

The role of learning disability nurses in promoting cervical screening uptake in women with intellectual disabilities: A qualitative study.

[Lloyd JL](#)¹, [Coulson NS](#)².

¹Derbyshire Healthcare NHS Foundation Trust, UK

²University of Nottingham, UK.

Original Article

Abstract

Research suggests that the uptake of cervical screening by women with intellectual disabilities (commonly known as learning disabilities within UK policy frameworks, practice areas and health services) is poor compared to women without intellectual disabilities. The present study explored learning disability nurses' experiences of supporting women with intellectual disabilities to access cervical screening in order to examine their role in promoting attendance and elucidate potential barriers and facilitators to uptake. Ten participants recruited from a specialist learning disability service completed a semi-structured interview and data were analysed using experiential thematic analysis. Identified individual barriers included limited health literacy, negative attitudes and beliefs, and competing demands; barriers attributed to primary care professionals included time pressures, limited exposure to people with intellectual disabilities, and lack of appropriate knowledge, attitudes and skills. Attendance at cervical screening was facilitated by prolonged preparation work undertaken by learning disability nurses, helpful clinical behaviours in the primary care context, and effective joint-working.

Keywords

Barriers, cervical screening, health professionals, intellectual disabilities, uptake

Introduction

Cervical cancer is the 11th most common cancer among women in the UK and the most common cancer in women aged under 35 (Cancer Research UK, 2010). Substantive evidence of a causative link between specific ‘high risk’ types of human papillomavirus (HPV) and cervical cancer has now been established and most sexually active women will be exposed to high risk HPV types at some point during the course of their lives (National Health Service Screening Programme (NHSCSP), 2013). Whilst having multiple sexual partners poses an increased risk of developing cervical cancer, any woman who has ever engaged in sexual activity is considered to be at risk (NHSCSP, 2013).

The NHS Cervical Screening Programme invites women between the ages of 25 and 64 registered with a general practitioner for a cervical screening test every three to five years and has reduced both the incidence of and mortality from cervical cancer in England since its implementation in 1988 (NHSCSP, 2013). Marteau (1993) proposed three primary factors influencing the uptake of population screening programmes, including patient factors (e.g. demographic variables, health beliefs and affective beliefs), health professional factors (e.g. communication processes) and organisational factors (e.g. means of invitation and place of screening). Current figures indicate that a significant number of women in the general population do not attend cervical screening

(Health & Social Care Information Centre, 2012) and despite clear policy frameworks for the delivery of equitable health care for people with intellectual disabilities in the UK (Department of Health, 2003, 2004, 2009), several studies have reported particularly poor uptake among women with intellectual disabilities (Reynolds, Stanistreet and Elton, 2008; Glover, Emerson and Eccles, 2012; Osborn, Horsfall, Hassiotis et al., 2012). A similar picture is evident in the USA with the findings of a national study that substantiated existing evidence of poor uptake suggesting that women with intellectual disabilities were 72% less likely to have received cervical screening compared to nondisabled women (Parish and Saville, 2006). On the basis of this research it has been argued that there is substantial evidence that the screening needs of women with intellectual are not met appropriately (Parish, Rose, Luken, Swaine and O' Hare, 2012).

Historically women with intellectual disabilities have not been offered routine cervical screening due to difficulties obtaining accurate sexual histories and assumptions of sexually inactivity by health professionals (Band, 1998; McCarthy, 2002; Watts, 2008). However, research suggests that some women with intellectual disabilities are at increased risk of developing cervical cancer due to their engagement in consensual and/or non-consensual sexual activity, limited knowledge of sexual health and sexuality, and lack of recognition of the importance of timely cervical screening (Broughton and Thomson, 2000; Murphy, 2003; Parish, Moss and Richman, 2008; Wacker, Macy, Barger and Parish, 2009). Literature reviews and empirical studies that have examined reasons for non-participation in cervical screening programmes by women with intellectual disabilities have identified a number of specific barriers,

including communication difficulties; perceived difficulties obtaining consent; attitudes of carers and staff; lack of accessible information; physical difficulties; limited liaison with specialist teams; and assumptions made by healthcare professionals (Stein and Allen, 1999; Broughton and Thomson, 2000; Broughton, 2002; Alborz et al., 2005; Wood and Douglas, 2007; Watts, 2008; Gribben and Bell, 2010).

Participation in disease prevention services has been explored empirically in the context of health literacy and this research has established a direct relationship between these variables (Rudd, 2013). The World Health Organisation defines health literacy as ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health’ (Nutbeam, 1998: p.357). Due to impairments in cognitive and social-adaptive functioning, it is evident that people with intellectual disabilities may be particularly vulnerable to inequitable access to cancer screening due to limitations in health literacy and communication skills. Support for this is provided by empirical studies conducted in the United States and Europe, which have demonstrated a relationship between low health literacy and limited use of cervical cancer prevention services (Scott, Gazmararian, Williams et al., 2002; Garbers and Chiasson, 2004; Lindau, Basu and Leitsch, 2006; Spadea, Bellini, Kunst, Stirbu and Costa, 2010).

A body of research within the field of health psychology has focused specifically on the role of health beliefs in predicting health-related behaviours, such as participation in cancer screening programmes. These beliefs have been measured using various psychological models that integrate a number of key factors associated with health

beliefs, including attributions for causality and control and perceptions of susceptibility and risk (Ogden, 2012). The health belief model (Janz and Becker, 1984) and the theory of planned behaviour (Ajzen and Madden, 1986; Ajzen, 1991) are two social cognition models that have been tested in the context of uptake of cervical screening in the general population. The health belief model focuses on the influence of the perceived threat of a health problem, hypothesising that an individual's fear of the severity of a disease and beliefs about personal susceptibility provide the motivational impetus to engage in protective health behaviours. The theory of planned behaviour proposes that health-protective behaviours are dependent on positive attitudes towards performing the behaviour, favourable social norms and motivation to comply; perceptions of the level of difficulty involved in performing the behaviour are also considered key. The predictive utility of social cognition models in relation to uptake of cervical screening among women in the general population has received some empirical support (Conner and Norman, 2005) however a dearth of research has examined the utility of these models in predicting uptake specifically among women with intellectual disabilities. Studies that have examined the role of health beliefs among women with intellectual have identified consistently that lack of knowledge and understanding of the purpose and benefits of cervical screening are key variables underpinning poor participation (Johnson, Strong, Hillier et al., 2002; Parish et al., 2008). It has also been demonstrated that lack of knowledge is associated with an increased likelihood of reporting negative beliefs regarding cancer screening (Dolan, 2004). In addition, studies have found that women with intellectual disabilities often report high levels of anxiety, fear, embarrassment and discomfort associated with cervical screening (Broughton and Thomson, 2000; Parish et al., 2008).

