

## HPV

## Social and psychological impact of HPV testing in cervical screening: a qualitative study

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**Objective:** Human papillomavirus (HPV) testing has been proposed for inclusion in the UK cervical screening programme. While testing may bring some benefits to the screening programme, testing positive for HPV, a sexually transmitted virus, may have adverse social and psychological consequences for women. The aim of this study was to examine the social and psychological impact of HPV testing in the context of cervical cancer screening.

**Method:** In-depth interviews generating qualitative data were carried out with 74 women participating in HPV testing in England between June 2001 and December 2003. Purposive sampling was used to ensure heterogeneity in age, ethnic group, marital status, socioeconomic background, cytology, and HPV results among participants.

**Results:** Testing positive for HPV was associated with adverse social and psychological consequences, relating primarily to the sexually transmitted nature of the virus and its link to cervical cancer. Women described feeling stigmatised, anxious and stressed, concerned about their sexual relationships, and were worried about disclosing their result to others. Anxiety about the infection was widespread, but the impact of testing positive varied. The psychological burden of the infection related to women's relationship status and history, their social and cultural norms and practices around sex and relationships, and their understanding of key features of HPV.

**Conclusion:** HPV testing should be accompanied by extensive health education to inform women and to de-stigmatise infection with the virus to ensure that any adverse impact of the infection on women's wellbeing is minimised.

Human papillomavirus (HPV) testing has the potential to change conventional methods of cytological screening. Five million women take part in cervical screening each year in the United Kingdom alone and any changes to incorporate HPV testing would have a widespread impact. HPV triage testing for women with mild cervical abnormalities has received much attention and is fast becoming part of routine care in the United States.<sup>1–6</sup> In the United Kingdom, trials of HPV triage testing and primary screening are currently under way to inform potential changes to the national screening programme.<sup>7–9</sup>

Although HPV testing offers potential advantages over conventional cervical screening,<sup>1–3</sup> it may have implications for the psychological wellbeing of women who participate.<sup>10</sup> The psychological effects of an abnormal smear result are well researched<sup>11–12</sup>; however, the sexually transmitted nature of HPV infection means it may cause additional anxiety and distress. At present women have very little understanding of HPV and its association with cervical cancer,<sup>13–15</sup> therefore any information given as part of HPV testing is likely to change their understanding of cervical cancer, which may in turn impact on their psychological response. Research investigating the psychosocial consequences of other sexually transmitted infections (STIs) suggests the impact of diagnosis can be extremely negative.<sup>16–17</sup> Although there has been much clinical and economic evaluation of HPV testing, attention to the psychosocial consequences of testing has been limited.<sup>18–19</sup> Existing research suggests that testing positive may be associated with some negative psychological outcomes,<sup>20–21</sup> but there has been no in-depth examination of the social and psychological consequences of HPV infection among women who have actually participated in HPV testing.<sup>13–22</sup>

This paper presents the first qualitative data on the psychological and social impact of testing for high risk HPV

among British women participating in HPV testing, either as part of a clinical trial, or specialist gynaecological management for their abnormal cervical smear. The study was designed to access a broad range of views and experiences so women from different ethnic groups and socioeconomic backgrounds were included.

## METHOD

## Participants

A total of 74 women were recruited in Manchester and London from clinical trials of HPV testing and from colposcopy clinics where HPV testing is carried out as part of routine care. Most participants had an HPV test at the same time as their routine smear, but for some, testing was offered alongside colposcopy following abnormal cytology results. All participants had received their test results (HPV and smear). Within each centre, all women had been given standardised information about HPV, although there was some variation in the detail between centres.

We used non-random, purposive sampling<sup>23</sup> to ensure heterogeneity with respect to age, marital status, socioeconomic background, and cytology result. Women from three broad ethnic groups were included: white British, south Asian (including Pakistani, Indian, and east African Asian) and African Caribbean. These groups have been shown to differ in attitudes towards sexual health<sup>24</sup> and uptake of cervical screening.<sup>25</sup> Women who had tested positive or negative on the Digene HCII HPV test were included.

