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ORIGINAL ARTICLE

Australian women's needs and preferences for information about human papillomavirus in cervical screening

Kirsten McCaffery¹ and Les Irwig²

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Objective: The role of human papillomavirus (HPV) in cervical cancer and developments in medical technology to prevent cervical cancer has changed information needs for women participating in cervical screening.

Design: Qualitative face-to-face interviews were conducted with 19 women diagnosed with HPV infection on their Pap smear following routine cervical screening.

Setting: Family planning clinics, general practice and specialist gynaecologist practices in Sydney and the surrounding area, Australia.

Main outcome measures: Women's information needs, preferences and experiences of HPV diagnosis.

Results: Women wanted further information on different HPV viral types, transmission, implications for sexual partners, prevalence, latency and regression of HPV, their management options and the implications of infection for cancer risk and fertility. Uncertainty about the key aspects of HPV, the style in which the clinician communicated the result and the mode of delivering the result (letter, telephone or consultation) influenced women's psychological response to the diagnosis of HPV. The delivery of results by letter alone was linked to considerable anxiety among the women interviewed. Women's experience of searching the Internet for further information about HPV was reported as difficult, anxiety provoking and contributing to the stigma of the infection because information was often located in the context of other sexually transmitted infections, with multiple sexual partners highlighted as a risk factor for infection.

Conclusion: Women participating in cervical screening need high-quality information about HPV and its role in cervical cancer prior to screening rather than afterwards, when they face an abnormal result. The clinician potentially plays an important role in moderating the effects of diagnosis through the manner and mode in which an HPV diagnosis is delivered. Revision of cervical screening policy and practice in light of the changes in the understanding of HPV is recommended.

See end of article for authors' affiliations

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INTRODUCTION

The establishment of high-risk types of human papillomavirus (HPV) as the primary cause of cervical cancer^{1,2} has transformed clinical understanding of cervical cancer. This has been accompanied by technological advances in cervical cancer prevention through developments in HPV DNA testing for use in cervical screening and HPV vaccination.³⁻⁹ Both areas have received a high level of scientific and media attention. These developments present profound changes to the way cervical cancer is understood by the women who participate in cervical screening worldwide.

Current cervical screening strategies rely on detecting and categorizing cellular abnormalities and treating those above a certain threshold, a concept that women are reasonably familiar with after decades of screening. However, awareness that a sexually transmitted viral infection (STI) underlies the cervical abnormalities detected at Pap smear is entirely new for the majority of women participating in cervical screening.¹⁰⁻¹² Previous research has shown that, among women offered HPV DNA testing, those who tested positive were more anxious and confused than women who tested negative or those who received an abnormal Pap smear result alone, without HPV status being reported.^{13,14} Research also reports that women felt embarrassed and ashamed, were worried about their sexual partners and

were concerned about disclosing their test results to others.^{15,16} These findings suggest that linking cervical cancer with HPV has adverse psychological consequences for women.

Changing the understanding of cervical cancer to incorporate HPV infection raises questions about the needs and preferences for HPV information among women undergoing cervical screening, and importantly how to inform women in ways that minimize anxiety. Previous research has been limited to the area of HPV DNA testing. One US study examined the information needs around HPV DNA testing among a community sample of women.¹⁷ The study reported that women wanted information about HPV transmission, prevention, treatment and risk of cancer. Another study in the UK¹⁸ examined how women undergoing testing interpreted their HPV DNA positive test results alongside their existing understanding of cervical cancer. Although informative, the research was again set in the context of testing for HPV DNA and did not examine the needs of women undergoing conventional screening. As such, no research to date has examined the experience and information needs of women who receive a diagnosis of HPV infection on their Pap smear (i.e. HPV changes on cytology – koilocytosis), who are participating in routine cervical screening. This is a significant group who are

experiencing changes in the way cervical screening results are understood and communicated to women.

In this paper, we interviewed Australian women participating in screening with conventional cytology, who had recently been diagnosed with HPV changes detected on their Pap smear. In Australia (as in the UK and many other countries), women are usually informed of the presence of 'HPV effect' (koilocytosis) on their Pap smear only in the presence of a low-grade abnormality. However, HPV infection as the causal agent of cervical abnormalities is increasingly discussed with women in the presence of a high-grade lesion. This study used qualitative methods to explore women's understanding of HPV, their information needs and experience of HPV infection using a method grounded in women's experience.

