The role of primary care professionals in women’s experiences of cervical cancer screening: a qualitative study

Abstract

Background: The UK Cervical Screening Programme, delivered mostly through primary care, commands impressive levels of public support. However, considerable evidence suggests that women find the experience of screening problematic.

Objective: To investigate this tension using women’s accounts of cervical screening, with a view to informing practice to better meet their needs.

Methods: A qualitative interview study with 34 participants focused on their experiences and understandings of cervical cancer screening in the UK. Analysis was based on the constant comparative method.

Results: The highly intimate and personal nature of the test is challenging, and many women report unsatisfactory experiences. Problematic issues include: embarrassment and discomfort (sometimes severe) in exposing an intimate and personal part of their body; surrendering control; and finding the test painful, uncomfortable and personally threatening. Though there is an important role for primary healthcare professionals in easing discomfort and facilitating positive experiences, women often report feeling disappointed with how the procedure is conducted. Women suggest that practitioners’ attempts to normalise the interaction and maintain a degree of detachment could have the perverse effect of making them feel more uncomfortable, and that more personalisation would be welcome.

Conclusion: This work identifies the ways in which women may find personal engagement with cervical screening difficult, and demonstrates the important role of primary care practitioners in contributing to women’s experiences of the encounter. We draw on Erving
Goffman’s work on the “interaction order” to explain some of the problems reported by women and to help inform good practice in primary care.

Keywords: cervical cancer; screening; health promotion; qualitative research; health professional
Introduction

Like many other countries, the United Kingdom (UK) runs a nationally-organised screening programme for cervical cancer. Known as the NHS Cervical Screening Programme (NHSCSP), it is organised and delivered through primary care. Cervical screening is available free-of-charge to women in England aged between 25 and 64 years; invitations are issued every three or five years depending on the woman’s age. The three other countries of the UK (Scotland, Wales and Northern Ireland) have slightly different arrangements regarding eligibility and screening intervals for the programme. Enclosed with all invitations to participate in the programme is the NHSCSP information leaflet, which describes the screening test as a straightforward procedure where the main risk is that “you might experience some discomfort or pain”.

Attitudes towards cervical screening remain something of a paradox. On one hand, the programme appears to command impressive levels of public support; campaigns to widen the eligibility criteria for the programme (and in particular to lower the age of first invitation) are often high profile and widely supported. They include those following the death from cervical cancer of the British celebrity Jade Goody at the age of 27 in 2009 and of 23-year old Claire Allan in the same year. \(^1\) Public pressure to widen the age criteria persisted following a review by the Advisory Committee on Cervical Screening, which agreed unanimously there should be no change to the current policy. \(^2\)

Tension between public support for the screening programme in principle and individual women’s experiences is, however, evident. Considerable evidence suggests that individual women find the experience of the screening test problematic. An invasive procedure, it
involves opening the vagina via the use of a speculum, and taking a sample of cells from the cervix. It violates important taboos about access to intimate body parts and nakedness. Reported concerns among women include fear, dislike of the procedure, anticipated embarrassment, possible pain or discomfort, and anxieties about being treated in an uncaring or disrespectful way.

Primary care professionals who conduct the test may have an important mediating role, in particular by reducing any gap between public enthusiasm for the program and women’s private experiences. However, surprisingly little is known about the role of primary care practitioners in managing women’s personal engagement with cervical screening. In this paper, we explore this drawing on Erving Goffman’s work on the “interaction order.” Goffman sees interaction as a ritual which gives a sense of social belonging and value as an individual, with the interaction order acting as a conceptual map to each occasion of face-to-face interaction. We use this to explain some of the problems reported by women and to help inform good practice in primary care.