A framework proposed by Von Wagner, Steptoe, Wolf et al. (2009) utilises established constructs from social cognition models and extant research to highlight the possible causal mechanisms that underpin poor participation in primary prevention services by people with limited health literacy. The framework proposes that the motivational impetus to form an intention to attend cervical screening emanates from a number of related social cognition variables, including knowledge of relevant information about screening programmes, opportunities for screening, and an individual's perception of their personal risk; additional concepts, including self-efficacy and practical barriers are also considered to impact on the translation of intentions into actions within a volitional phase. It is further proposed that system factors, such as attitudes of health care professionals towards patients with limited literacy, may impact on motivational and volitional processes. Whilst acknowledging that further empirical support is required to directly test the relevance of the framework in the context of cancer screening, it is argued that the framework can be used to design interventions to improve access to screening among people with poor health literacy.

In the UK the Single Equalities Act (2010) places an obligation on all health care organisations to make 'reasonable adjustments' to reflect the needs of disabled people. In addition, the updated good practice guidelines for women with intellectual disabilities and cervical screening stipulate that all women who are eligible for cervical screening have the right to access this service and stress the importance of adequate preparation, involving accessible information and familiarisation with the screening setting and the person who will perform the procedure (NHSCSP, 2006a). These

guidelines clearly represent an attempt to overcome identified barriers to cervical screening for women with intellectual disabilities, including the impact of poor health literacy on access to and use of services. However, it can be argued that the appropriate application of good practice guidance requires an understanding of the complex needs of women with intellectual disabilities and research indicates that generic health professionals have limited knowledge and self-efficacy in relation to supporting people with intellectual disabilities and are unacquainted with the legislative frameworks that exist for the delivery of equitable health care (Melville, Finlayson, Cooper et al., 2005; Disability Rights Commission, 2006).

Several authors have argued that learning disability nurses are pivotal to both highlighting the needs and rights of women with intellectual disabilities and preparing women to access cervical screening (Broughton, 2002; Alborz et al., 2005; Watts, 2008; Gribben and Bell, 2010). Learning disability nurses are the single professional group trained specifically to work with people with intellectual disabilities and adopt a pivotal role in identifying unmet health needs, promoting reasonable adjustments, and enabling increased access to mainstream health services (UK Chief Nursing Officers, 2012).

Studies designed to improve the uptake of cervical screening by women with intellectual disabilities using learning disability nurse interventions have demonstrated some improvement; however this research also suggests that cervical screening may not be considered in the best interest of some women on the basis of their established lifestyle behaviours and low risk status (Wilkins, 2004; Biswas, Whalley, Foster et al., 2005).

Watts (2008) in a review of the literature argued that there was ‘a notable gap in the research literature of fully reported empirical studies investigating factors that prevent women with intellectual disabilities from accessing cervical screening’ (p. 524).

Furthermore, despite evidence to suggest that learning disability nurses may play a fundamental role in increasing the uptake of cervical screening by women with intellectual disabilities, there appears to be a paucity of research examining the perspectives, experiences and practices of these specialist health professionals. *It has been argued that in order to implement effective healthcare, the behaviour of health professionals needs to be considered in addition to that of patients (Marteau and Johnston, 1990).* Furthermore, it has been highlighted that there is a dearth of research examining the role of health literacy in patient-health care provider interactions and that research would benefit from a stronger focus on the mediating contribution of health professionals’ experiences of supporting individuals with poor health literacy (Von Wagner et al., 2009). Consequently, this research explored the experiences, perceptions and clinical practices of learning disability nurses in order identify specific barriers and facilitators influencing cervical screening utilisation by women with learning disabilities and the role of learning disability nurses in promoting uptake.

Method

Participants, recruitment & data collection

Semi-structured, tape-recorded interviews were conducted with ten learning disability nurses recruited from Derbyshire Healthcare NHS Foundation Trust. The Trust’s senior learning disability nurse was contacted initially and agreed to distribute an email to all potential participants. Each participant received information sheets summarising the

purpose and nature of the study and expressed their interest in participating by contacting the researcher directly. All participants were white, female and had direct experience of supporting women with intellectual disabilities to access cervical screening as part of their clinical role. Participants ranged between 36-53 years of age and had been qualified learning disability nurses for between 12-35 years. An interview schedule was developed using topics generated by existing literature and informal discussion with learning disability nursing colleagues. The interview schedule included open-ended questions with additional prompts employed to generate detailed responses and was piloted on one interviewee.

As recommended by Rubin and Rubin (1995), interviews were deliberately broad-based and flexible, involving variability in question wording and order and the use of spontaneous questions according to the responses of participants. Participants were asked to respond to a series of questions exploring their experiences of supporting women with intellectual disabilities to access cervical screening. Specifically the questions were concerned with participants' experiences of primary care professionals; determining the need for and implementing reasonable adjustments; explaining cervical screening to women and alleviating women's fears and anxieties; and decision-making in relation to risk, capacity to consent and best interests. The interviews were held at the interviewee's place of work and informed consent to participate was obtained at the beginning of each interview. Interviews lasted between 30-60 minutes and were recorded in their entirety and subsequently transcribed verbatim using a simple orthographic notation suggested by system recommended by Braun and Clarke (2013).

