking it was important, being a virgin, not having a sexual partner, being too young, and being asymptomatic. Other barriers deal with socioeconomic status and education, and lack of access to screening and follow-up. Barriers tend to be similar in Latin America and in the U.S. among women of low socioeconomic status. When asked to define cervical cancer, women in Guatemala referred to it as “cancer of the womb”. These Guatemalan women were not able to define or describe cervical cancer accurately. In another study from Argentina, 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.

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. Research has found negative psychosocial reactions that surround Pap test utilization, including shame, fear, and pain. The stigma of cervical cancer and its association with sexually transmitted infections (STIs) further limits screening and vaccination. Latin American women 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.
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 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, the same as for Latinas in the US. Gaps in knowledge included misunderstanding of the appropriate age for screening, the risk factors and the causes of cervical cancer. 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 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.

In our randomized controlled telephone trial, we also examined the effectiveness of two educational films (Tamale Lesson and It's Time). 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 persona-

lized 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. 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 film 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 style 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.
bining 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 (infographics) that can be delivered electronically and in print, or short stories (webnovels, online photo-novels), and other materials that are culturally tuned to address perceived barriers may all provide innovative ways to address increased screenings. These innovative strategies 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.

**Acknowledgments**

We would like to acknowledge the National Cancer Institute (USC Norris Comprehensive Cancer Center P30 CA014089 (Wayne)) and Transforming Cancer Knowledge CA144052 (Murphy/Baezconde-Garbanati) and R01CA190366 (Gravitt). Special thanks to Megan Moran, PhD, John’s Hopkins University, Lauren Frank, PhD, Portland State University, Danielle Garcia and Kiana Rowshan for their leadership and contributions to Tamale Lesson, and the Southern California Clinical and Translation Institute (CTSI) (UL1TR000130) for their support of this study. The authors also wish to thank the National Alliance for Hispanic Health, National Health Organization, USF Health, Health Foundations for the Americas and the USC Center for Health Equity in the Americas. Also, we wish to thank Irene Martínez, Lourdes Arévalo, Lorena Báez, Roberto del Águla, Ximena Sgombich, Edwin Bolastig, Akenath Misir, Abena Peters and Chelsea Garcia for their assistance in Los Angeles and in Chile and Trinidad and Tobago.