**Abbreviations:** CIN, cervical intraepithelial neoplasia; GPs, general practitioners; HPV, human papillomavirus; STI, sexually transmitted infections

**Table 1** Topic guide

| Topic guide  |
|--|
| 1 Background demographic information                   |
| 2 Screening history and background knowledge           |
| 3 Information and understanding of HPV test            |
| 4 Experience of recent Pap test results, HPV diagnosis |
| 5 Understanding and perceptions of results             |
| 6 Disclosure of results to others                      |
| 7 Emotional impact of results                          |
| 8 Experience of treatment or follow up                 |
| 9 Improvements to cervical screening in the future     |

### Procedure

In-depth interviews were carried out with women, usually in their own homes. Interviews were structured around a topic guide (see table 1) which encouraged the individual to respond freely to open ended questions relevant to their experience. The topic guide provides a flexible set of content areas to direct the interview process while allowing the participants' experience to influence the specific content and direction of the interview.<sup>26</sup> Interviews were carried out by the first and second authors and trained freelance interviewers, using a mixture of ethnic matching and mismatching. They were transcribed verbatim and translated by the interviewer where necessary.

Framework analysis was used to organise the data and identify emerging themes.<sup>26</sup> The thematic framework is developed through familiarisation with a subset of transcripts. All data are summarised within the matrix to allow relationships and explanations for patterns within the data to be explored.

### RESULTS

Participant characteristics are shown in table 2 and demonstrate the heterogeneity of the sample. The data were examined to understand the impact of HPV testing on women and to explore how and why the impact varied. The

**Table 2** Demographic characteristics of the sample (n = 74)

| Demographic characteristics               | No |
|---|----|
| Age                                       |    |
| 20–29                                     | 22 |
| 30–39                                     | 27 |
| 40–49                                     | 16 |
| 50–64                                     | 9  |
| Relationship status                       |    |
| Single                                    | 20 |
| In a relationship (not cohabiting)        | 10 |
| Cohabiting                                | 11 |
| Married                                   | 24 |
| Divorced/separated/widowed                | 9  |
| Education                                 |    |
| Left school before 16/no qualifications   | 10 |
| Left school at 16 (GCSEs, CSEs, O levels) | 13 |
| Further education (diploma, BTEch, etc)   | 12 |
| Higher education (degree)                 | 33 |
| Missing data                              | 6  |
| Ethnic group                              |    |
| White                                     | 41 |
| South Asian                               | 17 |
| African Caribbean                         | 16 |
| Cytology result                           |    |
| Normal                                    | 34 |
| Abnormal                                  | 40 |
| HPV result                                |    |
| Positive                                  | 57 |
| Negative                                  | 17 |

analysis presented here focuses mainly on the 57 women who were HPV positive. Women's responses were clustered around two main themes, the first relating to anxiety about HPV in the context of increased risk of cervical cancer, and the second relating to the meaning, consequences, and understanding attached to the HPV infection (see table 3).

### General psychological wellbeing

Women's general response to a positive HPV test result was one of distress, anxiety, and upset. Women described feeling shocked at receiving a diagnosis of an infection of which they had little previous awareness or understanding. This was combined with anxieties about cancer risk, concerns about further investigation/treatment for cervical intraepithelial neoplasia (CIN), and worries about fertility; concerns which have been found to commonly accompany an abnormal smear result, even in the absence of HPV testing. The extent of anxiety some women described included intrusive thoughts and somatic responses to the diagnosis during the period when they first received their test results,

- "I was looking really ill. I wasn't sleeping. It was kind of nearly every day I was thinking about it" (W23 HPV+ CIN2)

(Participant ID numbers use W, SA, and AC to denote white, south Asian, and African Caribbean women, respectively.)