Data analysis

In order to obtain an in-depth and detailed insight into the experiences and perceptions of participants, the responses to the open-ended questions were analysed qualitatively using experiential thematic analysis. This analytic method facilitates the identification of themes and patterns of meaning across a dataset and was therefore considered pertinent to the aims of the study. Data analysis was conducted according to the procedure described by Braun and Clarke (2013), which facilitates the systematic identification, interpretation and reporting of the salient features of qualitative data using several interconnected phases. Firstly, each transcript was read repeatedly in order to facilitate familiarisation with the data; during this stage any items of potential interest in relation to the research question were noted. Secondly, significant features and emerging patterns in the data were coded using concise phrases and all instances of text relating to each code were collated. Thirdly, the codes and collated data were reviewed in order to identify similarity between codes, such as recurring topics or issues, and codes were combined into candidate themes. Fourthly, an informative label was constructed and allocated to the candidate themes and all data extracts applicable to each theme were collated. The final phase of analysis involved reviewing and revising the candidate themes in order to ensure they captured the meaning of the data appropriately in relation to the research question. The analysis was conducted within an essentialist/realist framework, which aims to elicit and describe the experience, meanings and reality of individual participants. Consequently, themes were identified at a semantic level and reflected the explicit content of the data (e.g. mirrored participant's language and concepts).

Ethical considerations

Initial ethical approval was sought and obtained from the University of Nottingham ethics committee as outlined by the ethical code of conduct published by the British Psychological Society. Issues relating to seeking participation from health professionals employed by the NHS, informed consent, confidentiality and the right to withdraw constituted the primary ethical concerns reviewed for this study. Approval to seek participation from NHS professionals was sought and gained through the required research governance procedures at the NHS Trust involved. Subsequently, all study participants were given detailed information regarding the objectives of the study, the research methodology and their right to withdraw prior to agreeing to participate. In addition, participants were informed that the interviews would be audiotaped and transcribed and written permission to use quotations in any dissemination of the work was obtained (no participants stated that they did not wish their quotes to be used in dissemination). Furthermore to protect the privacy and confidentiality of the participants, no personally identifying information is described in the results.

Results

During the process of thematic analysis, three overarching themes emerged in the participants' accounts of their experiences of and perceptions regarding supporting women with intellectual disabilities to access cervical screening: the role of individual factors, the role of the learning disability nurse, and the role of primary care professionals. A series of themes and subthemes articulated the properties of these overarching themes.

The role of individual factors

The psychological impact of cervical screening. In describing their experiences, participants frequently referred to the invasive and inherently unpleasant nature of cervical screening and there was a widely held perception that psychological factors impact negatively on many women's attitudes towards and ability to tolerate the procedure. One participant stated: '*[...] I think we made numerous attempts and we tried everything but I think the fear just overrode all the techniques we'd put in place.*' (Participant four). Another participant noted: '*[...] she's just so scared and I think it's the pain, I think she pre-empt's the pain and the discomfort that will come with it.*' (Participant seven). A related issue highlighted by several participants was the perception that women's prior experiences influence both their attitudes towards and the psychological impact of cervical screening. One participant stated:

'[...] I think a lot of the women that we work with if they haven't had either previous experience or previous good experience then they're not going to go back. You know nobody is going to volunteer for something that wasn't pleasant.' (Participant nine)

Another participant noted:

'[...] I've had quite a few positive experiences really but these are ladies that have been through the process of having children and then had smears before I've become involved with them.' (Participant six)

The influence of women's limited health literacy and competing demands on attitudes towards screening. Nearly all participants highlighted the issue of poor literacy skills, noting that many women with intellectual disabilities would discard the screening invitation letter as a result of this. There was also a perception that many women have limited understanding of the nature and implications of the cervical screening test due to the abstract and unfamiliar concepts involved and it was evident that this can impact on women's perception of their risk of cancer and attitude towards screening. One participant stated:

'[...] I suppose there's a lack of understanding you know about what the procedure is, why you have the procedure and an understanding of cancers [...] and I suppose the ability to understand the consequences of actions, you know to work through it and think what the consequences of not having it would be. If you're thinking in the here and now you might have difficulty understanding those consequences and the importance of the investigations would not be at the forefront of your mind would it.' (Participant eight)

However, even in circumstances when a woman was assessed to have an understanding of the procedure, a perception of apathy towards screening was evident in some accounts often as a result of competing demands. One participant stated:

'[...] she understands cancer, you know she's a smoker and she understands that she is putting her health at risk, she will tell you that, but she does still choose to

smoke and doesn't feel ready to stop smoking as much as she knows it would be a good idea and I do think she thought about cervical screening along those lines too. You know she knew she should do it, didn't really want to and there were other things happening, which I think probably there's a lot of ladies in the general population who know they probably ought to but they don't always get around to it.' (Participant one)

The role of the learning disability nurse

Two primary roles emerged for learning disability nurses in relation to supporting women with intellectual disabilities to access cervical screening: preparing women psychologically for screening and managing the challenges of supporting women with complex needs.

Preparing women psychologically for screening: The value of the preparation intervention. Participants' accounts illustrated that various strategies are employed as part of interventions to prepare women psychologically for screening in order to enhance understanding, increase predictability, and minimise anxiety. It was evident that integral components of preparation include the provision of procedural and sensory information and the use of pre-exposure and de-sensitisation in order to gradually familiarise women with the screening procedure under neutral conditions. The value of familiarising women with the steps involved in the procedure, the equipment used and the setting in which the screening takes place was emphasised repeatedly. One participant stated:

'[...] I mean we go down just to look at the room, let them sit on the couch you know look at the speculum all those kind of things, you know the little brush that actually takes the specimen you know takes the cells away, just so they've got an understanding of what it involves. You know getting in position without doing anything invasive at the time and just maybe build on that so you take two or three trips maybe beforehand just to kind of desensitise and build that bit of insight really and obviously the person who's going to actually do the procedure get them involved as well if possible [...] I would look at doing that really because that's automatically going to make the person hopefully feel comfortable.' (Participant six)

