

**The viral aetiology of cervical cancer:
psychosocial issues**

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A thesis submitted for the degree of Doctor of Philosophy

University College London

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ABSTRACT

This work stems from the discovery that certain sexually transmitted types of human papillomavirus (HPV) are the main causal agents in cervical carcinogenesis. The thesis sets out to explore the psychosocial issues that arise from linking a sexually transmitted infection with cervical cancer.

Four studies were carried out. Study 1 was a survey of women attending a well-woman clinic (n=1032) and assessed awareness and knowledge about HPV. Study 2 used a population representative sample of men and women (n=1937) to assess beliefs about the risk factors for cervical cancer. Study 3 used in-depth interviews to explore the beliefs and experiences of 74 women who had taken part in HPV testing. Study 4 was a continuation of Study 3, in which 30 women were interviewed following participation in their second HPV test, a year after the first.

Awareness of HPV and its link with cervical cancer was found to be low. Although there was higher awareness of sexual activity as a risk factor for cervical cancer, this was far from universal. Women testing positive for HPV who understood that it was sexually transmitted frequently reported negative emotional and social responses, different from those that have been found among women with abnormal smear test results. Leventhal's Common Sense Model of self-regulation in health and illness provided a useful framework within which to conceptualise the relationship between women's cognitive representations of HPV and their responses to the infection. It seemed that women were also engaged in the self-regulation of their relationships and were motivated to develop representations of HPV that did not impugn their current partners. Diagnosis with persistent HPV infection was associated with higher levels of anxiety about health and with the desire for immediate further investigation by colposcopy, rather than continued surveillance.

The introduction of HPV testing and vaccination should be accompanied by widespread public education. If information provision is not handled in a sensitive way, it could cause confusion and stigmatise cervical cancer. More research is needed to develop ways to communicate information about HPV effectively.

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CHAPTER 1 – INTRODUCTION¹

1. Overview

Certain sexually transmitted types of human papillomavirus (HPV) are now recognised as the main cause of cervical cancer. This has led to a growing interest in using HPV testing in cervical cancer screening programmes, and in the management of cervical abnormalities. Prophylactic vaccines against high-risk types of HPV are currently under development and may revolutionise the prevention of cervical cancer in the future.

Along with these clinical developments come what I have broadly termed ‘psychosocial issues’. Increasing publicity about the link between HPV – a sexually transmitted infection – and cervical cancer has the potential to i) change public understanding of the aetiology of cervical cancer, ii) change the way that cervical screening is perceived and the experience of women who take part in screening, and iii) alter levels of attendance at screening in the future when cervical cancer is understood to be caused by a sexually transmitted infection (STI). The term ‘psychosocial’ is deliberately broad, encompassing the cognitive, emotional, social and behavioural implications of bringing public understanding of the causes of cervical cancer into closer alignment with the medical model of a viral aetiology. The sexually transmitted nature of HPV is of key importance to these issues. Cervical cancer screening has not previously been associated with testing for an STI, and bringing together these two separate aspects of health raises a series of questions that urgently need to be addressed.

This thesis seeks to explore the psychosocial issues associated with the identification of HPV as the main cause of cervical cancer, and to contribute to the policy debate about the introduction of HPV testing. In a series of four studies, the following questions will be addressed:

1. What is currently known about HPV by women eligible to take part in cervical cancer screening?
2. What is the current public understanding of the aetiology of cervical cancer?

¹ Parts of the literature review in this chapter have been published elsewhere (Waller et al., 2004) and can be found in Appendix 1.1.

3. How do women participating in HPV testing make sense of information about the virus and incorporate this into their existing beliefs about cervical cancer?
4. What are the emotional and social consequences of testing positive for HPV in the context of cervical screening?
5. How do women make sense of and respond to results of repeated HPV testing?

In this chapter, the clinical background to HPV testing and vaccination will be presented. The psychosocial issues associated with raising public awareness of HPV will be laid out, and the theoretical and methodological approaches taken in this thesis will be described.

2. Clinical background

2.1. Cervical cancer

Worldwide, cervical cancer is the second most common cancer among women after breast cancer, with over 200,000 women dying from the disease each year (Parkin, Bray, Ferlay, & Pisani, 2001). In many developing countries it is the leading cause of death for women. In the UK, over 3,000 women are diagnosed with cervical cancer each year, and in the year 2000 just over 1,200 women died from the disease (Cancer Research UK, 2003). Although in the UK, cervical cancer is only the eleventh most common cancer for women, it is largely preventable through early detection and treatment of precancerous lesions, known as cervical intraepithelial neoplasia (CIN).

2.2. Cervical cancer screening

Since 1988, a computerised call-recall system has been in place in the UK, through which all women aged 25-64 are invited to attend for a smear test every three to five years. Uptake of screening is high, with around 80% of women attending at least every five years (NHS, 2003). Screening uses the Papanicolaou (Pap) smear test in which a sample of cells is taken from the cervix, and is inspected under a microscope by cytologists for signs of precancerous neoplasia (unusual cell growth, also known as dyskaryosis). Neoplasia is divided into three stages on the basis of the extent of the cytological abnormalities: CIN1, CIN2 and CIN3, with CIN3 being the most serious. It is assumed that cell abnormalities progress through the three stages and, if left untreated, ultimately become invasive cancer. At each stage, though, a proportion of

untreated lesions will regress. Management depends on the stage of detection, and may involve monitoring through repeat smear tests to determine whether progression or regression takes place, referral for visual inspection of the cervix by colposcopy, biopsy of the lesion, or treatment through ablation or excision of the affected area. Treatment is highly effective.

The screening programme has been highly effective in reducing mortality from cervical cancer. A recent paper modelling trends in mortality rates in Britain estimated that, had screening not been introduced, there would have been a steady increase in the number of deaths from cervical cancer, reaching about 6,000 deaths per year by 2030 (Peto, Gilham, Fletcher, & Matthews, 2004). Although this so-called ‘epidemic’ has been averted, the current screening system has its limitations, the main one being the relatively low sensitivity of the smear test. Approximately 20-60% of CIN2 and 3 is thought to be missed (Cuzick, Sasieni, Davies et al., 1999). Cytology relies on an adequate sample of cells and the skill of those inspecting the slides, and it is likely that without the introduction of new screening technologies, screening will not reduce mortality much further. Several new technologies for improving cervical screening are under consideration, including semi-automated cytology, liquid-based cytology and HPV testing. Liquid-based cytology has now been approved by the National Institute for Clinical Excellence (NICE) and will be rolled out across the country over the coming years. This involves a change to the way the samples are collected and slides prepared. Samples are currently placed directly onto a slide by the person taking the smear, and then sent to the laboratory for analysis. This means that the slide is frequently difficult to read as other matter such as blood or mucus may be obscuring the cells. Liquid-based cytology involves placing the sample in preservative fluid for transportation to the laboratory. Centrifuging is then used to remove any obscuring matter, allowing the preparation of a ‘cleaner’ slide that is easier to read. Although liquid-based cytology has the potential to improve screening, it will have little impact on the experience of participating women, other than reducing the number who are recalled following an unsatisfactory smear. From a psychological point of view, HPV testing has the greatest potential to impact on the experience of women taking part in screening and on the wider population, being a new test and one that will make the link between a sexually transmitted virus and cervical cancer explicit.

2.3. Human papillomavirus and its role in cervical cancer aetiology

High-risk types of human papillomavirus (HPV) are now known to play a fundamental causal role in the aetiology of the majority of cervical cancers (Bosch, Manos, Munoz et al., 1995; Franco, Rohan, & Villa, 1999; Bosch, Lorincz, Munoz, Meijer, & Shah, 2002). Over 100 types of HPV have been identified, some of which cause common warts on the hands, genital warts or verrucas, while other sexually transmitted types (most notably HPVs 16 and 18; Lorincz, Temple, Kurman, Jenson, & Lancaster, 1987) infect the cells of the cervix and can cause CIN. If infection persists, CIN can progress from low-grade lesions (CIN1 and 2) to high-grade lesions (CIN3), and ultimately invasive cervical cancer, though this process normally takes years or decades (Cox, 1995; van Oortmarssen & Habbema, 1995; Bosch et al., 2002). In most cases, the immune system is able to clear the virus without permanent damage to the cervix, and because of the absence of symptoms, the individual is unaware of being infected. The risk of viral persistence and cervical lesions is increased by behavioural cofactors including smoking (Moscicki, Hills, Shiboski et al., 2001; Santos, Munoz, Klug et al., 2001), and biological factors including suppression or compromise of the immune system (Sun, Kuhn, Ellerbrock, Chiasson, Bush, & Wright, Jr., 1997; Buchanan & Nieland-Fisher, 2001).

Studies have shown that sexual contact with an infected individual is necessary for HPV infection, although it seems that penetrative sex is not necessary and that transmission can take place between women, as well as between men and women (Schiffman & Kjaer, 2003). Unlike some other STIs, HPV is transmitted through skin-to-skin contact, rather than in bodily fluids. Although there has been some suggestion that there may be other modes of transmission, including vertical transmission from mother to baby, a review concluded that ‘the only quantitatively important mode of transmission of infection with oncogenic genital HPV types is sexual’ (Dillner, Andersson-Ellstrom, Hagmar, & Schiller, 1999).

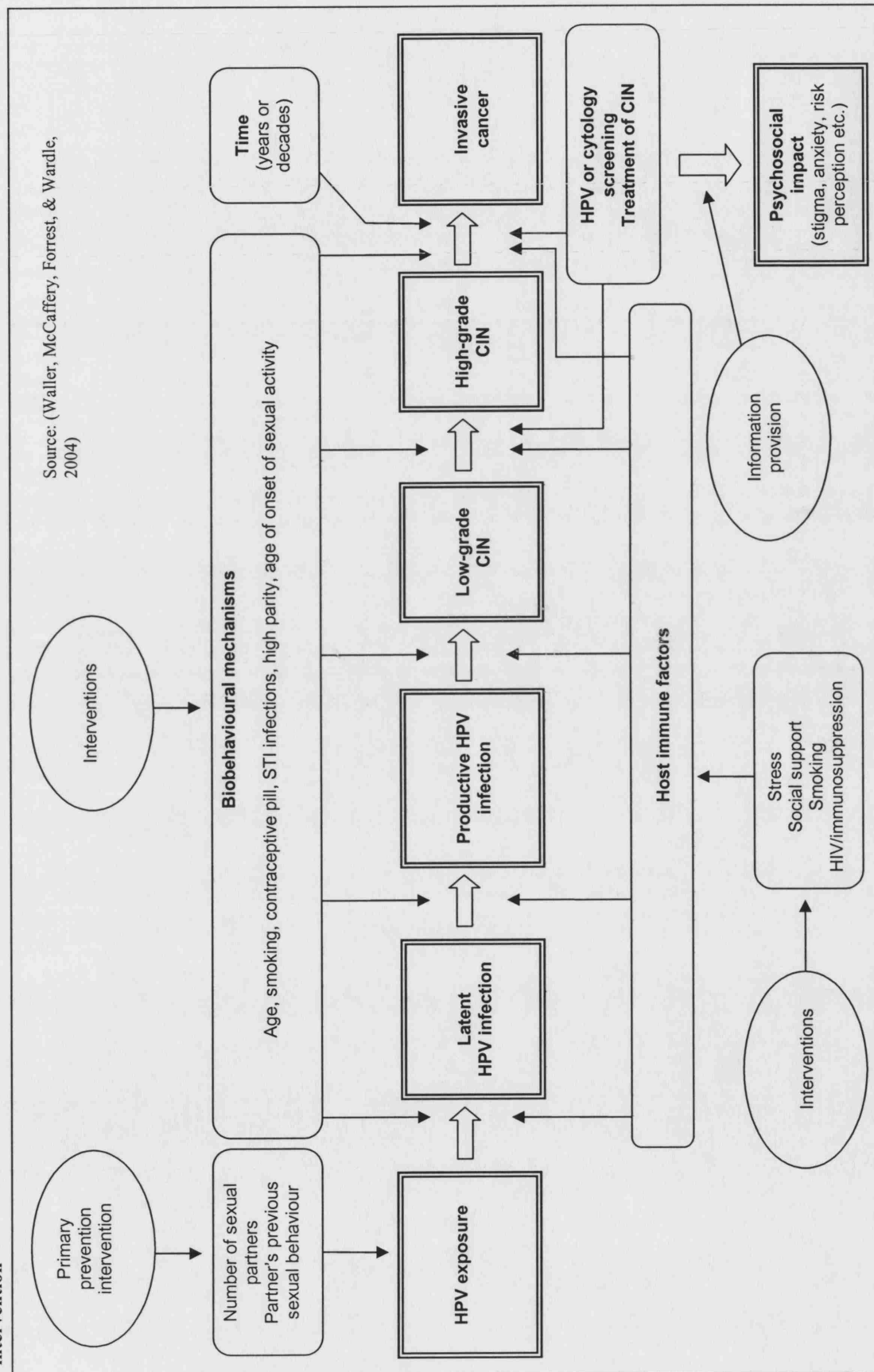
Men and women can both be infected with HPV, but the consequences are far more serious for women. Although HPV is implicated in the aetiology of other anogenital cancers, including penile cancer, these are very rare and are not addressed in this thesis. In considering cervical cancer, men can be seen as the vectors of the virus, facilitating its spread from one woman to another, without being at significantly increased risk of cancer themselves.

The prevalence and natural history of HPV are far from clearly understood, but it is widely acknowledged to be the most common STI in the United States (Carr & Gyorfi, 2000), with an estimated 5.5 million new cases each year (compared with three million new cases of Chlamydia and one million of herpes) (Centers for Disease Control and Prevention, 2000). Prevalence among women varies widely with age and method of detection, but in young, sexually active women in the US it has been estimated to be between 19% and 46% (Moscicki et al., 2001). An International Agency for Research on Cancer (IARC) review of studies of HPV detection in a wide variety of countries and settings (IARC, 1995) found that prevalence ranged from 0% among Australian women reporting no coitus, to 44% in a university-based US setting, and 48% in a gynaecology clinic in Tanzania. It should be noted, however, that point prevalences are difficult to interpret because of the transient nature of most HPV infections (Konya & Dillner, 2001). Lifetime incidence of HPV is therefore likely to be much higher. The IARC review concluded that younger women were most likely to test positive for HPV (although the infection is very likely to be transient), but there were no consistent geographical variations in prevalence of viral infection.

A schematic representation of the progression from HPV exposure to cervical cancer is shown in Figure 1.1. The virus infects the basal cells of the cervical epithelium and, although the existence of a true latent phase remains uncertain (Stubenrauch & Laimins, 1999), it seems clear that HPV can remain asymptomatic for a period before becoming a productive infection. If not cleared by the immune system, the virus continues to replicate in the differentiating cells of the epithelium, disrupting normal cell functioning and causing CIN. Left untreated, viral integration into the host cell DNA can eventually lead to invasive cancer. More detailed accounts of these processes can be found elsewhere (Man, 1998; Stubenrauch & Laimins, 1999). There is currently no treatment for HPV itself but, if detected at an early stage, any associated CIN can be monitored and treated effectively before it becomes cancer.

Figure 1.1 also shows the psychological and behavioural factors that are thought to have an impact on the risk of HPV infection and progression, and the points at which psychological interventions might be able to modify the progress of carcinogenesis.

Figure 1.1 Schematic representation of the pathway from HPV exposure to cancer, showing factors thought to moderate progression and points for intervention



2.4. HPV and cervical cancer prevention

2.4.1. HPV testing

Following recent technical advances, sensitive tests for the detection of HPV DNA in cells from the cervix are now available (see Cuzick et al. (1999) or Trofatter, Jr. (1997) for a review of current methods). This has made the introduction of HPV testing into cervical screening programmes a realistic possibility, and several studies have found support for the addition of HPV screening in some capacity. A systematic review (Cuzick et al., 1999) concluded that there are several ways in which HPV testing could improve current cytological screening methods. It could be used in addition to cytological screening in women over 35. This would improve the sensitivity of screening without the loss of specificity that would result from testing younger women for HPV.² HPV testing could also resolve uncertainty about treatment of borderline or mildly abnormal smear results (atypical squamous cells of undetermined significance – ASC-US). At present, services vary in their management of these patients since no agreement on treatment strategy has been reached. Thirdly, there is a possibility that women with normal cytology, who test negative for HPV, could be monitored less frequently than the current 3-5 yearly interval. However there is still debate about the safety of reducing surveillance in this group, as the negative predictive value of HPV testing is unclear. HPV testing could make a valuable contribution to the monitoring of women who have been treated for CIN. Finally, in addition to the use of HPV testing as an adjunct to cytology screening, some authors have proposed HPV testing as a primary screening tool (Sasieni & Cuzick, 2002). A recent UK study confirmed that HPV testing had a greater sensitivity than cytology for detection CIN2+, and the authors advocated the use of HPV as the primary screening tool, with only those testing positive needing to have a smear test (Cuzick, Szarewski, Cubie et al., 2003).

The use of HPV testing to triage women whose smear tests show ASC-US is now recommended in the US Bethesda consensus guidelines for the management of women with cervical abnormalities (Wright, Jr., Cox, Massad, Twiggs, & Wilkinson, 2002a), following a large scale clinical trial (Solomon, Schiffman, & Tarone, 2001). Two similar triage studies are being carried out in the UK (Wise, 2000; Little, 2001), and the use of HPV testing is being considered in other European countries (Franceschi, Herrero, & La Vecchia, 2000). The Food and Drug Administration in the US has also

² HPV prevalence has been found to vary widely with age (IARC, 1995). Infections are more common, but more likely to be transient in younger women (Hildesheim, Schiffman, Gravitt et al., 1994), so HPV positivity in young women is less indicative of cancer risk.

approved the use of HPV testing as an adjunct to cytology in primary screening in women aged 30 and over (Food and Drug Administration, 2003; Wright, Jr., Schiffman, Solomon et al., 2004).

It has been claimed that there is increasing pressure from patient and consumer groups for HPV testing to be made available (Watson, 2001), but the pressure group mentioned in this BMJ paper has recently been discovered to have been set up by the public relations company representing Digene, the pharmaceutical company that manufactures HPV tests. It is therefore less than certain that genuine public demand for HPV testing exists.

2.4.2. HPV vaccination

In addition to research into HPV testing, there has been increasing interest in developing therapeutic and prophylactic vaccines against high-risk types of HPV (as well as types associated with genital warts) (Arnold, 2001; Konya & Dillner, 2001; Man & Fiander, 2001; zur Hausen, 2001). A recent randomised controlled trial (Koutsky, Ault, Wheeler et al., 2002) of an HPV type 16 vaccine found it to be effective in reducing the incidence of HPV 16 infection as well as associated CIN. A total of 2393 women were randomised to received three doses of either the vaccine or a placebo. In the vaccine group, the incidence of HPV 16 per 100 woman-years at risk was 0, compared with 3.8 in the placebo group. Although the follow-up was relatively short (an average of 17 months), the results have been taken as very encouraging.

Other prophylactic vaccines are being developed to provide protection against more than one type of HPV and the cost-effectiveness of vaccination programmes has begun to be modelled (Goldie, Kohli, Grima et al., 2004). The authors of this study concluded that even if carried out in a setting where a cytology screening programme was in place, the addition of a vaccination against HPV types 16 and 18 would be cost-effective and would reduce the incidence of cervical cancer. Other authors have agreed with this finding, although the optimum age for vaccination has yet to be determined (Kulasingam & Myers, 2003). A large-scale Phase III trial of a vaccine for HPV types 16 and 18 has recently been launched by GlaxoSmithKline³ and Merck is currently

³ See <http://www.medicalnewstoday.com/medicalnews.php?newsid=8499>

running a Phase III trial of its quadrivalent vaccine targeting HPV types 16 and 18, as well as types 6 and 11, which are associated with genital warts.⁴

The development of therapeutic vaccines is some way behind that of prophylactic vaccines, but early results are encouraging and indicate that they might be effective in treating CIN (Garland, 2003).

