

Human papillomavirus (HPV) information needs: a theoretical framework



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Abstract

Background With the introduction of human papillomavirus (HPV) testing and vaccination in the UK, health professionals will start to receive questions about the virus from their patients. This study aimed to identify the key questions about HPV that British women will ask when considering having an HPV test or vaccination.

Methods Face-to-face interviews were carried out with 21 women to discover what they wanted to know about HPV. A thematic framework approach was used to analyse the data and identify key themes in women's HPV knowledge requirements.

Results Women's questions about HPV fell into six areas: identity (e.g. What are the symptoms?), cause (e.g. How do you get HPV?), timeline (e.g. How long does it last?), consequences (e.g. Does it always cause cervical cancer?) and control-cure (e.g. Can you prevent infection?). In addition, they asked procedural questions

about testing and vaccination (e.g. Where do I get an HPV test?). These mapped well onto the dimensions identified in Leventhal's description of lay models of illness, called the 'Common Sense Model' (CSM).

Discussion and conclusions These results indicated that the majority of the questions women asked about HPV fitted well into the CSM, which therefore provides a structure for women's information needs. The findings could help health professionals understand what questions they may be expected to answer. Framing educational materials using the CSM themes may also help health educators achieve a good fit with what the public want to know.

Keywords cervical cancer, HPV, lay models, qualitative research, sexual health

J Fam Plann Reprod Health Care 2009; **35**(1): 29–33
(Accepted 20 August 2008)

Background

Advances in medical science have demonstrated that infection with human papillomavirus (HPV) is the key factor in the aetiology of cervical cancer and genital warts.¹ Technologies to test for the presence of the virus are now available and are being evaluated at selected sites in the UK.^{2,3} A prophylactic vaccine has also been developed⁴ and this will be offered to all girls aged 12–13 years in the UK from 2008.⁵ Progress in this field has been so rapid that diffusion of HPV information to the public has not kept pace with scientific advances. Most people have never heard of HPV and are unaware that cervical cancer has an infectious aetiology.^{6,7} However, with testing and vaccination becoming available, health professionals will start to get questions about the virus from patients. An understanding of what questions women may ask could help prepare health professionals for what they will have to explain. There is also an urgent need for public education materials (such as websites and leaflets) that women can be referred to for answers to their questions, helping them to make informed decisions about participation in testing and vaccination. Understanding what women want to know about HPV could help inform the content and structure of these materials.

Several studies in the USA and Australia have begun to identify the issues in HPV that women ask about. In 2003, staff from the American Social Health Association identified the most frequently asked questions about HPV⁸

Key message points

- What women want to know about human papillomavirus (HPV) can be structured in a theoretical way.
- Women's questions about HPV relate to six dimensions: identity (e.g. symptoms), cause, timeline, consequences, cure-control and procedural aspects (in relation to vaccination/testing).
- This framework could inform development of information materials about HPV.

and more recently several qualitative studies have identified key issues about HPV that both women and men want to know.^{9–11} There has been one study in the UK considering HPV-related information needs in a sample of women who had recently been screened. Women were recruited through cervical screening centres in England to take part in focus groups. After reading information about HPV, women discussed their responses and identified various unanswered questions.¹² There has been a high level of consistency between the findings of these studies despite the different contexts that participants were recruited from. The most important issues about HPV seem to relate to transmission, prevalence, consequences, prevention and treatment.

HPV information should also be scientifically accurate and minimise any possible stigma that might be associated with the infection because of its sexually transmitted nature. Tristram¹³ used her clinical judgment to identify ten important points that addressed these criteria. These included the high prevalence of HPV, spontaneous clearance, that HPV may be present for some years before abnormalities arise, and that different HPV types cause cervical cancer and genital warts. Cuschieri *et al.*¹⁴ reviewed the existing literature on what the population want to know and what they should know with regard to HPV. They too focused on the importance of de-stigmatising HPV and highlighted the importance of emphasising its high prevalence and predominantly benign nature. They also noted the need to tell women that condoms are not always protective and that genital warts and cervical cancer are distinct consequences of HPV infection.

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One aim of this study was to identify the questions that British women have about HPV. We also examined whether a theoretical structure widely used in the literature on lay models of illness would successfully frame the questions women ask about HPV. This has not been done in previous studies of HPV information needs. Leventhal's 'Common Sense Model' (CSM) of illness representations¹⁵ has been successfully applied to a wide variety of illnesses.^{16–18} The theory posits that lay cognitive representations of illness fall into five dimensions: identity (labels/symptoms of the illness), perceived cause (determinants), controllability (prevention and treatment), consequences (to health and quality of life) and timeline (duration). The CSM's primary application has been in relation to chronic diseases, but if the model represents a 'natural' cognitive structure of illness then the questions that women ask about a new infection such as HPV should map onto the CSM dimensions. If so, the CSM could also provide a useful framework around which to structure HPV information for the public.