The benefits of the familiarity and predictability afforded by the preparation intervention were highlighted in a particular participant's account of a negative experience involving a young woman who became so distressed she could not tolerate the procedure:

'[...] we were sat in these rows of chairs and I could see her getting really wound up and thinking 'why am I here?' [...] when it came to it she couldn't remember and I was trying to reassure her but she couldn't remember what we were there for and I was probably the only consistent person that was there, everything else, the waiting room, the actual wait, the practice nurse, all an unknown.' (Participant three)

It was evident from participants' accounts that preparing women psychologically for screening is achieved within the context of an on-going, long-term relationship with the learning disability nurse that facilitates trust and minimises anxiety. This was illustrated in a participant's description of an experience involving a woman who was initially very reluctant to have screening and was eventually supported after many years and was found to have pre-cancerous cells. When asked how she alleviated the woman's anxieties in order to support her to screening the participant stated:

[...] I suppose a little bit is she's just known me for so long and you know I do have to admit that I'm sure I help her in such a lot of situations, you know I've been with her a long time and I suppose she's comfortable with me.' (Participant one)

An established long-term relationship also appeared integral to participants' ability to build in-depth understanding and advocate on a woman's behalf, enabling women to access screening and influencing the process positively:

'[...] I think if I was just referred to support somebody for cervical screening and I'd perhaps not got to know them very well and it was just support for that intervention I'd perhaps find that quite difficult you know around what their need is [...] whereas the people I've known them for quite some time because I've been doing other interventions so I'm able to predict how they're going to react to certain environments at certain times [...] so for me I think knowing

that I've advocated for them better so it's almost been very smooth.' (Participant eight)

The value of an established relationship with the person carrying out the procedure also recurred throughout the participants' accounts and was considered fundamental to reducing women's anxiety and level of discomfort experienced during the procedure in addition to potentially influencing the efficacy of the person taking the sample:

'[...] if they've met the person that's going to do it that person has started that relationship even if it's just 'hi how are you, you've come today to have a look round and stuff', that's that relationship started so you're not walking in to a stranger, which you find quite often can make people quite anxious and you know as soon as people get anxious then it is more difficult to actually carry out the procedure in which case it's not going to be particularly pleasant, not for the person having to undertake the test and certainly not for the person lying there you know having it done.' (Participant two)

Participants' accounts indicated that a further component of preparing women psychologically for screening involves encouraging women to take an active role in and control over the screening process wherever possible in order to increase predictability, facilitate trust and minimise anxiety:

[...] when she said she didn't want it to happen we stopped it we walked away you know we didn't say 'oh that's a shame', you know it was 'oh right well we can come another time don't worry' you know so that trust.' (Participant one)

Preparing women psychologically for screening: The value of the learning disability nurse's flexible approach. Participants' accounts indicated that the process of preparing women psychologically for cervical screening can be a prolonged journey that may involve multiple screening attempts prior to a successful outcome. It was evident that participants were in a position to work flexibly and creatively in order to accommodate this need:

'A couple of my experiences have been with women who have been reluctant who I've worked with for many months if not a couple of years, you know not the only issue I've worked with them on, but over the time I've worked with them trying to de-sensitise them and trying to educate them about the process and not been particularly successful, you know I've maybe had a few tries at supporting them through primary care and then actually in the end being able to get the cervical screen but at a different appointment.' (Participant five)

Managing the challenges of supporting women with complex needs: Balancing women's rights against the potential for distress. In discussing their experiences, a number of participants highlighted the ethical issues that can arise during the course of supporting women with intellectual disabilities to access cervical screening and emphasised the role of the learning disability nurse in managing these challenges. It was evident that

balancing women's right to access screening against the potential for significant distress, particularly in cases where a woman is unable to provide informed consent, is an important consideration of the learning disability nurse:

'[...] obviously you've got all the women with profound and multiple intellectual disabilities, what are you going to do about people who are non-verbal with an IQ of less than twenty, how are you going to make a decision that having a cervical screen will be in their best interest because the trauma for that procedure is likely to out-weigh the benefits.' (Participant 10)

Managing the challenges of supporting women with complex needs: The value of the learning disability nurse's expertise. The value of participants' expertise in managing the challenges of supporting women with more complex needs recurred across accounts. The importance of this expertise in relation to implementing an intervention requiring specialist skills due to the complexities involved and ensuring the necessary procedures are adhered to was highlighted by one participant:

'[...] it's difficult isn't it because it means you've got to look at consent, you've got to look at whether they've got capacity, you've got to look at whether you've got to go down the best interest route and I think that takes a bit of skill you know and it's one of those things that just gets side-lined I think if there isn't a nurse involved.' (Participant six)

The role of primary care professionals

Two primary roles emerged for primary care professionals in relation to supporting women with intellectual disabilities to access cervical screening: optimising women's experiences of cervical screening and maximising flexibility within the constraints of the primary care system.

Optimising women's experiences of cervical screening: The importance of knowledge, attitudes and skills. Participants' descriptions highlighted the contribution of primary care professionals' knowledge, attitudes and skills to patient-directed behaviour and the influence of these competencies on women's experience and the outcome of cervical screening. One participant noted: *'I've had a couple of GPs actually who didn't get it at all and you know, 'if you don't keep your legs floppy', that sort of attitude it's not going to happen.'* (Participant 10). Another participant stated:

'The environment is really important and the nurse and the language they use and actually sometimes they have a rapport with a person and the practice nurse is filled with confidence, you know 'we can do this' and you know 'this is what you need to do, this is what you need to think about' and actually asks those probing questions so see whether they understand.' (Participant three)

Issues relating to how women with intellectual disabilities are approached by primary care professionals who lack appropriate knowledge, attitudes and skills and the adverse impact of this on both the experience and outcome of cervical screening were revealed in the following account:

‘[...] she [the practice nurse] attempted to do the smear test, the lady couldn’t cope with it and was absolutely screaming and what have you and I just said ‘stop’. I don’t know why but the practice nurse didn’t stop at that point she just tried to carry on. So I intervened and said ‘stop’ so she did and then she was really sort of aggressive to me and mum saying ‘why have you come for this appointment, why have you put this woman through this?’ and tried to blame us [...] the lady involved had consented, she knew everything, but obviously it’s more uncomfortable when you’re in that position so we didn’t go for it and she had it on her notes that unless she becomes sexually active or has any symptoms, which unfortunately symptoms are a little bit too late, but she’s not going to be recalled.’ (Participant nine)

The expertise needed to assess a woman’s capacity to consent to cervical screening in more complex cases recurred throughout participants’ accounts and several participants had encountered gaps in primary care professionals’ knowledge and skills in relation to this. One participant stated: *‘there are a lot of GPs and consultants that still don’t seem to understand the Mental Capacity Act properly and we see that on a regular basis as learning disability practitioners.’ (Participant 10).*

Optimising women’s experiences of cervical screening: The problem of minimal exposure to people with intellectual disabilities. An issue that recurred across several accounts was primary care professionals’ lack of exposure to people with intellectual disabilities and the inevitable impact of this on the development of knowledge and skills and women’s experiences of cervical screening. One participant stated: *‘[...] they’re in*

a busy practice they don't see that many people with a learning disability so they don't get used to it do they?.' (Participant nine). Furthermore, the pertinent issue of primary care professionals having to perform sophisticated skills while having minimal exposure was also highlighted:

'[...] I don't think we always realise how difficult it is for people who haven't worked with people with a learning disability. We go in all guns blazing about reasonable adjustments but people who have no experience of people with a learning disability, it's understandable sometimes why their decision making process isn't okay or maybe their approach isn't. I've not ever seen it malicious, it's been lack of experience or skill or confidence and I think we sometimes forget that because we are so familiar with it we expect everyone to work the way we do and they're not able to and that's fair enough [...] I do think that we do have to think that someone's experience of learning disability is very limited and you're doing a very invasive procedure with someone who's very distressed. You may not handle it that well.' (Participant 10)

Maximising flexibility within the constraints of the primary care system: The issue of time pressures. More than half of the participants highlighted the negative impact of time constraints within the primary care context when describing their experiences of supporting women to access cervical screening. Participants' accounts indicated that such constraints can impact adversely on women's access to and experiences of cervical screening by limiting primary care professionals' ability to provide interventions tailored to individual need. One participant stated:

‘[...] we’re working very much individual you know whereas like primary care it’s a very different sort of setup really where people fit in to that system and if they don’t fit in to that system, we find it with health checks full stop, if they don’t fit in to that system, if the five minute appointment doesn’t suffice, then that’s you know where people drop through the net.’ (Participant two)

Another participant highlighted how time constraints impact adversely on primary care professionals’ ability to undertake appropriate assessments as part of the decision-making process:

‘[...] and I think GPs don’t often have time to do the level and complexity of a capacity assessment that we would do in intellectual disabilities. Got fifteen thousand patients on the books, they’re not going to. They’ll do it in a ten minute consultation, they will do that decision there, which they can but we’d be a lot more thorough. They wouldn’t show any accessible information, they wouldn’t check for retention, they wouldn’t even necessarily get the decision making process right.’ (Participant 10)

Maximising flexibility within the constraints of the primary care system: The importance of facilitating reasonable adjustments. When asked what specifically made cervical screening successful or hindered the process when it was not, nearly all participants emphasised the fundamental importance of primary care professionals facilitating reasonable adjustments. One participant reflected on the helpful contribution

of a practice nurse in this respect following a positive outcome demonstrating the important role of health professionals in maximising flexibility within the constraints of the primary care context:

‘[...] she’s just one of these nice ladies, you know a professional who you know will just give a little bit of time and will have a chat and you know you don’t feel rushed with her [...] a good professional who you know makes adjustments for anybody under the set of circumstances for having a smear test [...] I do think that she would have worked with me with in whatever we’d have thought we needed.’ (Participant one)

Discussion

The primary purpose of the current study was to qualitatively explore the experiences, perceptions and clinical practices of learning disability nurses in relation to supporting women with intellectual disabilities to access cervical screening. Data analysis revealed three overarching themes that reflected individual, health professional and service-related factors influencing cervical screening utilisation by women with intellectual disabilities.

Participants’ accounts indicate that the process of cervical screening involves several stages that have the potential to cause distress, anxiety and discomfort for women with intellectual disabilities. Consistent with previous research that has established links between limited health literacy and poor engagement with health promotion services (Scott et al., 2002; Garbers and Chiasson, 2004; Lindau et al., 2006), several

participants' perceived that the cognitive impairments associated with intellectual disabilities can limit women's ability to understand the full implications of cervical screening (e.g. what is involved and why the test is performed). It was apparent that this influenced women's attitudes towards screening (e.g. perceptions of risk and the acceptability of screening) and increased women's susceptibility to adverse effects of the procedure. There was also a widespread perception that women's prior experiences can influence the psychological impact of cervical screening, both negatively and positively (e.g. being a parent, engaging in a sexual relationship, or previous positive experiences of screening can minimise the adverse impact of the procedure).

The findings from this study demonstrate that a fundamental role of the learning disability nurse in supporting women with intellectual disabilities to access cervical screening is focused on preparing women psychologically for the procedure.

Participants' accounts indicated that learning disability nurses attempt to support women within a framework of careful preparation and support involving informational and behavioural strategies and it is evident that this has the potential to minimise negative psychological consequences. The description of these strategies indicated that cognitive-behavioural therapeutic principles often form the basis of the preparation intervention, with social learning, de-sensitisation and the provision of accessible procedural and sensory information frequently applied. Participants' descriptions indicated that these psychological adjuncts play an important role in increasing predictability and regulating women's emotions, which is consistent with findings from research conducted within a medical context demonstrating that psychological preparation of patients undergoing stressful medical procedures facilitates coping

(Johnston and Vogele, 1993). These findings also support conclusions from learning disability-specific research suggesting that adequate preparation of women for cervical screening is integral to enabling women to access mainstream cervical screening services (Broughton, 2002; Watts, 2008; Gribben and Bell, 2010).