3. Psychosocial issues in HPV testing

The establishment of an STI as the primary causal agent in cervical cancer, and the associated technological advances in testing and prevention, raise significant psychosocial issues in addition to clinical and economic ones. Major changes are already taking place in the US, with increasing numbers of women participating in HPV testing, and decisions will soon be made about the introduction of HPV testing in the UK. Changing the screening programme, introducing a vaccine programme and, more generally, raising awareness about HPV, has the potential to affect the population in a number of ways. Each of these will be dealt with in detail in the relevant chapters of this thesis, but the main issues to be addressed are outlined below.

3.1. Public understanding of HPV

In considering the likely impact of increasing public awareness of the link between cervical cancer and HPV, a first step is to evaluate current levels of awareness and understanding of HPV. Although knowledge itself is not generally regarded as being sufficient to predict psychological outcomes such as behaviour change, it is an important precursor to attitudes in models like the Health Belief Model (Rosenstock, 1974) and Theory of Planned Behaviour (Ajzen, 1991), and is integral to understanding the way in which people respond to health threats using dynamic models such as Leventhal's Common Sense Model of self-regulation in health and illness (CSM) (Leventhal, Meyer, & Nerenz, 1980). Assessing knowledge is also essential in order to monitor the way in which novel information about an aetiological agent is incorporated into people's understanding of cervical cancer.

⁴ See http://www.merck.com/newsroom/press_releases/corporate/2003_1209.html

In addition, knowledge is a key component of informed consent (Michie, Dormandy, & Marteau, 2002). To comply with the General Medical Council's guidelines for informed participation in screening (General Medical Council, 1998), women taking part in HPV testing must have an understanding of the virus and the test, and must have attitudes towards the test that are in line with the decision to take part in or decline screening (Marteau, Dormandy, & Michie, 2001). Assessing women's knowledge about HPV before screening is introduced provides insight into the degree of public education that will be necessary to ensure informed participation in any future screening programme.

3.2. Public understanding of the causes of cervical cancer

A different way of approaching the question of what people currently know about HPV is to explore causal beliefs about cervical cancer. Causal beliefs are central to the cognitive representation component of Leventhal's CSM, and are predicted to have an impact not only on the way that people cope with a health threat, but also on their emotional responses to it. Causal beliefs about cancer may be crucial in understanding both public perceptions and the experience of people with cancer. A recent study concluded that the identification of the link between smoking and the lung cancer had caused an increase in the stigma and shame felt by sufferers, even if they themselves did not believe smoking to be the cause of their own illness (Chapple, Ziebland, & McPherson, 2004). Similar consequences might be expected if cervical cancer is understood to be linked with an STI, particularly if most people have not previously been aware of a link between cervical cancer and sexual activity.

3.3. Impact of attending for cervical screening

Introducing HPV testing into cervical cancer screening and explicitly linking cervical cancer with an STI has the potential to change the psychosocial impact that attending for screening and receiving an abnormal result has on the women taking part in the programme. The psychosocial impact can be thought of as being made up of a variety of dimensions: cognitive, emotional, social and behavioural. Because HPV testing is so new and research in this area so scarce, the following are broad conjectures which will be addressed by the work in this thesis.

3.3.1. Cognitive impact

Taking part in HPV testing will be associated with receipt of information about the virus which, if understood and assimilated, is likely to change the way that women think about cervical cancer and its risk factors. In particular it will make explicit the link between cervical cancer and an STI, which could be associated with a change in emotional, social and behavioural factors (see below). This link could also have an effect on women's perceived risk of cervical cancer.

3.3.2. Emotional impact

The sexually transmitted nature of HPV potentially raises issues that are not commonly associated with conventional cytology screening. Being diagnosed with an STI has been found to be associated with negative emotional consequences including feelings of distress, stigma and shame, and this could impose additional emotional burdens on women testing positive for HPV. These emotional consequences need to be evaluated carefully before screening is introduced so that they can be considered alongside economic and clinical arguments for and against HPV testing.

Depending on the way in which HPV testing is introduced, it could increase the number of women receiving an 'abnormal' result (because HPV is so common, especially among younger women). We know from the cervical screening literature that abnormal cytology results are often poorly understood and anxiety-inducing (see Chapter 5). The unfamiliarity of HPV testing could compound these effects, and large numbers of women could be affected.

3.3.3. Social impact

The nature of STIs means that they have implications for relationships and the wider social context. While an abnormal smear result can be viewed as a problem for the individual woman, an STI diagnosis has an additional social impact. Testing positive for HPV might carry the risk of relationship problems if one or other partner is suspected of infidelity. Issues of guilt and blame may be raised, and women may feel less able to disclose their results to their partner and others. Women might also be expected to have concerns about transmission of the virus to their partners.

In a broader context, the explicit association between cervical screening and an STI could mean that attendance at screening is seen to convey a message about being sexual active, which might be unacceptable in certain communities.

3.3.4. Behavioural impact

Finally, the introduction of HPV testing might affect women's intentions to attend cervical screening. Women who do not see themselves as being at risk from an STI, or who do not wish to be seen as being sexually active, might be less likely to attend. Conversely, if all sexually active women understand that they are at risk, attendance could be increased. This is a question that needs to be addressed, but it is not the main focus of the thesis.

4. Theoretical background

The little work that has been carried out into the psychosocial aspects of HPV testing has tended to be atheoretical in nature (see the Introduction sections to Chapters 2, 3 and 4). This is understandable given that the field is very new, and most research to date has sought to establish basic levels of awareness and knowledge about HPV. However the research described in this thesis draws on theoretical approaches from health psychology.

Many health psychology models are primarily concerned with predicting behaviour, be it eating a healthy diet, engaging in exercise, taking prescribed medication or attendance at screening. The Health Belief Model (Rosenstock, 1974) and the Theory of Planned Behaviour (Ajzen, 1991) are probably the most widely used social cognition models but they are not designed to address the kinds of issues raised in this thesis. The linear nature of these models does not facilitate the examination of the dynamic processes involved in the acquisition of new health information and the way in which this affects beliefs about an illness and responses to it. More suited to these questions are theories of self-regulation.

4.1. Self-regulation theory

Self-regulation is a concept that has become widely used not only in health psychology, but also in educational and industrial/organisational psychology (Karoly, Boekaerts, &

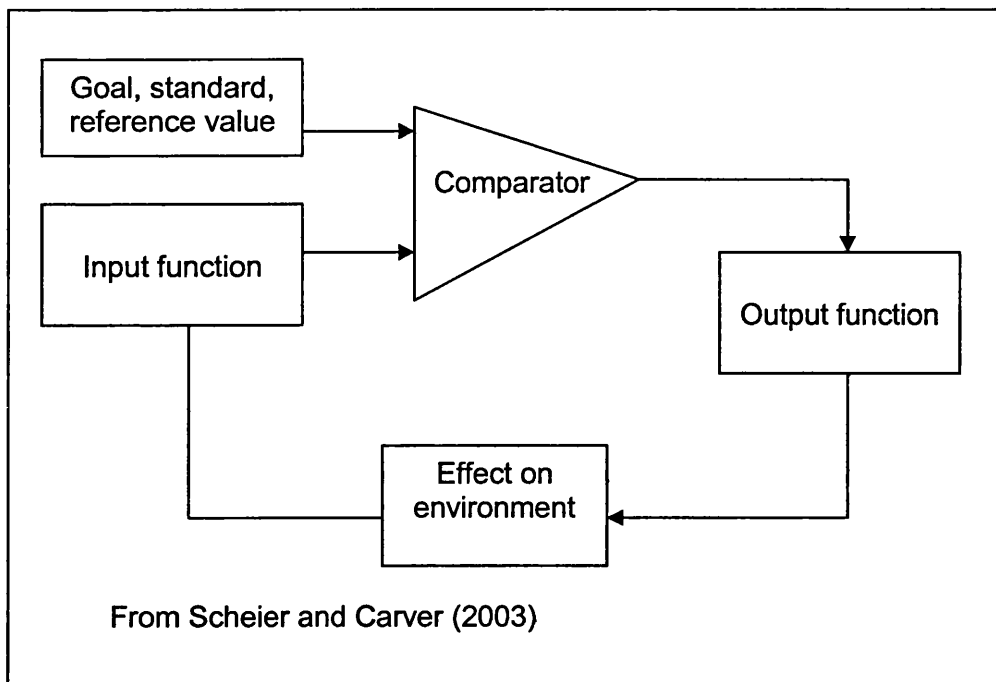
Maes, 2005). Self-regulation theory stems from the premise that individuals are motivated to act in a way that facilitates the attainment of goals. Self-regulation has been defined as

a goal-guidance process, occurring in iterative phases, that requires the self-reflective implementation of various change and maintenance mechanisms that are aimed at task- and time-specific outcomes (Maes & Karoly, 2005).

Goals can be anything from the mundane (getting to work on time) to the abstract (achieving an ideal self). Goals can be seen as forming a hierarchy of increasing levels of abstraction. For example, lower order health related goals might include specific behaviours such as taking exercise or attending screening, while a higher order, more abstract goal might be to stay healthy.

Achieving a goal is conceptualised as involving a feedback loop, in which the actual state of affairs is compared against the desired outcome. The feedback system has been conceived as being composed of four elements: the input function, the reference value, the comparator and the output function (Scheier & Carver, 2003a) (see Figure 1.2). The system operates in a way that minimises the discrepancy between the current situation (input function) and the desired outcome (reference value). The output function is the behaviour carried out to reduce the discrepancy, and the comparator compares the input function with the reference value. Unlike linear social cognition models, self-regulation theory is concerned with dynamic processes. Moving towards a goal is an iterative process – a behaviour is carried out, appraised in terms of movement towards the goal, altered if necessary, and reappraised. This self-regulatory system has also been summarised in the acronym TOTE, standing for ‘Test-Operate-Test-Exit’ (Leventhal, Brissette, & Leventhal, 2003).

Within the general framework of self-regulation theory, many different models have been developed. Those most commonly used in health psychology will be outlined before a more detailed discussion of the principal model used in the work of this thesis.

Figure 1.2 Feedback system involved in self-regulation

4.1.1. *Carver & Scheier's Self-regulation model*

A widely used model of self-regulation is that developed by Carver and Scheier (Carver & Scheier, 1981; Scheier & Carver, 2003a; Scheier & Carver, 2003b). The model is not specific to the health domain, and can be used to describe any behaviour that is goal-directed. As described above and depicted in Figure 1.2, the model conceptualises self-regulation as being driven by a feedback loop in which the discrepancy between the actual situation and a desired goal is altered. The discrepancy may be enlarged or reduced, depending on whether the goal is something to be achieved (e.g. eating five portions of fruit and vegetables each day) or avoided (e.g. smoking).

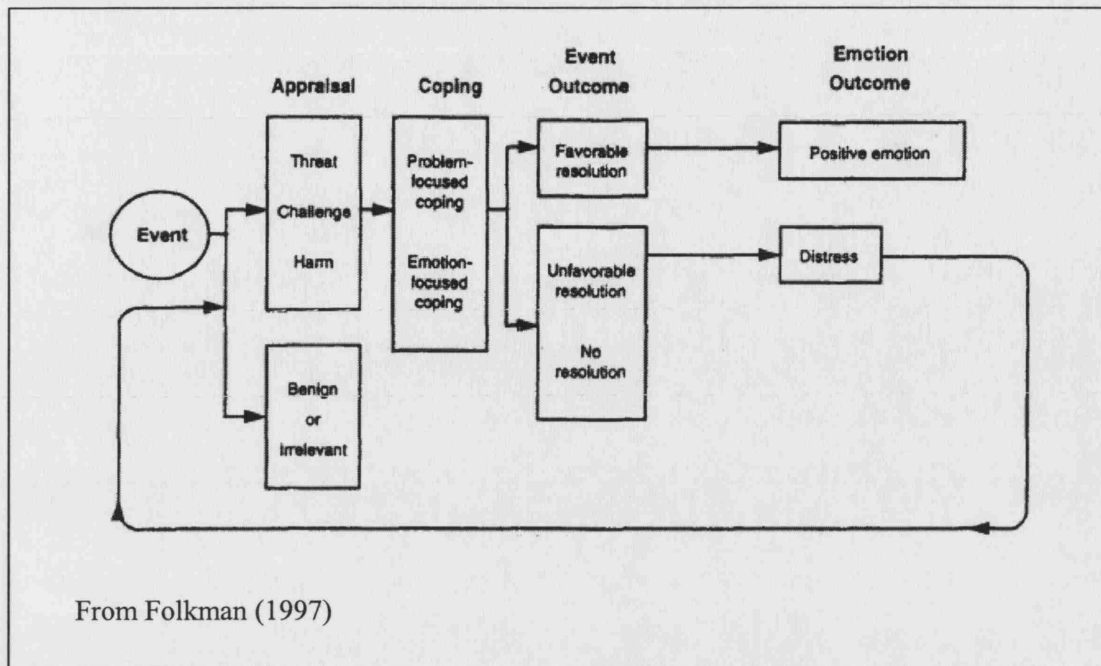
In common with other self-regulation models, Carver and Scheier highlight the importance of affect as well as cognition in the feedback loop. Regulation of affect is thought to take place in parallel with the feedback loop controlling behaviour (Scheier & Carver, 2003b). According to the model, discrepancy-*reducing* loops (i.e. moving towards a desired goal), are associated with feelings of elation as the goal is approached, and depression if the discrepancy is enlarged. By contrast, discrepancy-*enlarging* loops (i.e. moving away from an undesired goal) are thought to yield relief if the discrepancy is successfully increased, and anxiety if action is unsuccessful in moving away from the undesired situation. If a person lacks confidence in their ability to achieve a goal, they

may disengage in order to avoid feelings of anxiety or depression. Affect thus plays an important role in the self-regulation process.

4.1.2. Lazarus and Folkman's model of stress, appraisal and coping

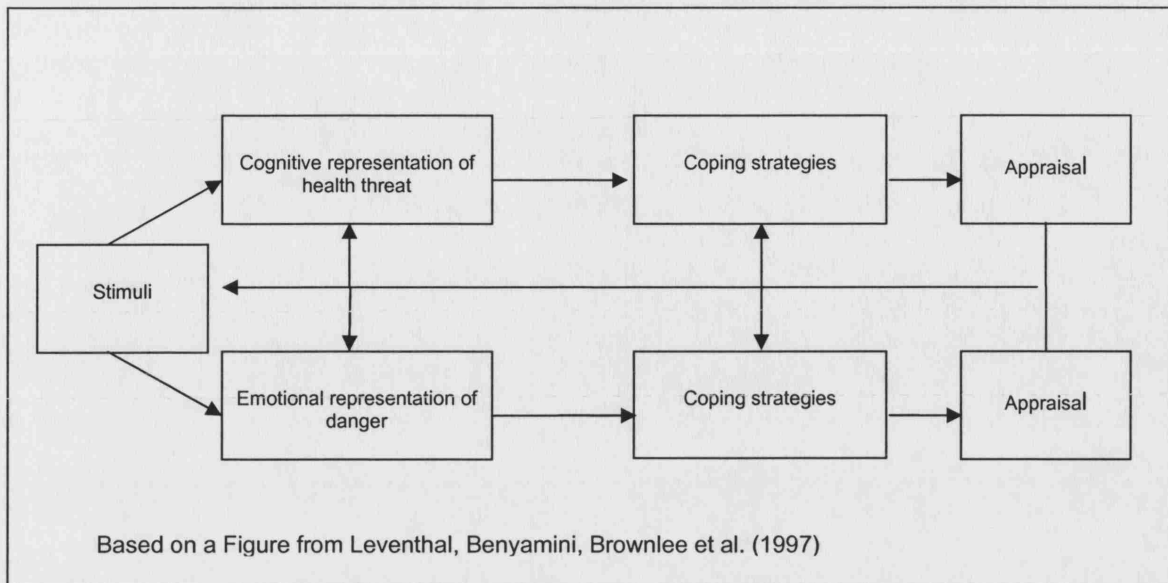
Another model used commonly in health psychology is Lazarus and Folkman's stress-coping model, which focuses on the regulation of stress (Lazarus & Folkman, 1984). The model theorises the way in which people respond and adjust to a potentially stressful situation, which could include diagnosis with an illness (see Figure 1.3). Appraisal is of key importance in the model and involves two steps: primary and secondary appraisal. At the primary appraisal stage, a situation or encounter is assessed and may be judged as irrelevant, benign-positive, or stressful. Irrelevant or benign-positive situations do not require coping strategies to deal with them, but if the situation is interpreted as stressful, further action is needed. If a stressful appraisal is made, the situation may be construed as involving harm or loss, threat, or challenge. When a threat or a challenge occurs, something needs to be done to manage the situation. This involves a second stage of appraisal (secondary appraisal) to evaluate coping strategies that might be useful. This secondary appraisal process involves what Bandura has termed outcome expectancy and efficacy expectation (Bandura, 1977). Outcome expectancy is the expectation of a particular coping strategy leading to a particular outcome, while efficacy expectation is the confidence an individual has in his or her ability to carry out the necessary action. The interaction between the primary and secondary appraisals is thought to determine the degree of stress experienced.

Coping strategies have been divided into problem-focused and emotion-focused coping. Problem-focused coping aims to alter the situation causing the stress, while emotion-focused coping aims to regulate the emotions engendered by the stressful situation. It has been argued that in situations where an individual has little or no control over the source of the stress, emotion-focused coping may be a very adaptive response. In other situations, though, emotion-focused strategies such as avoidance or minimisation may be less adaptive and may even exacerbate the cause of the stress. In the health field, for example, avoidance might be associated with non-adherence to a treatment regimen, which could in turn lead to deterioration in physical health.

Figure 1.3 Lazarus and Folkman's Stress Coping Model

4.1.3. *Leventhal's Common Sense Model*

A self-regulation model that has become increasingly popular in health psychology research is Leventhal's Common Sense Model of self-regulation in health and illness (CSM) (Leventhal et al., 1980; Leventhal, Nerenz, & Steele, 1984; Meyer, Leventhal, & Gutmann, 1985; Leventhal, Leventhal, & Contrada, 1998; Leventhal et al., 2003). The model aims to describe the way in which people make sense of and respond to an illness threat. This model differs from other models of self-regulation in its focus on the content of illness representations (Maes & Karoly, 2005; Leventhal et al., 2003). Given that much of the focus of this thesis is on the way in which new information about HPV alters the way in which people think about cervical cancer, the CSM, with its emphasis on illness representations, seemed an appropriate model within which to frame the research.

Figure 1.4 Leventhal's Common Sense Model (CSM) of self-regulation

Leventhal's CSM was developed to explain people's responses to health threats. The model assumes that people are active problem-solvers who develop representations of health threats and then employ strategies to cope with those threats. Developed from the so-called parallel processing model, it describes the cognitive and emotional processes involved in dealing with a health threat (see Figure 1.4). The cognitive pathway can be thought of as the way of dealing with the threat itself, and the emotional pathway can be thought of as a means of coping with the perceived danger or fear inherent in the threat (Leventhal et al., 1980). Both pathways are triggered by a stimulus, which may be either a symptom, or an illness threat such as a diagnosis.

4.1.3.1. *Cognitive pathway*

The cognitive representation of the illness or health threat was originally conceptualised as having five dimensions: identity (label or symptoms), causes, controllability, consequences and timeline (Lau, Bernard, & Hartman, 1989). A quantitative measure of these dimensions was developed in the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, & Moss-Morris, 1996). Recently, the psychometric properties of the questionnaire were called into question, and a new version was developed to address some of the problems of internal consistency within the scales (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). The revised version of the measure (the IPQ-R) splits the time-line dimension into chronic/acute and cyclical, splits the causal attributions into four separate scales, and addresses two additional components. The first is the emotional representation, which is separate from the cognitive representation,

and is described in more detail below. The second is illness coherence, which measures the extent to which people feel that they have a clear picture of their illness. Each of the cognitive dimensions is described in more detail below.