Methods

Participants

Face-to-face, individual interviews were conducted with a sample of 21 women aged between 18 and 53 years. A convenience sample was recruited using a 'snowballing' technique. Interviews were carried out at University College London and women were reimbursed £20 for their time. The study was conducted in line with the University Research Ethics Committee guidelines, but we did not seek independent approval from the ethics board because the methods used fell within the exemption criteria.

Procedure

Women were asked to describe their background, giving details of their age, education, employment status, marital status and cervical screening history. They were then asked what they knew about cervical cancer and HPV. Because very few women had even heard of HPV, some basic facts were presented to women on a card at the start of the interview (Box 1). These facts were also read aloud by the interviewer. Women were then asked what additional information they would need to be sufficiently informed to make a decision about HPV testing or vaccination. Their questions were answered as the interview progressed and the interview ended when they were satisfied with the information they had received. Two of the authors (LM and JoW) each carried out one interview and the rest were conducted by the third author (NG). All interviewers were female.

Analysis

Interviews were recorded and transcribed verbatim. We used a thematic framework analysis, which allowed us to

Box 1: Information given to women involved in the study

- A virus called human papillomavirus (HPV) is now known to be involved in the development of cervical cancer (cancer of the cervix, or neck of the womb).
- For most women, the immune system clears the virus and there are no health problems associated with it.
- If infection persists it can lead to abnormalities in the cells of the cervix.
- Regular attendance for smear tests can help to detect the cell changes that are caused by HPV. These can then be treated very effectively.
- HPV testing is currently being piloted by the NHS to see if its use will benefit the current cervical screening programme.
- HPV vaccinations have also been developed and are currently in the final stage of trials.

Table 1 Characteristics of the study group (*n* = 21)

| Characteristic | <i>n</i> |
|----------------------------|----------|
| Age (years) | |
| 18–25 | 9 |
| 26–33 | 4 |
| 34–41 | 5 |
| 42–49 | 2 |
| 50+ | 1 |
| Education status | |
| Degree level | 16 |
| A levels | 5 |
| Employment status | |
| Employed (full-time) | 6 |
| Employed (part-time) | 4 |
| Homemaker (full-time) | 3 |
| Student | 8 |
| Marital status | |
| Married/cohabiting | 9 |
| Single | 10 |
| Divorced/separated | 2 |
| Cervical screening history | |
| Never screened | 4 |
| Yes, once | 3 |
| Yes, more than once | 14 |

organise the data in a systematic and manageable way.¹⁶ After familiarisation with the transcripts, a framework was created based on the core themes that emerged from the interviews. Each question was entered into the thematic framework under one of these themes. This allowed for identification of specific questions within each theme.

Results

Characteristics of the study group are shown in Table 1. All participants were white except one Asian-British woman.

Women's knowledge of the causes of cervical cancer varied. Being sexually active was identified as a risk factor, as was a virus, with HPV also being explicitly mentioned by two participants. Many women, especially in the youngest age group, could not suggest any possible cause for cervical cancer.

Participants were very interested in HPV, but the number of direct questions ranged from just five to 28 questions. Between them the 21 women generated 300 questions about HPV. Many of their questions were similar, and all questions could be classified under six themes. The first five themes were consistent with the illness representation component of Leventhal's CSM.¹⁵ The themes have been labelled using terminology from this model as follows: *identity* (asymptomatic nature of HPV and its prevalence), *cause* (main cause and additional risk factors), *timeline*, *consequences* (cervical cancer, genital warts, social consequences) and *cure-control* (possible prevention, cervical screening, HPV testing, HPV vaccination). Women also had additional questions about the *procedures* for HPV testing and future options for vaccination, and these are presented as an additional theme. [NB. In the sections that follow, example questions are listed for each theme and the participant asking the question is indicated by a number.]

Identity

Most women wanted to know if there were any signs or symptoms relating to HPV. They asked about the prevalence of HPV, and once told that it is very common, they wanted to know why so many women become infected.

Does HPV have any symptoms? (P3)

Is it really common in England? (P19)

Cause

All women wanted to know the cause of HPV, and once told it was sexually transmitted, they asked if this was the only way to contract it. They asked many questions relating to additional risk factors (e.g. if HPV was more likely in a particular age group and whether having more sexual partners was associated with higher risk). Women asked if lifestyle factors such as diet or drinking alcohol increased risk of infection.

- How do you contract HPV? (P2)*
- Can you catch HPV any other way? (P5)*
- Is HPV more common in younger people? (P5)*
- Are more promiscuous women at greater risk? (P3)*
- Does drinking increase your risk? (P10)*

Timeline

Women were particularly interested in the time between contracting HPV and developing cervical cancer. Questions were raised about the potential for the virus to clear spontaneously and how long this process took.