Anxieties relating to cervical cancer are well described elsewhere<sup>11 12</sup> and will not be the focus of the current paper. The following data will therefore relate specifically to issues raised by the diagnosis of HPV infection.

### Concerns relating to the meaning, consequences, and understanding of HPV

Much of the concern which emerged about testing positive for HPV related to the sexually transmitted nature of the infection. This affected women across a number of social, emotional, and behavioural dimensions.

### Stigma of an STI

Shock, embarrassment, and shame were common responses to the infection, with women using terms such as "unclean," "dirty," "cheap and nasty" to describe how they felt in response to their positive HPV result.

**Table 3** Table of themes: psychological and social responses to HPV testing

|  |
|--|
| <b>(1) Social and psychological response</b>                               |
| <i>A General psychological responses</i>                                   |
| shock, distress, worry   |
| concerns about cancer  |
| reassurance of additional testing  |
| <i>B Concerns relating to the sexually transmitted nature of HPV</i>       |
| Stigma of STI  |
| Guilt and blame for the cause of the infection                             |
| Anxiety about disclosure to sexual partners                                |
| Anxiety about disclosure to family and friends                             |
| Concerns about transmitting the infection                                  |
| <b>(2) Factors influencing social and psychological response</b>           |
| <i>A Women's relationship status and history</i>                           |
| <i>B Social, cultural and religious norms around sex and relationships</i> |
| <i>C Understanding of HPV</i>  |
| Extremely common infection   |
| Can regress without treatment  |
| No visible physical signs, distinct from genital warts and herpes          |
| Treatment for CIN is highly effective                                      |
| Condoms do not necessarily prevent infection                               |
| Not necessary to inform sexual partners                                    |
| Impact on male sexual partner likely to be negligible                      |
| Need for consistent of information   |

- “It just made me feel so dirty ... there’s a sort of shame, there’s a leper type deal to it.” (W24 HPV+ normal smear)

Such reactions suggest connotations of promiscuity surrounding HPV that were linked to its mode of transmission and perceived connection with genital warts.

- “The stigma comes from it being sexually transmitted and the fact that it not only predisposes you to cancer but it predisposes you to genital warts and other things like that.” (SA3 HPV+ normal smear)

Confusion between high risk HPV types and low risk genital wart types was common and was linked to use of the term “wart virus” in information provided to women about HPV, and confusion among healthcare providers themselves about the different viral types. Notably, feelings of stigma and shame were not displayed among women who were unaware that HPV is sexually transmitted, suggesting an additional burden that awareness of HPV can bring.

The stigma associated with HPV also impacted on women’s feelings about sex and their sexual relationships. Some women said they felt “dirty” and therefore sexually unattractive. Others reported feeling “infected” or that something was “growing inside them” and were worried about transmitting the infection. Some seemed to be more affected by concerns that the physical act of sex would worsen their abnormal cells. However, there were also women who were clearly aware of the route of transmission but who did not attach any stigma or personal feelings of embarrassment or shame to it. Among this group of women, common STIs such as HPV were seen an inevitable part of sexual activity.

- “A normal thing for many women to have.” (SA2 HPV+ normal smear).

### Guilt and blame for the cause of the HPV infection

Searching for an understanding of who caused the infection was a common response. Some women described feeling angry that a previous partner had infected them with what they perceived as a serious and carcinogenic virus. Others felt guilty that they had acquired the infection by being careless or promiscuous. Some blamed themselves for trusting someone who had later let them down. Others described questioning whether their partner had been unfaithful; however, most of these women ultimately attributed the infection to another source, such as a previous partner.

- “Actually I think I had it anyway, I must have had it before I started seeing my partner now.” (AC4 HPV+ abnormal smear)

Where it was known that infidelity had occurred, feelings of considerable anger and upset were elicited and some women re-experienced the negative feelings that were associated with the infidelity.