METHODS

Participants

Twenty women diagnosed with an HPV infection (koilocytosis) on a conventional Pap smear were recruited from general practice, family planning clinics and specialist gynaecologists in Sydney, NSW and the surrounding area. We used non-random, purposive sampling¹⁹ to recruit a heterogeneous sample across a range of characteristics of interest to the study: age, marital status, ethnicity, socio-economic status and grade of cytological abnormality (Table 1). One participant with visible genital warts was excluded from the study since the research sought to focus on asymptomatic, non-visible HPV types detected by Pap testing alone. Visible genital warts are well known to cause significant psychological distress due to their symptomatic nature and longstanding stigma of the infection.²⁰

Procedure

In-depth interviews were carried out with women between June and December 2002. These were unstructured interviews which encourage the individual to respond freely to open-ended questions which are relevant to their experience. The questions were structured around a topic guide

Table 2 The topic guide

Topic
1. Background demographic information
2. Screening history and background knowledge
3. Information needs and understanding about HPV and cervical cancer
4. Experience of recent Pap test results, HPV diagnosis
5. Understanding and perceptions of results
6. Psychological impact of results
7. Experience of treatment or follow-up
8. Improvements to cervical screening in the future

covering a range of issues relating to the diagnosis of HPV and cervical screening, women's psychological response to their HPV infection, their understanding of HPV, and their information needs and preferences (see Table 2 for further detail). 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.²¹ Interviews were carried out by the first author and were conducted in English. All interviews were tape recorded and transcribed verbatim.

The Framework Analysis method was used to identify emerging themes and organize the data.²¹ This is a matrix-based approach to thematic analysis, with themes making up the columns and cases making up the rows. The thematic framework is developed through familiarization with the transcripts. The data are summarized within the framework and this organization enables examination of both themes and cases, allowing relationships between themes and explanations for patterns within the data to be carefully explored.

The study was approved by the FPA Health NSW and University of Sydney Ethics Committees.

RESULTS

The demographics of the sample are shown in Table 1

Women's information needs and preferences, and their relationship with women's psychological response, are divided into five broad areas which emerged from the analysis. The following analysis is organized around these themes:

- (1) women's understanding of HPV;
- (2) information needs around HPV;
- (3) mode of delivering HPV results;
- (4) clinician's communication style;
- (5) experiences of searching for HPV information.

Women's understanding of HPV infection

There was obvious confusion about HPV and the meaning of HPV infection among all the women interviewed.

Awareness of HPV prior to current diagnosis

None of the 19 women interviewed had any awareness that HPV caused the cell changes detected on Pap smears prior to their current diagnosis. Their surprise and lack of awareness led them to make inferences about the virus and its prevalence. Making sense of why they had never heard of such a common virus, for which they had routinely been screened for many years, was challenging to some women, and they struggled to make sense of the new information

Table 1 Women's characteristics

Characteristics	n (%)
Age	
< 35 years	10 (53)
> 35 years	9 (47)
Education	
Tertiary education	9 (47)
No tertiary education	10 (53)
Ethnicity	
Anglo-Australian	13 (68)
Chinese	1 (5)
Malaysian	1 (5)
Greek	1 (5)
Lebanese	1 (5)
Mixed (Italian, Burmese)	2 (11)
Marital status	
Married/ <i>de facto</i>	11 (68)
Not married	8 (32)
Cytology	
Mild atypia (borderline/ASCUS)	7 (37)
CIN 1	8 (42)
CIN 2+	4 (21)

(n.b. ID numbers are used with the cytology result given for each participant).

'I know that it's HPV that can cause changes which I didn't know before...I'd heard of genital warts and STDs ... all the rest of them but not that one' (M1_CIN1)
'Given that I'd never heard of it before I thought it must be uncommon' (H7_CIN1)
'If it's so common why don't people know about it' (F13_atypia)
'I don't think I had ever heard about it [HPV] until after' (H16_atypia)

All the women interviewed were aware of genital warts, and some thought that there was an association with genital warts and cervical cancer. Because of a greater familiarity with genital warts and because clinicians often referred to HPV as the 'wart virus', many of the women interviewed thought that they had genital warts on their cervix or elsewhere internally, and were concerned that they might spread to other visible genital areas or cause warts on their partner.

