

SHORT COMMUNICATION

ENSURING ACCESS: A SHORT COMMUNICATION ON CERVICAL CANCER SCREENING IN WOMEN WITH INTELLECTUAL DISABILITIES

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ABSTRACT: Cervical cancer represents a high burden in women's health. Introduction of cervical cancer screening and Human Papillomavirus (HPV) vaccination programs are making a measurable impact to reduce cervical cancer prevalence and mortality in a number of countries. However, there are still discrepancies in service provision and uptake in different countries, with women with intellectual disabilities being at greater risk of being impacted. The aim of this literature review is to highlight the current state of cervical cancer screening, with a special focus on the barriers and enablers affecting women with intellectual disabilities. We found that there are multiple obstacles for the uptake of cervical cancer screening among women in general, but even more in women with intellectual disabilities. Barriers to cervical cancer screening can be due to geographical, psychosocial or economic reasons, together with poor understanding by the caregiver/s and/or the patient herself or misconceptions from healthcare professionals. Improved knowledge for caregivers, health care professionals and persons with intellectual disability will lead to better uptake of cervical cancer screening. In conclusion, the implementation of enablers in order to overcome the obstacles faced by women, especially those with intellectual disability, is a public health priority which has the potential to lead to less morbidity and mortality related to cervical cancer.

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Impact statement: Women's health is heavily burdened by cervical cancer. Women with intellectual disabilities are more likely to be affected by cervical cancer, as there are still differences in service availability and uptake among different countries and regions.

Key words: cervical cancer; screening; barriers; enablers; intellectual disabilities.

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INTRODUCTION

Cervical cancer represents a high burden in women's health (1). It is well established that cervical cancer screening programs are effective in reducing morbidity and mortality. Significant progress has been made over the past years concerning screening strategies, namely the choice of screening test, its frequency as well as the age to start the screen-

ing. Introduction of Human Papillomavirus (HPV) vaccination programs is also making a measurable impact to reduce cervical cancer prevalence and mortality. However, there are still discrepancies in service provision and uptake in different countries, with women with intellectual disabilities being at greater risk of being impacted. The aim of this article is to highlight that, over and above the current discrepancies in cervical cancer

screening programs and access to HPV vaccination in different countries, there are further obstacles faced by women with intellectual disabilities. This is followed by an outline of the enablers and strategies on how to improve cervical cancer screening among this vulnerable group.

Current cervical cancer screening

According to a recent survey conducted by the European Board and College of Obstetricians and Gynaecologists (EBCOG) (2), 91% of European countries have an organized national or regional screening program for cervical cancer. Of these, 45% use both cytology and testing for HPV as screening test, 31% use cytology exclusively and 17% only perform HPV testing. There are considerable differences regarding the interval of the screening test. There are countries performing HPV detection triennially, while others perform only conventional cytology every 5 years. Up to 69% of countries begin screening for cervical cancer in women aged 25 to 29 years, four of them using HPV detection as the screening test. Six countries begin cervical cancer screening before the age of 25. Almost all countries have implemented national HPV vaccination program, except in Poland and Turkey. The 9-valent HPV vaccine is the most frequently offered (77% of countries). The majority of the vaccination programs include both girls and boys.

Cervical cancer screening in women with intellectual disability

When compared with the general population, adults with intellectual disabilities are more likely to die of cancer, particularly that affecting the female genital organs (3). Effective cancer screening must be available for all eligible individuals without discrimination. However low cancer screening participation rates are evident in women with intellectual disability (4, 5). According to Kuper et al, women with intellectual disabilities are less likely to undergo cervical cancer screening (RR = 0.65, 0.50-0.84) (6). In fact, the proportion of women with intellectual disability who are not screened for cervical cancer is nearly twice what it is in the women without intellectual disability, even in case of prior pregnancy (7, 8). There tends to be overreporting of receipt of Pap tests among women with intellectual disability. Son et al. (9) showed that, in the case of Pap smear, there was only a 75% total agreement between self-report and medical record of receipt of this test (9). A Swedish cohort study suggests that patients with cervi-

cal cancer and a preexisting diagnosis of an intellectual disability have worse overall and cervical cancer-specific survival than other patients (10). This may be partly attributable to cancer stage and sociodemographic characteristics at the time of diagnosis. To date, there are marked variations and discrepancies among countries in the delivery of cervical cancer screening programs (11), and this health inequity is even more evident among women with intellectual disability. These variations can be due to organizational, economic or cultural reasons. The implementation of a unified policy of prevention, screening and early detection of cervical cancer is urgently needed in order to optimize clinical outcomes and ensure equal access to screening.