4.1.3.1.1. Identity

The identity of a health threat is usually conceived as being composed of its (abstract) label and its (concrete) symptoms (see below for more discussion of the abstract and concrete aspects of cognitive representations). Leventhal and colleagues have argued that there is a symmetry between the two, so that experiencing symptoms will lead to a search for a label, and being given a label will be associated with a search for symptoms (Leventhal et al., 1980). In asymptomatic conditions such as hypertension, there is sometimes evidence of patients believing that they experience symptoms and can use these symptoms to monitor the severity of the condition (Meyer et al., 1985).

4.1.3.1.2. Cause

Causal attributions for illness have been studied both within and separately from the CSM. In the current research, understanding that HPV is sexually transmitted, and is causally related to cervical cancer, is a key consideration.

4.1.3.1.3. Control

The broad notion of the controllability of an illness has been divided into two sub-scales in the IPQ-R: personal control and treatment control. The first refers to the extent to which an individual feels that they can have control over the course of their illness, and the second incorporates perceptions of the perceived efficacy of the recommended treatment.

4.1.3.1.4. Timeline

The timeline of an illness or health threat refers to the perception of how long it will last, whether it is chronic or acute, or whether it might come and go in a cyclical way.

4.1.3.1.5. Consequences

The notion of illness consequences is very broad. In IPQ-R, the consequences scale includes items relating to perceived severity, as well as the financial and social impact of the illness.

4.1.3.1.6. Coherence

Though not explicit in Leventhal's model, the notion of 'illness coherence' has been added to the most recent version of the IPQ-R (Moss-Morris et al., 2002) and taps the extent to which people feel that they have a good understanding of their illness or condition, using items like 'My illness is a mystery to me'. It has been suggested that this might be important in predicting appropriate coping and adjustment (Hall, Weinman, & Marteau, 2004).

The model posits that the way in which an individual copes with a health threat is influenced by the cognitive representation of the threat. For example, a headache may be identified as a migraine, believed to be caused by stress, to be controllable through medication, to have serious short-term consequences in terms of reduced activity, and to have an acute timeline of 24 hours. The cognitive representation will feed into the chosen coping strategy e.g. taking pain-killers. This will then be appraised and if the coping strategy appears not to be working, the representation may be revised, leading to a change in coping strategy. This iterative process is common to other models of self-regulation, and has the aim of achieving the goal of good health.

An early study of people with hypertension found that people developed these 'common sense' models of their illness, and the models guided adherence to treatment (Meyer et al., 1985). A more recent study found that the illness cognitions of patients following myocardial infarction were predictive of a variety of outcome measures including behavioural measures of recovery such as speed of return to work (Petrie, Weinman, Sharpe, & Buckley, 1996). A meta-analysis of studies using Leventhal's model found cognitive representations were related to coping strategies and illness outcomes in a theoretically predictable way (Hagger & Orbell, 2003).

4.1.3.2. Emotional pathway

In parallel to this process, there is an emotional component to the response. Emotional responses to a health threat may include anger, worry, fear or anxiety. These responses to the illness are now included in the IPQ-R. The emotional representation might be dealt with through seeking social support, through denial or the venting of anger. The coping is appraised and the feedback loop operates in the same way as for the cognitive side of the model.

The two processes run in parallel but are also conceived as influencing each other. Thus the cognitive representation will affect the emotional representation and vice versa. For example, a label of cancer might be expected to be associated with different emotions from that of a benign lump.

The emotional component of the model has commonalities with other models of self-regulation, where the regulation of emotional responses is as important as regulating the stressful or threatening situation (Lazarus & Folkman, 1984), or may become a goal in itself (Scheier & Carver, 2003a).

4.1.3.3. Abstract vs. concrete representations

According to the CSM, processing can take place at both a concrete and an abstract level, and is thus seen as being hierarchical (e.g. Leventhal et al., 1984). The concrete aspect of the threat might be the symptom, for example pain, while the abstract label is concerned with the *idea* of having the illness or disease. The two may be inconsistent. For example someone with asymptomatic cancer being treated with chemotherapy might have concrete symptoms that are associated with the therapy, while the idea of having cancer must be processed on a more abstract level. Relieving the symptoms would mean stopping the treatment that is curing the cancer, whereas dealing with the more abstract threat of cancer involves continuing with treatment and enduring the side-effects.

It has been found that people strive for symmetry between the abstract and concrete aspects of an illness experience. For example, if people are given an illness label, they tend to search for symptoms, even in asymptomatic conditions like hypertension (Meyer et al., 1985). Conversely, if a symptom is experienced, there is a strong motivation to discover a label or diagnosis.

Like the illness representation component of the model, coping strategies also have abstract as well as concrete components. The experience of adhering to a particular treatment regimen might feel very different from the abstract understanding of the rationale for treatment.

4.1.3.4. Social context

Although not explicit in the model as depicted in Figure 1.3, the CSM acknowledges the vitally important role played by the social context of the individual (Leventhal et al., 2003). The social and cultural environment has a huge impact on the linguistic labels applied to symptoms and illnesses, and provides a context for normative beliefs (Bauman, 2003). Social interactions, from consultations with health professionals to talking with friends and family, are also important in the development of illness representations, and decisions about coping procedures. However, the mechanisms through which this happens have not been well elaborated within the model.

4.2. Theoretical approach of the thesis

The CSM provides an appropriate model within which to investigate the way that people make sense of a diagnosis with HPV and incorporate information about HPV into their existing representations of cervical cancer. The dynamic nature of the model may facilitate an understanding of how people's representations and coping strategies change over time, which could be especially important when people are adjusting to a diagnosis with a condition of which they were previously unaware. Unlike other models of self-regulation, the CSM elaborates the dimensions of illness representations and provides a clear framework within which to conceptualise beliefs about HPV and investigate the impact that specific beliefs have on adjustment and coping. The model acknowledges the importance of social and cultural context, which is likely to be particularly important when considering HPV as an STI. Other self-regulation models may also be useful in understanding how women appraise and adjust to an HPV diagnosis, and in thinking about the goals that women may be striving to achieve.

Very few previous studies have used the CSM as a way of understanding beliefs about cervical cancer. One exception is a paper by Hall et al. (2004). This study investigated the impact of giving female smokers information about the link between smoking and cervical cancer. It is argued that women who do not hold a coherent model of the relationship between smoking and cancer risk will be less motivated to stop smoking than those who have been given information to help them develop a coherent understanding of the link. As the CSM would predict, holding a coherent model was associated with greater motivation to quit smoking, but only among women with a high perceived vulnerability to cancer. This study demonstrates the potential link between cognitive representations of cervical cancer, and ways of perceiving and coping with the

threat of developing the disease. A qualitative study has also demonstrated that women who do not understand how smoking increases the risk of cervical cancer are sceptical about the link (Marteau, Rana, & Kubba, 2002). This may also be true of HPV, if women do not have a coherent model of the way in which an STI could cause the development of cancer.

The CSM will allow an examination of women's cognitive representations of HPV and cervical cancer, and identification of the specific aspects of these representations that are linked with different responses to testing positive for the virus.

5. Methodological approach

The thesis makes use of a mixture of qualitative and quantitative methods. This section describes the dichotomy that has tended to be drawn between quantitative and qualitative approaches, and the ontological and epistemological underpinnings of the work carried out in the thesis. Issues of reliability and validity, particularly in relation to qualitative methods, are also discussed.

5.1. Development of qualitative and quantitative methodologies in psychology

In the late nineteenth and early twentieth centuries, the development of experimental psychology included the use of introspection, and other qualitative techniques which were considered valuable in understanding psychological functioning (Hayes, 1997). Although it has been argued that this qualitative approach can be traced throughout the history of psychology (Marecek, 2003), a dominant quantitative paradigm was established with the development of behaviourism in the first half of the twentieth century, with an emphasis on methods taken from the natural sciences.

The logical positivist approach taken by the behaviourists, and continued with the rise of cognitive psychology in the 1970s and 80s, assumes the existence of an objective real world that is independent of the observer, and takes the position that the world can be known about using scientific observation and measurement. This approach can be thought of as being characterised by an emphasis on hypothesis testing and on the use of experimental methodology in which possible sources of error are minimised.

In the 1960s and 70s there was a backlash against these methods in the social sciences, attributable at least in part to a changing cultural climate and a move towards pluralism (Eisner, 2003). There was growing concern about oppressive and ideological uses of psychology and a perceived need to challenge the promotion of the ideas of dominant groups (Burr, 2003). The rise of feminist psychology, an emphasis on ethical issues in the treatment of research participants, and an interest by funding organisations in research that addresses questions of relevance to the ‘real world’ have all been cited as influencing the growing acceptability of qualitative approaches within the social sciences in general, and psychology in particular (Hayes, 1997). In addition, understanding the complexities of the social world was seen by many as requiring a different approach from the traditional hypothetico-deductive one. Post-modernist ideas pointed to the validity of varying approaches, and the rejection of ‘grand theories’ in favour of more context-specific explanations of social phenomena.

5.2. The apparent dichotomy between qualitative and quantitative methods

The differences between the two methodological approaches have frequently been defined in terms of a series of dichotomies, with qualitative methods often thought of in terms of the ways in which they differ from quantitative approaches. Table 1.1 illustrates the distinctions that are often drawn between the two approaches.

Quantitative research is concerned with numerical data, often collected in laboratory settings using a deductive approach. Outcomes of interest have been thought of as behavioural (although in psychology, emotional or cognitive outcomes are frequently measured using quantitative methods), and universal laws are sought. The natural sciences are taken as a model of scientific investigation, and a realist ontological perspective is taken.

In contrast, qualitative approaches are concerned with non-numerical (usually linguistic) data, collected in ‘natural’ settings, outside the experimental laboratory. The focus tends to be on meanings rather than behaviour and an inductive approach is often taken, in contrast to hypothesis testing. The scientific method of the natural sciences is rejected as a model of enquiry, and patterns are sought, rather than scientific laws. An idealist ontological approach is taken – we can only understand the world through interpretation and the construction of meanings. The existence of a knowable ‘real’ world is rejected.

Table 1.1 Dichotomies drawn between quantitative and qualitative approaches

Quantitative approaches	Qualitative approaches
Quantitative or numerical data	Qualitative or linguistic data
Artificial (often laboratory) settings	Natural settings
Focus on behaviour, emotions or cognition	Focus on meanings
Natural sciences adopted as a model	Natural sciences rejected as a model
Deductive approach	Inductive approach
Seeking scientific laws	Identifying psychological, social or cultural patterns
Realism	Idealism

Adapted from Hayes (1997) after Hammersley (1992)

5.3. Ontological and epistemological approaches

Perhaps the most fundamental of these differences lies in the ontological and epistemological underpinnings of the two approaches. At opposite ends of the ontological spectrum are realism and social constructionism. Each of these stances will be described, and then the approach taken in this thesis, which lies somewhere between these two poles, will be outlined. In the description of each of the ontological stances, the implications for epistemology and methodology within this thesis will be explored.

5.3.1. *Realism*

Quantitative methods are usually associated with a realist philosophy which, as mentioned above, assumes the existence of an objective real world that can be known about through systematic observation and measurement (Yardley, 1997). According to this approach, the existence of the real world is quite separate from our representations of it, and it is this world that is of interest, not beliefs about or representations of it. If this approach is taken, then a belief about something does not carry the same weight as a scientifically established fact. Universal truths can be established which are independent of social or historical context, and can be observed directly without the need for interpretation, and without distortion by the perceiver. The researcher is

regarded as independent of the findings, and is not seen as a social actor in the research process.

Taking a realist perspective in this thesis would lead to the use of solely quantitative methods aimed at discovering truths about people's knowledge and experience. It would involve the use of representative samples so that findings could be generalised to the whole population. The role of the investigator in interpreting the data would be seen as minimal (or non-existent). Current scientific understanding of HPV would be taken as the truth, against which people's knowledge could be measured. Experiences of women with HPV could also be measured objectively and would not be subject to interpretation. A realist approach would ignore the importance of the meanings that women attach to HPV and the way that beliefs are constructed within a social context.

5.3.2. *Social constructionism*

At the other end of the spectrum, social constructionism takes a relativist stance more commonly associated with qualitative methods. Social constructionism can be defined as 'the view that the phenomena of the social and cultural world and their meanings are created in human social interaction'.⁵ In contrast to the realist perspective, social constructionists do not consider that there is a real world that can be discovered through observation or scientific enquiry. Rather, reality is constructed through social interaction and is therefore historically and culturally specific. Knowledge can be seen as an artefact of culture and is sustained through social processes, with language playing a crucial role (Burr, 2003). Each of the concepts traditionally explored in psychology and thought of as emanating from the individual (e.g. emotion, motive) is

cut away from an ontological base within the head and is made a constituent of social process (Gergen, 1985).

Social constructionists find the notion of 'truth' problematic and deny the existence of objective facts. If this approach were taken in this thesis, the medical model of HPV as sexually transmitted and an individual's belief (e.g. that it occurs naturally within the body) would be seen as equally valid, although it would be acknowledged that because of the distribution of power within society, the medical model carries more weight. Using survey methodology to test people's knowledge would be meaningless if medical

⁵ See <http://www.brunel.ac.uk/~hsstcfs/glossary.htm>

understanding was seen as no more ‘true’ than lay beliefs. Taking a social constructionist approach to the question of how people understand cervical cancer, and the impact of information about HPV on that understanding, would point to the use of qualitative rather than quantitative methods, and would focus on the impact of medical discourse on individuals’ beliefs and the way in which those individual beliefs are constructed. This would be seen as taking place within the current historical and cultural environment, and no particular beliefs would be judged as more right or wrong than any others.

If we take the statement ‘HPV is sexually transmitted’ as an example, we can see that from a social constructionist perspective, the truth of the statement depends on the perspective taken. From a public health perspective, the statement is true. The risk of infection with HPV rises with the number of sexual contacts, and someone who has never had sex is at negligible risk. Therefore if one’s aim is to reduce the spread of infection through public health messages, the statement that HPV is sexually transmitted is useful. From a medical perspective, the statement may be somewhat less true. Some authors have suggested that there are other routes through which HPV can be acquired, be it vertical transmission from mother to baby, or from unsterilised medical instruments. If these possibilities are acknowledged, it would be more accurate to say that HPV is *usually* sexually transmitted. Finally, from an individual’s perspective, the statement that HPV is sexually transmitted may be completely untrue. If a woman is in a life-long monogamous relationship and is told that she has HPV, she knows that she cannot have caught the infection through having sex. From a social constructionist perspective, each of these versions of the truth is equally valid. However, this thesis takes the stance that HPV has already been constructed as an STI, and is concerned with the impact that this has on the individual, rather than investigating ways in which discourses around the virus are constructed at a societal level.

In addition, as has been described above, the theoretical background to the thesis relates to self-regulation. A common criticism of social constructionism is that it does not account for the ‘self’ (Burr, 2003). Concepts like personality, attitudes, motivations and personal agency, all of which are important in self-regulation theories, cannot be reconciled with social constructionist accounts, where explanations are sought at the level of society rather than the individual.

5.3.3. *Subtle realism*

Subtle realism (Hammersley, 1990; Hammersley, 1992) is a form of realism that acknowledges the fact that interpretation is needed in order to make discoveries about the social world. The notion of a real world is maintained, but it is acknowledged that the social world cannot simply be observed and measured objectively. The researcher is seen as a social actor in the process. Subtle realism is compatible with the use of both qualitative and quantitative methodologies (see below), and is the approach taken in this thesis.

The questions addressed in this thesis concern the impact that the identification of a causal relationship between HPV and cervical cancer has on public understanding of cervical cancer and the experience of women taking part in screening. The scientific discovery that HPV is a key aetiological agent in cervical carcinogenesis is taken as an established fact, and it is this impact of this fact, and the impact of the medical discourse that flows from it, that is of interest, rather than the construction of that discourse. This points to a realist approach to epistemology and methodology. However, it is also acknowledged that the interpretation of data, be they qualitative or quantitative, involves subjective processes in which the investigator plays a crucial role. In quantitative studies this involves decisions about what questions to ask, how items are worded, and which statistical analyses are carried out. In qualitative studies, the role of the investigator is even more important as a large degree of interpretation is involved in analysing women's accounts. It is anticipated that the meanings that women attach to HPV results will also be important in explaining their responses to infection. A subtle realist approach using a mixture of quantitative and qualitative methodologies is therefore adopted as most appropriate for achieving the aims of the thesis.

5.4. Using mixed methods

Although the kinds of dichotomies shown in Table 1.1 have often formed the basis of definitions of the range of approaches included under the umbrella of 'qualitative methods', Hammersley (1992) has argued that the apparent dichotomies are, in fact, better thought of as continua. For example, while many qualitative researchers eschew the use of any numerical data, terms such as 'fewer' or 'most' are often seen in reports of qualitative research and are clearly concerned with some degree of quantification.

In elaborating his subtle realist approach, Hammersley (1990; 1992) has also argued against a simplistic view of the differences in philosophical underpinnings of the two methodologies, suggesting that not all quantitative researchers are realists, just as not all qualitative researchers are idealists. Although the ethnographic methods he uses would meet many of the criteria defining qualitative methods, he argues that these can be used to gain insight into an objective social reality, albeit one that can only be known about through interpretation. If this stance is taken, qualitative and quantitative methods can be used together to investigate different aspects of the social world.

Others have argued that we should choose methods appropriate to the research question being addressed, and that although philosophical debate is important, it should not prevent us from carrying out pragmatically driven research to answer questions of importance (Seale, 1999). Qualitative and quantitative approaches can be complementary and through the use of mixed methods, we may be able to understand social and health-related phenomena better than with exclusive use of one approach or other (Yardley, 2000; McPherson & Leydon, 2002; McGrath & Johnson, 2003).

Qualitative methods are increasingly being used in mainstream health psychology and other health-related research to investigate areas about which little is known, or which are sensitive or complex and therefore difficult to explore using more traditional quantitative measures (e.g. Pope & Mays, 1995; Yardley, 2000). Following the publication of Pope and Mays' (1995) BMJ paper introducing qualitative methods to the journal's readers, there has been a steady increase in the publication of qualitative studies in that journal from three papers in 1993 to 18 papers between January and July 2004 (see Figure 1.5). As most of these papers are concerned with health services and policy, extreme relativist positions are generally rejected; otherwise, it has been argued, conclusions for practice could not be drawn (Mays & Pope, 2000). Instead a subtle realist approach is usually adopted, in which qualitative methods are seen as compatible with quantitative methods, with both providing insight into phenomena which exist independently of the research process. This raises questions about how to ensure the validity and reliability of qualitative research, and ensure that the findings have applicability beyond the context of the specific research project.