Consistent with previous research that has demonstrated that optimising patients' control during medical procedures has a positive effect on well-being and levels of distress (Hudcova, McNicol, Quah et al., 2006), it is evident that learning disability nurses attempt to relinquish control during both the preparation intervention and the screening procedure in order to regulate women's anxiety. It is also evident that learning disability nurses are often able to invest time to develop long-term relationships with women in order to build trust and in-depth understanding and several of the participant's accounts highlighted that this was crucial to championing the diverse needs of the women being supported. Furthermore, it is apparent that learning disability nurses can support colleagues in primary care by contributing to decision-making around capacity to consent and best interests and that this specialist expertise may influence women's uptake and experience of cervical screening.

The findings of the study indicated that assessing and obtaining informed consent can present challenges for primary care professionals and may act as a barrier to women with intellectual disabilities accessing cervical screening, reflecting similar findings previously identified by Watts (2008) and Gribben and Bell (2010). Additionally, whilst it was apparent that participants considered that women with intellectual disabilities should have equal access to mainstream cervical screening services in line with policy

direction, ethical complexities in decision-making in relation to women with more severe intellectual disabilities were acknowledged. It was evident that participants often contributed to a cost-benefit analysis during which the benefits of carrying out screening were balanced against the potential for distress as part of best interest decisions and, consistent with previous research (e.g. Biswas et al., 2005), that decisions not to proceed with screening are appropriate in some circumstances.

The findings of the study support previous research suggesting that lack of experience, skills and appropriate attitudes among primary care professionals act as a barrier to women with intellectual disabilities accessing cervical screening (Stein and Allen, 1999; Broughton, 2002; Watts, 2008). In describing their experiences, participants indicated that women's experience of cervical screening was influenced by primary care professionals' level of understanding of individual needs and preferences and willingness to adjust their clinical behaviour accordingly. It was also evident that when achieved, this optimised women's experience of cervical screening and influenced women's emotional response to screening positively. The supplementary role of the learning disability nurse in assisting primary care to optimise women's experience of cervical screening was also evident, supporting the recommendations made by previous researchers (Broughton and Thomson, 2000; Broughton, 2002; Watts, 2008).

From a theoretical perspective, interactions between a number of the facilitators and barriers identified in the current study can be conceptualised hypothetically using the framework outlined by Von Wagner and colleagues (2009), which describes routes through which health literacy might impact on actual health actions or the motivational

or volitional determinants stipulated by social cognition models. It can be hypothesised that a combination of individual knowledge-based perceptions (e.g. low perceived susceptibility to and threat of cervical cancer due to limited understanding) and attitudinal factors (e.g. negative beliefs/fear of the procedure resulting from past experience or limited understanding) contribute to the decision regarding whether to attend screening. When an intention to be screened has been made, additional factors including practical barriers (e.g. difficulties accessing cervical screening services and competing priorities) can inhibit the translation of intention into behaviour. It is evident that by addressing individual (e.g. motivational and skill-based deficits) and practical barriers (e.g. by facilitating reasonable adjustments to improve access), learning disability nurses are in a position to influence this 'intention-behaviour' gap and improve cervical screening attendance. The findings of the current study also highlight the facilitative role of specific competencies among primary care professionals (e.g. appropriate knowledge, attitude & skills) and the importance of the application of management strategies recommended for women with intellectual disabilities (e.g. adherence to good practice guidelines).

The current study is limited by the exclusive focus on the perspectives of learning disability nurses and absence of the views of both women with intellectual disabilities and primary care professionals. In addition, participants were self-selected and may not be representative of learning disability nurses in general.

Clinical implications and future directions

The findings of the present study highlight several considerations in relation to the role of primary care in delivering cervical screening services to women with intellectual disabilities. Policy and service development emphasise the promotion of access to mainstream services and the improvement of skills in this setting as opposed to the development of specialist intellectual disabilities screening services (Gribben and Bell, 2010). The experiences and perceptions reported by learning disability nurses in this study suggest that lack of training, limited exposure to people with intellectual disabilities and time pressures in the primary care context can impede health professionals' ability to undertake cervical screening effectively with women with intellectual disabilities, particularly women with more complex needs. In addition, the majority of adults with intellectual disabilities in England do not access learning disability services (Emerson, Hatton, Robertson, Baines, Christie and Glover, 2012), indicating that a significant number of women with intellectual disabilities will not receive support from learning disability nurses in order to access cervical screening. Due to cognitive limitations and reduced health literacy, many people with intellectual disabilities who are not receiving specialist support will still require 'reasonable adjustments' from health services to access care. This highlights the pivotal importance of primary professionals recognising the need for and facilitating any necessary adjustments to cervical screening provision through appropriate discussion with women with intellectual disabilities in order to ensure that screening is both accessible and equitable. Consequently, primary care professionals may benefit from interventions that highlight evidence of the impact of their behaviour on attendance at cervical screening by women with intellectual disabilities and the importance of their role in promoting

and improving access. Additional training to address complex issues such as capacity and consent may also be beneficial.

Whilst the findings of the present study suggest that learning disability nurses are currently well placed to provide specialist support, information and guidance to primary care professionals, formalised joint-working arrangements (e.g. clear service pathways) may need to be embedded to facilitate these working relationships. Although currently not a common model of service provision, there is an increasing move towards the co-location of learning disability nurses in primary care services. By utilising their expertise in facilitating and supporting access to general health care services through the elimination of identified barriers, learning disability nurses may have the potential to increase the uptake of cervical screening by women with learning disabilities as part of this new role opportunity. Models of working within learning disability nursing services are currently under review as part of significant strategic, structural and economic change within the NHS. In the current context of cuts to existing services, it is likely that learning disability nurses will face the challenge of how they should prioritise their work with women with intellectual disabilities who are in need of cervical screening as opposed to other aspects of their work and the often competing health needs of many people with intellectual disabilities.