- How long does it take for HPV to become cervical cancer? (P3)*
- So can it clear by itself then? (P13)*
- For how long can the virus lie dormant? (P13)*

Consequences

In relation to cervical cancer, women wanted to know how common it was for this to be the consequence of HPV, and whether cervical cancer could be caused by other things. They also wanted to know if HPV could cause any other cancers, if it had any effect on pregnancy, and if the virus had any other effects on the body. The possibility of cancer being related to genital warts was also raised.

- How many cases of HPV become cervical cancer? (P4)*
- Is HPV the only cause of cervical cancer? (P5)*
- What other cancers are caused by a virus? (P3)*
- What about getting pregnant? (P15)*
- Does HPV have any other effects on your body? (P15)*
- Are genital warts and cancer related? (P14)*

Younger women (i.e. those aged 18–25 years) asked many questions about the prevalence of cervical cancer and treatments available for the disease.

- How many women get cervical cancer? (P1)*
- How is cervical cancer treated once you have it? (P5)*

Consequences for men were frequently mentioned, including whether men are just carriers of the virus or are likely to experience harmful effects. The matter of disclosing an HPV diagnosis to a sexual partner was raised, which introduced the issue of indirect social and psychological consequences from the disclosure.

- Can a man get HPV? (P20)*
- Does it have any effect on men? (P4)*
- If you test positive should you tell your partner? (P10)*

Cure-control

Women asked how they could protect themselves and whether condoms were an effective way to reduce their risk. They also wanted to know if there was any treatment available for HPV, and requested more details about what was involved in the treatment of pre-cancerous cells. When it was explained that in most cases HPV clears spontaneously, women wanted to know how quickly this could happen and why it did not clear in all cases.

- Is there any way to protect yourself against HPV? (P19)*
- Does using a condom protect you? (P1)*

- What kind of treatment is there for HPV? (P12)*
- What does treatment for cell changes involve? (P8)*
- How quickly does it get cleared? (P8)*
- Why do some people clear it with their immune system but others don't? (P9)*

The younger women (i.e. those aged 18–25 years) – who had no experience of cervical screening because screening in England begins at the age of 25 years – asked many questions about cervical screening, including the purpose of screening, the recommended frequency, and the age at which screening should be initiated.

- How often do you go for screening? (P19)*
- What age do you start to go for screening? (P19)*

Procedures: HPV testing/vaccination

Although the existence of HPV testing and vaccination would be included in the cure-control dimension, women in this sample were asked to imagine they were offered testing/vaccination, and this prompted a variety of additional procedural questions. Women wanted to know what the HPV test would involve, and the practicalities of the test including where it would be carried out, how long it would take to get results, and if it was included in screening for sexually transmitted infections (STIs). Several women also asked how an HPV test would be different from the current cervical screening procedures.

- What does the [HPV] test involve? (P1)*
- Can you get it at the doctors? (P7)*
- How long would it take to find out the result? (P7)*
- Is HPV included in STI testing? (P21)*
- How would an HPV test differ from a smear test? (P20)*

Women were extremely interested in the prospect of HPV vaccination and asked many questions about effectiveness, possible risks, mechanisms, research trials, likely coverage, and availability. They wanted to know how likely the vaccine was to provide full protection and if it would reduce deaths from cervical cancer to zero. They were concerned about adverse effects following the vaccination including possible side effects in the future. Women asked if the vaccine would be 'a bit of the virus' and if it was possible to get infected with the virus from the vaccine. They also asked if the vaccine would be only preventive or also therapeutic, and wondered whether it would be effective if the virus was 'dormant'. The practicalities of vaccination (e.g. How many doses, whether a booster was required?) also attracted interest.

- How effective is the vaccine? (P2)*
- What are the side effects of the vaccine? (P3)*
- What are the long-term effects of the vaccine? (P15)*
- How does the vaccine work, is it a bit of the virus? (P4)*
- Can you get the virus from the vaccine? (P18)*
- Is the vaccine for prevention or cure? (P17)*
- How many times would you have to have the vaccination? (P6)*

Women had many questions about current vaccine trials, wanting to know details such as how long the trials had been underway, how the vaccine had been tested, and who it had been tested on. There was also interest in who had carried out the trials. Women wanted to know what exactly the vaccination would protect against, including if it would protect against all HPV types, genital warts and any other STIs. They asked questions about who the vaccine would be offered to, whether the vaccine would be just for girls, and if it would be targeted at a specific age group. They wanted to know when the vaccine would be available and how it would be offered [i.e. through general

practitioners (GPs) or in schools]. They asked if it would be offered at the same time as other vaccinations and if it would be possible to opt out of having the vaccine. The potential cost of the vaccination was also brought up, with women asking if it was likely to be offered on the National Health Service (NHS). Women were also interested in the implications for the screening programme, and particularly whether vaccination would mean the end of cervical screening.