**Methods**

Semi-structured interviews were conducted with 34 women from across the East Midlands who had all experienced cervical screening in England. We opted to recruit participants outside of the formal healthcare system, as we wished to avoid any misunderstanding that the work constituted any form of ‘service evaluation’ of particular professionals or care organisations. Participants were recruited through a range of community groups that had a predominantly female membership (for example, mother and toddler groups, and women’s groups). In each case, contact was made with the group lead and she was asked to circulate written information about the study. Willing volunteers were asked to contact the
researchers directly. In addition, snowball sampling was used to a limited degree in order to recruit from groups that proved hard to reach, including older South Asian women. Due to the recruitment strategies used, we do not know how many women received the information but declined to participate.

Individual semi-structured interviews, focusing on participants’ experiences of cervical screening, were conducted by the first author, facilitated in three interviews by an interpreter. The interviews lasted approximately one hour and took place in women’s homes or community group premises. An interview guide was used to ensure coverage of a number of key areas identified in advance of the data collection, but no attempt was made to restrict the interviews to these topics or control the order in which they were discussed. Women were free to influence the course of their interviews and to introduce issues of particular importance or relevance to themselves. All interviews were audio-recorded, fully transcribed, and anonymised.

Institutional ethical approval for the project was obtained. All participants received written information about the study, were assured of anonymity, and gave their informed consent to participate.

Data analysis was led by the first author, with support and checking provided by the second author. Analysis was based upon the constant comparative method. Key themes within the data were identified, analysed and explored through repeated close readings and annotation of interview transcripts concurrent with data collection. Individual transcripts were compared and contrasted, and deviant cases identified and explored. The identified themes were then used to develop and refine a coding framework which was subsequently
applied systematically to the full data set. NVivo software was used to aid the coding, management and retrieval of data. The illustrative quotes included below were selected as particularly clear and/or concise examples.

Findings

A diverse sample of 34 participants was recruited, including women from a range of ages and ethnic backgrounds (Table 1). Thirty-two women had had at least two cervical screens at the time of interview; the other two had had one test.

Table 1. Summary of sample characteristics

<table>
<thead>
<tr>
<th>Age range</th>
<th>26-60 years</th>
</tr>
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<tbody>
<tr>
<td>Ethnic background</td>
<td>13 White British, 10 South Asian, 11 African Caribbean</td>
</tr>
<tr>
<td>Socio-economic group</td>
<td>18 higher socio-economic group (1, 2 and 3 non-manual), 16 lower socio-economic group (3 manual, 4 and 5)</td>
</tr>
<tr>
<td>Marital status</td>
<td>22 married, 4 co-habiting, 2 widowed, 2 single, 4 separated/divorced</td>
</tr>
<tr>
<td>Children</td>
<td>29 with children, 5 without children</td>
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Cervical screening as a problematic encounter

The occasion of cervical screening can be understood as what Goffman terms a “focused interaction”: one in which there is a mutual activity in which both parties are engaged. Both parties must cooperate to sustain activity. This is an interaction with some very distinctive features, however. The healthcare professional (primary care doctor or, more usually, nurse) is able to gain access to parts of the body that social norms would otherwise prohibit, and the woman is expected to permit penetration of the vagina. Our data suggest that the accomplishment of this interaction is an unsatisfactory experience for many women. Although some women did not find the experience problematic, most participants (25 of the 34 women) reported embarrassment and discomfort (sometimes severe) in
exposing an intimate and personal part of their body to the practitioner conducting the procedure. Some felt the cervical screening procedure involved surrendering control over their body, and described the experience as painful, uncomfortable and personally threatening.

*Personally I still find it embarrassing exposing my body to people I don’t know. So yes, it does matter to me. I find it terribly embarrassing you know just stripping off my clothes.* (Participant 32)

*The one they did when they found the abnormal cells really hurt me…it was really, really painful.* (Participant 34)

Among women’s anxieties was fear that their body would betray them, and that they would suffer shame and humiliation as a result.