Barriers to cervical cancer screening

In general, barriers to cervical cancer screening can be due to geographical, psychosocial or economic reasons, together with poor understanding. Access to services can be an issue, especially in remote areas. Cultural issues and embarrassment, particularly in case of lack of female health care professionals can lead to failure to turn up for appointments. Other psychosocial issues can include previous negative experience, and possibly even sexual assault. Fear of pain and/or anxiety about the result itself may also deter women from undergoing cervical cancer screening. The cost of a gynecological appointment or time constraints could be some of the economic barriers. Poor understanding of the significance of cervical cancer screening and its role in cancer prevention, especially in asymptomatic women, is another major factor where women end up not considering it as a health priority.

In addition to the above, there are also barriers which are specific to women with intellectual disability (12, 13). These challenges include communication barriers, lack of access to appropriate health-care and social stigma. Another contributing factor is a possible lack of understanding among health-care providers and/or caregivers about the needs of women with intellectual disability. One factor is that of caregivers not knowing or not believing that the exam is needed for their family member (14). This can be due to family caregivers themselves lacking knowledge about the need for cervical screening by women in general, and in women with intellectual disability. This can be coupled with the physician's or caregiver's assumptions that screening is unnecessary because they assume that women with intellectual disability are not sexually active (15). Cervi-

cal cancer screening and HPV vaccination inevitably come with resource and budget implications, especially if strategies need to be adapted for populations with intellectual disability. These adaptations include extended time slots, special training for healthcare professionals and modified equipment.

Enablers for cervical cancer screening

It is important for every community to work on enablers in cervical screening, in particular in women with intellectual disability. First and foremost, caregivers need to be better informed on the importance of cancer screening, thus increasing their own knowledge as well highlighting the importance of screening women with intellectual disability. The accessibility to screening to women with intellectual disability needs to be facilitated. The national screening program has to be adapted accordingly to ensure equity. According to Swaine *et al.* (14), the most common response to what enabled women with intellectual disability to receive the exam was appropriate preparation prior to the exam itself.

DISCUSSION

The implementation of enablers to overcome the obstacles faced by women, especially those with intellectual disability, is a public health priority. The latter has the potential to lead to less morbidity and mortality related to cervical cancer. Improving cervical cancer screening for women with intellectual disabilities requires a multi-faceted approach that addresses the unique challenges faced by this population. Several strategies can be employed to enhance cervical cancer screening in this group. Education and awareness need to be tailor-made and aimed towards women with intellectual disabilities; caregivers and families; and healthcare providers respectively. Women with intellectual disabilities need to be provided with accessible, easy-to-understand information about cervical cancer, the importance of screening, and how the screening process works (16). This can be done through simple language, visual aids, and videos (17). Empowering women with intellectual disabilities to understand the importance of regular screening and their rights can improve engagement. Since caregivers and family members often make healthcare decisions on behalf of women with intellectual disability, they also need to be educated and informed about the need for regular screening. Hence, they can

become more supportive in facilitating the screening process (15).

Healthcare providers including general practitioners, gynecologists and nurses, need to be trained on the unique needs of women with intellectual disabilities (Power *et al.*, 2024). This includes understanding the communication challenges and how to modify their approach to make these women feel comfortable and supported during the screening. In the clinic, strategies need to be adopted by healthcare professionals for building good rapport to help build trust, especially in women with intellectual disability. This is crucial to obtain equitable and accessible informed consent from the person with intellectual disability (18).

According to the Queensland Council of Social Services (19), these strategies include being clear about the healthcare professional's role and the purpose of the interaction. Using a person's preferred name when speaking with them and having a pleasant tone that is clear and precise. Words and expressions that may be unfamiliar need to be explained using age-appropriate language and avoiding jargon. One needs to speak slowly and leave pauses for the person to process the healthcare professional's words. It is important to speak directly to the person concerned. The healthcare professional should ask one question at a time and provide adequate time for the person to process the question and then formulate and communicate their response. If the person uses a communication device, it must be ensured that they have access to it, and if necessary, the healthcare professional should read the directions (usually on or in the device/book) and use the device with them. If it is necessary to obtain part/all history from the carer, it is important to still maintain the focus on the person with the intellectual disability through eye contact and body language. Throughout the consultation, particularly during examinations involving intimate areas, any healthcare professional should convey acceptance by showing interest and concern. This applies to all patients, but in particular to women with intellectual disabilities. Longer appointment times are needed to allow for more time to explain the procedure itself, manage anxiety, and offer breaks if needed (20). The environment needs to be adjusted to create a welcoming, non-judgmental atmosphere that caters to the sensory and communication needs of women with intellectual disabilities. This might include a quiet room, visual cues, or the presence of a trusted person to help reduce anxiety. Healthcare assistants or sup-

