

Community-Based Learning Disabilities Nurses Supporting Patients with Breast, Cervical, and Bowel Cancer Screening.

Abstract

People with learning disabilities participate in cancer screening) at lower rates than people without learning disabilities. The reasons for these disparities are somewhat unclear, although in the United Kingdom (UK), community-based learning disabilities nurses are a key professional group who may help facilitate screening. Our aim was to understand how learning disabilities nurses facilitate cancer screening among their patients with learning disabilities.

We interviewed 11 nurses, finding that while there are some characteristics that are unique to each screening modality, there are many similarities in accessing screening. Nurses described supporting their patients by making reasonable adjustments. These adjustments include providing easy-read information, allowing for advance appointments and providing training for people with learning disabilities, their carers, and health professionals involved in the screening.

By understanding how nurses may support patients, future interventions can be implemented to increase how many people with learning disabilities accessing screening and reduce this screening disparity.

Keywords

Intellectual disabilities, cancer screening, learning disabilities nurses, reasonable adjustments, interpretive description

Introduction

People with learning disabilities (also known as intellectual disabilities) participate in many forms of cancer screening, including breast, cervical, and bowel cancer screening, at rates significantly lower than those without learning disabilities. For instance, women with learning disabilities may access screening mammograms (to check for breast cancer) and cervical cancer tests at lower rates than women without learning disabilities (e.g. Cobigo et al., 2013). Both men and women with learning disabilities also participate in bowel cancer screening tests at rates lower than those without learning disabilities (Ouelette-Kuntz et al., 2015).

In recent years in the UK, women with learning disabilities aged 50-69 years access screening mammograms at significantly lower rates. In 2021-2022, only 47.2% of women with learning disabilities in this age group had had breast cancer screening, relative to 61.9% of women without learning disabilities (NHS Digital, 2022). Similarly, men and women who have learning disabilities who were between the ages of 60-74 years had also completed bowel cancer screening at rates lower than individuals in the same age range without learning disabilities (NHS Digital, 2022). In 2021-2022, 50.3% of adults with learning disabilities in this age group had taken part in bowel cancer screening, relative to 66.8% of adults in this age range without learning disabilities (NHS Digital, 2022).

When the authors examined other countries' more recent screening rates, in Denmark, which has a population-based breast screening mammography programme, 25% of eligible women with intellectual disabilities had participated in breast screening, relative to 62% of women in the same

age group without intellectual disabilities (Horsbol et al., 2023). More recently, in an observational study from Denmark (which has a multi-stage population-based bowel screening programme for individuals aged 50-74 years) only 30.2% of participants with intellectual disabilities completed the first stage of screening, relative to 56.1% of individuals without intellectual disabilities completing the first stage screening (Horsbol et al., 2026).

In the UK National Health Service (NHS) in England, there are three main forms of cancer screening that are offered: (1) breast screening using mammograms for women aged 50-71 years, and women receive an invitation in the post every 3 years (NHS, 2025a); (2) cervical screening (cervical smears) every five years for women aged 25-64 years in a primary care settings (women are invited by post) (NHS, 2025b); (3) bowel screening using Faecal immunochemical tests (FIT) that are provided via post every two years to both men and women aged 50-74 years of age (NHS, 2024).

The reasons for these screening disparities are not well understood. One potential reason, offered by Breau et al. (2020) is that primary care providers such as general practitioners (GPs) may not recommend cancer screening as often to adults with learning disabilities. This phenomenon may be exacerbated when clinicians have preexisting negative attitudes towards people with learning disabilities, which may be more common among certain clinician demographic groups (Breau et al., 2021). An alternative suggestion that family medicine trainee physicians wish to adhere to clinical guidelines and offer breast, cervical, and bowel cancer screening to all of their patients who meet eligibility guidelines, however, they may have less clinical experience to discern the best course of treatment for each individual patient (Breau et al., 2023).

Taking an international perspective, a key barrier to accessing screening is if female patients have a comorbid physical condition or mobility challenge, for example, a diagnosis of cerebral palsy that may make the physical demands of breast and cervical cancer screening difficult. (Chan, 2022). However, breast and cervical cancer screening for women with learning disabilities may be facilitated if women with learning disabilities have support from carers and/or primary care staff, and good patient-provider communication from primary care staff (Chan et al., 2022; Power et al., 2024; Sykes et al., 2024). Another facilitator for screening is if a women with learning disabilities is knowledgeable regarding the cervical cancer screening process (Sykes et al., 2024).

