

Determinants of Cervical Cancer Screening Among Women with Intellectual Disabilities



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Overview

Women with intellectual disabilities have lower overall health and lower quality health care than women without intellectual disabilities.¹⁻³ Our study looked specifically at rates of Papnicolau (Pap) tests among women with intellectual disabilities in one southeastern state. Barriers to Pap tests for women with intellectual and developmental disabilities include limited transportation,⁴ lack of knowledge about pelvic exams amongst patient,⁵⁻⁶ and lack of training and discriminatory social attitudes amongst providers.⁷ Of women 18-65 years of age with intellectual disabilities, only 55% received a Pap test between 2008-2010. Assertive measures are required to improve the receipt of cervical cancer screening among women with intellectual disabilities. Such measures could include education of women with intellectual disabilities, as well as their paid and family caregivers, and incentives for health-care providers who achieve screening targets.

Cervical cancer was once the leading cause of U.S. women's cancer deaths. Death rates have declined in the past 50 years, because more women are receiving Pap tests.⁸⁻⁹ In 2008, it was estimated that 85% of U.S. women received a Pap test according to clinical guidelines.¹⁰ It has been reported that women with disabilities are less likely than their non-disabled peers to receive a Pap test. One national study found that women with disabilities are 72% less likely than women without disabilities to receive a Pap test.¹¹

However, the existing evidence of Pap test rates of women with intellectual disabilities has been based on self-reported or proxy-reported (i.e., caregiver) interview data. Estimates of accurate Pap test recall by women without intellectual disabilities range from 65% to 89%. Over reporting may occur because of social desirability bias.¹² In addition, problems with telescoping, or reporting that an exam occurred more recently than it actually did, may also be prevalent.¹³⁻¹⁴ Women with intellectual disabilities often have limited knowledge or understanding of the exam¹⁵ and may be unable to accurately report receipt or may confuse routine care such as a pelvic exam with the Pap test.¹²⁻¹³ Caregiver or proxy reports can also be problematic not only for the recall difficulties outlined previously, but also because the reporter may lack knowledge about the woman's medical care. Therefore, it is important to establish rates of cervical cancer screening receipt from sources other than self- and proxy-reported data.

This study aimed to determine rates of Pap test receipt for women with intellectual disabilities from the women's medical records, which are valid sources of data for receipt of this type of testing and identify the determinants of such screening.

Findings

- About half (55%) of the sample received a Pap test in 2008, 2009, or 2010
- Women who lived at home with family caregivers were less likely to receive Pap screening than women living in residential setting
- Women who lived in a rural setting also had a greater likelihood of receiving Pap tests in any of the three years than women who lived in urban settings
- Women who had a general practitioner as their physician were less likely to receive the screening than women who had an obstetrician/gynecologist (OB/GYN) as their physician

Summary & Recommendations

Women with intellectual disabilities are not receiving cervical cancer screening at recommended rates or at rates similar to women without intellectual disabilities. Interventions to improve Pap test rates for women in the general population have failed to reach women with intellectual disabilities. There is a need for specialized screening guidelines for women with intellectual disabilities. Such guidelines could effectively include having health-care providers give women with intellectual disabilities adequate time, support, and preparation to understand the procedures.

Our finding that women living at home with family are screened at lower rates further emphasizes the need for targeted education of family caregivers about the importance of screenings. Previous research suggests that physicians may not recommend exams and/or family caregivers may refuse them.¹² Therefore, educating physicians about the health of women with intellectual disabilities and ways to administer exams in a way that reduces their fear and anxiety is also warranted.

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