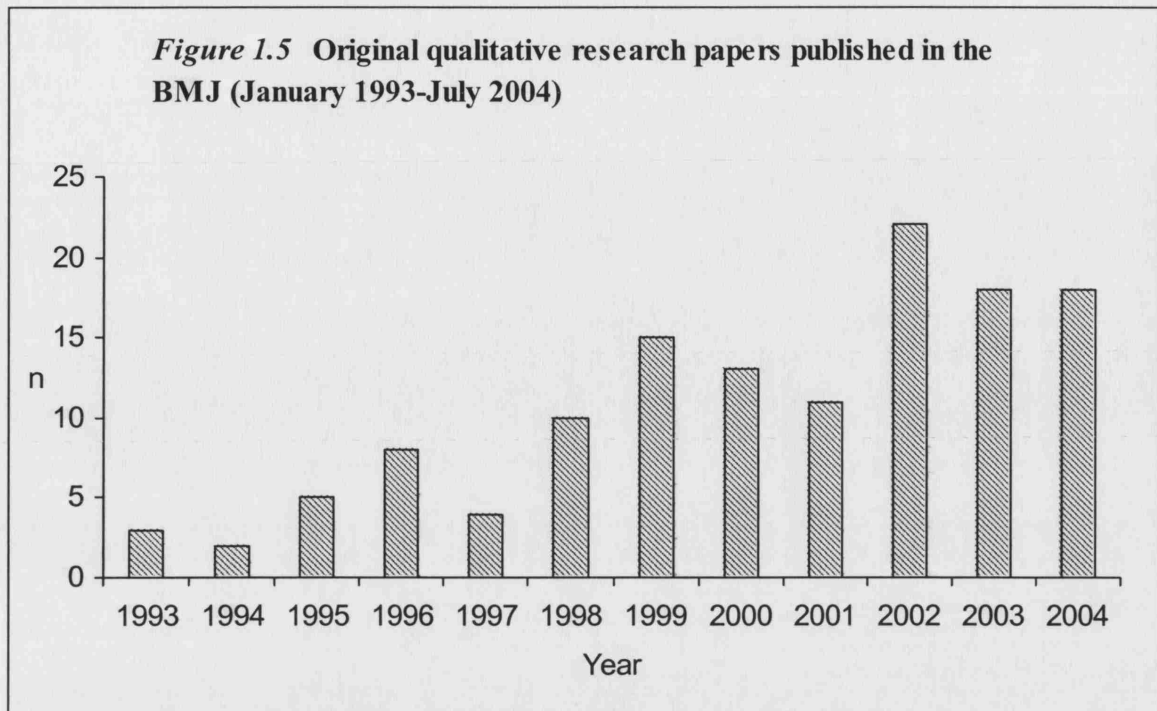


Figure derived from a PubMed search of all papers in the BMJ including the word 'qualitative'⁶

5.5. Issues of validity and reliability

There has been much debate about appropriate ways to evaluate the quality of qualitative research. Consensus has not been reached, and the vast variety of approaches and methodologies within what are broadly termed 'qualitative methods' makes it difficult to identify appropriate criteria for evaluation. What is clear is that the specific criteria applied to quantitative research are not appropriate to qualitative studies. For example, while quantitative researchers aim to achieve population representative samples, qualitative researchers tend to use theoretical sampling to ensure a range of participants and experiences (Yardley, 2000). However, in both qualitative and quantitative research, issues of validity and reliability are of key importance.

5.5.1. *Reliability*

Reliability refers to the consistency of the results of a study. In quantitative research this includes the extent to which findings are stable over time (test-retest reliability) and, if scales are being used, the extent to which all of a scale is all measuring a single construct (split-half reliability). In qualitative research, reliability can be established if data are coded and interpreted consistently by the same researcher across time, or by

⁶ Abstracts of all papers identified in the search were inspected and only those describing primary qualitative analysis have been included in the figure. Some papers included both qualitative and quantitative analysis.

different researchers. If different analysts draw the same conclusions, the findings can be said to be reliable.

5.5.2. Generalisability

Generalisability is the extent to which the findings from a study can be generalised to other contexts. In taking a subtle realist approach, is it important that both quantitative and qualitative findings have reliability and hold true to a certain extent beyond the specific research population (Mays & Pope, 2000; Lewis & Ritchie, 2003). In quantitative research this is achieved by appropriate representative sampling, and an adequate description of the measures, procedures and analysis to allow replication of the study. In qualitative research, methodological rigour is again important in ensuring reliability and this includes all stages of the research from sampling and fieldwork to analysis, interpretation and presentation of the findings. It is important that readers can see how the research has led to the conclusions presented (Seale, 1999), and for each stage of the process to be described in sufficient detail for replication in other contexts to be possible. Purposive sampling improves the generalisability as differences between sub-groups of the sample should hold true beyond the study sample.

5.5.3. Validity

The validity of research findings refers to the correctness or precision of the conclusions drawn. Conclusions can be very reliable (over time and between researchers) but if they are not correct (e.g. if a scale fails to measure the construct it aims to measure) then the study has no validity. Hammersley (1990) has argued that even if uncertainty exists within the findings, the validity can be judged by the plausibility and credibility of the claims being made, and an evaluation of the evidence presented. Other authors writing about validity in qualitative research have drawn comparisons between validity in quantitative research and ‘trustworthiness’ in qualitative research. This incorporates notions of truth, applicability, consistency and neutrality (McGrath & Johnson, 2003).

5.5.4. Ways of validating qualitative findings

There is little consistency among different authors about the appropriate ways to validate qualitative research. There is, however, general agreement about the need for rigour at every stage of the research (design, conduct and analysis of the data) and a transparency in describing the procedures. Yardley (2000) has argued for the need for sensitivity to the context of the research, commitment, rigour, transparency and

coherence in the conduct of the research, and the importance of the impact of the research. Hammersley (1990) has also emphasised the fact that research must be relevant, whether this is for theory development or for policy or practice.

Check-lists for evaluating qualitative research have been criticised as constraining (Barbour, 2001) and are not always helpful, but some of the key methods for assuring quality that have been frequently put forward (e.g. Mays & Pope, 2000; Lewis & Ritchie, 2003) are outlined briefly below.

5.5.4.1. Constant comparison

The constant comparative method was developed by Glaser and Strauss as part of their method of grounded theory (Glaser & Strauss, 1967). It involves testing hypotheses that are derived from the data against other cases to ensure that conclusions drawn are consistent with all cases, rather than just some.

5.5.4.2. Deviant case analysis

Deviant case analysis is another means of ensuring that all the data are considered when interpretations are made. Cases that do not fit the developing theory or pattern are examined to see whether they contradict and therefore challenge the theory, or can be explained within it (Lewis & Ritchie, 2003).

5.5.4.3. Triangulation

Triangulation means using different methods or approaches to investigate a particular phenomenon. It has been argued that taking diverse perspectives on an issue can provide a fuller and more valid understanding of it (Madill, Jordan, & Shirley, 2000; Mays & Pope, 2000). But whether triangulation is deemed appropriate depends on the epistemological assumptions of the research. Relativist investigators would question the notion that different approaches could somehow uncover a greater truth (Yardley, 1997). Within a subtle realist perspective, triangulation is useful as a means of investigating different aspects of a phenomenon, even if different methods (e.g. qualitative vs. quantitative) yield contrasting results.

5.5.4.4. Member validation

Member validation means checking the analysis with the participants of the research (Mays & Pope, 2000). Although in some contexts this might be useful to ensure that

the investigator has not misinterpreted or misrepresented the participants, in other situations it is less appropriate. In the qualitative research in this thesis, one of the key questions is about women's beliefs about HPV. The medical model is assumed to be more 'correct' than the participants' perceptions, so confronting the participants with an analysis that highlights what might be regarded as deficiencies or errors in their knowledge would not be useful. This is particularly true in the case of women's understanding of the sexually transmitted nature of the virus. The research seeks to remain neutral in its interactions with participants, so changing their perceptions and making all women aware that HPV is an STI (as would be inevitable if the analysis were presented) would be contrary to the aims of the research.

5.5.4.5. Reflexivity

Reflexivity is a way of overcoming the illusion of objectivity in research (Marecek, 2003) and although it has usually been applied to qualitative methods, it is also relevant in quantitative enquiry. No researcher can be objective, and if sources of bias are openly acknowledged, the reader is able to judge the interpretations and conclusions of the research more easily. Reflexivity involves making clear the prior assumptions of the researchers, their theoretical and personal perspectives, and characteristics such as sex, ethnicity, class and profession, all of which might have an impact on the research process (Mays & Pope, 2000).

5.6. The methodological approach used in the thesis

The methodological approach used here is one developed by researchers at the National Centre for Social Research in the context of social policy research (Ritchie & Lewis, 2003) and adopts the subtle realist approach described above (Hammersley, 1990; Hammersley, 1992). The existence of a real social world, independent of beliefs or understanding, is assumed, but it is acknowledged that this can only be accessed through a process of interpretation. The aim of the research process is to capture a multifaceted external reality. In terms of its epistemological position, the approach draws heavily on quantitative methods, striving for objectivity and neutrality in data collection, while acknowledging possible sources of bias. However, interpretation of the data is a key role for the researcher (Snape & Spencer, 2003).

This position is consistent with a pragmatic approach to the selection of methodologies, allowing the researcher to choose the method most suited to a particular research

question, and to mix quantitative and qualitative methods. Seale (1999) has endorsed this notion, describing social research as ‘a collection of craft skills, driven by local, practical concerns’ and asserting that

pragmatic social researchers can use philosophical and political debates as resources for achieving certain mental attitudes, rather than a set of underlying principles from which all else must flow, creating unnecessary obstacles to flexible and creative inquiry (p. 26).

Given the paucity of research on the psychosocial aspects of HPV testing, and the complex and sensitive issues involved, a mixture of quantitative and qualitative approaches was selected to explore the issues surrounding HPV testing. While survey data can be used to provide a broad picture at a population level, qualitative methods allow women’s responses to HPV testing to be explored in depth, with a particular focus on the beliefs of women testing positive for HPV, and the meanings they attach to both HPV and cervical cancer.

The qualitative chapters of the thesis use methods developed by the National Centre for Social Research, and specifically Framework Analysis (Ritchie & Spencer, 1994; Ritchie, Spencer, & O'Connor, 2003). This is a matrix-based approach to thematic data organisation, which facilitates an examination of relationships both between and within cases. The methods involved in analysis will be described in more detail in Chapter 4. Framework Analysis was developed for social policy research and was appropriate to the qualitative studies in this thesis. As described in detail in Chapter 4, on the basis of previous focus group work (McCaffery, Forrest, Waller, Desai, Szarewski, & Wardle, 2003b) it was hypothesised that a relatively large number of demographic variables would play an important role in predicting women’s experience of participation in HPV testing. In order to explore these, a fairly large sample size was needed so that it could vary along a number of demographic dimensions (e.g. ethnicity, age, marital status). The need for large samples precluded the use of approaches like Interpretative Phenomenological Analysis (Smith, Flowers, & Osborn, 1997), which rely on in-depth analysis of a very small number of transcripts. Grounded theory (Glaser & Strauss, 1967) was inappropriate, as the qualitative studies sought to answer specific questions about the experience of participation in HPV testing rather than developing an emergent theory in a purely inductive way. Framework Analysis is compatible with the research questions being addressed and has the advantage of facilitating the organisation and

sorting of large numbers of transcripts, allowing patterns in the data to be explored, while keeping closer to the accounts of participants and involving more interpretation than semi-quantitative methods like content analysis. It allows comparison of different groups (e.g. by ethnicity or HPV status), and so was well-suited to the aims of the research.

6. Definition of terms

As much of this thesis is concerned with the way in which people make sense of information about cervical cancer and HPV, and the extent to which their understanding of the virus is consistent with the currently accepted medical model, it is useful to define some terms at this stage. Table 1.2 (overleaf) defines what is meant in the thesis by knowledge, understanding, belief, perception, model and representation. Broadly speaking, ‘knowledge’ and ‘understanding’ will be used to denote the extent to which an individual is aware of currently accepted medical facts about HPV and cervical cancer, whereas ‘belief’ and ‘perception’ will be used to describe anything that is held by an individual to be true, regardless of whether this is generally accepted to be the case. ‘Model’ and ‘representation’ will be used where interlinking beliefs are being described, specifically in the context of the CSM.

7. Aims

To recap, the aims of the thesis, as laid out on page 14 are to address the following questions:

1. What is currently known about HPV by women who take part in cervical cancer screening?
2. What is the current public understanding of the aetiology of cervical cancer?
3. How do women participating in HPV testing make sense of information about the virus and incorporate this into their existing beliefs about cervical cancer?
4. What are the emotional and social consequences of testing positive for HPV in the context of cervical screening?
5. How do women make sense of and respond to results of repeated HPV testing?

Table 1.2 Definition of terms

Term	OED definition⁷	Use within this thesis
<i>Knowledge</i>	1. Intellectual acquaintance with, or perception of, fact or truth; the fact, state or condition of understanding. 2. Acquaintance with ascertained truths, facts or principles; information acquired by study.	Knowledge will be used to indicate acquaintance with medically accepted facts.
<i>Understanding</i>	The faculty of comprehending and reasoning; comprehension of something.	Understanding will be used to indicate comprehension of medically accepted facts.
<i>Belief</i>	A proposition or set of propositions held to be true.	Belief will be used to indicate something that is held by the individual to be true, regardless of whether it is a medically accepted fact.
<i>Perception</i>	An interpretation or impression based upon one's understanding of a situation etc., an opinion or awareness.	Perception will be used to indicate an interpretation or opinion.
<i>Model</i>	A conceptual or mental representation of something	Model will be used indicate a mental representation involving several elements and the relationship between them (e.g. causation). It will also be used to refer to theoretical models.
<i>Representation</i>	A clearly conceived idea or concept	Representation will be used as it pertains to the CSM, to indicate concepts conceived within the cognitive and emotional components of the theoretical model.

⁷ From Oxford English Dictionary on-line at <http://dictionary.oed.com/>

Chapters 2 to 6 of the thesis address each of these questions in turn, using the theoretical and methodological approaches that have been outlined above. Study 1 uses a questionnaire survey to assess levels of awareness and knowledge about HPV using a sample of screening-aged women attending a well-woman clinic. This provides an indication about background levels of knowledge in this group, and the extent of the public education that will be needed to ensure that women participating in HPV testing can provide informed consent and can understand the meaning of their screening results.

On a wider population scale, Study 2 examines knowledge about that causes of cervical cancer in a general population sample. The study uses an unprompted (i.e. recall) question format to estimate levels of awareness about the link between HPV and cervical cancer. It also assesses what proportion of the population, and which demographic groups in particular, are unaware of any link between cervical cancer and sexual activity. This provides an indication of the disparity between public perceptions of cervical cancer aetiology and the current medical understanding of the disease. Causal attributions can be of key importance in predicting the impact of a health threat and, in the case of HPV and cervical cancer, understanding the sexually transmitted nature of the virus could have a huge impact on how women experience their screening results, and on the way in which cervical cancer is viewed by society more generally, in terms of stigma or blame.

Study 3 investigates the effect of participation in HPV testing, in the context of cervical cancer screening, on the women taking part. By interviewing women who have had an HPV test as part of one of the clinical trials being conducted, it was possible to describe the likely impact that the introduction of HPV testing will have on women who participate in cervical screening. To gain insight into the experiences of these women and the meanings they attribute to their results, a qualitative approach is used in this study. The results are divided between two chapters. Chapter 4 considers the way in which women make sense of the information they receive about HPV, and the impact that this has on their beliefs about cervical cancer. This builds on the findings of Studies 1 and 2 in investigating the possible changes in beliefs about cervical cancer that might accompany a wider public understanding of HPV testing. The study uses Leventhal's CSM as a framework within which to interpret the data, with particular focus on the cognitive representations aspect of the model. In Chapter 5, the impact of testing HPV positive is considered. This includes psychological and emotional factors

such as anxiety and distress, as well as social factors like relationship issues and the disclosure of the results. Continuing the use of the CSM, the links between the cognitive representations explored in Chapter 4 and the impact of results will be explored.

The final study is an extension of Study 3 and investigates the impact of taking part in repeated HPV testing. If HPV testing is introduced into the screening programme in the UK, many women will undergo repeated tests. No studies have yet been published examining the potential impact of persistent HPV infection, or the way in which women understand the concepts of viral persistence and clearance. Given that repeated HPV testing is already being carried out in the United States, and may be introduced in the UK to monitor women with borderline or mildly abnormal cytology, this is an important issue to address.

CHAPTER 2 – HPV KNOWLEDGE IN A WELL-WOMAN CLINIC SAMPLE (STUDY 1)⁸

1. Introduction

As a first step towards exploring public understanding of human papillomavirus (HPV), Study 1 used a convenience sample to measure HPV awareness and knowledge among women attending a well-woman clinic. Some work of this type has been carried out in the United States and Canada, but few studies have addressed the issue of HPV knowledge in the UK.

1.1. Previous studies of HPV knowledge

The earliest study to assess HPV knowledge was carried out over a decade ago in North Carolina (Vail-Smith & White, 1992). Of their sample of 263 female college students surveyed in 1989, only 13% said that they had heard of HPV and only 8% knew that HPV is associated with cervical cancer. Yacobi et al. (1999) also surveyed American university students (mean age 25), but included male students. Respondents rated their knowledge of HPV as being lower than their knowledge of any of six other sexually transmitted infections listed. They showed poor awareness of its symptoms (or lack of symptoms) and most did not know exactly how HPV is transmitted, although they were told in the introduction to the questionnaire that HPV is a sexually transmitted disease. This information might account for the fact that 53% believed that condoms would help prevent transmission.

In a study of younger American students (most were under 18), Baer et al. (2000) found that 29% of men and 35% of women reported having heard of HPV infection of the cervix. Most did not know how HPV is transmitted, and more believed the exchange of bodily fluids to be important (41%) than skin-to-skin contact during intercourse (18%). Just over 10% of respondents endorsed HPV as a risk factor for cervical cancer.

Awareness of HPV was found to be lower among high school students in Toronto, Canada (Dell, Chen, Ahmad, & Stewart, 2000). Eighty-seven percent of students had never heard of HPV or were unsure whether they had heard of it. As in the other

⁸ A version of this chapter has been published elsewhere and can be found in Appendix 2.1 (Waller, McCaffery, Forrest, Szarewski, Cadman, & Wardle, 2003).

studies, knowledge about the prevalence, symptoms and consequences of HPV infection was poor.

One US study sought to carry out a more in-depth evaluation of women's knowledge about HPV and related issues using semi-structured interviews (Mays, Zimet, Winston, Kee, Dickes, & Su, 2000). Twenty adults (mean age 34) and 20 adolescents (mean age 16) were recruited from health clinics serving populations of low socioeconomic status (SES). None of the participants spontaneously mentioned HPV when asked to recall as many sexually transmitted infections (STIs) as they could, although some mentioned genital warts. Respondents knew 'almost nothing' about HPV. This extremely low level of knowledge compared with other studies might in part reflect the methodology used. Open-ended questions have been demonstrated to provide a more stringent test of knowledge than question formats where response options are provided (Waller, McCaffery, & Wardle, 2004b). The lower knowledge may also be due to the low SES backgrounds of the women taking part, who would be expected to have lower knowledge than affluent university students.

In contrast to these studies, one US study found much higher HPV knowledge in a female student sample (Ramirez, Ramos, Clayton, Kanowitz, & Moscicki, 1997). Seventy-two percent of women had heard of HPV. Most of these knew that it was sexually transmitted and was related with genital warts, but only 44% were aware of its link with cervical cancer. However, extreme caution should be exercised when drawing any conclusions from this study which had a response rate of less than 5% to its mailed survey. Respondents are therefore unlikely to be in any way representative of the student population surveyed. As HPV testing was offered as part of the study, a disproportionate number of women with an interest in HPV are likely to have taken part. Perhaps not surprisingly, young women with a diagnosis of HPV or cervical dysplasia have also been found to have good knowledge of HPV (Gerhardt, Pong, Kollar, Hillard, & Rosenthal, 2000).

An intervention study designed to educate students about HPV (Lambert, 2001) found pre-intervention HPV knowledge to be poor. The study appears not to have assessed awareness of HPV, but only 45% of HPV-related true/false items were answered correctly in the pre-intervention survey.

In the most recent US study to be published (Holcomb, Bailey, Crawford, & Ruffin, 2004), 289 men and women attending a university medical centre and two family practices completed a questionnaire on HPV knowledge. Awareness of HPV was higher than has been found in most other studies, with only 33% never having heard of it. This might be due in part to the fact that the US guidelines now recommend HPV testing for women with borderline or mildly abnormal smears. Knowledge about HPV was measured using the scale developed by Yacobi and colleagues (1999) and was found to be somewhat higher than among Yacobi's participants. Men scored an average of 4.0 out of 14, compared with 3.9 in Yacobi's study; women scored 5.9, compared with 5.0 in Yacobi's study. As can be seen from these scores, although HPV awareness was higher, specific knowledge about the virus and its effects was still very low.

