Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling

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Abstract

Background This study investigates the breast and cervical screening status of women with moderate to severe learning disability and whether uptake could be improved by one to one counselling.

Methods An audit of screening uptake of women in contact with the National Health Service (NHS) learning disability service within the eligible age groups for breast and cervical screening before and after one to one counselling by a learning disability team nurse.

Results Of the eligible 48 women, 37 (77 per cent) had undergone breast screening indicating that uptake was excellent and comparable to the average national and local uptake. As for cervical screening, of the 160 women who were identified as eligible and were contactable, only 26 (16 per cent) were having regular smear tests. At the end of the project, which involved one to one counselling by the nurses to encourage uptake, nine additional women underwent smear tests bringing the uptake rate to 22 per cent. For the remaining 96 women (60 per cent) the reasons at the time for non-uptake were recognized as appropriate.

Conclusions Although the uptake of breast screening was found to be good, cervical screening uptake for women with learning disability was low and remained low after a supportive intervention designed to increase uptake. The greater acceptability of breast screening in women with moderate to severe learning disability compared to cervical screening has been confirmed.

Keywords: breast screening, cervical screening, counselling, learning disability

Introduction

Uptake of breast and cervical screening in women with learning disability has been reported to be low in many areas in the United Kingdom. National statistics for 1998–1999 indicated that the uptake figures for women with learning disability were 40 per cent for breast screening and only 5 per cent for cervical screening, compared to national targets of 70 per cent for breast screening and 80 per cent for cervical screening. The National Health Service (NHS) Cancer Plan proposed that all Primary Care Groups should review their screening coverage rates and draw up plans to improve accessibility of screening for women in minority ethnic and socially excluded groups. Women with learning disability fall into the latter category. The National Cancer Plan implied that women with a learning disability often do not have the information and support they need to decide whether or not to attend for screening. The White Paper 'Valuing People' (2001) makes specific reference to The National Cancer Plan and advocates that patients with a learning disability should benefit from all the initiatives contained within the Plan.

The Department of Health Guidelines for Screening Women with Learning Disability were published in October 2000 and describe good practices to ensure that women with a learning disability have the same rights of access as all other women. These guidelines also suggest that health authorities should undertake regular audits of women who are ceased from the screening programmes to identify those who may have been ceased inappropriately.

In Burnley, Pendle and Rossendale (BPR) Primary Care Trust (PCT), the Learning Disability Team nurses' experience was that the DoH 2000 Screening Guidelines for women with learning disability had not been rigorously implemented and that many women with learning disability could have been wrongly excluded from the screening programmes. Although the incidence of cervical cancer is known to be low in women who are sexually inactive, people with learning disability are not always sexually inactive. It can be difficult to establish whether a woman with learning disability is sexually active or...
not and, therefore, the presumption should be that a woman should be invited to the cervical screening programme. We therefore carried out an audit of breast and cervical screening uptake in women with learning disability in the eligible age groups who were registered with GP practices in BPR PCT. In the event of low uptake, an intervention of one to one counselling by a community learning disability team nurse, designed to encourage women to accept screening where appropriate, was carried out and uptake was reassessed. Reasons for non-uptake were recorded and are reported here.

Method

The computerized system (COMWISE) for registering people in contact with the NHS Learning Disability Service was introduced in BPR in 1990, but incorporated details before that date by a retrospective entering of data from the preceding paper system as far back as 1981. The community nurses from the learning disability team compiled a list with names, dates of birth and GP details from the computerized list of all women with learning disability falling within the eligible age groups for screening. The community learning disability team nurses attempted to record the breast and cervical screening status of all women identified, using GP practice data and the Exeter system. If a woman was no longer registered with the listed GP, attempts were made to find if she had registered with another GP in the local area.

When it became clear that cervical screening uptake was low, the nurses then approached all unscreened woman individually to identify the reasons for non-uptake, to decide whether they were in fact eligible for screening and, if appropriate, to encourage uptake by delivering an informative and structured programme which explained the process and benefits of cervical screening. The Learning Disability Nurses developed a tool kit to aid this programme. The tool kit comprised a health education pack, incorporating picture resources to use when working with the women. A care pathway was also designed to guide the nurses when working with women with differing levels of understanding and ability. The pathway gave guidance to the nurses on issues of consent and best interest. Where women did not have the capacity to consent to the screening, in line with good practice and the Department of Health guidance on consent to treatment, a best interest discussion was initiated with the relevant people present. The best interest discussion examined the benefits and risks to the woman of proceeding or not proceeding with the screening. It took into account the woman’s past lifestyle and sexual activity, which could indicate the possibility of increased risk of developing cervical cancer. It also considered the woman’s ability to comply either physically or behaviourally with the procedure.

For any woman who demonstrated an understanding of the process and consented for a screening test, the nurse made an appointment for screening with her practice nurse or doctor and, if needed, accompanied the woman to the surgery. Tests were not undertaken if the woman was not able to cooperate or if a valid consent was not obtainable.

Results

The number of women identified from the learning disability team list in the eligible age group of 20–64 years was 235 in total. The group mainly consisted of women with moderate and high learning disability. However, 54 (23 per cent) women were found to have left their GP practice and not reregistered with another in BPR PCT, and to no longer be resident at their COMWISE recorded address, so it was not possible to contact them. A further three (1 per cent) women could not be contacted at their home, even with repeated attempts. Eighteen (8 per cent) women with learning disability were found to have died from various causes; none had cervical cancer as ascertained by the information obtained from the GP practices and the centralized agency. Nurses were eventually able to visit and counsel 160 women, representing 68 per cent of the initially identified eligible group (Table 1).