The community-based learning disabilities nurse is a clinical designation and professional role in the United Kingdom (UK). These professionals support people with learning disabilities who live in the community with accessing preventive, primary, and specialist health care, including cancer screening. However, there has been limited research to date regarding how learning disabilities nurses currently support patients in their care with accessing screening, especially in light of the previously mentioned screening disparities people with learning disabilities may face.

While there is scope in the learning disabilities nurse role to support patients with cancer screening, nurses may feel they lack sufficient training in this area on how to support their patients with cancer screening (Taggart et al., 2011; Tyler et al., 2010). However, nurses may feel supported if they have changes to how they support patients with this process such as additional time during an appointment to educate patients and carers about the cancer screening process, and additional training for nurses on how they can make reasonable adjustments to practice to support the cancer screening process (Lee et al., 2024; Weise et al., 2024).

Given these demonstrated inequalities in cancer screening participation among people with learning disabilities, and given the potential facilitating role that community-based learning disabilities nurses can play in supporting patients with learning disabilities in accessing screening, the main research question for the current study was: how do community-based learning disabilities nurses support adults with learning disabilities in their care to access breast, cervical, bowel, and other forms of cancer screening? The current study utilized qualitative methods, following an interpretive description approach (Thorne, 2008). This allowed for a rich description of nurses' experiences with this form of care, and produced findings grounded in the participants' own words.

Methods

A series of eleven open-ended interviews were carried out in February 2022-February 2023, by the second author. The eleven nurses who took part were all community-based learning disabilities nurses (a specialized qualification recognized in the United Kingdom). Convenience and snowball sampling was used for recruitment: the study was advertised through one of the study author's professional networks. Inclusion criteria were any learning disabilities nurse working in the UK who as part of their role might promote cancer screening and/or prevention to their patients. Most nurses worked in London or Southeast England, although a minority practiced in other areas of the UK. Most nurses had much experience (i.e. 10+ years) working as learning disabilities nurses, and the majority (n= 9, 81%) were female.

Most interviews (for participant convenience) were carried out via Microsoft Teams (and were recorded in Microsoft Teams), although one took place in person and was audio recorded. The interviews were transcribed using the Microsoft Stream transcription function and reliability checked against the recording, and transcripts were anonymized prior to analysis. The open-ended interview guide allowed for nurses to provide rich descriptions of their experience supporting patients with all forms of cancer screening, and had broad questions, and nurses were also able to discuss which forms of cancer screening they support.

The transcripts were analysed utilizing the interpretive description method, as described by Thorne (2008), in which inductive coding using NVivo codes is conducted, and there are at least two levels of coding of themes. First, the interviews were read by the authors, and initial coding was conducted by the first author. The codes were reviewed and combined by the first author, and codes were combined until three key themes emerged, and these themes were shared with the second authors for further feedback on the themes, and they agreed with the three themes that emerged. At all times, the themes were grounded in the participants' own words. The first author who was conducting the analysis was also aware of their experience as a non-clinician with a health promotion background, and an expert in the subject area, and reflected on these biases throughout the analysis process through reflexive memoing. The second author, who is a nurse and a researcher in this area, was also aware of their clinical biases and how these biases may have influenced the interpretation of the themes identified as part of the inductive analysis process, and how this experience may have also biased the data collection phase.

Ethical approval from the university research ethics board was obtained for the study by the study authors. Informed consent was sought from all participants prior to conducting the interviews.

Findings

Generally, nurses discussed supporting patients with breast, cervical, and bowel cancer screening. In some cases, nurses also spoke of supporting patients with testicular cancer screening and skin cancer prevention and screening, but these forms of screening were more infrequent.

There were many similarities in nurses supporting their patients in accessing screening across the three main screening modalities (breast, cervical, and bowel), and similarities in how nurses reported supporting patients with the physical and emotional challenges of people with learning disabilities face participating in all three forms of screening. However, there were a few characteristics regarding screening that were unique for each type of screening. Accordingly, the three main themes emerging from the analysis are: (1) screening characteristics that are specific to each modality; (2) how nurses support patients with cancer screening; and (3) nurses exercising clinical judgement as to whether an individual patient engaging in screening is the best clinical option for this patient.