port workers who are trained in working with individuals with intellectual disabilities are needed to ensure that this vulnerable group feels comfortable and supported throughout the screening process. For women with intellectual disabilities who face transportation or other access barriers, telemedicine consultations might be useful for initial pre-screening assessments, education, and follow-up (21). Pre-screening assessments can help identify the specific needs and challenges of women with intellectual disabilities before they undergo cervical cancer screening, such as anxiety, lack of understanding or any previous trauma. However, actual screenings would still need to occur in a clinical setting. For women who experience anxiety or fear around screenings, allow for a gradual introduction to the process. Using mobile health clinics or community outreach programs can facilitate the provision of cervical cancer screening services in community centers or at locations where women with intellectual disabilities and their caregivers can easily access them. Peer support networks can be established where women with intellectual disabilities who have undergone screening can share their experiences with others. This could reduce fear and provide a sense of community.

Increased outreach and advocacy can be carried out via public health campaigns. These campaigns raise awareness about cervical cancer screening specifically targeted at women with intellectual disabilities, their families, caregivers, and community-based organizations. In addition, if held in collaboration with disability advocacy groups, these can focus on the benefits of screening and how to navigate the process. Educational materials and training can be provided for both the women and healthcare professionals.

Access to affordable and convenient healthcare services, including routine screenings, may involve policy changes or advocacy for better coverage of these services for women with intellectual disabilities. The promotion of the integration of services for these people within mainstream health services makes the process of screening and follow-up more inclusive. By incorporating these strategies, it is possible to improve cervical cancer screening rates and outcomes for women with intellectual disabilities, ensuring they have equal access to preventative care and health services. Co-production studies to address inequities in cervical screening participation, such as the one carried out by Bateson *et al.* (22) and Petitpierre *et al.* (17), are very much needed.

CONCLUSIONS

While great progress has been achieved in the fight against cervical cancer, it is important to continue working on enablers for cervical cancer screening, in particular in women with intellectual disability. While HPV vaccination during the teenage years plays a crucial role in cancer prevention, cervical cancer screening is still necessary. This is a very pressing public health issue which can lead to less morbidity and mortality among women with intellectual disability. Future research is needed on pilot programs testing modified screening protocols, to be able to better inform policy makers and thus implement the very much needed changes.