Forty-eight women fell within the eligible age groups for breast screening, i.e. 50–64 years and their breast screening uptake status was ascertained from the local mammography unit. Table 2 summarizes the results of this audit.

Thirty-seven out of 48 women had undergone breast screening indicating a screening rate of 77 per cent in this group, which was excellent when compared against the national standard of 70 per cent and local uptake rate of 75 per cent in East Lancashire. Out of 37 women who underwent breast screening, 11 (30 per cent) were also having regular cervical screening. It was agreed that the Breast Screening Unit would run a catch up programme for the defaulters with the help of the community learning disability team nurses.

Of the 160 women in the eligible age group for cervical screening, only 26 (16 per cent) were having regular cervical smears, as summarized in Table 3. This figure is very low compared to the national target of 80 per cent for all women in this age group.

Table 1 Breakdown of women with learning disability initially identified as eligible for screening

<table>
<thead>
<tr>
<th>Category</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contacted and counselled</td>
<td>160 (68%)</td>
</tr>
<tr>
<td>Current address not known and no longer</td>
<td>54 (23%)</td>
</tr>
<tr>
<td>registered with a BPR GP</td>
<td></td>
</tr>
<tr>
<td>Address known, but unable to contact</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>18 (8%)</td>
</tr>
<tr>
<td>Total initially identified as eligible</td>
<td>235 (100%)</td>
</tr>
</tbody>
</table>

Table 2 Breast screening uptake by women with learning disability

<table>
<thead>
<tr>
<th>Category</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had breast screening in the last 3 years</td>
<td>37 (77%)</td>
</tr>
<tr>
<td>Failed to attend or cancelled appointments</td>
<td>11 (23%)</td>
</tr>
<tr>
<td>Total eligible for breast screening (age 50–64 years)</td>
<td>48 (100%)</td>
</tr>
</tbody>
</table>
The one to one interviews to encourage uptake of cervical screening were time consuming and it took about a year to complete the entire project. This process nonetheless, provided some insight into the practical problems involving carrying out smear tests for women with learning disability, as well as helping us to understand the reasons for not having the smear tests. Table 4 summarizes the cervical smear test status of women who received the nurse led one to one counselling.

The community nurses successfully supported nine (6 per cent) women to take a cervical smear test for the first time. Given that 26 (16 per cent) women were already having regular smears, this increased the uptake rate to 22 per cent. Twenty-nine (18 per cent) women decided not to take the smear test, some having painful experience in the past. These women were kept on the call recall system if they changed their mind and wanted to have the test in the future.

For the remaining 96 women (60 per cent), a smear test was not considered appropriate. For 68 (42 per cent) of these women, this decision was based on the assessment and best interest discussions, the main reason being that they were not or had not been sexually active as asserted by the women and their carers during the interview. Ten women (6.3 per cent) did not have the smear test because of medical reasons (these included treatment for gynaecological problems, treatment for psychiatric problems, pregnancy and severe physical disability.) One woman with severe learning disability was unable to understand and consent. Nine women (5.6 per cent) had undergone hysterectomy for non-cancerous reasons, one of which was for a non-medical reason. Another 8 (5 per cent) women had consented but were unable to tolerate the procedure; many of them had additional physical disability, e.g. muscular spasticity making it impossible for them to position themselves or relax on the bed.

Those who underwent cervical screening were also found to have taken up breast screening if they fell in the eligible group.

Discussion

Main finding of this study

The audit results showed highly satisfactory rates of uptake by women with learning disability for breast screening which compared well with the local uptake rate. The uptake of cervical screening was very low, but the reasons for this were found to be largely appropriate.

What is already known on this topic?

Uptake of both breast and cervical screening were known to be low in women with learning disability. Screening was recognized as a neglected area in relation to the health of women with learning disability. Previous studies have reported low screening was very low, but the reasons for this were found to be largely appropriate.

What this study adds

No difference was found locally in breast screening uptake in women with learning disability compared to the whole population.

For cervical screening, we undertook a one to one process to promote cooperation from the women and their carers. Although the initial hopes were that close intervention would lead to a large increase in uptake, this failed to materialize. Only a modest number underwent cervical screening for the first time because of this project. Many women were assessed as low risk from their known lifestyle behaviours. Many women, although they consented, could not cooperate in the actual procedure; some had physical disabilities, which made it difficult to perform the test. The project nevertheless, helped the community nurses to identify those who should be kept on the call recall system. It also supplied comprehensive information as to why women had not presented for screening or had not completed the screening process as illustrated in Table 4. The project helped to ensure that women were not excluded from screening on the grounds of learning disability or assumed lack of sexual inactivity.

Limitations of this study

The sample group did not represent the whole spectrum of learning disability, as women with mild learning disability were not likely to be known to the PCT Learning Disability Service. It is possible that the approach might be more effective in women with milder learning disability.
A main reason for exclusion from cervical screening was reported as lack of current or previous sexual activity. This information was ascertained during the interview with the woman and her carer and may in some cases not have been reliable.

The study concludes that cervical screening uptake in women with moderate to severe learning disability could be modestly increased by intensive one to one counselling but that overall uptake rates are likely to remain low.

References