**Declaration of conflict of interests.** The authors declare that they have no conflict of interests.

**References**

1. Alfaro KM, Gage JC, Rosenbaum AJ, Ditzian LR, Maza M, Scarinci IC, et al. Factors affecting attendance to cervical cancer screening among women in the Paracentral Region of El Salvador: a nested study within the CAPE HPV screening program. BMC Public Health. 2015;15:1058. https://doi.org/10.1186/s12889-015-2360-7
2. Petrocy A, Katz ML. Cervical cancer and HPV: Knowledge, attitudes, beliefs, and behaviors among women living in Guatemala. J Health Care Poor Underserved. 2014;25(2):624-36. https://doi.org/10.1335/hpu.2014.0804
3. Gravitt P. Research on human papillomavirus and global cancer prevention: Translation of technological advances in cervical cancer prevention in high disease burden countries. Promoting Health Equity and Transnational Partnerships in Cancer Prevention and Control in the Americas Strategic Planning Summit; 2016 Oct 7; Panama City, Panama. https://healthequityamericas.usc.edu/summit/health-equity-research-summit/
4. Baezconde-Garbanati L, Murphy ST, Moran MB, Cortessis VK. Reducing the excess burden of cervical cancer among Latinas: Translating science into health promotion initiatives. Calif J Health Promot. 2013;11(1):45-57.
5. Bradley J, Coffey P, Arrossi S, Agurtu I, Bingham A, Dzuba I, et al. Women’s perspectives on cervical screening and treatment in developing countries: Experiences with new technologies and service delivery strategies. Women Health. 2006;43(3):103-21. https://doi.org/10.1007/ j013v43n03_06
6. Jeronimo J, Castle PE, Temin S, Denny L, Gupta V, Kim J, et al. Secondary prevention of cervical cancer: ASCO resource-stratified clinical practice guideline. J Glob Oncol. 2017;3(5):635-57. https://doi.org/10.1200/ JGO.2016.006577
7. World Health Organization. WHO guidelines for screening and treatment of precancerous lesions for cervical cancer prevention. Geneva: WHO, 2013 [cited 2013 Oct 2]. Available from: https://www.who.int/re productive-health/publications/cancers/screening_and_treatment_of_pre cancerous_lesions/en/
8. Agurtu I. Resultados de Focus Groups: comprensión de mensajes sobre VPH y cáncer cervicouterino. Promoting Health Equity and Transnational Partnerships in Cancer Prevention and Control in the Americas Strategic Planning Summit; 2016 Oct 7; Panama City, Panama. https://healthequityamericas.usc.edu/summit/health-equity-research-summit/
9. Leyva M. Attitudes towards cervical cancer screening: A study of beliefs among women in Mexico. Calif J Health Promot. 2006;4(2):12-24. http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.531.8604&rep=rep1&type=pdf
10. Vamos CA, Calvo AE, Daley EM, Giuliano AR, Lopez-Castillo H. Knowledge, behavioral, and sociocultural factors related to human papillomavirus infection and cervical cancer screening among inner-city women in Panama. J Community Health. 2015;40(6):1047-56. https://doi.org/10.1007/s10900-015-0030-4
11. American Cancer Society. Cancer facts and figures for Hispanic/Latinos 2015-2017: Atlanta: American Cancer Society, 2015. [cited 2013 Oct 2]. Available from: https://www.cancer.org/content/dam/cancerorg/research/cancer-facts-and-figures/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-hispanics-and-latinos-2015-2017.pdf
12. Murphy S, Frank L, Chatterjee J, Moran MB, Zhao N, Baezconde-Garbanati L. Comparing the relative efficacy of narrative versus non-narrative health messages in reducing health disparities using a randomized trial. Am J Public Health. 2015;105(10):2117-23. https://doi.org/10.2105/ AJPH.2014.302332
13. Baezconde-Garbanati L, Chatterjee J, Frank L, Murphy S, Moran M, Wherl L, et al. Tamale Lesson: A case study of a cancer narrative health
communication intervention. J Commun Healthc. 2014;7(2):82-92. https://doi.org/10.1179/1753807614Y.0000000055

14. Paolino M, Arrossi S. Women’s knowledge about cervical cancer, Pap smear and human papillomavirus and its relation to screening in Argentina. Women Health. 2011;51(1):72-87. https://doi.org/10.1080/03630242.2010.542547

15. Soneji S, Fukui N. Socioeconomic determinants of cervical cancer screening in Latin America. Rev Panam Salud Publica. 2013;33(3):174-82. https://doi.org/10.1590/S1020-49892013000300003

16. Bingham A, Bishop A, Coffey P, Winkler J, Bradley J, Dzuba I, et al. Factors affecting utilization of cervical cancer prevention services in low-resource settings. Salud Publica Mex. 2003;45(supp 3):S408-16. https://doi.org/10.1590/S0036-36342003000900015

17. Agurto I, Bishop A, Sánchez G, Betancourt Z, Robles S. Perceived barriers and benefits to cervical cancer screening in Latin America. Prev Med. 2004;39(1):91-8. https://doi.org/10.1016/j.ypmed.2004.03.040

18. Baezconde-Garbanati L, Murphy S. Intervenciones innovadoras: Tamale Lesson and Es Tiempo. Promoting health equity and transnational partnerships in cancer prevention and control in the Americas Strategic Planning Summit, 2016 Oct 7; Panama City.

19. University of Southern California. The Tamale Lesson: Narrative Education on Cervical Cancer [video]. California: USC, 2015 [cited 2013 Oct 2]. Available from: https://www.youtube.com/watch?v=Lyyh9KmLtrc