In the UK, a significant number of adults with intellectual disabilities reside with family or paid carers and are dependent on some level of assistance from these support networks in order to manage everyday life (Foundation for People with Learning Disabilities, 2014). This indicates that carers may perform a fundamental health

advocacy role in assisting people with intellectual disabilities to access health care services. Consequently, the role of carers in assisting women who do not access specialist learning disability services to understand and access cervical screening may warrant further exploration. Identifying the knowledge, skills and support carers require to optimise this health advocacy role may help to improve poor uptake of cervical screening by women with intellectual disabilities.

The influence of health beliefs and demographic, contextual and emotional factors on the uptake of cervical screening by women with intellectual disabilities is poorly understood and requires further empirical consideration. Eliciting the perspectives of women with intellectual disabilities and their carers directly may help to elucidate the impact of these factors. In addition, primary care professionals' attitudes and beliefs regarding women with intellectual disabilities and the influence of these variables on clinical behaviours and women's cervical screening attendance may warrant further exploration. Future research may wish to directly test the utility of the framework proposed by Von Wagner and colleagues (2009) in the context of participation in cervical screening by women with intellectual disabilities in order to document the array of individual and system barriers impeding uptake and inform intervention strategies.

Conclusion

Prior literature on cervical screening describes multiple factors influencing poor uptake by women with intellectual disabilities. This study offers an in-depth insight into the experiences, perceptions and clinical practices of learning disability nurses in relation to supporting women with intellectual disabilities to access this type of screening. From

the perspective of learning disability nurses, psychological (e.g. motivational and skills-based) factors appear to impact on women's attendance at and ability to tolerate cervical screening. Learning disability nurses also perceive that they can help to prepare women psychologically for screening and manage the challenges associated with supporting women with more complex needs. Furthermore, the perceptions of learning disability nurses suggest that primary care professionals have the potential to optimise the cervical screening experience for women with intellectual disabilities providing they have the appropriate knowledge, attitudes and skills. The findings of this study suggest that the expertise of the learning disability nurses may help to facilitate this when effective partnership working exists.

Declaration of interest

There is no interest to declare.

References

- Alborz, A., McNally, R. and Glendinning, C. (2005) Access to health care for people with intellectual disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy* 10(3): 173-182.
- Ajzen, I. (1991) The Theory of Planned Behaviour. *Organizational Behavior & Human Decision Processes* 50(2): 179-211.
- Ajzen, I. and Madden, T.J. (1986) Prediction of goal-directed behaviour:

attitudes, intentions, and perceived behavioural control. *Journal of Experimental Social Psychology* 22(5): 453-74.

Band, R. (1998) *The NHS – Health for All? People with Learning Disabilities and Healthcare*. London: Mencap.

Biswas, M., Whalley, H., Foster J., Friedman, E. and Deacon, R. (2005)
Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. *Journal of Public Health* 27(4): 344-347.

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A practical guide for beginners*. London: Sage Publications Ltd.

Broughton, S. (2002) A review of the literature: interventions to maximize capacity to consent and reduce anxiety of women with intellectual disabilities preparing for a cervical smear test. *Health Services Management Research* 15(3): 173-185.

Broughton, S. and Thomson K. (2000) Women with intellectual disabilities: risk behaviours and experiences of the cervical smear test. *Journal of Advanced Nursing* 32(4): 905-12.

Cancer Research UK (2010) *Cervical cancer – UK incidence statistics*

[online]. Available at <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/cervix/incidence/> (Accessed 3 September 2013).

Conner, M. and Norman, P. (2005) *Predicting Health Behaviour*. 2nd ed. Maidenhead: Open University Press.

Department of Health (2003) *Tackling Health Inequalities: A Programme for Action*. London: The Stationery Office.

Department of Health (2004) *Choosing Health: Making Healthy Choices Easier*. London: The Stationery Office.

Department of Health (2009) *Valuing People: A New Three-year Strategy for People with Intellectual disabilities*. London: The Stationery Office.

Disability Rights Commission (2006) *Equal Treatment: Closing the Gap. Interim Report of a Formal Investigation into Health Inequalities*. London: Disability Rights Commission.

Dolan N.C., Ferreira M.R., Davis T.C., Fitzgibbon M.L., Rademaker, A., Liu D. et al. (2004) Colorectal cancer screening knowledge, attitudes, and beliefs among veterans: Does literacy make a difference? *J of Clin Onco*, 22: 2617-2622.

Emerson, E., Hatton, C., Robertson, J., Baines, S., Christie, A. and Glover, G. (2012).

People with Learning Disabilities in England 2012. Durham: Improving Health & Lives: Intellectual disabilities Public Health Observatory.

Foundation for People with Learning Disabilities (2014) *Learning Disability Statistics:*

Support [online]. Available at: <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/?view=Standard>

Garbers, S. and Chiasson, M.A. (2004) Inadequate functional health

literacy in Spanish as a barrier to cervical cancer screening among immigrant

Latinas in New York City. *Preventing Chronic Disease* 1(4): A07.

Glover, G., Emerson, E. and Eccles, R. (2012) *Using local data to*

monitor the health needs of people with intellectual disabilities. Durham:

Improving Health & Lives: Intellectual disabilities Public Health Observatory.

Gribben, K. and Bell, M. (2010) Improving equality of access to cervical

screening. *Learning Disability Practice* 13(7): 14-20.

Health & Social Care Information Centre (2012) *Cervical screening*

programme, England 2011-12 [online]. Available at:

https://catalogue.ic.nhs.uk/publications/screening/cervical/cerv-scre-prog-eng-2011-12/cerv_scre_prog_eng_2011-12_rep_v3.pdf (Accessed 3 September 2013).

Hudcova, J., McNicol, E., Quah C., Lau, J. and Carr, D.B. (2006) Patient

controlled opioid analgesia versus conventional opioid analgesia for postoperative pain [systematic review]. *The Cochrane Database of Systematic Reviews Issue 6*. Article No. CD003348. Chichester, UK: John Wiley and Son, Ltd.