*Now that would be embarrassing for me if, because they were pressing on the bladder and it’s cold, if I wet myself and that is a fear that I have.* (Participant 28)

*I thought well, you know, that’s it, I’m going to let off wind (laughs) and (I was) really sort of nervous. Talk about contracting your pelvic floor muscles, it was really hard to sort of get the instrument inside me, you know, oh god. So that was one of my worst sort of fears I think (laughs).* (Participant 34)

Concerns about the potential for discrediting of the self were joined by feelings of acute vulnerability. Cervical screening could be experienced as an invasion of privacy, or even a violation; some women’s accounts represented the procedure as an invasion with overtly sexualised connotations.  

*I don’t know what the implement is called but it is quite big and erm I suppose it’s shaped like a penis as well, isn’t it. But it’s cold and you know that there’s an implement that is pushed in and so that’s painful as well.* (Participant 10)

*It’s almost like invasion of privacy and sometimes I think to myself, you know like, you think of some doctors that like abuse patients, probably either male or female and I think to myself “I wonder if they get off on it” [...]You don’t know what kind of person they are and what they’re thinking of when they examine you, you know what I mean, you can’t see what they are doing but I suppose you can feel what they’re doing but then again I don’t know. I mean anything can happen…you’ve got no*
control, at all, especially when they’ve got instruments up you, it’s not like you can say “Look drag it out” and get down because you could injure yourself.

(Participant 18)

The pivotal role of the healthcare professional

Submitting to cervical screening implicitly relies on trust in the person performing the procedure, and one useful definition of trust sees it as “the willingness of a party to be vulnerable”. However, 14 of the 34 women explicitly reported poor quality encounters with primary care practitioners during cervical screening, and described disappointment at how they had been treated – suggesting a betrayal of trust.

Women’s complaints focused in particular on a failure of healthcare professionals to reach with them a shared definition of the situation, which Goffman defines as “agreement concerning perceptual relevancies and irrelevancies, and a ‘working consensus’ involving a degree of mutual considerateness, sympathy, and a muting of opinion differences”. For women, what the professional performing the procedure selected for attention and what they deemed irrelevant was poorly aligned with women’s own priorities for attention. For women, the cervical screening encounter was something significant and out of the ordinary, yet they were often confronted by a health professional who treated the encounter as routine and empty of any emotional significance. They reported that the norms governing the interaction were often far from what they would see as optimal, yet they felt passive and deprived of any power to influence the conduct of professionals.

*I didn’t very much care for the person that did it. I thought, I found her very abrupt and he kind of said “come on relax” you know and of course that makes you…. I just think erm anybody who carries out these tests should be very aware of people’s feelings and err I think they should pick up on the fact that some people are more nervous than others definitely… I tried to make a joke about something and she was just, she completely ignored me and err, you know, I just found her very abrupt and I felt like slapping her face to be honest.* (Participant 14)
It was the nurse she wasn’t very, you know, she didn’t make me, make me relaxed, you know. I just felt like she just had to do what she had to do and I didn’t know what was happening. Maybe she didn’t prepare me enough. (Participant 26)

These encounters were typically characterised as cold and impersonal, or even as degrading. Professionals’ attempts to adopt a ‘businesslike’ approach or normalise the encounter were a particular focus of criticism. Women found it unacceptable to be approached as ‘just another body’ by a professional who appeared to act as though the emotional response of the woman to the encounter, or her characteristics as an individual, were, in Goffman’s terms, “irrelevant”.

They were hurting me and just kind of ignoring me. Not putting any attention on what I was feeling, you know and that it was actually hurting me, they thought I was just joking. You know they were kind of like, I felt that they were just not considerate at all, they were really harsh, they weren’t gentle at all. (Participant 23)

It’s just so cold. You go in, you take your clothes off, she does that and I mean it’s just so, it’s just so degrading and embarrassing. It’s just horrible. (Participant 2)

Some techniques used by professionals for normalising the encounter – such as stressing its routine nature or emphasising that the doctor or nurse had seen many vaginas before - could, for women, make things worse not better, as they suggested the apparent potential for comparisons to be made and for an individual to be found wanting in some way.