- “He was actually having an affair with my best friend and I suspected... I kept saying are you, are you, are you? ... A double betrayal plus ill health ... I feel that it was very unlucky that my first lover should have done this.” (W25 HPV+ CIN1)

### The influence of relationship status and history

Women’s response to their HPV test result varied and seemed to be influenced in part by the status and history of their primary sexual relationships. For example, in relationships where there had been recent discord, infidelity, or had ended

unhappily, the HPV test result led to questions about trust and fidelity and accusations of blame for the infection. One woman highlighted the significance of the HPV result in the context of her marriage and her husband’s recent affair.

- “I did worry about my husband not being a good boy ... I remember saying to my husband if this is positive this is going to be hard ... when I die of cervical cancer you’ll be sorry ... I think it was the fact that I’d been married for so long and it was like where’s that come from sort of thing? But if I was in my twenties and having lots of partners then it wouldn’t have been such a big deal ... It [the affair] really shook our marriage up and I never thought I’d be able to stay with him. And it was like this [HPV] was something I hadn’t even thought of coming out to get me just when I thought it [the affair] had been dealt with.” (W24 HPV+ normal smear)

For women entering new relationships testing positive led to worries about transmitting the infection to their new partner and anxieties about disclosing their infection to someone they had only recently met. In contrast, in more established relationships where there had been openness about previous sexual relationships, the HPV was simply attributed to a previous partner and appeared to cause little problem.

- “My husband could have been the carrier or boyfriends I had before him. Or somebody afterwards. It could have been anybody. It’s not something that they’re likely to know they’ve got either. So I just thought well I have it so that’s where we are.” (W28 HPV+ mildly abnormal smear)

### Disclosure

Women repeatedly described anxiety about disclosing their HPV positive test result to their partner or family and friends. For some, the stress of disclosure appeared to be the most difficult aspect of managing the HPV infection.

#### Disclosure to sexual partners

Women reported feeling highly anxious about informing their partner, with descriptions of “bursting into tears” and feeling intensely “guilty” and worried that they may have infected their partner with the virus.

- “I’ve infected him and this is the man I want to spend the rest of my life with...how am I going to tell him?” (W31 HPV+ CIN3)

The underlying concern about the disclosure centred on embarrassment and shame about the promiscuity attached to an STI and also a fear of being sexually rejected.

- “If I told men that I had it they might not want to have sex with me.” (W2 HPV+ CIN2)

To manage the anxiety many women chose not to tell their partner about their HPV infection, instead focusing on their abnormal cytology result which did not carry direct connotations of sexual transmission. In other cases women described being deliberately vague about how HPV was transmitted or playing up their own confusion:

- “I have told my partner that they don’t know where it comes from ... obviously because he’d look at me in a different light because ... he’d be like, have I got it or has she been with somebody else?” (W13 HPV+ normal smear)

Sometimes, the choice not to tell their partner was based on the information that the HPV infection had no impact on their partner and disclosure was therefore unnecessary. In other cases, women did not know what they should tell their partner and in the absence of clear advice simply elected not to say anything. This decision was motivated by women's desire to minimise their own anxiety during an already stressful period and to avoid dealing with a difficult issue of which they had only limited understanding.

- "It seemed easier and less stressful not to tell him and it was nothing that was going to affect him physically." (W6 HPV+ CIN1)

In contrast, where previous sexual activity was freely acknowledged and accepted, women found no difficulty in confiding in their partner, although the HPV infection was typically attributed to a previous partner.

- "He was really supportive about it. It was me saying to him it's because I've been stupid and blah blah ... and he was saying well maybe it's not, how do you know?" (W35 HPV+ CIN2-3)

### Disclosure to family and close friends

Women were also highly anxious about talking to family members. Some women chose not to tell anyone, others gave family and friends information only relating to their smear result rather than HPV. Again, worries around disclosure centred on concern about the stigma of an STI and its associations with promiscuity.

