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Anticipated shame and worry following an abnormal Pap test result: The impact of information about HPV

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ABSTRACT

Objectives. To evaluate the impact of HPV and cervical cancer information on women's anticipated feelings of worry and shame if they received an abnormal cervical screening result.

Measures. Data were obtained from a British population-based survey of 1081 women aged 25–64 years, carried out in 2006–7. Women were given 'phased' information about HPV and asked whether it would make them feel more or less worried and ashamed if they had an abnormal Pap result.

Results. At baseline, 5.5% women anticipated shame if they had an abnormal Pap test but 88.8% anticipated worry. General and prevalence information about HPV led 4.6% and 5.8% of women to say they would feel more ashamed, while 14.2% said they would feel more ashamed following sexual transmission information. About a third of women also said they would feel more worried having read the information. These responses were more common in women with little education and from non-white ethnic groups.

Conclusions. HPV information could make women feel more worried about getting an abnormal Pap result, and may make some women feel more ashamed. Worryingly, this may particularly be true for women in groups with low screening uptake rates. Care needs to be taken to ensure HPV information is clear and does not raise unnecessary anxiety.

Introduction

Human papillomavirus (HPV) testing is increasingly being used alongside cytology in cervical cancer screening (e.g. Wright et al., 2002, 2004; NHS Cervical Screening Programmes, 2008), although support for its use, particularly in primary screening, is not universal, mainly due to its low specificity for detecting high-grade cervical lesions, resulting in over-diagnosis of lesions that would spontaneously regress (Kotaniemi-Talonen et al., 2008).

Public knowledge of HPV is currently low (Marlow et al., 2007; Tiro et al., 2007) but with the introduction of testing and now vaccination, people will increasingly become aware of the viral aetiology of cervical cancer. This will involve adjustment to the idea that cervical cancer is caused by a sexually transmitted infection (STI); a notion that can seem shocking (McCaffery et al., 2006; Waller et al., 2005) and is inconsistent with views of cancer as striking an unfortunate victim 'out of the blue'. Qualitative research with women participating in HPV testing as part of cervical screening found striking differences in their attitudes to testing positive for HPV and receiving an abnormal cervical screening result (McCaffery et al., 2006). Women who tested positive for HPV reported feelings of stigma and shame, which are well-documented responses to STI diagnoses (e.g. Fortenberry et al., 2002) but not to abnormal Pap test results. These feelings raise additional issues about disclosure and trust in relationships, and can lead to increased anxiety (McCaffery et al., 2006). Quantitative studies carried out in clinical research contexts have confirmed that a positive HPV result poses an additional psychological burden over and above the impact of an abnormal Pap test result, at least in the short term (Maissi et al., 2004; McCaffery et al., 2004). Longer-term follow up in one study found that the impact of an HPV positive result had disappeared 6 months later (Maissi et al., 2005).

The so-called 'common sense model' of self-regulation in health and illness (Leventhal et al., 2003) proposes that people form cognitive representations of illnesses and that the content of these representations is associated with responses to the illness. If HPV information influences women's causal beliefs about cervical abnormalities and cancer, this might be expected to change their cognitive and emotional responses to an abnormal Pap result. This is of clinical importance if, even without the introduction of HPV testing, women receiving abnormal Pap results begin to experience shame and stigma. It also raises the possibility that uptake of screening might be affected if women either believe themselves to be at low risk of an STI (Marlow et al., in press) or become concerned that simply attending for cervical screening conveys messages about sexually activity (McCaffery et al., 2003).

Qualitative studies have found that information about the high prevalence of HPV can reassure women who test positive for the virus (McCaffery et al., 2006; Waller et al., 2005). In an experimental study, women who were provided with information about the high prevalence of HPV anticipated less stigma and shame following a positive HPV test

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than women who were just told about its sexually transmitted nature (Waller et al., 2007). However, most participants in this study were too young to have been screened, and they were asked to think about a positive HPV test result rather than an abnormal Pap test.

The present study was designed to see whether these findings generalise to feelings about an abnormal Pap result among women eligible for screening after receiving information about HPV and its link with cervical cancer. In particular, we were interested in the effect of messages about the sexually transmitted nature of HPV and its high prevalence, since these pieces of information appear to have different effects (Waller et al., 2007). The study aimed to answer the following questions:

1) What proportion of women anticipate feeling worry and shame if they have an abnormal Pap test result?
2) Does basic information about the link between cervical cancer and HPV increase anticipated worry and shame following an abnormal Pap test result?
3) What effect does information about i) HPV transmission and ii) HPV prevalence have on anticipated worry and shame?