Although you’re in a room, you feel open and naked you know. It’s such an intrusion on your person. Doctors have seen a lot of vaginas but they didn’t see mine and that’s it for me. You may have seen hundreds but you didn’t see mine before. So I just saw it as an invasion of my person and my privacy. (Participant 10)

Rather than a detached approach, women reported that they would welcome some degree of engagement, personalisation and tailoring on the part of the healthcare professional, and that emotional preparation and reassurance would help them cope better.
You know it’s that dreaded thing, but yeah the last two times have been a lot better because it’s been performed by the nurse so it’s been a totally different, a totally different experience. Still sort of…but not as horrific as it was when the doctor does it. (Participant 16, 50-64, African-Caribbean)

I think that the nurses are very good, certainly mine was. Partly that was explaining what she was doing and why she was doing it, and partly making you as comfortable as you could possibly be, so that it doesn’t last long and it isn’t as embarrassing and it isn’t as painful. It is as acceptable as it can be. (Participant 8, 50-64, White British)

These two examples demonstrate the key role of practitioners in rendering the procedure more tolerable.

**Discussion**

The information leaflet given to women participating in the UK Cervical Screening Programme presents cervical screening as a straightforward procedure, and the programme itself enjoys massive public support – including enthusiasm for both widening the age criteria for inclusion and for more frequent screening. Our study suggests that women’s private experiences of the cervical screening test are often negative, and are not consistently managed optimally in primary care. Women report feeling passive, helpless and vulnerable in the face of a situation where they risk pain and discomfort, shame and humiliation, and violation and invasion of privacy. These are the very features of their experiences that may not be selected for attention by primary care professionals, but rather treated as irrelevant. As Strong notes, the main concern of rules of relevance is with indelicacy – what must be avoided or ignored. Yet efforts by health professionals to minimise or ignore any personal significance associated with the encounter, to construct it as a routine, everyday occurrence, or to distance themselves from the physical and emotional intimacy of the interaction, may all backfire. Such behaviour may signal a failure
to reach a shared definition of the situation. Ignoring women’s fears, anxieties and concerns can appear to deny the reality, or at least the validity, of women’s emotional responses.

This study would have been strengthened by inclusion of interviews with practitioners, and by observations of cervical screening encounters – though this latter would be ethically problematic. It is also a small study that makes no claims to representativeness; a survey approach would be needed to quantify frequency of the views expressed. Nonetheless, it offers some useful suggestions on how women’s experiences might be improved.

Our work suggests that more emphasis on what Goffman calls “the minor courtesies” might go a long way towards making cervical screening a less challenging experience for women. Better routines for primary care professionals’ management of the procedure, going beyond providing standard information and seeking to engage more personally with the woman, might help facilitate more positive experiences. This should include more explicit recognition of the particular significance of the intimate and personal nature of the procedure, and its associated anxieties and fears. There is unlikely to be a ‘one size fits all’ solution in terms of what specifically health professionals need to do to better support women. For example, women are likely to find different aspects of cervical screening challenging, and these concerns may arise from a range of different sources including both those linked to prior screening experiences and those that women bring to the screening encounter from elsewhere. Explicitly asking women about their expectations of the screening encounter and whether they have any worries or concerns may help to surface issues that the health professional and woman involved can then seek to tackle together. In this way, both parties can be involved in developing a shared understanding and definition of the interaction in which they are co-present, and the likelihood that they will be able to
successfully work together to sustain the activity and complete it to their mutual satisfaction may be increased.

Primary care professionals need to undertake interpersonal, emotional work \(^{23}\) to solicit the willing participation of patients and foster a trusting and safe environment in which women can feel comfortable about breaching what can be very strongly held ideas about what is and is not appropriate bodily conduct. Working with and on bodies in healthcare settings can be emotionally draining, laborious and demanding, \(^{24}\) but explaining what is being done and why, and being attentive to women’s comfort and individual preferences, go a long way towards making the cervical screening experience “as acceptable as it can be”.
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