To date, only two studies have investigated HPV knowledge in UK samples. Pitts and Clarke (2002) surveyed female university employees on their knowledge of smear tests, colposcopy, risk factors for cervical cancer and HPV. Only 30% of the sample had heard of HPV. Knowledge about HPV as assessed in open-ended questions was judged to be 'good' for 17% of the sample. When specific questions were asked, around 30% were aware that it was transmitted sexually and that multiple partners and having a partner with multiple previous partners increase the risk of contracting the virus. Knowledge about the symptoms of HPV was poor, with 77% unsure about whether it was always, sometimes or never symptomatic. Only 20% knew that it affects both men and women, and 11% had a good knowledge of the long term effects of HPV, such as cancer.

Due to the way in which the study is reported, it is not clear whether the 30% who had heard of HPV corresponded exactly with the 30% who knew about its sexual transmission, or whether some of the women who had never heard of it were guessing the answers to subsequent questions. It appears, however, that the majority of those who had heard of HPV had good knowledge of its mode of transmission, but poorer awareness of symptomatology and long term consequences.

The second British study investigated HPV knowledge in a female student sample (Philips, Johnson, Avis, & Whynes, 2003). Consistent with the findings of Pitts and Clarke, 31% of respondents had heard of HPV. Fifty-one percent endorsed HPV as a risk factor for cervical cancer, which implies that many of the women who had not

heard of the virus were guessing. More specific knowledge about HPV was not measured.

1.2. Why is it important to establish HPV knowledge?

It is critical that women participating in cervical screening are aware of HPV and its causal role in cervical intraepithelial neoplasia (CIN) and cancer. Information about HPV has been found to cause confusion among women with no prior knowledge of the virus or its link with cervical cancer (McCaffery et al., 2003b) and smear results which mention ‘wart virus’ (a term commonly used for HPV) are poorly understood (Kavanagh & Broom, 1997). A recent study of HPV testing for the triage of women with borderline or mildly abnormal smear results found that poor understanding of the result was associated with higher anxiety (Maissi, Marteau, Hankins, Moss, Legood, & Gray, 2004). Thus being aware of HPV and having a reasonable knowledge of the virus might be expected to minimise misunderstanding of results, and this could have an impact on levels of anxiety and confusion associated with an HPV result for those taking part in testing. But the association between knowledge and anxiety is by no means established in HPV testing, and it might equally be that very low, as well as very high, levels of knowledge are correlated with low levels of anxiety.

In addition, knowledge is essential for ensuring that women make an informed decision to take part in screening (General Medical Council, 1998). In order to meet the GMC guidelines, women taking part in HPV testing must understand the purpose of HPV testing, the likelihood of a positive or negative result, the implications of a positive result, and follow-up options if they are found to have HPV. Awareness of social implications is specifically included in the guidelines, implying that women must know that HPV is sexually transmitted, and must have thought through the possible implications of a positive result for their relationships.

Knowledge about HPV is also an important component of the Leventhal’s Common Sense Model (CSM). Measuring knowledge is a way of accessing some aspects of women’s cognitive representations of HPV and cervical cancer, but a first step is to establish awareness of HPV, since one cannot hold a cognitive representation of a disease one has not heard of. HPV provides an interesting case study of the way in which illness representations develop for ‘new’ conditions.

1.3. The current study

In this study, HPV knowledge was assessed among women attending a well-woman clinic to investigate the level and accuracy of public awareness of the virus in a context where HPV testing will be carried out if or when it is introduced. Demographic and sexual history predictors of HPV awareness and knowledge were explored.

The survey was part of a larger study investigating self-sampling for HPV testing. The primary aims of the study were to evaluate the sensitivity and specificity of HPV testing on a self-collected sample compared with a sample taken by a clinician, and to evaluate the psychological consequences of testing positive for HPV (McCaffery et al., 2004). The results of these aspects of the study are not presented here. The assessment of HPV awareness and knowledge was carried out at baseline, before women had been given any information about HPV or about the self-test study. An abbreviated version of the results of the survey has been published elsewhere (Waller et al., 2003, see Appendix 2.1).

2. Methods

2.1. Participants

Participants were women attending the Margaret Pyke Centre, an NHS well-woman clinic in central London, run by Camden and Islington Health Authority. The clinic serves a mainly young and affluent population. Speaking English was the only inclusion criterion. Participants' reasons for attending the Centre included having smear tests, seeking contraceptive advice and attending for colposcopy, and are shown in Table 2.1. The reasons for attending in this sample were broadly representative of the clinic as a whole.

2.2. Measures

HPV knowledge was measured as part of a longer questionnaire on cervical screening and HPV (see Appendix 2.2). Knowledge of HPV was measured using a series of questions similar to those used in other studies (Yacobi, Tennant, Ferrante, Pal, & Roetzheim, 1999; Dell et al., 2000; Pitts & Clarke, 2002). Women were asked 'Have you ever heard of HPV?' to which they responded 'yes' or 'no'. Women who reported having heard of HPV were asked how they had heard about it, with response options

‘GP’, ‘Friend’, ‘Family member’, ‘Internet’, ‘TV/Magazine/Newspaper’, and ‘Other (please state)’. They also responded to six statements about HPV with ‘true’, ‘false’ or ‘don’t know’ (see Table 2.4). These statements related to the mode of transmission of HPV (‘HPV is transmitted during sexual intercourse’ and ‘Men can carry HPV’), the relationship between HPV and cervical cancer (‘HPV infection is the main cause of cervical cancer’), and methods of protecting against infection (‘The contraceptive pill can protect against HPV’ and ‘Condoms protect against HPV’). A final item tapped into possible confusion around genital warts, HPV and cancer (‘Genital warts cause cervical cancer’). Women were also asked ‘Do you personally know anyone who has had a positive HPV result?’ to which they responded ‘yes’ or ‘no’.

Demographic characteristics and STI and cervical screening history were also assessed with simple questions (see Appendix 2.2 for a copy of the questionnaire).

2.3. Procedure

Women attending selected clinic sessions at the Margaret Pyke Centre over approximately 15 months between 2000 and 2002 were approached in the waiting room and asked to complete a survey about cervical screening and HPV self-sampling. Smear test clinics were initially targeted to try to recruit women eligible for the self-test trial, but as the study progressed, women were also given questionnaires in other clinics to ensure that the inclusion of women attending for different reasons. Those attending for smear tests were invited to participate in the trial of HPV self-testing mentioned above, the results of which are not presented here.

The study was approved by Camden and Islington local research ethics committee (see Appendix 2.3).

3. Results

3.1. Characteristics of the sample

The response rate was high, with approximately 80% of women who were asked agreeing to complete a questionnaire. Those who declined mostly did so because of time constraints. Of the 1045 women completing the questionnaire, 13 did not respond to the question about having heard of HPV and are excluded from all analyses, leaving a

sample size of 1032. Participants were broadly representative of the clinic population being predominantly young (mean age 30.2 ± 7.7), white (84%), well educated (most had left full-time education after the age of 18) and in full-time employment (73%) (see Table 2.1). Most women were either renting their home from a private landlord (47%) or owned their own home (35%). Equal numbers of women were married/cohabiting (47%), and single (47%). Most (88%) reported having had between one and three sexual partners in the last year and 27% reported a previous diagnosis of an STI. Thirty-four percent were smokers and 26% reported having had an abnormal smear at some time.

Most women were attending the clinic for a smear test (33%) or contraceptive advice (47%) or both.

3.2. HPV awareness

About 30% of women (316 out of 1032) had heard of HPV. Chi-squared tests demonstrated that there were significant, but generally small associations between HPV awareness and demographic characteristics (see Table 2.2). Awareness of HPV increased with age. Only 25% of women aged 16-25 had heard of HPV, compared with 47% of those aged 46 years and over. There were no significant differences in HPV awareness by education, ethnicity, housing tenure, marital status, work status, number of sexual partners or reason for attending the clinic. Women reporting a history of Candida or genital warts had higher awareness of HPV, as did those who reported ever having an abnormal smear result. Not surprisingly, knowing someone who had had HPV was associated with greater awareness. Awareness was lower among smokers (22%) than non-smokers (35%).

Table 2.1 Demographic and sexual history characteristics of the Study 1 sample

	Whole sample (n=1032)	
	%	n
Age		
16-25	30.0	310
26-35	47.9	494
36-45	15.6	161
46 and over	5.5	57
Age of leaving full-time education		
16 and under	8.1	84
17-18	15.7	162
19 and over	74.0	764
Still in full-time education and under 19	0.6	6
Ethnicity		
White	83.7	864
Black	3.4	35
Asian	4.5	46
Other	5.5	57
Housing tenure		
Rent from local authority	5.7	59
Rent from private landlord	47.4	489
Own/buying home	35.0	361
Live with parents	4.5	46
Other	6.2	64
Marital status		
Married/living with partner	47.1	486
Single	47.4	489
Separated/divorced/widowed	4.4	45
Work status		
Working full-time	73.2	755
Working part-time	9.2	95
Not working at present	6.4	66
Student	10.0	103
Do you smoke cigarettes? (yes)	34.3	354
Number of sexual partners in the last year		
None	4.1	42
1	65.8	679
2-3	22.4	231
4 or more	6.2	64
STI history		
Candida (thrush)	51.4	530
Genital warts	10.1	104
Other STI*	20.5	212
Previous abnormal smear result (yes)	26.4	272
Know someone who has had HPV (yes)	8.7	90
Reason for attending clinic		
Smear test	32.7	337
Smear test & contraceptive advice	11.5	119
Contraceptive advice	46.8	483
Colposcopy	2.8	29

*Herpes simplex, Trichomonas vaginalis, Chlamydia, gonorrhoea, anaerobic vaginosis, pelvic inflammatory disease, non-specific urethritis

Table 2.2 Awareness of HPV by demographic characteristics

	Women aware of HPV (n=316)		Difference between groups Chi ² [df] (p)
	%	n	
Age			
16-25	25.2	78	13.3 [3] (.004)
26-35	30.2	149	
36-45	34.8	56	
46 and over	47.4	27	
Age of leaving full-time education			
16 and under	25.0	21	n.s.
17-18	27.2	44	
19 and over	32.3	247	
Still in full-time education and under 19	0	0	
Ethnicity			
White	30.7	265	n.s.
Black	25.7	9	
Asian	28.3	13	
Other	26.3	15	
Housing tenure			
Rent from local authority	23.7	14	n.s.
Rent from private landlord	31.9	156	
Own/buying home	32.1	116	
Live with parents	19.6	9	
Other	28.1	18	
Marital status			
Married/living with partner	31.3	152	n.s.
Single	29.9	146	
Separated/divorced/widowed	28.9	13	
Work status			
Working full-time	31.5	238	n.s.
Working part-time	25.3	24	
Not working at present	31.8	21	
Student	29.1	30	
Do you smoke cigarettes?			
No	34.8	232	17.0 [1] (<.0001)
Yes	22.3	79	
Number of sexual partners in the last year			
None	26.2	11	n.s.
1	30.6	208	
2-3	30.7	71	
4 or more	32.8	21	
STI history			
Candida (thrush)	35.5	188	15.3 [1] (<.0001)
Genital warts	54.8	57	33.8 [1] (<.0001)
Other STI*	35.4	75	n.s.
Previous abnormal smear result			
No	27.0	203	17.9 [1] (<.0001)
Yes	40.8	111	
Know someone who has had HPV			
No	27.6	230	114.2 [1] (<.0001)
Yes	83.3	75	
Reason for attending clinic			
Smear test	31.2	105	n.s.
Smear test & contraceptive advice	40.3	48	
Contraceptive advice	29.8	144	
Colposcopy	24.1	7	

* Herpes simplex, Trichomonas vaginalis, Chlamydia, gonorrhoea, anaerobic vaginosis, pelvic inflammatory disease, non-specific urethritis

When the significant predictors of HPV awareness were entered into a logistic regression model (see Table 2.3), all remained significant independent predictors of

awareness of HPV except experience of an abnormal smear result. The odds of having heard of HPV were 2.40 times greater in the oldest compared with the youngest age group (95% CI: 1.23-4.68). Cigarette smokers were significantly less likely to have heard of the virus (OR=0.52, 95% CI: 0.36-0.74). Those with a history of Candida or genital warts were significantly more likely to have heard of it. The odds ratio for women with a history of Candida was 1.47 (95% CI: 1.06-2.03) and for those with a history of genital warts, it was 2.37 (95% CI: 1.41-3.56). By far the strongest predictor of HPV awareness was knowing someone who had tested positive for the virus, which was associated with increased odds of 11.80 (95% CI: 6.47-21.54).

Table 2.3 Multivariate logistic regression using significant predictors of HPV awareness

Odds ratio of having heard of HPV [95% CI]	
Age	
16-25	1.00
26-35	1.19 [0.82 – 1.74]
36-45	1.20 [0.72 – 1.98]
46 and over	2.40 [1.23 – 4.68]
Do you smoke cigarettes?	
No	1.00
Yes	0.52 [0.36 – 0.74]
History of Candida (thrush)	
No	1.00
Yes	1.47 [1.06 – 2.03]
History of genital warts	
No	1.00
Yes	2.37 [1.41 – 3.56]
Previous abnormal smear result	
No	1.00
Yes	1.28 [0.88 – 1.85]
Know someone who has had HPV	
No	1.00
Yes	11.80 [6.47 – 21.54]

Table 2.4 HPV knowledge among those who had heard of it (n=316 out of total sample of 1032)

	%	n
HPV sexually transmitted (true)		
True	64.9	205
False	7.3	23
Not sure	25.3	80
HPV main cause of cervical cancer (true)		
True	40.2	127
False	15.2	48
Not sure	42.7	135
Men can carry HPV (true)		
True	63.9	202
False	3.8	12
Not sure	29.7	94
Genital warts cause cervical cancer (false)		
True	24.1	76
False	34.2	108
Not sure	38.9	123
The pill protects against HPV (false)		
True	7.0	22
False	55.1	174
Not sure	34.8	120
Condoms protect against HPV (uncertain)		
True	66.5	210
False	9.5	30
Not sure	20.6	65
How did you hear about it?		
GP	18.7	59
Friend or family member	13.9	44
Internet	2.2	7
TV/Magazine/Newspaper	38.3	121
Other	23.4	74

3.3. HPV knowledge

Between 20% and 40% of women who claimed not to have heard of HPV nevertheless responded to the true-false items about it. These responses are excluded from analyses since they must have been guesses, and it does not make sense to evaluate people's knowledge about something they claim not to have heard of.

Among women who had heard of HPV (n=316), knowledge was fairly poor (see Table 2.4). These women generally knew that HPV was sexually transmitted (65%) and could be carried by men (64%), but fewer than half knew that it is the main cause of cervical cancer (40%), and only a third knew that genital warts do *not* cause cervical cancer (34%). The majority believed condoms to be protective (67%) and, worryingly, only half knew that the contraceptive pill does not protect against HPV infection (55%). The

most common sources of information were the media or a GP. Women who had heard about it from an ‘other’ source cited a wide variety including pamphlets, sexual health classes, through having had HPV in the past, or having a medical background.

Chi-squared tests were used to see whether demographic factors that predicted HPV awareness were also associated with responses to each of the knowledge items. Neither smoking status nor history of Candida was predictive of specific knowledge. Age was associated with response to the question on the pill. In the youngest age group, 73% knew that the pill does not protect against HPV, compared with 49%, 52% and 67% in the three older groups ($\chi^2[6]=13.77, p=.03$). Women with a history of genital warts were more likely to know that men carry HPV (80%) than women with no history (63%) ($\chi^2[2]=6.39, p=.04$). Worryingly, those who had experience of genital warts were *more* likely to believe incorrectly that warts can cause cervical cancer (46% compared with 19% of those with no history, $\chi^2[2]=16.98, p<.0001$). Respondents who knew someone who had tested HPV positive were more likely to know that HPV is sexually transmitted (85% compared with 61%, $\chi^2[2]=16.12, p<.0001$), and to know that men carry it (87% compared with 59%, $\chi^2[2]=20.17, p<.0001$). They were also more likely to believe that condoms protect against HPV (80% compared with 66%, $\chi^2[2]=12.88, p=.002$). A greater proportion of this group also knew that the pill is not protective against HPV (74% compared with 51%, $\chi^2[2]=17.00, p<.0001$).

A composite knowledge score was calculated by allocating women one point for each correct answer. As the evidence on condom efficacy is unclear, this item was excluded, giving a scale of 1 to 5. The mean score was 2.86 (± 1.24). T-tests were used to see whether any of the dichotomous demographic or sexual history measures that were associated with HPV awareness also predicted knowledge. A one-way ANOVA was used to compare the four age groups (see Table 2.5). Having had an abnormal smear was associated with higher knowledge ($p=.03$), as was knowing someone who had tested positive for HPV ($p<.0001$). The other factors were not predictive.

Further one-way ANOVAs showed that there were no significant associations between knowledge score and education, housing tenure, car ownership, marital status, ethnicity, number of sexual partners or previous history of an STI.

Table 2.5 Demographic predictors of HPV knowledge score

Demographic factor	N	Mean knowledge score (out of 5)	t	df	p
Age					
16-25	77	3.10	F=1.77	3,294	n.s.
26-35	143	2.71			
36-45	52	2.92			
46 and over	26	2.81			
Do you smoke?					
Yes	76	2.88	0.23	297	n.s.
No	223	2.84			
History of thrush					
Yes	181	2.95	1.19	288	n.s.
No	109	2.77			
History of genital warts					
Yes	53	3.13	1.66	279	n.s.
No	228	2.81			
History of abnormal smear					
Yes	107	3.06	2.14	301	.03
No	196	2.74			
No anyone with HPV?					
Yes	73	3.37	4.14	297	<.0001
No	226	2.69			

4. Discussion

This is the first study to evaluate HPV knowledge among women in a primary healthcare setting in the UK. In the predominantly young and sexually active population, only 30% reported awareness of HPV. This level of awareness is exactly consistent with the UK-based studies of Philips et al. (2003) and Pitts and Clarke (2002). Thirty percent of the university students and employees in these studies reported having heard of HPV.

Given that our sample was highly educated, and there was some evidence of a trend towards poorer knowledge among less educated women, it is likely that knowledge in the general population is even lower. However, the age effect would be in the opposite direction, as the sample was skewed towards younger women who had lower awareness of HPV.

Awareness of HPV was associated with experience of Candida, genital warts or an abnormal smear, indicating that attending for treatment for these might expose women to information about HPV. Knowing someone who has had HPV was another predictor of awareness, although women generally cited the media or their GP as sources of information about the virus.

HPV awareness was lower among smokers, which is of concern as smoking increases the risk of cervical abnormalities and cancer among women with HPV infection (Plummer, Herrero, Franceschi et al., 2003). This effect of smoking status was independent of level of education, and the reasons for it are unclear. It could perhaps be that women who smoke are less interested in health related information. Raising awareness of the virus and the role of cigarette smoking in viral persistence and CIN progression among smokers should be a priority.

Specific HPV knowledge was analysed only for women who claimed to have heard of the virus. Less than two-thirds knew that it was sexually transmitted and that men carry it, and only 40% believed that it was the main cause of cervical cancer. Only a third knew that genital warts do not cause cervical cancer and there was widespread uncertainty about the possible protective role of the pill. It is difficult to compare these results with those of previous UK studies (Pitts & Clarke, 2002; Philips et al., 2003) as these studies have assessed knowledge even among women who have never heard of HPV. It is therefore inevitable that a proportion of women who appear to know about HPV are in fact guessing, probably using cues from elsewhere in the questionnaire. For example in the study by Pitts and Clarke, 120 women report having heard of HPV, but 135 believed that having multiple sexual partners increases the risk of contracting it.

Women's uncertainty about whether the pill protects against HPV partly reflects their lack of knowledge about the sexually transmitted nature of the virus. Of those who knew that HPV is sexually transmitted, 70% were aware that the pill is not protective, compared with only 32% of those who did not know or were not sure that HPV is an STI. It is also possible that the protective role of the pill in other gynaecological cancers might have influenced women's beliefs about its impact on HPV risk.

The majority of women believed that condoms are protective against HPV, although the evidence for this is unclear. It seems likely that condoms provide some protection

(Manhart & Koutsky, 2002), but the message about condom use will need to be clarified so that women can be given consistent information. It is important that the mode of transmission is understood to be skin-to-skin contact so that women can use condoms appropriately to protect themselves.