Janz, N.K. and Becker, M.H. (1984) The health belief model: A decade later. *Health Education & Behaviour* 11(1): 1-47.

Johnson, K., Strong, R., Hillier, L. and Pitts, M. (2002) *Screened Out! Women with Disabilities and Cervical Screening*. Australia: The Cancer Council Victoria.

Johnston, M. and Vogele, C. (1993) Benefits of psychological preparation for surgery: a meta-analysis. *Annals of Behavioral Medicine* 15(4): 245–56.

Kalichman, S. C. and Rompa, D. (2000) Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes* 25(4): 337-344.

Lindau, S.T., Basu, A. and Leitsch, S.A. (2006) Health literacy as a predictor of follow-up after an abnormal Pap smear: A prospective study. *Journal of General Internal Medicine* 21(8): 829-834.

Marteau, T.M. (1993) Health related screening: Psychological predictors of

uptake and impact. In: Maes S., Leventhal H. and Johnston, M. (eds).

International Review of Health Psychology. Vol. 2. Chichester: John Wiley & Sons Ltd, pp.149-174.

Marteau, T.M. and Johnston, M. (1990) Health professionals: a source of variance in health outcomes. *Psychology and Health* 5(1): 47-58.

McCarthy, M. (2002) Sexuality. In: Noonan-Walsh, P., and Hellers, T (eds.). *Health of women with intellectual disabilities*. Oxford: Wiley-Blackwell, pp. 90-102.

Melville, C., Finlayson J., Cooper S.A., Allan L., Robinson, N., Burns E., Martin, G. and Morrison, J. (2005) Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research* 49(3): 190–198.

Murphy, G.M. (2003) Capacity to consent to sexual relationships in adults with intellectual disabilities. *Journal of Family Planning & Reproductive Healthcare Care* 29(3): 148–9.

NHS Cancer Screening Programmes (2006a) *Equal access to breast and cervical screening for disabled women*. Cancer Screening Series No.2. Sheffield: NHSCSP Publications.

NHS Cancer Screening Programmes (2013) *Achievable standards, benchmarks for reporting, and criteria for evaluating cervical cytopathology.*

Publication No.1. Sheffield: NHSCSP Publications.

Nutbeam, D. (1998) Health promotion glossary. *Health Promotion International* 13(4): 349–364.

Ogden, J. (2012) *Health Psychology: A Textbook*. 5th ed. Maidenhead: Open University Press.

Osborn, D.P.J, Horsfall, L., Hassiotis, A., Petersen, I., Walters, K. and Nazareth, I. (2012) Access to Cancer Screening in People with Intellectual disabilities in the UK: Cohort Study in the Health Improvement Network, a Primary Care Research Database. *PLoS ONE* 7(8).

Parish, S. L., Moss, K., and Richman, E. (2008) Perspectives on health care of adults with developmental disabilities. *Intellect Dev Disab* 46: 411-426.

Parish, S.L., and Saville, A. W. (2006) Women with cognitive limitations living in the community: Evidence of disability-based disparities in health care. *Ment Retard* 44: 249–259.

Parish, S.L., Rose, R.A., Luken, K., Swaine, J.G. and O'Hare, L. (2012) Cancer

Screening Knowledge Changes: Results From a Randomized Control Trial of Women With Developmental Disabilities. *Res Social Work Prac* 22: 43-53.

Reynolds, F., Stanistreet, D. and Elton, P. (2008) Women with learning disabilities and access to cervical screening: retrospective cohort study using case control methods. *BMC Public Health* 8(30): 1-7.

Rubin, H.J. and Rubin, I.S. (1995) *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage Publications Inc.

Rudd, R. (2013) Needed action in health literacy. *Journal of Health Psychology* 18(8): 1004-1010.

Scott, T.L., Gazmararian, J.A., Williams, M. V. and Baker, D.W. (2002) Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care* 40(5): 395-404.

Spadea, T., Bellini, S., Kunst, A., Stirbu, I. and Costa, G. (2010) The impact of interventions to improve attendance in female cancer screening among lower socioeconomic groups: a review. *Prev Med* 50: 159–64.

Stein, K. and Allen, N. (1999) Cross sectional survey of cervical cancer Screening in women with learning disability. *British Medical Journal* 318: 641.

UK Chief Nursing Officers (2012) *Strengthening the commitment. The report of the UK modernising intellectual disabilities nursing review.* Edinburgh: Scottish Government.

Von Wagner, C., Steptoe, A., Wolf, M.S. and Wardle, J. (2009) Health literacy and health actions: a review and a framework from health psychology. *Health Education & Behavior* 36(5): 860-877.

Wacker, J., Macy, R., Barger, E. and Parish, S. (2009) Sexual assault prevention for women with intellectual disabilities. *Intellect Dev Disab* 47: 249-262.

Watts, S. (2008) Access to cervical screening for women with learning disabilities. *British Journal of Nursing* 17(8): 518-525.

Wilkins, J. (2004) Making a difference. *Learning Disability Practice* 7: 8-10.

Wood, R. and Douglas, M. (2007) Cervical screening for women with learning disability: current practice and attitudes within primary care in Edinburgh. *British Journal of Intellectual disabilities* 35(2): 84-92.

The role of learning disability nurses in promoting cervical screening uptake in women with intellectual disabilities: A qualitative study.

Authors:

Jennifer L Lloyd (Learning Disability Service), Derbyshire Healthcare NHS Foundation Trust, UK and Neil S Coulson (School of Medicine), University of Nottingham, UK

Corresponding author contact details:

Jennifer Lloyd, Assistant Clinical Psychologist, Erewash Community Team for Learning Disabilities, Outlook, 99 Briar Gate, Long Eaton, Nottingham, NG10 4BQ, UK. Tel. No. 01629 531889.

Email: Jennifer.Lloyd@derbyshcft.nhs.uk