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REFERENCES

1. Goddard KAB, Feuer EJ, Mandelblatt JS, Meza R, Holford TR, Jeon J, et al. Estimation of Can-

- cer Deaths Averted From Prevention, Screening, and Treatment Efforts, 1975-2020. *JAMA Oncol.* 2025;11(2):162-7. doi: 10.1001/jamaoncol.2024.5381.
2. Vieira-Coimbra M, Nogueira-Martins N, Zadykowicz R, Rodrigues Gaspar H, Calleja-Agius J, Pakiz M, et al. Provision of screening services for cervical and breast cancer - A scientific study commissioned by the European Board & College of Obstetrics and Gynaecology (EBCOG). *Eur J Obstet Gynecol Reprod Biol.* 2023;289:208-16. doi: 10.1016/j.ejogrb.2023.08.385.
 3. Ward LM, Cooper SA, Sosenko F, Morrison D, Fleming M, McCowan C, et al. Population-based cancer incidence and mortality rates and ratios among adults with intellectual disabilities in Scotland: a retrospective cohort study with record linkage. *BMJ Open.* 2024;14(8):e084421. doi: 10.1136/bmjopen-2024-084421.
 4. Reidy M, Denieffe S, Foran S. Cancer screening in women with intellectual disabilities: an Irish perspective. *J Intellect Disabil.* 2014;18(1):51-60. doi: 10.1177/1744629514521067.
 5. Chen CY, Kung PT, Chiu LT, Tsai WC. Comparison of Cervical Cancer Screening Used between Individuals with Disabilities and Individuals without Disabilities. *Healthcare.* 2023;11(10):1363. doi: 10.3390/healthcare11101363.
 6. Kuper H, Andiwijaya FR, Rotenberg S, Yip JLY. Principles for Service Delivery: Best Practices for Cervical Screening for Women with Disabilities. *Int J Womens Health.* 2024;16:679-92. doi: 10.2147/IJWH.S428144.
 7. Cobigo V, Ouellette-Kuntz H, Balogh R, Leung F, Lin E, Lunskey Y. Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *J Intellect Disabil Res.* 2013;57(5):478-88. doi: 10.1111/jir.12035.
 8. Brown HK, Plourde N, Ouellette-Kuntz H, Vigod S, Cobigo V. Brief report: cervical cancer screening in women with intellectual and developmental disabilities who have had a pregnancy. *J Intellect Disabil Res.* 2016;60(1):22-7. doi: 10.1111/jir.12225.
 9. Son E, Parish SL, Swaine JG, Luken K. Accuracy of self-reported cervical and breast cancer screening by women with intellectual disability. *Am J Intellect Dev Disabil.* 2013;118(4):327-36. doi: 10.1352/1944-7558-188.4.327.
 10. Herweijer E, Wang J, Hu K, Valdimarsdóttir UA, Adami HO, Sparén P, Sundström K, Fang F. Overall and Cervical Cancer Survival in Patients With and Without Mental Disorders. *JAMA Netw Open.* 2023;6(9):e2336213. doi: 10.1001/jamanetworkopen.2023.36213.
 11. Vieira-Coimbra M, Nogueira-Martins N, Zadykowicz R, Gaspar HR, Calleja-Agius J, Pakiz M, et al. EBCOG position statement on Inequalities in screening for cervical and breast cancer. *Eur J Obstet Gynecol Reprod Biol.* 2023;289:217-8. doi: 10.1016/j.ejogrb.2023.08.386.
 12. Lee MS, Peart JR, Armin JS, Williamson HJ. A Scoping Review of Barriers and Facilitators to Pap Testing in Women with Disabilities and Serious Mental Illnesses: Thirty Years After the Americans with Disabilities Act. *J Health Dispar Res Pract.* 2021 Fall;14(3):25-56. PMID: 38550304.
 13. Power R, David M, Strnadová I, Touyz L, Bascikin C, Loblinz J, Jolly H, Kennedy E, Ussher J, Sweeney S, Chang EL, Carter A, Bateson D. Cervical screening participation and access facilitators and barriers for people with intellectual disability: a systematic review and meta-analysis. *Front Psychiatry.* 2024;15:1379497. doi: 10.3389/fpsy.2024.1379497.
 14. Swaine JG, Dababnah S, Parish SL, Luken K. Family caregivers' perspectives on barriers and facilitators of cervical and breast cancer screening for women with intellectual disability. *Intellect Dev Disabil.* 2013;51(1):62-73. doi: 10.1352/1934-9556-51.01.062.
 15. Caltabiano P, Bailie J, Laycock A, Shea B, Dykgraaf SH, Lennox N, et al. Identifying barriers and facilitators to primary care practitioners implementing health assessments for people with intellectual disability: a Theoretical Domains Framework-informed scoping review. *Implement Sci Commun.* 2024;5(1):39. doi: 10.1186/s43058-024-00579-8.
 16. Chinn D, Homeyard C. Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expect.* 2017;20(6):1189-200. doi: 10.1111/hex.12520.
 17. Petitpierre G, Otandault A, Neumann-Michel E, Olivier E, Palpacuer M, Lecluse A, et al. Co-construction of an instructional module to improve the understanding of cancer screening by people with intellectual disabilities: Strategic choices. *Patient Educ Couns.* 2025;130:108471. doi: 10.1016/j.pec.2024.108471.
 18. Dunn M, Strnadová I, Scully JL, Hansen J, Loblinz J, Sarfaraz S, Molnar C, Palmer EE. Equitable and accessible informed healthcare consent

- process for people with intellectual disability: a systematic literature review. *BMJ Qual Saf.* 2024;24;33(5):328-39. doi: 10.1136/bmjqs-2023-016113.
19. Queensland Council of Social Services. (2017). Utilise specialist communication skills to build relationships. Available from: <http://etraining.communitydoor.org.au/mod/page/view.php?id=114> (accessed on 30th November 2024). Accessed: mar 18, 2025.
 20. Tyrer F, Morriss R, Kiani R, Gangadharan SK, Kundaje H, Rutherford MJ. Comparing the number and length of primary care consultations in people with and without intellectual disabilities and health needs: observational cohort study using electronic health records (2024). *Fam Pract.* 2024;41(4):501-9. doi: 10.1093/fampra/cmact135.
 21. Dam LT, Heidler P, King I. Bridging the gap in healthcare: creating an online health information prototype for individuals with intellectual disabilities to promote equity and knowledge transfer. *Front Public Health.* 2023;11:1194892. doi: 10.3389/fpubh.2023.1194892.
 22. Bateson D, Ussher J, Strnadová I, Loblinzk J, David M, Chang EL, et al. Working together with people with intellectual disability to make a difference: a protocol for a mixed-method co-production study to address inequities in cervical screening participation. *Front Public Health.* 2024;12:1360447. doi: 10.3389/fpubh.2024.1360447.