- "I lied, I told them irregular activity, I didn't say HPV. I only told my sister when I knew I didn't have it [I didn't want people saying that I had a] genital wart problem or weird STD thing ... association of genital warts isn't great." (W4 HPV+ normal smear)

Those who did tell friends and family reported them being supportive and helpful, although a few described negative experiences.

- "My mum was like, 'I told you so' ... it's not something you really want to hear." (W35 HPV+ CIN2-3)

### The role of social, cultural, and religious norms around sex and relationships

Women's norms and practices around sex and relationships emerged as an important in influencing their ability to disclose the result to others and draw on social and emotional support. This was most apparent among some of the south Asian women, particularly younger unmarried south Asian women who hid their sexual relationships from their parents. In this context attendance for cervical screening per se was seen as an indicator of sexual activity and was hidden.

- "I don't even know if my mum's ever had a smear test and she must have done she's had three kids. But it's not something we ever spoke about. So it's one of those forbidden topics of conversation as sex is. The only time my mum ever spoke to my sister about sex was the day before her wedding day and she's never spoken to me about it." (SA6 HPV- normal smear)

In this context, it was not possible for women to disclose either their HPV or cytology result. For some women this was described as contributing to the anxiety that they felt following their positive result.

- "I mean the emotional pressure that you are under, I mean nobody knows that I have a partner, and then to find out that you have something like this, you just think to yourself maybe I shouldn't have done this in the first place and then I wouldn't be in this situation today. So there is all this guilt as well as everything else." (SA2 HPV+ normal smear)

However, other south Asian women seemed comfortable in excluding their parents from discussions that in any way related to sex or relationships, instead they gained social and emotional support from their friends, sisters, and partners.

In contrast, African Caribbean and white British women rarely spoke about hiding information on standard cervical screening, and most of them seemed reasonably comfortable discussing an abnormal smear result. However, they were concerned about disclosing to others that they had HPV. As such, HPV testing presented a change to how and with whom their cervical screening results were discussed, in effect becoming stigmatised and taboo, not dissimilar to the south Asian women's response to smears. There were also similarities between the south Asian group and the white British and African Caribbean women with strong religious beliefs. Among these women there was some existing stigma around an abnormal smear, and a direct link with sexual activity and promiscuity.

- "I had this association in my head, an old Catholic thing that um ... promiscuity and cell changes would go together." (W17 HPV+ CIN2)

### Understanding of HPV

Although understanding that HPV was sexually transmitted was central to women's response, there were other key features of knowledge about HPV that also seemed to be closely associated with the psychological and social burden imposed by the infection.<sup>27</sup> Understanding that HPV is an extremely common infection and can potentially clear up on its own appeared to reduce the stigma and embarrassment some women felt. Indeed, HPV was likened to infections that, while possibly sexually transmitted, are common and accepted such as candida.

- "I was under the belief that it could go away on its own. I presumed that it was, because it was a common thing...um the initial thing I read...suggested that it can sort of clear up on its own." (W7 HPV+ normal smear)

Awareness that there are no visible physical symptoms, in particular, genital warts, and understanding that treatment for CIN is highly effective also appeared important to reassure women. In contrast, where women were still worried about the development of genital warts or confused HPV with other symptomatic STIs such as herpes, there seemed to be considerable distress.

There was also concern about the risk of spreading HPV infection and confusion about the protective role of condoms. One participant described having sex with a new partner when the condom broke.

- "I was absolutely terrified that I would pass on the infection." (W23 HPV+ CIN2)

Another woman described concern that she had passed HPV to her ex-partner during unprotected sex. She was unsure and worried whether to inform him so that he could warn future partners of the risk. Understanding that the impact of HPV on men was negligible and condoms did not necessarily prevent infection therefore appeared to alleviate considerable anxiety. Importantly, it meant that there was no

necessity to inform sexual partners about the infection, which allowed women to avoid the challenges of disclosure, such as embarrassment, fear about rejection, and damage to their reputation. Understanding of the limits of condoms also seemed to help women feel less to blame for contracting or passing on the HPV infection.

