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Closing the cervical cancer disparity gap

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Cervical cancer is a sexually transmitted infection that is now completely preventable. Primary prevention is possible with HPV vaccine, secondary prevention with an established primary health system that provides women with Pap screening tests, and tertiary prevention with treatment of precancerous lesions and early disease. The existence of these resources makes particularly disturbing a recent report about a severe undercounting of cervical cancer mortality in the United States. Using figures that corrected for hysterectomy, that is, eliminated this group of women from the analysis as they would not be susceptible to cervical cancer, researchers found that data from the National Center for Health Statistics underestimated mortality by 44% (Beavis, Gravitt, & Rositch, 2017). Black women in the oldest age group had a mortality rate from cervical cancer of 37.2 per 100 000, suggested in an accompanying editorial as one that “rivals the rates of undeveloped countries” (Dalton & Farley, 2017, p. 915).

Our work with women in a variety of health care settings suggests four reasons why this mortality and disparity exists in a country with a highly developed health system.

First is the ongoing and seemingly intractable understanding held by women from a variety of educational and economic groups that all pelvic exams include a Pap test (Ramaswamy & Kelly, 2015). This confusion leads to an overestimation by patients of whether they have received a Pap test, and has been found in studies conducted in emergency departments, and adolescent, family medicine and general health clinics (Beavis et al., 2017; Blake, Weber, & Fletcher, 2004; Lyons, Lindsell, & Trott, 2004).

Second, a corollary of the first, is the belief that a Pap smear is a universal test for the detection of all women’s health problems, including sexually transmitted infections, pregnancy, ovarian cysts, and cancer cells (Kelly, Hunter, Daly, & Ramaswamy, 2017). Such misunderstanding leads women to over report Pap abnormalities and muddies the waters in assessing who needed what type of follow-up.

Third, recommendations have changed from an easy to remember guideline, yearly Pap testing for all women, to a more complex algorithm of every 3 years between the ages of 21 and 65 (CDC, n.d.). While this recommendation, agreed to by the American College of Obstetricians and Gynecologists, the U.S. Preventive Services Task Force and the American Cancer Society has been in place for several years, its implementation into practice has been slower (Teoh et al., 2015; Verrilli, Winer, & Mao, 2014).

Fourth, the reality is that follow-up of true Pap abnormalities often involves a referral to a different provider, greater expense, and the need for multiple visits and negotiations with health insurers—a complex process in which women can easily get lost. Many women, even those who receive recommended Pap tests, can misunderstand the limits of screening and the consequences of delaying follow-up (Westin et al., 2008). Abercrombie's (2001) review of older articles about follow-up of care for Pap abnormalities found that barriers to follow-up included child-care commitments, lack of understanding of results, inaccessibility of information, staff attitudes, male providers, lack of scheduling flexibility, and poor staff communication about appointments. Each of these remains a barrier in current practice more than a decade later. Screening programs may not always have the resources to pay for treatment or be available for women without the proper documentation. All of these have been ignored as problems serious enough to be addressed (Westin et al., 2008).

Very little of this information is new; it has been documented, researched and essentially ignored in practice and policy. The true current statistics reported by Beavis et al. also reflect the reality that it is largely women with limited income, undocumented immigration status, and histories of drug use, trauma, mental health problems, who bear the brunt of this disparity. They are being doomed by our health care system to painful deaths from cervical cancer.

What does this mean for public health nurses, educators, researchers and administrators?

The health care system, which includes all of us, bears a large part of the responsibility for these deaths. We must, therefore, take responsibility to change it. This means we must work to educate patients and to train students and providers to discuss with women during every pelvic exam what is and is included, when they are getting a Pap smear and when they are not, and what the results will or will not reveal. We must make accessible educational materials, such as clear posters in understandable language, and ensure the availability of individualized education (Hunter & Kelly, 2012). The systems in which we provide care must be encouraged to have hours that can accommodate working adults and follow-up on referrals and ensure their completion. Our responsibility does not end with making a referral; the referral has to be realistic, that is, to a provider that the woman can access and afford. We must ensure that referrals are made to affordable facilities (if necessary that accept Medicaid or have sliding fee scales) and are otherwise feasible for women to access. Follow-up of every referral is critical to be sure that the woman was seen and has a treatment plan in place. Finally, we must work to ensure that women's health care is covered by third party insurance—the Affordable Care Act and Medicaid expansion now provide this financial safety net for at least some women.

Cervical cancer is completely preventable, and yet an unconscionable number of American women are dying from it nonetheless. We cannot allow this to continue.

References

- Abercrombie PD. Improving adherence to abnormal Pap smear follow-up. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*. 2001; 30(1):80–88.

- Beavis A, Gravitt P, Rositch A. Hysterectomy-corrected cervical cancer mortality rates reveal a larger racial disparity in the United States. *Cancer*. 2017; 1123:1044–1050.
- Blake D, Weber B, Fletcher K. Adolescent and young adult women's misunderstanding of the term Pap smear. *Archives Pediatric and Adolescent Medicine*. 2004; 158(10):966–970.
- CDC. Cervical cancer screening guidelines for average risk women. (n.d.). Retrieved from www.cdc.gov/cancer/cervical/pdf/guidelines.pdf
- Dalton H, Farley J. Racial disparities in cervical cancer: Worse than we thought. *Cancer*. 2017; 1123:915–916.
- Hunter J, Kelly PJ. Imagined anatomy and other lessons from learner verification interviews with Mexican immigrant women. *Journal of Obstetric, Gynecologic and Neonatal Nursing*. 2012; 41(6):E1–E12.
- Kelly PJ, Hunter J, Daly E, Ramaswamy M. Challenges to pap smear follow-up among women in the criminal justice system. *Journal of Community Health*. 2017; 42(1):15–20. [PubMed: 27449030]
- Lyons M, Lindsell C, Trott A. Emergency department pelvic examination and Pap testing: Addressing patient misperceptions. *Academic Emergency Medicine*. 2004; 11(4):405–408. [PubMed: 15064218]
- Ramaswamy M, Kelly PJ. The vagina is a very tricky little thing down there”: Cervical health literacy among incarcerated women. *Journal of Health Care for the Poor and Underserved*. 2015; 26(4): 1265–1285. [PubMed: 26548678]
- Teoh D, Marriott A, Vogel R, Marriott R, Lais C, Downs L, Kauasingam S. Adherence to the 2012 national cervical cancer screening guidelines: A pilot study. *American Journal of Obstetrics and Gynecology*. 2015; 212(1):62, e1-62–9. [PubMed: 24992692]
- Verrilli L, Winer R, Mao C. Adherence to cervical cancer screening guidelines by gynecologists in the Pacific Northwest. *Journal of Lower Genital Tract Disease*. 2014; 18(3):228–234. [PubMed: 24633168]
- Westin S, Bustillos D, Gano J, Fields M, Coker A. Social factors affecting treatment of cervical cancer: Ethical issues and policy implications. *Obstetrics and Gynecology*. 2008; 111(3):747–751. [PubMed: 18310380]