'Well I'd heard of genital warts which is what I'd consider it to be' (F12_atypia)
'I didn't know I had these wart things before I didn't have any physical signs so I was a bit worried' (A4_CIN1)
'Am I going to get the physical warts?' (F20_CIN1)

Current understanding

Despite often having had several consultations relating to the HPV/abnormal Pap smear, and even treatment, many of the women interviewed still had a very poor understanding of HPV and the meaning of their infection, and wanted more information. There was an awareness that the information was highly complex, and, although some women had spent time reading information they had been given or sought from elsewhere, they still often felt that they had a limited understanding.

'I've read the literature but I don't really understand it' (F20_CIN1)

There was a strong sense that the screening provider had a responsibility to explain clearly in terms that women understood about the infection and the recommended management.

'I think they need to tell people in layman's terms what it is because not everyone understands medical terminology or exactly what's happening to them' (F8_atypia)

There was also a suggestion that women were given education while they attended for their smear.

'You might as well get more educated about it while you are there' (F13_atypia)

Women's information needs around HPV

There were key areas where women lacked understanding. Confusion in these areas seemed to be linked to the experience of anxiety

High-risk HPV types versus genital warts

Women were confused about the relationship between high-risk HPV and genital warts. The term 'wart virus',

which is commonly used to describe HPV, was found to be confusing and unhelpful, and contributed to the embarrassment and stigma women felt about the infection.

'The whole wart virus thing – I think they should change the name – why's it called the wart virus... it's horrible' (F8_atypia)
'I would have liked the virus to be referred to by its name [HPV] ... it would have helped me to accept it a little better...I suppose disconnecting the link it has to the wart virus and genital warts – I think...separating that would have helped me mentally a bit better' (M1_CIN1)

Sexual transmission – where did it come from

The use of wart virus terminology raised questions about where the virus came from.

'I suppose knowing it's linked to the wart virus brings it more to the foreground of OK how did I get it or where did I get it or and things like that especially I suppose in married couples because you kind of look at your partner and go hmmm' (M1_CIN1)

Some women were uncertain how HPV was transmitted, and wanted clear information on this issue.

'Whether it was an STD or not I still don't know to this day' (M3_CIN2 +)
'How did I get it...what are the implications' (H15_CIN1)

Impact on sexual partner, future partners and transmission

Women felt that they had a poor understanding of the impact of the virus on sexual partners and wanted more information. Their concerns included transmitting the infection and visible genital warts to their partner, worries that their partner might re-infect them with the virus and continue to increase their risk of cervical cancer. Women also wanted to know the likelihood of infecting future partners and the health implications of HPV infection for men. Questions also arose concerning how to prevent catching the infection, how to avoid spreading the infection to partners and the importance of disclosing an HPV infection to future partners. The implications for sex in general were an important area for concern: the risks associated with oral sex were mentioned in particular.

'What can I do and is there any way I can stop passing it on? My partner said well could you give it to me and then you get rid of it and then I reinfect you, I don't know' (F20_CIN1)

'Another issue for D and I was oral sex. No information about that and Dr P couldn't give us any information...I just thought to myself it's like oooh...maybe one of us will end up with it [HPV] in our throat or lungs' (H15_CIN1)

Prevalence of HPV, regression and latency information

Several of the women interviewed were aware that the virus was very common. This seemed to be important information which was readily understood by women and drawn on to ease their concerns about the infection.

'I feel comfortable with it because it seems a fairly common sort of thing' (F8_atypia)

'She [Dr] said that it was very common –at least 20% of the population have probably got it' (H7_CIN1)

Questions also related to issues of latency and regression. Women wanted to know how long the virus could lie dormant and whether it would ever completely clear. If women had had a previous abnormality in the past, they wanted to know whether this was a new infection or a recurrence of the previous infection.

