

Protecting and improving the nation's health

Health Inequalities: Cervical cancer

Introduction

There were 3,126 new cases of cervical cancer in the UK in 2015 and 854 deaths in 2016¹. One in 135 women will be diagnosed with cervical cancer during their lifetime¹.

Cervical cancer primarily affects young adult women² with incidence rates for cervical cancer in the UK being highest in females aged 25 to 29 (2013-2015)¹. However, the epidemiology of cervical cancer will change due to the introduction of human papillomavirus (HPV) vaccination for girls in 2008 and the introduction of HPV testing as the primary screening test³.

Prevalence and risk factors

Very little is known about the prevalence of cervical cancer in women with learning disabilities in the UK. Studies from other countries suggest that the prevalence of cervical cancer is lower in women with learning disabilities than other women^{4 5 6}. For example, a study in Australia found an age standardised incidence ratio of 0.35 (95% CI 0.04, 1.27)⁴. Similarly, studies from other countries suggest that the prevalence of abnormalities on cytologic examination appears to be low among women with learning disabilities compared to other women^{7 8}. However whilst lower, the risk of cervical cancer is not negligible⁹.

Nearly all cases of cervical cancer can be attributable to HPV infection¹⁰. Whilst there are many types of HPV and many do not cause problems, a small proportion of infections with certain types of HPV can persist and progress to cancer¹⁰. Risk factors for HPV persistence and the development of cervical cancer include early first sexual intercourse, multiple sexual partners, tobacco use and immune suppression¹⁰. The World Health Organization (WHO) recommends HPV vaccination for girls aged 9-13 years before they become sexually active¹⁰. In the UK, immunisation against HPV has been routinely offered to all girls aged 12–13 years as part of the childhood immunisation programme since 2008¹¹. There are no known studies that consider risk factors for cervical cancer specifically among women with learning disabilities.

Impact on people with learning disabilities

There is no known evidence regarding death rates from cervical cancer among women with learning disabilities. It is clear that women with learning disabilities are less likely to receive a cervical screening test¹² ¹³ ¹⁴ ¹⁵ ¹⁶ and more likely to be ceased from screening (not receive invitations for screening) than other women¹². Data from the General Practice Extraction Service (GPES) for 2017/18 indicates that 31.2% of women aged 25 to 64 with learning disabilities had a cervical smear in the prior 5 years compared to 73.2% of women without learning disabilities¹³. Similarly, data from the Joint Health and Social Care Assessment Framework 2012/2013 indicates that cervical cancer screening was received by 27.6% of women with learning disabilities may be less likely to receive the HPV vaccine^{11 17}.

The low uptake of cervical screening by women with learning disabilities does not appear to be primarily due to these women being excluded from invitation for screening⁹. Women with learning disabilities have been found to be significantly less likely to respond to invitations for screening than other women (OR 0.13 (95% CI 0.098 – 0.181)¹². Other barriers to the uptake of cervical screening by women with learning disabilities include practical issues such as not being registered with a GP or not receiving an invitation letter due to out of date contact details, lack of accessible information regarding cervical screening, fear and anxiety around having the test performed, concerns around the capacity of women with learning disabilities to consent to the test¹⁸ ¹⁹, lack of understanding of the purpose of the test²⁰, and patient refusal¹².

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that some women with learning disabilities were denied access to cervical screening on the basis of their assumed lack of sexual activity²¹. Whilst sexual inactivity has been reported as a reason given by GPs for not performing a smear test for women with learning disabilities²², it may not be possible to predict who has had sexual experience²³. Most young people with mild/moderate learning disabilities in England have had sexual intercourse by age 19/20 and education and health services, and families, need to operate on the assumption that most young people with mild/moderate learning disabilities will have sex and are more likely to have had unsafe sex than their peers²⁴.

Healthcare and treatment

Cervical cancer is one of the few malignancies that now can be largely prevented through vaccination and adequate screening². The cervical screening programme aims to prevent the development of cancer by identifying and treating precancerous disease³. As noted above, women with learning disabilities are less likely to access cervical screening and girls with learning disabilities may be less likely to receive

HPV vaccination. There is some anecdotal evidence that screening liaison nurses for adults with learning disabilities can improve uptake of cervical screening¹⁷. Attendance at cervical screening may also be facilitated by prolonged preparation work undertaken by learning disability nurses, helpful clinical behaviours in the primary care context and effective joint working²⁵. There are no known studies regarding the treatment of cervical cancer in women with learning disabilities.

Social determinants

Cervical cancer in England is more common in females living in the most deprived areas¹ and studies suggest that lower socioeconomic groups have a lower uptake of cervical screening^{26 27}. However, there does not appear to be any data specifically relating to women with learning disabilities. The quality of social care support received and access to appropriate healthcare is likely to impact on the prevention and early diagnosis of cervical cancer in women with learning disabilities but there does not appear to be any research that has specifically addressed this issue.

Resources

Public Health England & NHS England (2019) <u>Supporting women with learning disabilities to</u> <u>access cervical screening</u> (includes link to 'An easy guide to cervical screening')

Public Health England <u>Reasonable adjustment for people with a learning disability</u> (includes a link to 'The Smear Test Film', a health education film resource for women eligible for cervical screening who have mild and moderate learning disabilities)

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