Among women who had heard of HPV, patterns of specific HPV knowledge between demographic groups are difficult to interpret. The oldest and youngest groups were more aware of the fact that the pill does not protect against the virus than those in the 26-35 and 36-45 age groups. There does not seem to be any obvious explanation for this and it is interesting to note that although in the whole sample HPV awareness increased with age, there does not seem to be a corresponding pattern of increasing knowledge with age among those who are aware of HPV.

Women with a history of genital warts were more aware of the fact that men carry HPV than those with no history of warts. This may reflect that fact that the diagnosis and treatment of genital warts would inevitably involve a discussion of sexual transmission, and if it was explained that the warts are caused by a type of HPV then women would be expected to know that HPV is carried by men. It appears, however, that this group of women is confused about the relationship between HPV, genital warts and cervical cancer, with almost half of them incorrectly believing that genital warts cause cervical cancer. This illustrates the complexity of the information that women must assimilate about the different types of HPV, and the misconceptions that can be engendered by referring to high-risk HPV as 'wart virus'.

Women who reported knowing someone who had tested positive for HPV appeared to be the most well-informed group. They were more likely to know that the virus is sexually transmitted, that men carry it and that the pill is not protective. However, they were also more likely to believe that condoms are protective against HPV which might lead to a false sense of security.

To assess overall HPV knowledge, a composite knowledge score was calculated. The average score was just under 3 out of a possible 5 and only 6.6% of women (n=21) responded correctly to all 5 items. Only two factors were associated with higher overall knowledge: having had an abnormal smear in the past, and knowing someone who had tested positive for HPV. This might be taken to indicate that an in-depth discussion

about HPV, either with a friend who has it, or in the context of the management of an abnormal smear, is necessary to achieve an understanding of the basic facts about the virus. This contrasts with the finding of Pitts and Clarke (2002) that women with a history of abnormal smears or colposcopy were no more likely to be well-informed about HPV than those without.

This low level of knowledge indicates that if these women were to take part in HPV testing, they would need a considerable amount of education to ensure that they were giving informed consent for the screening test. For 70% of women, the test would be for something that they had never heard of, and which they knew nothing about.

Previous studies have suggested that being tested for HPV with such a poor understanding of the virus, and especially testing positive, might be expected to be associated with confusion and anxiety (McCaffery et al., 2003b; Maissi et al., 2004), although the relationship between knowledge and psychological impact needs to be tested empirically.

This study also confirms the fact that most women do not have cognitive representations of HPV. Responses to an HPV positive result, and ways of coping with it, might therefore be highly dependent on the information provided about the virus by the screening programme. If women have no prior awareness of the virus on which to draw, their beliefs are likely to centre on the information provided at the time of testing. This will be investigated in Study 3 (see Chapter 4), and will provide insight into the ways in which people develop illness representations for a novel condition.

4.1. Limitations

This study suffers from several limitations which reduce the confidence with which conclusions can be drawn. Firstly, the sample is very different from the general UK population. The clinic in which the study was conducted is situated in central London, and most of the women attending work in professional occupations in the area around the clinic. This means that patients at the clinic and participating in the study are generally from high socio-economic backgrounds, and are not representative of the wider population. As the clinic does not hold any data on the SES of patients, we cannot be sure of having a sample which is representative of the clinic population.

Women in our sample are also much younger than women in the general population. A very small proportion (5.5%) of women was aged over 45 years, compared with 41% of the female English population,⁹ so our findings cannot be generalised to women in older age groups with any confidence. One could argue that a far greater proportion of younger women are likely to be HPV positive so knowledge in this group is especially important. However, the consequences of testing HPV positive are considerably more serious for older women (both in terms of likely persistence and, potentially, in terms of threat to a long-term relationship), so it is vital that older women are included in HPV research.

In addition, the sample was predominantly white. Although almost 30% of the population of London come from non-white ethnic minority groups,¹⁰ this is not reflected in the clinic population or in our sample. Other studies of HPV knowledge in this country have suffered from the same limitation, and it is important that this problem should be overcome in future work.

Although we estimate the response rate of the study to be high, the exact response rate is hard to determine as women were approached and asked to take part by a number of different people, including the clinic receptionists. No data are available on women who declined to participate in the survey, so the possibility of a systematic bias cannot be ruled out.

4.2. Conclusions

This study found low awareness and poor knowledge of HPV in an affluent sample of young and mainly white women attending an inner-London well-woman clinic. Despite the caveats outlined above, the high level of consistency between these findings and those of other UK studies lends credence to the low awareness identified.

If the low awareness of HPV found in this study is reflective of low awareness in the population as a whole, public education about HPV will be essential. It is important that women participating in cervical screening understand the possible results of the smear test, particularly if HPV testing is introduced. This is essential for ensuring informed participation in screening, and may also have implications for the impact of an

⁹ See <http://www.statistics.gov.uk/census2001/>

¹⁰ See <http://www.statistics.gov.uk/census2001/>

abnormal smear or HPV positive result. Clear and consistent messages about HPV transmission, cancer risk and protection must be developed in order that women are fully informed when they participate in cervical screening.

Further work is needed with more representative samples to gain a clearer picture of levels of HPV knowledge in the wider population.

CHAPTER 3 – BELIEFS ABOUT THE RISK FACTORS FOR CERVICAL CANCER (STUDY 2)¹¹

1. Introduction

Having carried out an initial exploratory study of human papillomavirus (HPV) knowledge on a convenience sample of women in Study 1 (Chapter 2), Study 2 takes a different approach and investigates beliefs about the risk factors for cervical cancer in a representative population sample of both men and women, to establish levels of knowledge that HPV is the main cause of cervical cancer, and awareness of the link between sexual activity and cervical cancer.

For more than a century, the medical profession has known of a link between cervical cancer and sexual activity. Rigoni-Stern published his observations of the low incidence of cervical cancer in nuns as long ago as 1842 (Rigoni-Stern, 1987). But only with the development of tests for HPV has the mechanism for the link clearly been established. Despite the well known link between sexual activity and cervical cancer, the domains of cervical screening and sexual health have tended to remain quite separate, and the role of a sexually transmitted virus in causing cervical cancer has not been emphasised in public health messages. Authors in New Zealand have investigated the discourses surrounding cervical screening policy in that country, and have found evidence of deliberate suppression of information about the link between sexual activity and cervical cancer (Braun & Gavey, 1998; Braun & Gavey, 1999b; Braun & Gavey, 1999a). Fears of stigmatising cervical cancer, and of deterring women from attending screening seem to have been the motivation for the lack of information about sexual behavioural risk factors in the patient literature on cervical screening. In the UK, the most recent National Health Service (NHS) screening leaflet mentions sexual behavioural risk factors (having sex at an early age, many sexual partners and not using condoms) but the involvement of a sexually transmitted virus is not made clear (NHS, 2001). The previous NHS leaflet made no mention of any specific risk factors but did state that ‘cervical cancer is much less common in women who have never had sex’

¹¹ A version of this chapter has been published elsewhere and can be found in Appendix 3.1 (Waller, McCaffery, & Wardle, 2004)

(NHS & Cancer Research Campaign, 1996). Only in the latest Cancer Research UK leaflet on cervical cancer (published in April 2004) is HPV explicitly referred to.¹² The introduction of HPV testing into cervical screening and the management of cervical abnormalities has the potential to make this link explicit, and to change public perceptions of cervical cancer substantially, especially if awareness of HPV and its sexual behavioural risk factors is low. As one author has put it 'Clients and providers will have to learn to live with the new paradigm, one which places the emphasis of prevention not only on women but on their partners as well' (Franco, 2003). As we saw in Chapter 2, few studies have explicitly investigated HPV knowledge. A UK study of female university employees found that around 30% of women reported having heard of HPV (Pitts & Clarke, 2002). Only about 10% were aware that HPV could have long-term implications like cervical cancer. A study of female university students again found that 30% had heard of HPV although 50% endorsed it as a cause of cervical cancer (Philips et al., 2003).

Low levels of HPV knowledge have been found in a variety of samples in the US, with knowledge only reaching higher levels in samples diagnosed with HPV or volunteering for HPV testing (see Chapter 2 for a full description). These US studies have several limitations. Most focus on HPV and genital warts, so only limited conclusions about knowledge of the link between HPV and cervical cancer can be drawn. In addition, none uses representative population samples, and very few include men.

While relatively few studies have assessed knowledge of the role of HPV in the aetiology of cervical cancer, a greater number have investigated beliefs about cervical cancer risk factors more generally. A population survey study in Britain asked people to choose risk factors for cervical cancer from a list of correct responses and distracters (Wardle, Waller, Brunswick, & Jarvis, 2001). In the sample, 51% of men and 67% of women endorsed 'many sexual partners', 21% of men and 28% of women endorsed 'smoking' and 26% of men and 31% of women endorsed 'viruses or infection'. HPV *per se* was not one of the response options. In Australian women aged 50 to 75 years, 32% recognised having many partners as a risk factor, 6% recognised smoking, and 5% recognised both of these (Pearlman, Clark, Rakowski, & Ehrich, 1999). In a large

¹² The leaflet is available at http://www.cancerresearchuk.org/aboutus/publications/pubmisc/pdfs/leaflet_cervical_apr04.pdf

American survey (Breslow, Sorkin, Frey, & Kessler, 1997), 35% of women recognised having many sexual partners as a risk factor and 13% recognised smoking.

Overall, these survey studies indicate that around a third to half of women (or perhaps more in the UK) recognise a link between sexual behaviour and cervical cancer. Other studies have used open-ended questions and qualitative methods to gain an understanding of women's beliefs about cervical cancer and its risk factors, without imposing the constraints of fixed response options. One such study of women from ethnic minority groups in East London (Box, 1998) found that women associated cervical cancer with promiscuity. Sexual activity was clearly regarded as a risk factor, and attending for screening was thought to convey messages about being sexually active. Promiscuity was also cited as a risk factor in a study of working class women in the UK (McKie, 1993a; McKie, 1993b), and was mentioned by some of the women in Posner and Vessey's (1988) study of women who had been treated for cervical abnormalities. In the latter study, the perceived link had been mentioned in newspaper articles and a television documentary around the time that the interviews were being carried out. Building on the work of Posner and Vessey, Palmer and colleagues (1993) found that in women with cervical intraepithelial neoplasia (CIN), 'the sexually transmitted wart virus' was the most-mentioned explanation for their condition, although it is not clear what proportion of women knew this, or whether this was information that they had been given at the time of treatment. Another study of women attending for colposcopy had quite different findings, with 'chance' being the most frequent explanation, cited by 28% of respondents (Gath, Hallam, Mynors-Wallis, Day, & Bond, 1995). The discrepancy between these two findings suggests that the process of having a colposcopy or treatment for cervical abnormalities, and the information provided during the process, might have an impact on women's understanding of cervical cancer aetiology.

Research in the US has also found that women from various ethnic backgrounds know about a link between sexual activity and cervical cancer (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995). For women from Anglo-American backgrounds, this was associated with sexually transmitted infections (STIs), but for some women from Latino backgrounds risky sexual behaviour had moral implications, with cancer seen as a punishment from God. Another study of mainly Latina women who had received abnormal smear results found that sexual activity and 'misbehaviour' were cited by

some as causes of the results. However the authors note that women's explanatory models were complex with different factors emerging as the interview progressed (Karasz, McKee, & Roybal, 2003). Although these studies may point to a relatively high awareness of the link between cervical cancer and sex, it should be noted that in a UK study, women with abnormal smear results seemed not to accept this explanation in their own case (Kavanagh & Broom, 1998).

These studies give hints about knowledge in different populations, and indicate that although people may be aware of a link between cervical cancer and sexual activity, very few know about the role of HPV, an STI. Few of these studies have included men in their samples, which is consistent with a tendency to place the burden of responsibility for sexual health on women (Hart, Duncan, & Fenton, 2002).

In order to understand the potential impact of the introduction of HPV testing on public perceptions of cervical cancer, Study 2 sought to quantify beliefs about the risk factors for cervical cancer, particularly those related to HPV and sexual activity, in a more detailed way than has previously been done in a population sample. Causal beliefs form a key part of Leventhal's cognitive representation of illness (Leventhal et al., 1980; Weinman et al., 1996; Moss-Morris et al., 2002), and might be expected to have an impact on the way in which the public conceptualises cervical cancer. The identification of smoking as the primary risk factor for lung cancer has led to a perceived stigmatisation of that disease in people who have it (Chapple et al., 2004), and if perceptions of cervical cancer change so that the public understand the cause to be an STI, a similar process of stigmatisation and perceived blame might take place. An important starting point in exploring this issue is the investigation of current causal beliefs in the population.

Demographic predictors of beliefs were also examined. Given the sexually transmitted nature of cervical cancer, men and women play an equal role in its aetiology so it is important to establish men's beliefs as well as women's. It is plausible that beliefs might vary with age, particularly as discourses surrounding risk factors may have changed over time, leading to cohort effects. Finally, social class differences in health beliefs are well-established in other domains of cancer-related knowledge (Wardle et al., 2001; McCaffery, Wardle, & Waller, 2003a), and we wanted to see whether they applied in this case. In order to gauge the extent to which the general population

currently perceives a link between STIs, sexual activity and cervical cancer, a large, representative population survey was conducted. Through eliciting beliefs about the causes and risk factors for cervical cancer, we can gain some insight into the current state of public knowledge into which information about HPV would need to be incorporated.

2. Methods

Data were collected as part of the Office for National Statistics monthly Omnibus survey in June 2002. Three thousand addresses were selected from the Postcode Address File of all private households in Great Britain. The sample was stratified by region and socio-economic markers. Attempts were made to contact all households. In households with more than one adult, a random selection procedure was used to select one person aged 16 or over for interview. Computer assisted face-to-face interviews were conducted by trained interviewers in the respondents' homes.

Respondents were asked: 'What do you think are the things that cause a woman to develop cervical cancer or increase her chances of developing it?' The prompt 'What else?' was used to maximise the number of beliefs elicited. This wording has been used successfully in previous surveys (Wardle et al., 2001; McCaffery et al., 2003a). We included the word 'cause' as well as 'increase chances' in case respondents distinguished between something like HPV which is a necessary causal agent, and having many partners, which is a behavioural risk factor. Responses were coded by the interviewer using a coding frame developed from known risk factors for cervical cancer as well other factors which previous literature suggested might be thought to increase risk. Any response which could not be coded was recorded verbatim and coded when all the interviews were complete.

Demographic characteristics were assessed using simple questions.

Table 3.1 Demographic characteristics of the Study 2 sample

	%	n
Gender		
Men	43.7	846
Women	56.3	1091
Age		
16-24	8.4	162
25-34	17.7	342
35-44	19.7	381
45-54	14.9	289
55-64	14.2	276
65-74	13.1	254
75 and over	12.0	233
Ethnic group		
White	92.5	1792
Mixed	0.9	17
Asian	3.9	75
Black	1.9	36
Other	0.6	12
Marital status		
Married/cohabiting	53.8	1043
Single	21.7	420
Separated/divorced/widowed	24.5	474
Age of leaving full-time education		
15 and under	32.2	623
16	28.0	543
17-18	16.0	310
19 and over	22.6	437
Still in education and under 19	1.2	23
Occupation		
Managerial & professional	33.4	646
Intermediate	13.3	258
Small employers/own a/c workers	6.4	123
Lower supervisory & technical	9.9	191
Semi routine & routine	31.2	605
Not classified	5.9	114

3. Results

3.1. Sample

Of the 3000 addresses selected, 266 (9%) were ineligible, leaving 2734 eligible households. Of these, 596 (22%) refused to take part, and 198 (7%) could not be contacted after three visits. The response rate was 71% of eligible households

(n=1940). Three people refused to answer the question on cervical cancer risk factors and are excluded from all analyses, leaving a sample size of 1937. Demographic characteristics of the sample are shown in Table 3.1 and are broadly representative of the British population.

3.2. Risk factor beliefs

Table 3.2 shows the responses, grouped into categories, for men and women. The most common single response after ‘don’t know’ (38.1%) was ‘having many sexual partners’ (25.2%). Beginning sexual activity at an early age was mentioned by 10.5%, frequent sexual activity by 4.1% and sexual activity in general by 5.7%. In total, 35.9% mentioned some kind of sexual activity, either specified or unspecified.

Specific STIs were named by 4.5% of respondents. These included genital warts or wart virus (2.4%), herpes (1.2%), Chlamydia (1.3%), HIV/Aids (0.9%) and HPV (0.6%). Almost 6% mentioned STIs or STDs, but did not name a specific infection. Failure to use condoms was cited as a cause by 6.3%. The total percentage of respondents who mentioned anything relating to an STI/STD or condom use was 13.5%.

When all risk factors relating to sexual activity or STIs were grouped together, 41.4% of people were found to have mentioned at least one of them.

A small number of people (2.6%) mentioned a virus, disease or infection, but did not specify that it was sexually transmitted.

Another widely accepted risk factor is smoking, which was known by 14.1% of respondents. More people believed family history or genetics to play a role (17.6%), with 13.7% mentioning family history of cervical cancer, 5.8% family history of cancer in general, and 0.6% citing genetics or heredity. The contraceptive pill has been linked to an increased risk of cervical cancer by some studies, but this was only mentioned by 5.6% of the sample. Not attending for regular screening was cited as a risk factor by 11.9%, and older age, another well-established risk factor, by only 2.1%. Having many children, which has been associated with an increased risk, was mentioned by 1.4%.

A variety of dietary factors was mentioned, including a low fibre diet (0.6%), low fruit or vegetable intake (1.1%), and a high fat diet (1.4%). In all, 3.5% mentioned something relating to diet.

Other causes mentioned by at least 1% of the sample were fate or bad luck (3.0%), poor hygiene (2.0%), and stress (1.2%). Causes mentioned by fewer than 1% included immunosuppression, young age, obesity or overweight, tampons, alcohol, childbirth, male hygiene or circumcision, exercise, using contraception, radiation, toxins, carcinogens, talcum powder or nothing.

3.3. Demographic differences

3.3.1. *Gender differences*

Chi-squared tests revealed some differences between men and women's risk factor beliefs (see Table 3.2). Women were more aware of the sexual behavioural risk factors: sexual activity ($\chi^2[1]=32.08, p<.0001$), sexual activity or STIs ($\chi^2[1]=25.09, p<.0001$), having many partners ($\chi^2[1]=26.24, p<.0001$) and having sex at a young age ($\chi^2[1]=14.03, p<.0001$). They were also more likely to mention family history or genetics ($\chi^2[1]=9.43, p=.002$) and family history of cervical cancer ($\chi^2[1]=6.52, p=.01$), as well as taking the pill ($\chi^2[1]=9.63, p=.002$) and not attending regular screening ($\chi^2[1]=29.66, p<.0001$). Women were also more likely than men to be fatalistic and believe that fate, chance or bad luck cause cervical cancer ($\chi^2[1]=13.47, p<.0001$). There were no gender differences in knowledge about STIs, condom use, or smoking. Men were significantly more likely to be unaware of any risk factors ($\chi^2[1]=38.38, p<.0001$).