'I suppose the question is can it just stay in your body that whole time, did I ever lose it' (F20_CIN1)

Information on management and treatment options

Women had little understanding about the management of HPV and the reasons behind it. This was related to a lack of understanding about the virus and the likelihood of regression. The urgency to treat the virus also related to worries about infecting sexual partners with genital warts and about the continued risk of cervical cancer.

'There's no treatment for that. I just couldn't believe it. Why's there no treatment? How can I prevent it not getting worse? That's my only worry at the moment. And the sexually transmitted – give to the partner or give back to me?' (F18_atypia)

'Do I pass it to my husband – can I get rid of it? Can you give me something to get rid of it?' (FPA12_atypia)

Implications for cancer risk and fertility

Women wanted information about the meaning of HPV infection in relation to the increased risk of cervical cancer. They also wanted to know what they could do about it themselves and whether HPV could impact on their fertility.

'What do I need to look out for...is it understood how long it would take for the presence of HPV to start causing some changes...[what are the implications for].children...birth' (H15_CIN1)

Some health-care providers had mentioned smoking as a risk factor for persistent HPV infection. In some cases, women wanted a clearer understanding of how smoking could affect their cervical cancer risk.

'How does something that I am breathing into my lungs affect the cervical area?' (F13_atypia)

Lack of available information

Many of the women interviewed felt under-served by the amount of information they had been given or had been able to access relating to HPV.

'I get the impression there isn't a huge amount of information available [about HPV]. There wasn't enough information for me' (H15_CIN1)

Some highlighted the importance of having written information that could be taken home.

'Information that I can take away things that went through my mind that happened outside the surgery and I didn't know where to look...that information isn't available at the moment that's why it is so important to get it to a state where it is available to people' (H16_CIN1)

Also noted by women was a lack of information about colposcopy, and, in particular, the bleeding experienced by some women after a biopsy.

Key information women reported as reassuring

Some key pieces of information emerged as important to women managing their psychological and social response to the infection.

High prevalence of HPV

Many women cited the high prevalence of HPV infection as an important piece of information about the virus. This seemed to help them normalize and de-stigmatize the infection.

'Was made easier because I understood that it wasn't dirty and that it was really prevalent, that it was out there and I wasn't like I could have got it from anyone....' (F20_CIN1)

Spontaneous regression

Information that their immune system could clear the virus itself over time without intervention also appeared to reduce the perception of the severity of the infection, especially when it was related to age for younger women.

'It kind of put me at rest being under 35 and there's a good chance it would clear up by itself.... they'd rather leave it for 6 months than start chopping away...I was much more reassured by that actually, I would rather keep everything there' (A4_CIN1)

Slow developing cancer

Information that the transition from HPV infection to cervical cancer is slow was an important factor which reduced some women's anxiety about their infection. This appeared particularly useful for women following observational management by repeat Pap smear.

'[it is a] slow cancer and there's no need to rush'. (F8_atypia)

Not genital warts

Having a clear understanding that the physical symptoms of warts were not likely to develop and recognition of the distinction between high-risk and genital wart types was also linked to lower levels of anxiety about HPV infection. This was partly a result of reducing the association with an already stigmatized infection and alleviating concerns about passing on a wart infection to partners.

'I knew it was unlikely to show any clinical signs on me or him' (F10_CIN1).

Mode of delivering HPV results to women

Women spontaneously raised issues about the circumstances in which they first received their HPV result and how this impacted on their distress about the infection. Among the women who were interviewed, several different modes of receiving their results were described: by letter alone, by letter and telephone call, and during a consultation.

Result given by telephone

On the whole, most experiences where the result was given by a nurse during a phone call were described as positive. It gave women the opportunity to ask questions and to gain reassurance from the nurse or doctor.

'The fact that she talked to me on the phone and sent out the stuff and they said they'd ring me again when it's time so I don't have to sit around worrying...is good they've got my best interests at heart, I think they work it really well' (F13_atypia)

Letter

When women received their results by letter alone, some described feeling distressed and confused. Often this was because the letter was opened at a time or location where there was little privacy and because there was confusion about what the result meant. This sometimes led to an unprepared discussion about the letter contents or rapid efforts to try to conceal it.