Screening characteristics that are modality specific

While there were similarities in how nurses reported supporting patients with learning disabilities with screening, there were some forms of support that differed by screening modality. For instance, a key concern nurses had with respect to breast cancer screening, specifically accessing mammograms, was whether women with physical needs, such as those who use a wheelchair or who have mobility needs, are physically capable of accessing a mammogram.

...[P]ulling up with a van or going in for your ... screening at a car park and then ... going up the steps and ... into the back of a of a lorry to have your mammogram again is another [issue] [participant #2].

Nurses spoke of needing to explain to carers and family members that it is possible to participate in screening even if women have difficulties with mobility. However, nurses felt that it can be easier to support their patients with mammograms more easily than other forms of screening given that mammograms happen less frequently and are only provided for older women.

For cervical cancer screening, a key concern for many family members was around the stigma associated with sexual activity and cervical cancer screening in women with learning disabilities. Many nurses reported that family members would not wish to have their relative undergo cervical cancer screening under the assumption that their family member with learning disabilities was not sexually active. Another key feature that is changing with cervical cancer screening is the increasing prevalence of HPV vaccination and HPV testing, and how that may affect cervical cancer screening delivery in the future.

And I wonder as well if... somebody was in a sexual relationship with somebody else that ... had a learning disability, a man with a learning disability, would they have been vaccinated themselves? I mean, I don't know [participant #11].

Finally, for bowel cancer screening, there were some concerns that while it is less invasive than the other two forms of screening, if a patient has an abnormal result, they may need to undergo a

colonoscopy, and some nurses expressed concerns regarding whether a patient with learning disabilities would be able to cope with both the colonoscopy itself and the preparation required for a colonoscopy. With regards to the bowel screening kit, some nurses explained that for some patients, they may find the test “icky”, and especially for those who use the toilet independently, they may have difficulty completing the test themselves and may be reluctant to ask for help from carers to complete the kit.

I had a lady the other day and she said, “ I don't need to have a colonoscopy, I don't need to have a camera at my bum for bowel screening”. I was like, no, you know, the little kit you got sent, I said that's all you got to do [participant #5].

Supporting patients with screening

While there were some unique features of each type of screening modality (breast, cervical, and bowel) there were also some similarities across the types of screening in how learning disabilities nurses support patients with all three forms of screening. For example, nurses spoke of supporting their patients with the screening itself, and also supporting patients if, following an abnormal result, further tests were required to investigate the issues. Nurses also spoke of how staff at a general practitioner's (GP) surgery may reach out to them to help support someone with a learning disability if that patient was listed with the GP surgery as having a learning disability, especially for cervical screening, which generally takes place in primary care settings in this country.

Nurses also spoke of making reasonable adjustments for people with learning disabilities to help them access screening. Some of these reasonable adjustments would include offering advance appointments to where the screening was taking place, having easy read information about the screening, and providing training and performing screening demonstrations for health professionals, carers, and people with learning disabilities themselves.

Nurses often spoke of liaising with the staff at the hospital performing tests such as mammograms, to ensure the right supports are in place. An example of this would be:

In [name of hospital] hospital, we get notification of every patient that has an appointment coming up. We get the date, the time and the location and then we contact that patient to see whether they've been before, whether they have any questions. Whether they want to visit the unit, whether they want us to visit. Sometimes they'll say, no, it's absolutely fine...But sometimes it will be like [patient]...doesn't want to go. And then we'll go and do a home visit and say, look, is there any way that we can do, you know, get you along, can we help you, can we support you? [participant #1]

In this instance, nurses spoke of how to liaise with staff to support mammography. While, for bowel cancer screening, while the initial screen is less invasive, it may be difficult to intervene to support screening for someone who uses the toilet independently, and has difficulty completing the kit themselves:

So yeah, we've had posters put on bathroom doors with stop before you go, tell a carer so that they can get help. [participant #3]

199 If a patient does have an abnormal result from screening, nurses spoke of supporting patients with
200 follow-up tests at the hospital, to ensure that the patient is supported:

201 Again, if they had to go to colposcopy [follow-up test for an abnormal cervical smear], it
202 depends on the person, but it may be because they've met us and built up a bit of
203 relationship. We would be involved until we hand over. So yeah, we may support them for a
204 little bit afterwards. [participant #1]

205 if there's a positive result [i.e. abnormal result], if ... it's breast screening, ... if we've been to
206 see that patient and we've sort of gone through everything with her and then the result's
207 positive, then we would go and support her, ...for a biopsy or whatever the next sort of thing
208 is and explain what's going to happen. But then we'd hand over to the acute team at the
209 hospital. [participant #3]

210 With some of the difficulties around people with learning disabilities accessing cancer screening,
211 sometimes reasonable adjustments need to be made. One such support may be assisting women
212 with learning disabilities to understand an invitational letter for a mammogram, and then attending
213 the appointment at the hospital:

214 And then they would that would take a [look that] you're of age. You haven't had a letter.
215 Let's find out if you had a letter or you got a letter and you didn't go, Why didn't you go?
216 [participant #2]

217 Nurses also described that either if the letter regarding breast or bowel cancer screening is in easy
218 read format, or if either they themselves or the hospital staff have easy read leaflets regarding
219 screening, this can also be a facilitator for screening:

220 It can be helpful ...but I wouldn't normally just send it to them in the post and leave them
221 with it. I would go through it with them... I have a range of easy read leaflets, and I generally
222 pick bits I like out of different ones, and I would also combine that with some videos.
223 [participant #10]

224 In this instance, a nurse describes that not only supplying easy read information but also reviewing
225 the information with the patient during an appointment, can assist them in accessing the
226 screening. Related to this, if patients could have an advance appointment at the hospital (for
227 mammograms) or at the GP surgery (for cervical smears) to allow the patient to meet the staff
228 performing the screening and see the equipment that would be used, this can be a key enabler to
229 allow screening to take place and go smoothly.

230 You know appointments with people who are who are sick let alone . doing extra ...
231 desensitization visits and things but ... I have found the hospital that our local hospital for
232 the mammography service has been really good and they are really always open for them to
233 come around and visit. [participant #10]

234 And it could just be that for instance they've been referred to me for breast screening, and
235 they want a visit to the hospital first to see the screening machinery and then meet the
236 radiographers. [participant #1]

237 In addition to making reasonable adjustments to the screening process, providing education to
238 health professionals, carers, and people with learning disabilities themselves can help them
239 understand the importance and process of screening, and dispel any misconceptions about the
240 screening process. Two nurses spoke of performing demonstrations with models or the screening
241 kit to show people with learning disabilities how to perform the screen, such as breast self-checks
242 and bowel screening kits:

243 We can educate. We do have the equipment, you know the, the breasts to show you with the
244 lumps and show them how it's done [participant #6]

245 So, we have easy read information. We have demonstration kits that we do for home visits,
246 right. OK and to be honest, we use a bit of chocolate spreads as an example of, ... how to
247 run it through the middle of something so you can show them that you only need a very
248 small amount rather than. So, yeah, so we have the whole box and when we have the tube
249 inside, so we use that as well. [participant #1]

250 Nurses also spoke of how to work with carers and support staff to encourage cancer prevention
251 and screening practices, and being proactive to ensure all recommended screenings for adults
252 with learning disabilities are up to date:

253 I mean I did a healthy living pack in the community around. All aspects of health including ...
254 looking off your skin [to check for skin cancer] and obviously in in people's care, passports,
255 healthcare, passports...it goes through kind of cancer, skin cancer and things like that and
256 prevention from sun and monitoring for sun, how you support someone around you know
257 their exposure to sunlight and things like that. [participant #7]

258 Thus, given their expertise and experience, and role to facilitate preventive care and early detection,
259 nurses often spoke of what they could do to promote screening, and how to liaise with staff at
260 hospitals, GP surgeries, and support workers/carers and family members to support cancer
261 screening.