Table 3.2 Risk factor beliefs by gender, with Chi-squared tests for gender differences

Risk factor	All (n=1937) % (n)	Women (n=1091) % (n)	Men (n=846) % (n)	X2 for gender difference (p) df=1
Don't know	38.1 (738)	32.1 (350)	45.9 (388)	38.38 (<.0001)
Any link with sex, STIs or condom use	41.4 (801)	46.3 (505)	35.0 (296)	25.09 (<.0001)
Sexual activity (specified or unspecified)	35.9 (696)	41.4 (452)	28.8 (244)	32.80 (<.0001)
Many sexual partners	25.2 (489)	29.7 (324)	19.5 (165)	26.24 (<.0001)
Early age of first sexual activity	10.5 (204)	12.8 (140)	7.6 (64)	14.03 (<.0001)
Frequent sexual activity	4.1 (79)	4.7 (51)	3.3 (28)	n.s.
Sexual activity (unspecified)	5.7 (110)	5.7 (62)	5.7 (48)	n.s.
Family history/heredity/genetics	17.6 (340)	19.9 (217)	14.5 (123)	9.43 (.002)
Family history of cervical cancer	13.7 (266)	15.5 (169)	11.5 (97)	6.52 (.01)
Family history of cancer	5.8 (112)	6.2 (68)	5.2 (44)	n.s.
Genetics / heredity	0.6 (11)	0.7 (8)	0.4 (3)	n.s.
Smoking	14.1 (274)	15.3 (167)	12.6 (107)	n.s.
STI or not using condoms	13.5 (262)	14.7 (160)	12.1 (102)	n.s.
Not using condoms	6.3 (122)	7.1 (77)	5.3 (45)	n.s.
Any STI (named or unnamed)	8.5 (165)	9.0 (98)	7.9 (67)	n.s.
STD/STI (unnamed)	5.7 (111)	5.9 (64)	5.6 (47)	n.s.
Named STI (warts, Chl, HSV, HPV, HIV)	4.5 (88)	4.6 (50)	4.5 (38)	n.s.
Genital warts/wart virus	2.4 (47)	2.7 (29)	2.1 (18)	n.s.
Herpes virus	1.2 (23)	0.9 (10)	1.5 (13)	n.s.
Chlamydia	1.3 (25)	1.5 (16)	1.1 (9)	n.s.
HIV/Aids	0.9 (17)	0.7 (8)	1.1 (9)	n.s.
HPV	0.6 (12)	0.9 (10)	0.2 (2)	n.s.
A virus/disease/infection	2.6 (51)	2.1 (23)	3.3 (28)	n.s.
Not attending regular screening	11.9 (230)	15.4 (168)	7.3 (62)	29.66 (<.0001)
Contraceptive pill	5.6 (109)	7.1 (77)	3.8 (32)	9.63 (.002)
Dietary factors	3.5 (67)	2.9 (32)	4.1 (35)	n.s.
Misc. dietary factors	1.3 (25)	1.0 (11)	1.7 (14)	n.s.
High fat diet	1.4 (27)	1.1 (12)	1.8 (15)	n.s.
Low fruit / veg diet	1.1 (21)	1.1 (12)	1.1 (9)	n.s.
Low fibre diet	0.6 (11)	0.5 (5)	0.7 (6)	n.s.
Miscellaneous risk factors endorsed by >1%				
Fate/chance/bad luck	3.0 (59)	4.3 (47)	1.4 (12)	13.47 (<.0001)
Older age	2.1 (41)	2.1 (23)	2.1 (18)	n.s.
Poor hygiene	2.0 (39)	1.5 (16)	2.7 (23)	n.s.
Stress	1.2 (24)	0.9 (10)	1.7 (14)	n.s.
Having many pregnancies/children	1.4 (27)	1.4 (15)	1.4 (12)	n.s.
Misc. risk factors (each endorsed by <1%)*	8.3 (161)	9.3 (102)	7.0 (59)	n.s.

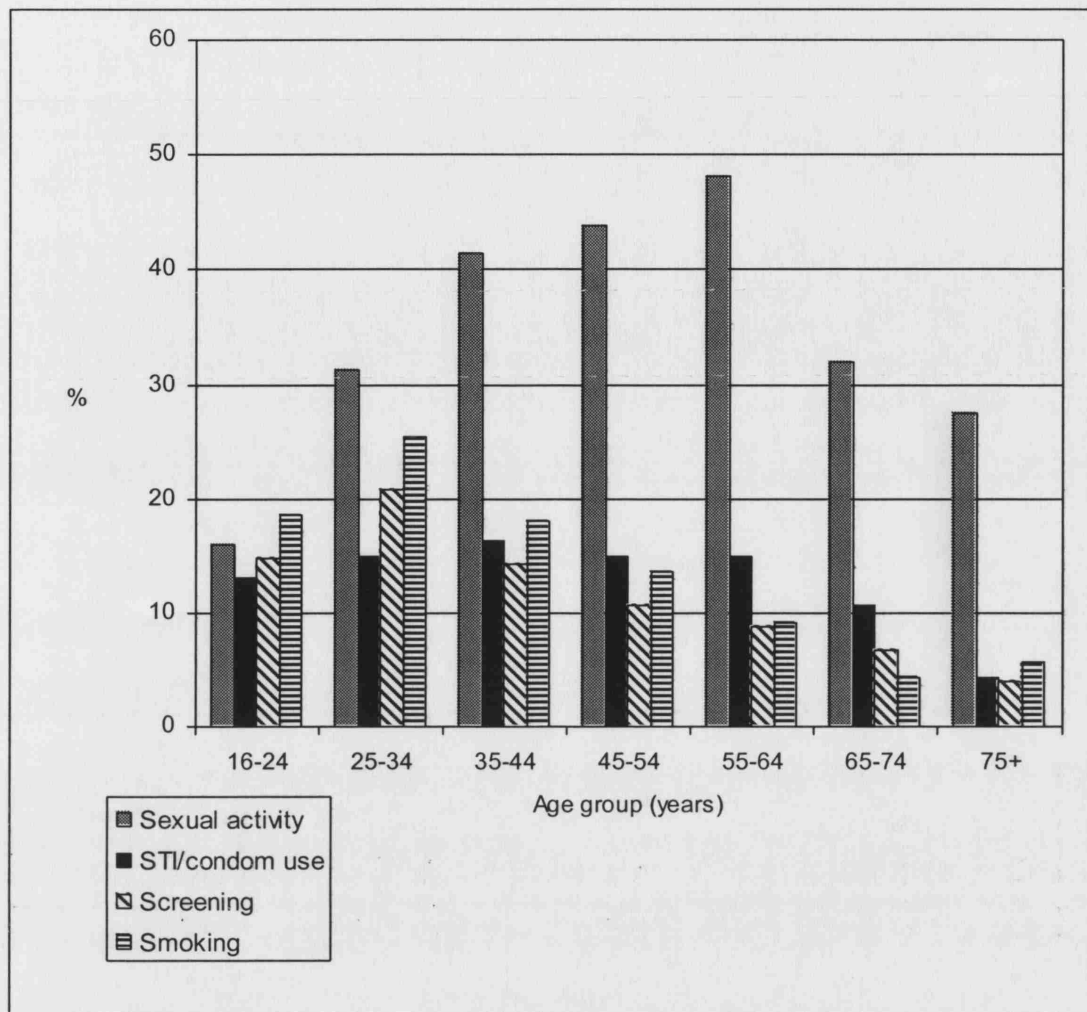
*Risk factors included are: nothing, immunosuppression, young age, obesity/overweight, tampons, alcohol, childbirth, male hygiene/circumcision, exercise/general health, using contraception, radiation, toxins, carcinogens, talcum powder.

3.3.2. *Age differences*

Risk factors for which there was a significant difference by age are shown in Table 3.3. Awareness of most of the risk factors was lowest in the 16-24 and 75 and over age groups, with the oldest group the most likely to respond that they did not know of any risk factors ($\chi^2[6]=68.10$, $p<.0001$). However, the pattern of knowledge across age groups differed considerably between risk factors (see Figure 3.1 for an illustration). The 55-64 age group were most likely to know that sexual activity ($\chi^2[6]=71.22$, $p<.0001$) and having many sexual partners ($\chi^2[6]=67.45$, $p<.0002$) were risk factors, and were also most likely to mention any kind of sexual activity, or STI, or not using condoms ($\chi^2[6]=67.22$, $p<.0001$). The risk associated with becoming sexually active at a young age was best known by the 45-54 group ($\chi^2[6]=29.79$, $p<.0001$). This group also had the highest endorsement of dietary factors ($\chi^2=12.64$, $p=.05$).

The 35-44 age group were most aware of the link between STIs and cervical cancer. They were most likely to mention a named STI ($\chi^2[6]=15.78$, $p=.02$), any STI ($\chi^2[6]=17.42$, $p=.008$) and any STI or not using condoms ($\chi^2[6]=13.49$, $p=.04$).

The 25-34 year olds were most aware of smoking as a risk factor ($\chi^2[6]=83.61$, $p<.0001$), of the need to attend regular screening ($\chi^2[6]=52.91$, $p<.001$) and of the role of the pill ($\chi^2[6]=43.57$, $p<.001$). They were also most likely to believe family history of cervical cancer ($\chi^2[6]=26.45$, $p<.0001$) and family history or genetics in general ($\chi^2[6]=21.15$, $p=.001$) to be risk factors.

Figure 3.1 Risk factor beliefs by age group

3.3.3. *Education differences*

Risk factors for which there was a significant education effect are shown in Table 3.4. Respondents who were under 19 and reported still being in full-time education ($n=23$) are excluded from these analyses. It is notable that, with the exception of becoming sexually active at a young age ($\chi^2[3]=12.97$, $p=.005$), none of the sexual behavioural risk factors showed any differences between education groups, although awareness of the link with STIs increased with increasing education. There were significant differences in most of the other risk factors, with knowledge increasing with higher levels of education. More educated respondents were also more likely to mention risk factors such as family history and stress, for which there is inconsistent evidence. The only response to show the opposite pattern was 'don't know' ($\chi^2[3]=60.25$, $p<.0001$). Almost 50% of those who had left full time education before the age of 16 did not know any risk factors, compared with 29% of those in the most educated group.

Table 3.3 Risk factor beliefs by age group with Chi-square tests for age differences

Risk factor	Age group							X ² for age difference (p) df=6
	16-24 (n=162) % (n)	25-34 (n=342) % (n)	35-44 (n=381) % (n)	45-54 (n=289) % (n)	55-64 (n=276) % (n)	65-74 (n=254) % (n)	75 and over (n=233) % (n)	
Any link with sex, STIs or condom use	24.1 (39)	37.4 (128)	47.5 (181)	50.9 (147)	52.2 (144)	36.2 (92)	30.0 (70)	67.22 (<.0001)
STI or not using condoms	13.0 (21)	14.9 (51)	16.3 (62)	14.9 (43)	14.9 (41)	10.6 (27)	7.3 (17)	13.49 (.04)
Any STI (named or unnamed)	4.9 (8)	10.5 (36)	11.3 (43)	10.0 (29)	9.1 (25)	5.5 (14)	4.3 (10)	17.42 (.008)
Named STI	2.5 (4)	6.4 (22)	6.8 (26)	5.2 (15)	3.6 (10)	2.0 (5)	2.6 (6)	15.78 (.02)
Chlamydia	1.9 (3)	2.6 (9)	2.4 (9)	0.7 (2)	0.4 (1)	0.4 (1)	0	15.99 (.01)
Sexual activity (specified or unspecified)	16.0 (26)	31.3 (107)	41.5 (158)	43.9 (127)	48.2 (133)	31.9 (81)	27.5 (64)	71.22 (<.0001)
Many sexual partners	8.0 (13)	19.3 (66)	30.4 (116)	33.2 (96)	35.1 (97)	22.4 (57)	18.9 (44)	67.45 (<.0001)
Early age of first sexual activity	4.9 (8)	11.1 (38)	13.9 (53)	15.2 (44)	12.0 (33)	6.7 (17)	4.7 (11)	29.79 (<.0001)
Smoking	18.5 (30)	25.4 (87)	18.1 (69)	13.5 (39)	9.1 (25)	4.3 (11)	5.6 (13)	83.61 (<.0001)
Not attending regular screening	14.8 (24)	20.8 (71)	14.2 (54)	10.7 (31)	8.7 (24)	6.7 (17)	3.9 (9)	52.91 (<.0001)
Family history/heredity/genetics	14.2 (23)	24.0 (82)	19.2 (73)	18.3 (53)	16.3 (45)	15.7 (40)	10.3 (24)	21.15 (.002)
Family history of cervical cancer	9.9 (16)	19.9 (68)	15.7 (60)	14.9 (43)	12.7 (35)	11.4 (29)	6.4 (15)	26.45 (<.0001)
Dietary factors	1.9 (3)	4.1 (14)	4.2 (16)	5.9 (17)	1.1 (3)	3.1 (8)	2.6 (6)	12.64 (.05)
Contraceptive pill	3.7 (6)	12.3 (42)	7.1 (27)	3.1 (9)	4.3 (12)	2.4 (6)	3.0 (7)	43.57 (<.0001)
Don't know	45.1 (73)	29.5 (101)	32.8 (135)	33.6 (97)	32.2 (89)	48.0 (122)	56.2 (131)	68.10 (<.0001)

3.4. Multivariate analyses

Logistic regression analyses were used to establish whether the demographic factors had independent associations with beliefs. Analyses were restricted to those risk factors with significant bivariate associations with gender, age and education (see Table 3.5). The odds of mentioning any link with sex, STIs or condom use, early age of first sexual activity, not attending for regular screening, taking the pill, family history of cervical cancer, and family history or genetics in general, were significantly greater for women than men, after controlling for age and education. Women were significantly less likely not to know of any risk factors.

Table 3.4 Risk factor beliefs by age of leaving education with Chi-squared tests for education differences

	15 or under (n=623) % (n)	16 (n=543) % (n)	17-18 (n=310) % (n)	19 and over (n=437) % (n)	X ² for education difference (p) df=3
Any link with sex, STIs or condom use	36.8 (229)	39.0 (212)	46.1 (143)	48.3 (211)	18.13 (<.0001)
STI or not using condoms	8.8 (55)	12.2 (66)	16.1 (50)	19.9 (87)	18.13 (<.0001)
STI (named or unnamed)	5.1 (32)	6.3 (34)	10.3 (32)	14.9 (65)	36.63 (<.0001)
STI (unnamed)	3.5 (22)	4.6 (25)	7.1 (22)	9.4 (41)	18.65 (<.0001)
Named STI	1.9 (12)	3.9 (21)	4.8 (15)	8.7 (38)	28.12 (<.0001)
Genital warts/wart virus	1.0 (6)	2.0 (11)	3.9 (12)	4.1 (18)	13.85 (.003)
HPV	0	0.6 (3)	0.3 (1)	1.8 (8)	14.60 (.002)
Herpes virus	0	0.6 (3)	1.0 (3)	3.4 (15)	30.39 (<.0001)
Chlamydia	0.3 (2)	1.5 (8)	1.3 (4)	2.3 (10)	8.37 (.04)
Virus/ disease/infection	0.8 (5)	2.2 (12)	2.3 (7)	6.2 (27)	29.75 (<.0001)
Early age of first sexual activity	7.4 (46)	10.9 (59)	11.3 (35)	14.2 (62)	12.97 (.005)
Smoking	7.4 (46)	16.8 (91)	19.4 (60)	17.2 (75)	36.55 (<.0001)
Contraceptive pill	2.4 (15)	6.6 (36)	8.7 (27)	6.9 (30)	19.93 (<.0001)
Not attending regular screening	5.3 (33)	14.9 (81)	15.5 (48)	15.6 (68)	39.63 (<.0001)
Family history/heredity/genetics	11.4 (71)	16.9 (92)	24.2 (75)	23.3 (102)	35.60 (<.0001)
Family history of cervical cancer	8.8 (55)	12.5 (68)	18.7 (58)	19.5 (85)	31.48 (<.0001)
Family history of cancer	2.9 (18)	7.0 (38)	8.7 (27)	6.6 (29)	16.30 (.001)
Dietary factors	2.4 (15)	2.0 (11)	3.5 (11)	6.9 (30)	20.33 (<.0001)
High fat diet	0.8 (5)	0.9 (5)	1.0 (3)	3.2 (14)	13.13 (.004)
Low fruit/veg diet	1.0 (6)	0.2 (1)	1.3 (4)	2.3 (10)	10.09 (.02)
Stress	0.5 (3)	0.7 (4)	2.6 (8)	2.1 (9)	10.87 (.01)
Don't know	49.3 (307)	36.8 (200)	29.4 (91)	28.6 (125)	60.25 (<.0001)

There were significant age effects for most of the risk factors analysed. Odds of mentioning anything related to sex were significantly greater in all groups compared with the youngest age group, and were greatest for the 55-64 group (OR=4.59, CI: 2.84-7.43). The 45-54 group had the greatest odds of citing early age of first sexual activity as a risk factor (OR=4.44, CI: 1.83-1-.79). Not attending for regular screening was less likely to be mentioned by the oldest age group compared with the youngest (OR=0.26, CI: 0.11-0.61). The other groups did not differ significantly from the youngest group. There were few differences in knowledge of the contraceptive pill as a risk factor, but the 25-34 group was more likely to mention this than the youngest group (OR=3.65, CI: 1.41-9.48). The same pattern was observed for family history of cervical cancer, with the 25-34 group having an odds ratio of 1.88 (CI: 1.04-3.39). There were no significant age effects for mentioning any aspect of family history, genetics or heredity. Those in the 25-64 groups had smaller odds of not knowing any risk factors than the youngest group.

Education showed a linear association with endorsement of most of the risk factors. The most educated group had significantly greater odds of mentioning anything related to sex (OR=1.91, CI: 1.42-2.57), early age of first sexual activity (OR=1.91, CI: 1.20-3.04), and family history of cervical cancer (OR=2.08, CI: 1.36-3.19). Those who left education at the age of 17-18 were most likely to mention not attending for regular screening (OR=2.07, CI: 1.22-3.50), taking the pill (OR=2.51, CI: 1.19-5.26), and anything related to family history, heredity or genetics (OR=2.33, CI: 1.56-3.49). The least educated group was most likely not to be aware of any risk factors included.

These analyses indicate that the effects of gender, age and education on risk factors beliefs were largely independent of each other.

Table 3.5 Logistic regression analyses using demographic variables to predict risk factor beliefs

OR [95% CI]							
	Any link with sex, STIs or condom use	Early age of first sexual activity	Not attending for regular screening	Contraceptive pill	Family history of cervical cancer	Family history/ heredity/genetics	Don't know
Gender							
Men	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Women	1.73 [1.43-2.10]	1.88 [1.37-2.59]	2.34 [1.72-3.20]	1.93 [1.25-2.97]	1.44 [1.10-1.90]	1.48 [1.15-1.89]	0.51 [0.42-0.62]
Age							
16-24	1.00	1.00	1.00	1.00	1.00	1.00	1.00
25-34	1.85 [1.18-2.92]	2.60 [1.07-6.33]	1.17 [0.69-1.96]	3.65 [1.41-9.48]	1.88 [1.04-3.39]	1.56 [0.93-2.61]	0.60 [0.39-0.91]
35-44	3.09 [1.98-4.82]	3.73 [1.56-8.93]	0.79 [0.46-1.35]	2.06 [0.77-5.48]	1.50 [0.83-2.71]	1.23 [0.73-2.07]	0.64 [0.42-0.96]
45-54	3.81 [2.40-6.07]	4.44 [1.83-10.79]	0.66 [0.37-1.19]	1.00 [0.33-3.07]	1.53 [0.82-2.85]	1.32 [0.77-2.29]	0.58 [0.37-0.89]
55-64	4.59 [2.84-7.43]	3.83 [1.53-9.59]	0.62 [0.33-1.18]	1.66 [0.55-4.96]	1.47 [0.76-2.82]	1.35 [0.76-2.40]	0.45 [0.29-0.71]
65-74	2.45 [1.49-4.02]	2.07 [0.77-5.55]	0.50 [0.25-1.01]	0.96 [0.27-3.35]	1.40 [0.70-2.78]	1.42 [0.78-2.58]	0.85 [0.54-1.34]
75 and over	1.74 [1.04-2.90]	1.36 [0.48-3.90]	0.26 [0.11-0.61]	1.16 [0.34-3.93]	0.72 [0.33-1.56]	0.84 [0.44-1.60]	1.28 [0.81-2.04]
Age of leaving education							
15 or under	1.00	1.00	1.00	1.00	1.00	1.00	1.00
16	1.21 [0.91-1.60]	1.34 [0.84-2.12]	1.94 [1.19-3.17]	1.75 [0.85-3.59]	1.22 [0.79-1.88]	1.46 [1.00-2.15]	0.69 [0.52-0.91]
17-18	1.59 [1.16-2.19]	1.37 [0.82-2.29]	2.07 [1.22-3.50]	2.51 [1.19-5.26]	2.01 [1.29-3.15]	2.33 [1.56-3.49]	0.49 [0.35-0.68]
19 or over	1.91 [1.42-2.57]	1.91 [1.20-3.04]	2.05 [1.23-3.40]	1.83 [0.87-3.86]	2.08 [1.36-3.19]	2.21 [1.50-3.26]	0.45 [0.33-0.62]

In order to test the goodness of fit of each model, a pseudo R^2 was calculated for each one by dividing the model chi-square by the initial -2 log likelihood. The results for each model are shown in Table 3.6.