How long have they been working on the vaccine? (P5)

Who has the vaccine been tested on? (P15)

Who has been trialling the vaccinations? (P8)

Will the vaccine be for everyone? (P19)

Will vaccination only be for a certain age group? (P10)

When will the vaccine be available? (P4)

Would this be available from the GP? (P13)

Will it be free for everyone? (P19)

Would the vaccine protect against warts too? (P2)

Would I still have to go for smear tests? (P3)

Discussion

The aims of this study were (1) to explore HPV information needs in a sample of British women both in general and in the context (albeit hypothetical) of informed consent for HPV testing or vaccination and (2) to examine the applicability of a theoretical structure for lay representations of illness in this context.

The most frequently asked questions regarding HPV itself in this sample related to symptoms and prevalence, transmission of the virus, duration of infection, time course of cancer risk and viral infection, health and social consequences (e.g. effects on relationships) and prevention and treatment for HPV. The questions that our sample of women asked were very similar to those that have been reported in other qualitative studies in the USA and Australia^{8–11} and in one other study of British women who had recently been for cervical screening.¹² They also mapped reasonably well onto the key points that expert health professionals suggest should be covered in educational materials.^{13,14}

We found that the themes that emerged in the interviews were consistent with a well-known psychological model of lay representations of illness, namely Leventhal *et al.*'s CSM.¹⁵ This model identifies five core dimensions (identity, perceived cause, controllability, consequences and timeline) that are activated and modified on the basis of experience of, or information about, an illness.¹⁷ The results of the present study showed that when people are thinking about a disease (or in this case an infection) they have not personally experienced, they seek information on the same five domains, together with additional practical information. One feature of the CSM is recognition that the content of illness representations are not necessarily consistent with medical facts.¹⁸ By structuring scientifically accurate information in line with the dimensions that lay people use to conceptualise illnesses, it may be possible to create greater consistency between the individualised illness representation and the accepted medical model. This could be of particular benefit if future experience with the illness does arise. Although cervical cancer is a possible (albeit rare) consequence of HPV, the virus itself is not an identifiable disease and is therefore very different to what the CSM traditionally refers to; however, we have made the assumption that the lay public are likely to find this distinction arbitrary and will find the illness representations approach useful in this context despite the complexities of HPV as a causative agent rather than a disease.

In addition to general questions about HPV, women asked many specific procedural questions about HPV testing and vaccination. The younger women also asked questions about cervical cancer and screening, because at this age these details were also novel (women are not invited for cervical screening in England until they attain the age of 25 years). Context is likely to be very important in relation to what women want to know. Women who are thinking about vaccination for their daughter may focus on very different aspects compared with women who have received an abnormal smear result, or women who are simply interested in finding out more about HPV.

Study limitations

There are several limitations to this study. The analyses were based on interviews with predominantly white, well-educated women, and we can not be sure that the same questions would arise in interviews with women from different backgrounds; however, we did achieve saturation in understanding the perceived information requirements of this group and the similarities between our results and those of Goldsmith *et al.*¹² suggest the most important themes in questions about HPV are consistent across different samples of British women. It will be essential that public information about HPV is evaluated with women from a broader demographic sample to ensure that its content is appropriate for all women.

Women were encouraged to generate as many questions as they could in the framework of an interview, and they may have generated more questions than they would have asked in a more natural setting. We were particularly interested in questions about HPV in the context of vaccination or testing. As neither of these procedures are routinely available at present, we used a hypothetical methodology, asking women to 'imagine you had been invited for a test or vaccine', which is an imperfect substitute for testing reactions to an actual screening/vaccination invitation.

We also asked women to consider vaccination for themselves, despite the fact that women of this age are unlikely to be offered HPV vaccination. It may have been more pertinent to ask mothers about vaccination for their daughters or to ask adolescent girls (who will be offered that vaccination) what questions they have. Future work could explore whether the same questions would arise in these groups.

Conclusions

To date, no theoretical framework has been used to structure the questions women ask about HPV. In this qualitative study the questions women asked about HPV – an infection about which they previously knew very little – mapped well onto the framework of the illness representations approach (CSM), supplemented with procedural questions about vaccination and testing. This could provide a useful framework for information health professionals ought to be aware of in relation to patients' information needs. Framing information in this way could also provide an effective structure to help health educators present the scientific facts in a way that fits with what the public want to know.

Statements on funding and competing interests

Funding Laura Marlow, Jane Wardle and Jo Waller are funded by Cancer Research UK. Nina Grant is funded by ESRC/MRC. Funding for this work was provided by Sanofi Pasteur MSD.

Competing interests None identified.

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J Fam Plann Reprod Health Care 2009 35: 29-33
doi: 10.1783/147118909787072432

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