We addressed these questions using data from a population-based sample of women in Great Britain who received 'phased' information about HPV, and reported on their anticipated feelings about an abnormal Pap result at each phase. A hypothetical methodology was used as women attending for cervical screening in the UK are not currently given information about HPV.

Methods

Participants

Data were collected in two waves of the National Centre for Social Research omnibus survey (November 2006 and February 2007). The survey uses stratified random probability sampling to select addresses in England, Scotland and Wales using the Postcode Address File as a sampling frame. One adult aged 16 or over is interviewed at each selected address. Data are collected by face-to-face computer assisted interview.

From 6100 addresses selected, 5585 were eligible and 2981 interviews were carried out (response rate = 53.4%). Our questions were only asked to women, and for the purposes of these analyses, we only included women in the English cervical screening age range, i.e. 25 to 64 years ($n = 1081$). The exact response rate for women in this age range is not known.

Measures

As part of a longer module including questions about cervical cancer knowledge, women were asked to respond to two statements on a five point Likert scale from 'strongly agree' to 'strongly disagree': 'If I had an abnormal smear result I would feel ashamed' and 'If I had an abnormal smear result I would be worried' ('smear' is a common term used for the Pap test in the UK). After a series of other questions, the results of which are reported elsewhere (Marlow et al., 2007, 2008), women were asked to read basic information about cervical cancer and HPV (see Fig. 1). This information was developed by the pharmaceutical company GSK, as part of HPV vaccination market research. It was checked by medical experts to confirm its scientific accuracy, and piloted with women to ensure it was easily understood. When participants had read the information, they were asked whether it made them feel they would be i) more ashamed if they had an abnormal Pap test, ii) less ashamed if they had an abnormal Pap test, or iii) would make no difference to how they would feel. A similar question was asked about worry. Women were then given information on i) the high prevalence of HPV (Prevalence information; see Fig. 1) and ii) its sexually transmitted nature (Transmission information; see Fig. 1); the order in which the two pieces of information were given was randomised. Shame and worry questions were repeated after each piece of information.

General HPV information

Cervical cancer kills 250,000 women every year worldwide.

The total number of women worldwide who currently have cervical cancer is greater than 1.4 million.

500,000 women are diagnosed with cervical cancer each year.

It has recently been established that cervical cancer is caused by certain types (high risk types) of the HPV virus (Human Papillomavirus).

Most of the time, no symptoms are felt, but, in certain cases (3%), infection becomes persistent and leads to precancerous lesions, which can in turn develop into cervical cancer if not detected and treated on time.

Cervical cancer can take a long time to develop, i.e. up to 15 – 20 years.

Detection of precancerous changes in the cervix which could lead to cervical cancer is currently carried out by means of smear tests in doctorís surgeries and that is why regular examinations are important. However, smear testing is not a perfect means of detection.

In addition to high risk HPV types, low risk HPV types also exist. These low risk HPV types do not lead to cervical cancer but are responsible for genital warts. Although genital warts are not life threatening, they can cause physical and psychological burden.

Prevalence information

At some point in time throughout her life, one woman in two gets exposed to the virus.

Transmission information

The virus is generally transmitted via skin-to-skin contact, most commonly during sexual activity. The risk starts right from the first sexual encounter.

Condoms do not completely protect against the HPV virus, as it is possible for the virus to be transmitted by sexual contact without intercourse

Fig. 1. General HPV information, and information about prevalence and transmission provided to women in the study.

Women were also asked about their age, education, employment, martial status, ethnicity, screening history, and awareness of HPV before the study.

Analysis

Data were analysed using SPSS v15. Because there were no significant differences in responses related to the order in which the transmission and prevalence information were presented, the groups were combined for all analyses. The sampling method allowed us to weight the data to account for household size and responder demographics. The 'complex samples' function in SPSS was used to analyse weighted data. Difference scores were calculated to compare responses to the three phases of information. These were standardised into z-scores for significance testing. Logistic regression was used to examine demographic predictors of feeling more worried or ashamed following each piece of information, first in univariate and then multivariate regression models.

Results

Characteristics of the sample

The weighted demographic characteristics of the sample are shown in Table 1. Women were predominantly white (94%), married/cohabiting (71%) and employed (69%). Fewer than half (45%) had more than basic educational qualifications (i.e. had continued