'[on opening the letter] I thought I've got an STD...I was with my boyfriend at the time...should I tell him?' (F10_CIN1)

'I was more worried about my partner reading it and saying "aha". I was worried about him thinking it was sexually transmitted and that I picked it up before I met him which would have concerned him a lot as we had only been together about 4 or 5 months at that stage...I was worried that it might change his opinion of me and being early in a relationship [it was a] bit of a concern' (H7_CIN1)

Another participant described opening the letter at the breakfast table with her husband. Since English was her second language, her husband translated the letter and the couple ended up looking up the meaning of 'wart virus' in the dictionary. She described the experience as extremely difficult for her and her husband.

During the consultation

Women who were given their results during a consultation described feeling fairly satisfied with this mode of delivery when the consultation had been pre-arranged. In contrast, calling women to a consultation only when the result was abnormal seemed to cause high anxiety for some women as they waited for their appointment aware that something was wrong, but not knowing what. One woman described being telephoned unexpectedly and told to make an urgent appointment with her GP to discuss her Pap test result. She found waiting for the appointment highly stressful 'I freaked out because I had this girl ring me from the medical centre' (AT04). She later was annoyed to find that it was over her mildly abnormal Pap test result, which was, she perceived, relatively minor, and felt her anxiety had been unnecessary.

Preferences for clinician's communication style

Women described different ways that clinicians had discussed their diagnosis and information about HPV and how this had impacted on their feelings about their infection.

Information-giving style

Certain ways of giving information were described by women as positive and reassuring. Some reported feeling

comforted when the doctor was relaxed and minimized the seriousness of the diagnosis.

'He didn't seem to think it was a big deal, it was like going to have a tooth pulled for him, which did make it easier' (A6_CIN2+)

'I feel fairly comfortable with it because it seems a fairly common sort of thing and she [Dr] wasn't worried' (F8_atypia)

Some women also described feeling positive about having the opportunity to discuss different management options with their doctor and being involved in the decision. One respondent reported how the doctor had stated her own preferred management and then given her the option to choose between an immediate colposcopy or a repeat Pap smear in six months: 'I said let's do it...I think I couldn't have been happier' (H16_atypia)

Another positive strategy highlighted by one woman was her doctor conceding her own lack of knowledge to certain questions about HPV.

'I think saying things like I don't know with respect to questions. As much as it's frustrating not having the information, knowing that she's in a position to have access to the information if it was there and she's not aware is a good thing. It made me feel better if that makes any sense' (HJ15_CIN1)

Women described dissatisfaction to what was perceived as a patronizing or a 'pat on the back' style of information giving. This was described as the clinician giving only limited information, avoiding responding to certain questions or stating that patient's concerns were not important. The following participant describes the frustration she felt when her doctor avoided her questions about the sexually transmitted nature of HPV and her concerns about transmitting the infection to future partners.

'I feel they've skipped around what I really want to know... They talked around the point. I don't know if they were protecting me –they don't want me to...I really don't know. Obviously if it is a virus and I got it from someone then I can give it to someone else...I'm still not clear...if it's the virus if it's transmitted through having sex then it's got to be... To get a straight answer out of them to whether it was an STD or not I still don't know to this day... I said to the doctor if I broke up with L and went and slept with someone else could I pass something on and he goes well you're going well with L and I don't think you're going to break up with him...I thought there is something but I don't know' (M3_CIN2+)

Women also complained that their doctor had not given sufficient time to explain results.

'[he should have] sat me down and told me what this HPV is and what I could do to help myself' (M2_atypia)

Some participants reported being so unsatisfied that they arranged a further consultation with either their GP or a specialist gynecologist.

Preferences for amount of information

Women varied in how much information they said they liked about health issues in general; however, almost all

women interviewed said they felt they had insufficient information about HPV. Being more informed was a way of coping with anxiety for some women, 'the more information I have about something the better I feel' (H7_CIN1). For others, having information enabled them to feel that they could ask the right questions to deal with the problem appropriately.