262 **Exercising clinical judgement**

263 Generally, nurses described wishing to offer the same standard of care with regards to cancer
264 screening to all patients with learning disabilities. However, sometimes they spoke of tailoring care
265 to ensure that it was appropriate for the individual patient. One key factor, especially for breast
266 cancer, was whether the individual with learning disabilities was at increased risk of cancer:

267 ... I've worked with people who have had familial breast cancers as a person with a learning
268 disability... that's a massive part of it. And that's the kind of history I don't think we get
269 terribly often because those are tricky questions to ask and particularly if we've got adults
270 who don't have parents maybe in their lives... it's a bit more tricky. [participant #11]

271 They also considered other risk factors that could inform the cancer screening regimen:

272 A number of risk factors to do with their lifestyle...are they smoking, lung cancer, ... eating a
273 healthy diet, ... are they a certain age, are they a certain weight ..., are they... sedentary or
274 active, [participant #2]

However, although risk factors for cancer would be considered by nurses, sometimes nurses would feel the screening would be traumatic, or follow-up tests would be unacceptable to their patients, and nurses would advise their patient against screening:

[I will] work with the GP and if it's in their best interest, if they decide that it is, then they'll sort of try to do this smear.... So, if they're quite happy to have the procedure, then we go... by that and it's [determined to be in their] best interest. [participant #3]

We were asked by somebody to be involved in a best interest meeting and about not supporting the person because if it was positive result [i.e. abnormal result] would be too traumatic then we'll be able to continue with the treatment. [participant #8]

While sometimes nurses would feel that screening was not in the patient's best interests, at other times patients would have misconceptions around screening, that nurses would try to address in order to facilitate screening:

And there are some concepts that are just really hard to explain ... I find it really difficult to explain what cancer is. It's just something that... I can get as far as them understanding. ... if I'm screened for this thing, it will check for this illness, but not really much more than that... Some of them [patients with learning disabilities] do ... have experience of cancer, but that's usually to do with relatives dying. So normally then when you mention the word cancer, it sends them into panic and they think they're dying. [participant #10]

Thus, generally nurses would facilitate and support screening, especially for breast, cervical, bowel, and skin cancer. They would offer support for both the screening and follow-up procedures, and deliver reasonable adjustments, such as advance appointments and easy read materials, as necessary. However, while generally nurses would promote cancer screening to all eligible patients, in some cases they may feel, in consultation with others, that screening was not in the patient's best interests. Although, in the event the patient or carer had misconceptions about either the need for screening or the screening process, the nurse would work to help dispel these misunderstandings.

Discussion

Given the aim of the study was to examine how learning disabilities nurses support patients with cancer screening, three key themes emerged from the interview data. The first finding was that there are elements of breast, cervical, and bowel cancer screening that are unique to each screening modality. However, there are also some similarities across all forms of screening that were examined, especially with regards to how nurses reported supporting patients with these forms of screening. A recent integrative review about the role and scope of practice of learning disabilities nurses in the UK highlighted that these nurses may help facilitate access to care for people with learning disabilities and increase care continuity by coordinating the work of multiple specialist services and ensuring person-centred care is delivered (Bur et al., 2021).

Another key finding that emerged is that nurses offer support to people with learning disabilities to assist them in accessing cancer screening in a myriad of ways, including offering social and emotional support both with screening itself and any potential follow-up tests in the event of an abnormal screening test result. In terms of areas of examples of how learning disabilities may

support patients with learning disabilities with accessing cancer screening, the factors identified in the current study, providing training to health professionals, support workers, and patients themselves regarding the need for screening has been identified as an important facilitator for screening by other authors (i.e. Taggart et al., 2011; Tyler et al., 2010; Weise et al. 2024). Offering a reasonable adjustment, such as providing more time during an appointment (or alternatively offering an advance appointment) was also identified by previous authors as a method of helping facilitate access to cancer screening (Lee et al., 2024)

Nurses may also make reasonable adjustments, such as providing easy-read information, working with hospital or GP surgery staff to allow patients to have an advance appointment at the screening clinic before the screening takes place, and having models to demonstrate the screening. They may also provide training to health professionals and carers on how to support the adults in their care with screening. The importance of learning disabilities nurses in coordinating care, especially with regards to ensuring that reasonable adjustments for routine procedures are in place for patients with learning disabilities, has been discussed by multiple authors when examining this role (Bur et al., 2021; MacArthur et al., 2015; Marriott et al. 2015). The importance of having multidisciplinary working for health professionals providing care to patients with learning disabilities, especially with respect to cervical cancer screening by primary care providers, was also raised in the systematic review by Sykes et al. (2024).