It was also apparent that poor understanding of the virus among partners, family, and friends enhanced anxiety around disclosure. In some cases women had to challenge prejudiced beliefs and defend their reputations to others armed with only a little information. Taking on the burden of explaining something poorly understood, particularly to a partner, was described as extremely difficult. Women also reported receiving inconsistent information from health professionals, which contributed to their confusion and distress about the infection.

- “What really, really bothered me was the lack of consistent clear information ... one health clinic in one hospital, they would say right this can completely be cleared up. And then I'd speak to someone else and they'd say no don't be silly it's a virus you've got it for life. And then someone else would say you're going to get warts and somebody else would say you're not going to get warts it's a different strain of the virus. And someone would say a condom will not protect you it's sexually transmitted. And I would say what's the protocol here? Should I be telling sexual partners that I have this? And one person would say yes of course you must and another would say don't be silly almost all the population's been exposed to it. And there was such a conflict of information, that was what really upset me. I couldn't get to the truth ....they were giving me conflicting advice. ... I found that very distressing that I couldn't actually get real information that I could trust.” (W17 HPV+ normal smear)

## CONCLUSION

The findings suggest that testing positive for HPV was associated with adverse social and psychological consequences that were beyond those experienced by an abnormal smear alone. These related primarily to the sexually transmitted nature of the virus, which led to stigma and anxiety about the virus and concern about sexual relationships. In particular, women were worried about disclosing their result to their partner and their family, restricting their usual channels of support. Although anxiety about the infection was widespread, the impact of testing positive varied in relation to the women's relationship experience, social and cultural norms, and practices around sex and relationships, and women's understanding of key features of the virus.

The findings of this qualitative study are highly consistent with quantitative studies of the psychological impact of HPV infection<sup>20 21</sup> and other STIs.<sup>16 17 28 29</sup> They also contribute to our understanding of the underlying processes influencing psychological and social responses and provide a starting point to explain the variation in women's response through their relationships, norms, and understanding of HPV. The study is strengthened by its inclusion of a socially and ethnically heterogeneous sample who had participated in HPV testing in a variety of clinical settings, and the use of a qualitative approach to understand the complexities of how women respond to HPV infection. The results suggest that HPV testing imposes an additional social and psychological burden on women beyond that already experienced in conventional cytology screening and the findings have implications for plans to include HPV testing in national cervical screening programmes in the United Kingdom and worldwide.

The results highlight the crucial role of information about HPV in moderating the experience of women taking part in testing. It suggests that clear consistent information about key features of HPV, such as its high prevalence, the distinction between high risk types and genital warts, and the implications for sexual partners and disclosure, may alleviate some important anxieties. This hypothesis needs to be carefully tested, but on the basis of these results it seems that clear standardised information should be made available and screening providers should consider carefully the information and advice they give to women participating in cervical screening. The burden of information provision may fall to general practitioners (GPs) who carry out the majority of smear tests in the United Kingdom and in many other countries. It is well known that GPs find discussion of sex and STIs with patients extremely difficult,<sup>30</sup> particularly with older patients,<sup>31</sup> so support may be important.

HPV testing is complex for lay people and health professionals alike. The challenge will be to communicate information to women in a way that ensures they understand the facts while limiting their anxiety and the sense of stigma around the infection. We have a responsibility to ensure that women who are encouraged to participate in cervical screening and HPV testing are adequately informed so that the social and psychological harm of detecting HPV is minimised.

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## CONTRIBUTORS

KM, JN, and JW conceived the study; KM, JoW, JN, and JW developed the interview topic guide; KM and JoW carried out and supervised the fieldwork; KM, JoW, and JN carried out the analysis; KM wrote the first draft of the paper; all authors commented on and contributed to the final draft; KM is the guarantor.

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## Social and psychological impact of HPV testing in cervical screening: a qualitative study

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