'Not just the pat on the back kind of information but the real stuff so that you really know what you're dealing with and the right questions to ask when you are dealing with something' (H7_atypia)

Some women wanted to know enough information to make an informed choice, but recognized that too much could be overwhelming,

'Dr B is very subtle, she gives enough information so you know what's going on and make an informed decision but she doesn't give you masses of information so you break out' (M1_CIN1)

Women's experiences of searching for information

Since many of the women interviewed felt they were inadequately informed about HPV, a high proportion had sought additional information elsewhere, most commonly on the Internet. Women who were regular Internet users reported finding useful information; however, the information was often not straightforward to obtain.

'The first thing I did was go on to the internet and other places...I suppose my age means I am pretty computer literate...it is confusing but I had to persevere and a lot of stuff you have to get multiple resources and cross reference and stuff' (H7_atypia)

Often, women described finding information about HPV alongside material on genital warts and other STIs where risk factors, such as having multiple sex partners, were highlighted. Such information was found to be highly distressing by some women, and contributed to feelings of embarrassment and shame about the infection.

'Then I stupidly went on the internet and looked it up and then I felt pretty disgusting and dirty and like I wanted to scrub my insides out.... The genital wart thing upset me. I just thought bluh. The causes of it...having numerous partners before a certain age blah blah blah. I read through it and thought ugh I don't want this to be happening and then I felt really dirty' (M1_CIN1)
'I looked up on that [internet] and it just inferred that it was something that was commonly spread through sex' (H15_CIN1)

Some women also talked about looking up HPV in medical textbooks and even the dictionary.

'I also think I had done what I probably shouldn't have done and looked up in the Medic manual and on the internet...and of course one of the things that I had seen was hysterectomy as the extreme treatment and so being a drama queen I suddenly thought oh my god am I going to be faced with the removal of my womb' (H15_CIN1)

The information women received or sought from other sources and the way in which it was delivered to them by

their clinician appeared to influence their psychological response to the HPV infection.

DISCUSSION

The diagnosis of HPV changes on cytology alongside a cervical abnormality detected at cervical screening led to high levels of anxiety among the women interviewed. Confusion and uncertainty about the key aspects of HPV, the style in which the clinician presented the information and the mode of delivering the result appeared to contribute to distress and concern experienced by women. Seeking information from alternate sources also added to some women's anxiety by presenting information about HPV in the context of other highly stigmatized STIs and highlighting multiple sexual partners as a risk factor for infection. All these factors seemed to contribute to women's conceptualization of HPV, and consequently their psychological response to the infection.

The finding that the reporting of HPV changes on Pap smear to women leads to high levels of anxiety raises an important dilemma. The diagnosis of koilocytosis may represent the presence of either high- or low-risk HPV types, and as such holds little prognostic significance in the aetiology of cervical cancer; hence, the usefulness of reporting HPV changes to women is unclear. However, as awareness of HPV becomes more widespread, this dilemma may become outdated since the diagnosis of *any* cervical abnormality may be correctly interpreted by women as representing a HPV infection, and potentially lead to the anxiety described here.

The finding that women are anxious, distressed and confused by the diagnosis of HPV is highly consistent with research reporting the impact of an HPV DNA positive test result.^{13,14,22} The finding that 'wart virus' is a poorly understood term has also been reported in a previous qualitative study.²³ Determining the factors that influence women's understanding of HPV and their psychological response to the infection is crucial if we want to deliver cervical cancer prevention to women in ways that minimize confusion and psychological harm. Previous research has identified individual factors such as relationship status and history and women's cultural norms around sex and relationships, in addition to HPV information, as potential mediators of the psychological response to an HPV infection.¹⁶ This study looks further at the role of information and understanding on women's psychological wellbeing following diagnosis, and suggests that not only the content of information about HPV is important but also the way that it is delivered.

The study has implications for policy and practice of cervical screening delivery in existing programmes.