In spite of the recognized need for screening, nurses also cited times when they might exercise their clinical judgement to determine the best course of care for their patients. For instance, they may weigh the risk factors for cancer with the potential distress associated with screening, such as with potential follow-up tests, to decide the most appropriate care for their patient. Accordingly, for some individual patients they may decide that if the patient pursued that a form of cancer screening, It may not be in the patient's best interests. Therefore, nurses may support patients with cancer screening in multiple ways, but with some patients, nurses may be concerned regarding whether it is in the patient's best interests to pursue screening based on multiple factors, including the patient's ability to cope with further tests in the event of an abnormal result. This balance that nurses wish to offer screening to everyone who is eligible, but at the same time exercising their clinical judgement as to the best course of care for each patient, is similar to the findings of Breau et al. (2023). This study also found that among Canadian family medicine trainee physicians, these professionals wish to offer screening to everyone who is eligible, while at the same time using clinical experience to determine the best course of care for each individual patient.

One of the key strengths of this study was the prior professional relationships the interviewer had with many of the participants, which allowed for access to learning disabilities nurses and for them to participate in the study, given that it can be difficult to recruit professionals who have heavy clinical workloads and limited time to contribute to research. This co-author's clinical background in learning disabilities nursing also helped facilitate and guide the data collection, and the scope of practice for these professionals was known to the researchers.

There were, however, some limitations. First, this study used a convenience sample, and snowball sampling was used, thus the sample may not be representative of learning disabilities nurses throughout the UK. For instance, because the nurses volunteered to the request to be interviewed,

they were likely more motivated to explore how they could best support their patients with accessing cancer screening and were also more likely to be aware of inequalities in screening in this patient group. In addition, many of the participants had a professional relationship with one of the authors, which may have also influenced their eagerness to participate in the study.

Secondly, although there were some similarities in how screening is accessed across all types of screening as previously discussed, there are also unique aspects of each form of screening which may not have been fully elucidated in the current study due to the smaller sample size. Given there are approximately 16,500 learning disabilities nurses registered in the UK (Beebee, 2026), the eleven nurses interviewed in this study are a very small sample of the whole workforce in the UK, and the participating in this study were concentrated in two distinct geographic locations in England, the study sample were not truly representative of the wider UK workforce. In light of this small sample size, a larger, mixed methods survey of how learning disabilities nurses support patients with learning disabilities in accessing cancer screening across the whole of the UK is needed to learn what current supports are employed throughout the country.

Nurses also primarily focused on their experiences providing care one-to-one for patients, there was limited discussion of systems-level pressures (e.g. time in appointments, workload, staffing) in the interviews, which a future study of nurse managers or commissioners may better capture this phenomenon. While nurses did note some variation in the abilities of the patients, they provide care for (for example, the reasonable adjustments needed for patients with physical disabilities or mobility challenges) they did not generally discuss the diversity of patients with intellectual disabilities. However, this may in part be due to the fact that patients in England who do have the support of a community-based learning disabilities nurse may be more likely to have more severe learning disabilities and may also be more likely to have other, co-morbid medical conditions.

Finally, while when this study was developed and conducted (2021-2023) it was less of a stated requirement to conduct inclusive (participatory) research with self-advocates with learning disabilities, although this form of research predates Walmsley and Johnson's 2003 seminal book on inclusive research. Due to resource limitations for the study and given this study was envisioned as a pilot study with a larger study with health professionals on their clinical experiences supporting cancer screening, this study did not include people with learning disabilities in an advisory or co-researcher role. Future studies including health professionals should consider having self-advocates with learning disabilities to work as co-researchers as part of the research team for this type of study, and to serve on study advisory groups.

While this research was smaller and exploratory in scope, this study did point to some good examples of how nurses might support patients with learning disabilities with accessing cancer screening. For instance, allowing advance appointments for women with learning disabilities undergoing breast and cervical cancer screening, having models and training sessions for adults with learning disabilities, their carers, and health professionals, and having easy read information available, and taking the time to review this information with patients, are all examples of methods utilized by nurses to support patients with cancer screening. A more widespread study, such as using survey methods, of current supports that learning disabilities nurses provide their patients with accessing cancer screening across the UK would allow for interventions aimed at nurses,

professionals, and people with learning disabilities and their carers to be developed to help close the disparities in cancer screening currently experienced by this group.

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