- (1) Women need clear, consistent information about HPV in key areas (Table 3). Information should be provided to women before they receive a diagnosis of the infection. The General Medical Council guidelines on screening²⁴ and the National Screening Committee²⁵

Table 3 Women's HPV information needs

HPV viral types (high risk versus low risk), Mode of transmission Implications for sexual relationships and partners, Prevalence, latency and regression of HPV Management and treatment options Implications for cancer risk and fertility
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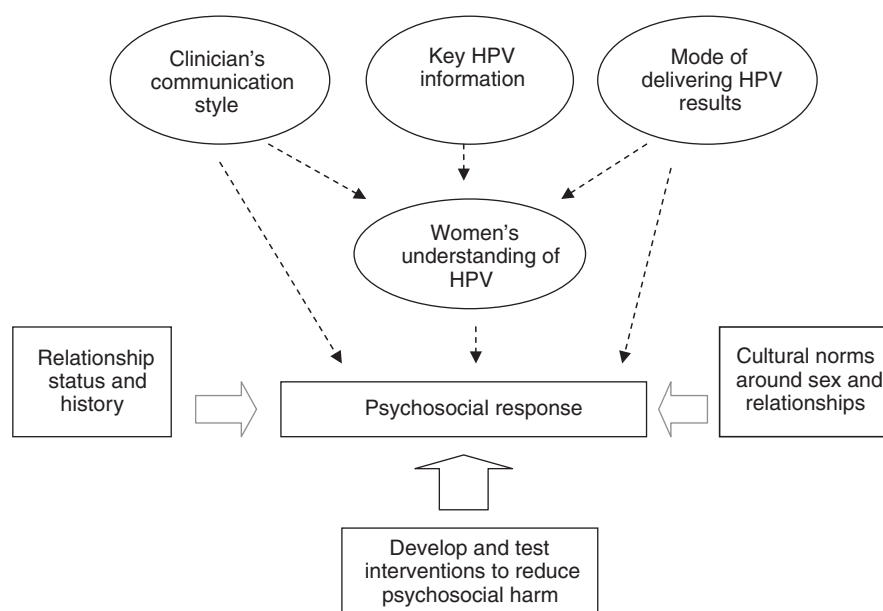


Figure 1 Possible pathways: HPV information and psychological response

already advise that information about the full outcomes of screening, which include abnormal results, follow-up tests and treatment, should be provided to consumers before they participate in screening rather than after. This may help to alleviate the initial panic and anxiety around an abnormal result and reduce the need to seek information from other sources (e.g. the Internet), which was reported as confronting and distressing by women.

- (2) The clinician can play an important role in moderating the psychological effects of the diagnosis. Delivery of information in ways that normalize the HPV infection, providing direct responses to patient questions (particularly in relation to sexual transmission), discussing information options and making time to deal with patients' information needs around HPV, all were linked to greater satisfaction and less worry among the women we interviewed.
- (3) Reconsidering the mode used to deliver HPV diagnoses is important. In particular, the use of mail-based strategies as the first point of delivery should perhaps be avoided for the delivery of such sensitive information. Since women we interviewed varied, tailoring the delivery of results to women's expressed preference would be optimal.

The study is subject to the limitations of any qualitative enquiry. As is usual in qualitative research, participants were not selected to be statistically representative, rather they were selected to represent a range of women who had experienced the diagnosis of an HPV infection so that different experiences and attitudes could be covered. The findings seek to provide insight on the range of understandings, perceptions and responses, and their depth and complexity, rather than seek to quantify their occurrence in any way. Although the study is qualitative and our sample was purposively selected, its findings have implications beyond the study population.²⁶ The data provide insight into the needs and experiences of women coping with an HPV infection and suggest some of the pathways that link knowledge, communication and psychological response to HPV infection (see Figure 1). Further research is needed to

quantify and test the relationship between the understanding of HPV, communication of information and psychological outcomes, so that we may develop a more elaborate understanding of their interaction. Importantly, we need to develop and test interventions to improve understanding, communication and psychological outcomes. As with research of any intervention, the strongest designs will be randomized trials.

Whether or not cervical prevention strategies change with the availability of HPV DNA testing or HPV vaccination, information about HPV is in the public domain and women will continue to have access to it through their experience with cervical screening, via the media and the Internet. Women have the right to be fully informed about the outcomes of the screening tests they undergo. Millions of women participate in cervical screening programmes worldwide and have a high lifetime chance of being affected by an HPV infection and abnormal smear result. Screening providers have the responsibility to at least do no harm. Providing high-quality information and delivering results in sensitive and effective ways to women should be a priority in cervical screening. Expert understanding of the role of HPV in cervical cancer has changed the information needs for women participating in cervical screening. Revision in policy and practice informed by high-quality evidence is now needed.

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