Table 3.6 Goodness of fit of the logistic regression models

Risk factor	Model χ^2	Initial -2 log likelihood	Pseudo R^2
Any link with sex, STIs or condom use	119.195	2597.182	0.046
Early age of first sexual activity	56.121	1290.134	0.044
Not attending for regular screening	97.935	1405.607	0.070
Contraceptive pill	55.257	830.633	0.067
Family history of cervical cancer	51.323	1542.768	0.033
Family history, hereditary or genetics	54.041	1790.323	0.030
Don't know	142.305	2536.817	0.056

It can be seen from the table that each model on predicted between 3% and 7% of variance in risk factor awareness. This indicates that these demographic variables are not the main contributors to risk factor beliefs.

3.5. Number of causes mentioned

The total number of risk factors mentioned ranged from 1 to 17. The mean was 1.80 (± 1.57). Only 10% of the sample mentioned four risk factors or more. The mean number of risk factors given by men was 1.65, compared with 1.92 for women ($F(1,1935)=13.61$, $p<.0001$). There was significant variation in the number of risk factors cited by different age groups ($F(6,1930)=8.51$, $p<.0001$). The 25-34 year olds mentioned the highest number (2.12), while the oldest group mentioned only 1.37. Number of risk factors mentioned also showed an linear association with level of education ($F(3,1909)=22.38$, $p<.0001$). Those who left school before the age of 16 mentioned an average of 1.45 risk factors, compared with 1.77, 2.04 and 2.19 in the other three groups, in increasing order of education.

4. Discussion

The study used a representative population sample to assess beliefs about the risk factors for cervical cancer in Britain. An open-ended (recall) question format was used. Consistent with previous findings, this seemed to provide a more stringent test of knowledge than recognition tasks where response options are provided (Weinstein, 1999; Waller et al., 2004b). For example, only 30% of women and 19% of men in this study mentioned having many sexual partners as a risk factor, compared with 67% of women and 51% of men in a previous study using a question format that provided response options (Wardle et al., 2001).

Perhaps the most striking finding was the extremely low knowledge of HPV. Less than 1% named HPV as a risk factor. This is in contrast to assertions by some authors that the link between HPV and cervical cancer is well-known (Wright, Jr., Cox, Massad, Twiggs, & Wilkinson, 2002b). The much lower awareness of HPV in this study compared with Study 1 (Waller et al., 2003) and other British research (Pitts & Clarke, 2002; Philips et al., 2003) may partly be a function of the open-ended question format, but probably also indicates that although a larger number of people may be aware of the virus (perhaps in the context of genital warts or sexual health), few know about its relationship with cervical cancer.

There was evidence that only a small proportion of the population is aware of the sexually transmitted nature of cervical cancer. Only about 13% mentioned STIs or not using condoms as risk factors, which indicates that for the majority of the population, information about the role of HPV in cervical cancer aetiology may be at odds with their current beliefs. A greater number of people were aware of a link with sexual activity in general. Thirty-six percent mentioned some form of sexual activity. However, this implies that the mechanism may be understood in other terms, e.g. trauma to the cervix caused by sex, or the transfer to bodily fluids, rather than the transmission of a virus. About 60% of the sample did not mention anything related to sexual activity or sexual transmission, indicating that awareness of the link between sexual behaviour and cervical cancer is far from universal. This suggests that awareness of the link with sexual activity in the general population may be much lower than studies of women attending for colposcopy or treatment for CIN have suggested (Posner & Vessey, 1988; Palmer, Tucker, Warren, & Adams, 1993; Gath et al., 1995).

In terms of other risk factors, more people believed family history to be a factor than either smoking or not attending for regular screening, in contrast to the epidemiological evidence. The associations between cervical cancer and non-attendance at screening and smoking are far more robust than any suggestion of the role of family history. However, in the case of screening, non-attendance might not be seen as a risk factor *per se*, but rather attendance might be thought of as a preventive measure. The format of the question may therefore have led to an underestimation of the number of people who are aware of the importance of screening attendance.

As might be expected for a cancer that only affects women, gender differences in beliefs were found. Women's knowledge of the sexual behavioural risk factors and of the importance of screening attendance was greater than men's, but interestingly there were no gender differences in awareness of the role of STIs. Gender differences persisted once age and education had been controlled for.

Age differences in health related knowledge are well-documented, with people in middle age usually having better knowledge than younger or older people. Interestingly, we found that the pattern of beliefs by age varied between the risk factors. Younger groups were more aware of the risks associated with smoking, not attending for screening and taking the pill, but were also more likely to believe family history to be a risk factor. The 35-44 year olds were most aware of the link with STIs, whereas the older age groups (45-64 years) were most likely to cite sexual behavioural risk factors.

It is encouraging that health education messages about smoking and screening appear to be getting through to young women, which may in part be due to contact with health professionals associated with family planning. However, it is concerning that only about 9% of 55-64 year olds (and 12% of women in this group) cited not attending screening as a risk factor, when women in this age group should still be attending.

The pattern of awareness of sexual behavioural risk factors points to a cohort effect. It seems that older people are much more aware of this link, which may be due to changes in health messages over the years. In an attempt to avoid cervical cancer carrying implications of promiscuity, the behavioural risk factors have been underplayed in favour of an emphasis on screening attendance. It is worrying, however, that young

people (particularly those in the 16-25 age group) are least aware of a link between cervical cancer and sex, when this is the age at which sexual activity is initiated and numbers of new partners are most likely to be high.

The introduction of HPV testing in the US, and the likely introduction in the UK, makes it essential that awareness of the virus is raised. Women participating in HPV testing must be fully informed and aware that they may be diagnosed with an STI (General Medical Council, 1998). Another study that we have done indicated that the prospect of being tested for an STI as part of cervical screening is shocking to women unfamiliar with HPV (McCaffery et al., 2003b) and the findings of the present study confirm that the majority of people are unaware of a link between an STI and cervical cancer.

Stigma associated with both attending for testing for, and diagnosis of, STIs is well-documented (e.g. Gilmore & Somerville, 1994; Duncan, Hart, Scoular, & Bigrigg, 2001; Scoular, Duncan, & Hart, 2001; Cunningham, Tschann, Gurvey, Fortenberry, & Ellen, 2002; Fortenberry, McFarlane, Bleakley et al., 2002) and care must be taken to ensure that the 'promiscuity' model of cervical cancer, which has been so successfully quashed, is not resurrected in light of information about HPV. While a 'right to know' discourse has been advocated to enable women to make choices about their sexual behaviour (Braun & Gavey, 1999b), sensitive information provision will be necessary to prevent women with cervical abnormalities or cancer being blamed or labelled as promiscuous. This might usefully emphasise the high prevalence of HPV and the fact that the majority of sexually active women are likely to come into contact with it at some point. The role played by men in the spread of the virus is also important; a woman with a single sexual partner can easily contract the virus if her partner has had previous partners. Women's and men's information needs must be taken into account when developing education materials (Anhang, Wright, Jr., Smock, & Goldie, 2004).

The findings of this study need to be reconciled to the very different findings of Study 1. In Study 1, 30% of women claimed to have heard of HPV which is in stark contrast to the 0.6% citing HPV as a risk factor for cervical cancer in this study. There are several reasons for this huge discrepancy. Firstly, the samples of the two studies differ dramatically. In Study 1, only women were included and we know that women have higher knowledge of cervical cancer and screening than men. The sample was well-educated, which would also be associated with greater knowledge. Study 2 was a

representative population sample and so provides a much more accurate picture of knowledge in the general population. Secondly, the context and question format was very different. In Study 1, a closed question was used ('Have you heard of HPV?') which may have acted as a prompt to women who might have heard of the virus but knew nothing about it. The questionnaire as a whole would have acted as a cue to retrieval of information about cervical cancer and STIs. In contrast, Study 2 used an open-ended question so respondents had no cue to the retrieval of information about HPV, unless they associated it closely with cervical cancer. In a previous study, we have identified huge differences in cancer-related knowledge depending on the question format used (Waller et al., 2004b).

The two studies taken together provide a suggestion that people's cognitive representations of cervical cancer do not include HPV as a causal component, and that this might be the case, even if people have heard of HPV in another context. Bringing together beliefs about HPV and cervical cancer, and the importance of causal attributions in this process, will be explored in greater detail in the next chapter.

4.1. Limitations

One possible limitation of the question wording is that some people may not have understood the term 'cervical cancer'. If people do not know what cervical cancer is, then it is of course impossible for them to suggest risk factors. It could be that 'cancer of the neck of the womb' or another form of wording would lead to different responses. However, as the screening programme is commonly referred to as the 'cervical screening programme' people may have been confused by reference to the neck of the womb and might not have associated it with attendance for smear tests.

Although the response rate was relatively high, we cannot exclude the possibility that non-responders differed from participants which would limit the generalisability of the findings. However, underrepresented groups, particularly those in lower social class groups and with less education might be expected to have lower knowledge. The findings might therefore represent an overestimation of true knowledge in the population.

4.2. Conclusions

As far as I am aware, this study is the first to assess beliefs about the risk factors for cervical cancer in a representative population sample in the UK, using an open-ended question format. The results indicate that although a significant proportion of the population is aware of a link between sexual activity and cervical cancer, very few seem to hold an aetiological model involving sexual transmission. This suggests that bringing public understanding of cervical cancer into closer alignment with the medical model, which will be essential if HPV testing or vaccination is introduced, will involve a radical change in the way in which people perceive cervical cancer.

CHAPTER 4 – BELIEFS ABOUT HPV AND CERVICAL CANCER AMONG WOMEN PARTICIPATING IN HPV TESTING (STUDY 3)¹³**1. Introduction**

The two preceding quantitative studies have provided evidence of low awareness of human papillomavirus (HPV) in the British population, and low knowledge about the virus among women who might be eligible for HPV screening were it to be introduced in this country. The very low awareness of HPV, and the large number of people who are unaware of a link between cervical cancer and sexual activity, gives an indication that the introduction of HPV screening might alter women's perceptions of cervical cancer. It is important that the impact of HPV testing be established, as screening has already been introduced in the US, and is likely to be introduced in the UK and other countries. The need to evaluate the psychological and social consequences of HPV testing alongside clinical and economic considerations has been highlighted (McCaffery, Waller, Forrest, & Wardle, 2002) and one of the recommendations of a recent International Agency for Research on Cancer (IARC) working group was the evaluation of 'the consequences of using a test for a sexually transmitted agent as a primary screening test in terms of behavioural and psychosocial impact' (IARC, 2004). Chapters 4 and 5 use data from Study 3 to explore two aspects of impact: 1) the impact of participation in HPV screening on women's cognitive representations of HPV and cervical cancer, and 2) the emotional and social impact of testing positive for HPV.

Given the lack of knowledge about HPV in the general population, participants in Study 3 (described in this and the next chapter) and Study 4 (described in Chapter 6) were women who had participated in HPV testing and might therefore be expected to know more about the virus. This enables us to move beyond hypothetical studies of the impact of HPV testing (e.g. McCaffery et al., 2003b) and to find out the views of women who have actually taken part in HPV testing in the context of cervical screening.

1.1. Causal beliefs about cervical cancer

The literature pertaining to people's causal beliefs about cervical cancer has been described in detail in the preceding chapter. Most of the studies reviewed show a lack

¹³ A paper including some of the analyses from this chapter has been published in the British Journal of Cancer (Waller, McCaffery, Nazroo, & Wardle, 2005). A copy of the paper can be found in Appendix 4.1.

of knowledge about the link between HPV and cervical cancer, although, as noted in Chapter 3, some women who have taken part in cervical screening and who have been diagnosed with cervical intraepithelial neoplasia (CIN) hold causal beliefs that are consistent with the medical model of the aetiology of cervical cancer. Although sexually transmitted infection (STIs) are seldom mentioned as the cause of CIN, some women talk about promiscuity or ‘risky’ sexual behaviour in relation to cervical cancer and CIN (Posner & Vessey, 1988; Box, 1998; Palmer et al., 1993; McKie, 1993b; McKie, 1993a; Chavez et al., 1995; Gath et al., 1995; Karasz et al., 2003). But the findings from Study 2 (Chapter 3) clearly demonstrate that a large proportion of the general population is unaware of this link, so information about HPV might be expected to be at odds with many women’s existing models of cervical cancer aetiology.

Information about HPV has the potential to change women’s causal beliefs about cervical cancer, and one of the aims of this study was to explore women’s longstanding causal beliefs, and to try to understand the way in which these change (or do not change) in response to information about HPV. Other dimensions of women’s cognitive representations (see Chapter 1) of cervical cancer are less relevant to the topic of this thesis and so are not considered here.

1.2. Beliefs about HPV

As has been described in Chapter 2, there is generally very low awareness of the existence of HPV, and limited knowledge about the virus even among people who have heard of it. The clinical trials of HPV testing provide a unique opportunity to investigate the way in which women make sense of the information they receive about the virus, and to see whether women testing positive for HPV develop cognitive representations of the virus, as would be predicted by Leventhal’s Common Sense Model (CSM) (Leventhal et al., 1980) (see Chapter 1). The link between HPV and cervical cancer also provides an opportunity to see how women integrate their beliefs about HPV with their beliefs about cervical cancer.

By studying women who are in the vanguard of being informed about HPV, it will be possible to gain a sense of the likely impact of introducing HPV testing more widely, as well as to evaluate the utility of the CSM in describing the way in which people respond to a health threat of which they have previously been unaware.

1.3. The present study

Study 3 provides the data for this chapter and Chapter 5. Findings relating to the emotional and social impact of testing positive for HPV will be the subject of Chapter 5. This will include an examination of the emotional representation, coping and appraisal aspects of Leventhal's CSM.

The aims of this chapter are:

- 1 To explore inductively women's beliefs about HPV following participation in testing.
- 2 To investigate the way in which women reconcile information about HPV, and particularly its aetiology, with existing causal beliefs about cervical cancer.
- 3 To see whether women develop cognitive representations of HPV that fit the dimensions of Leventhal's CSM, as laid out in Chapter 1.

Given the paucity of the research in this area and the sensitive nature both of cancer and STIs, it was thought to be appropriate to use qualitative methods to explore the issues that were important to the women taking part, rather than constraining their responses by using a questionnaire study.

2. Methodology

2.1. Study design

Study 3 consisted of in-depth interviews with 74 women who had participated in HPV testing. The aims of the study were to explore women's beliefs about HPV and its relationship with cervical cancer, and gain an understanding of the emotional and social impact of testing positive for HPV (which will be described in Chapter 5).

The study was approved by the North West Multi-centre Research Ethics Committee (MREC), and local ethnics committees in the Manchester area, as well as at UCL, UCH, St Bartholomew's Hospital and Guy's Hospital were informed about the study prior to local recruitment (see Appendix 4.2 for the MREC approval letter).

2.2. Sampling

Purposive sampling was used to select women to take part in the study. This is a method of non-random sampling which ensures the inclusion of participants who vary on key characteristics of interest to the research (Coyne, 1997). In order to overcome the common limitation of carrying out research on white, middle class participants, white British, South Asian and African Caribbean women were included. These three ethnic groups were selected to contrast in terms of risks of and attitudes towards STIs (Elam, Fenton, Johnson, Nazroo, & Ritchie, 1999). The target sample was 40 white British, 20 South Asian and 20 African Caribbean women. The white British sample was selected to include 20 women from high socio-economic backgrounds and 20 from low socio-economic backgrounds. Women with different levels of education were found to have different beliefs about cervical cancer risk factors in Study 2 (Chapter 3) (Waller et al., 2004a) and women from deprived areas have been shown to differ from women in affluent areas in their screening participation (Baker & Middleton, 2003).

Other demographic variables of interest were age and marital status. It was hypothesised that older women and those in stable relationships might have different responses to their HPV result compared with younger, single women, as a diagnosis with an STI might raise questions about trust and fidelity within their relationships (McCaffery et al., 2003b). We also know from Study 2 that beliefs about the causes of cervical cancer, and knowledge of the established risk factors, vary by age. Women aged 20-64 were included as this was the age range eligible for the national cervical screening programme at the time of the study.

It was considered to be important to include women with normal cytology results as well as women with abnormal smears, to see whether the impact of an HPV positive result would be moderated by the accompanying cytology result.

At the start of the study, only women who had tested positive for HPV were recruited but as it progressed, increasing difficulties were experienced with the recruitment of women from the two ethnic minority groups, particularly HPV positive South Asian women. The sampling strategy was therefore changed to allow the inclusion of some HPV negative women. This is described in more detail below.

2.3. Recruitment

Patients who had taken part in HPV testing were recruited from four centres. As the recruitment methods varied slightly from one to another, they will be described separately.

2.3.1. *Manchester ARTISTIC trial*

The ARTISTIC trial (A Randomised Trial of Screening To Improve Cytology) was run by St Mary's Hospital in Manchester, and screened over 23,000 women for high-risk HPV at the same time as their routine smear, between July 2001 and September 2003. Women were recruited to the trial when they attended for their smear test at their GP or family planning clinic.

Patients were selected at random from the ARTISTIC trial database by the trial coordinator if they were aged between 20 and 64, had received an HPV positive result (although as mentioned already, this later changed), and had received their cytology result. Those who had received an inadequate smear result were excluded until they had returned for a repeat smear test and received a satisfactory result. Approximately 16% of women in the trial tested positive for HPV at baseline, ranging from 39% of those aged 20-24, to 5% of those aged 60-64 (unpublished data).

Women were sent a letter from the principal investigator of the ARTISTIC trial, telling them about the interview study and asking them to opt out if they did not wish to be contacted regarding the study (see Appendix 4.3). A study information sheet was enclosed (see Appendix 4.4). Women were given 10 days to opt out. Those women who had provided a telephone number on the consent form for the ARTISTIC trial were contacted by phone and invited to participate. If no phone number was available, a contact number was searched for using directory enquiries. If a phone number could not be obtained, women were sent a letter asking them to complete a slip with a contact number to be returned in a freepost envelope, or to phone UCL if they were willing to participate. Recruitment letters were sent out in batches of 50 until the sample was complete.

As the study progressed, increasing effort was put into targeting women from the ethnic minority groups. Women taking part in the trial were not asked their ethnic group, so other methods had to be used to reach these women. Letters were sent to women living

in areas of Manchester identified as having high ethnic minority populations, and a computer programme (Nam Pehcham) was used to scan the trial database to identify women with South Asian names (Cummins, Winter, Cheng, Maric, Silcocks, & Varghese, 1999). As very few identifiable South Asian women had tested positive for HPV, the inclusion criteria were broadened to allow the inclusion of some HPV negative women in this group.

2.3.2. Margaret Pyke Centre

A similar protocol was used to recruit women who had participated in a trial of HPV self-testing at the Margaret Pyke Centre, a well-woman clinic in central London (this was the same trial as was used to recruit women for Study 1). Women who had taken part received a letter from the principal investigator of the study, introducing the interview study and giving them the option of opting out (see Appendix 4.5). In this trial, data on ethnic group were available, so women who were self-identified as black or Asian were targeted to try to fill the quotas for the South Asian and African Caribbean groups. Women were contacted by telephone or in writing as before.

2.3.3. Colposcopy Clinic, University College Hospital (UCH)

The UCH colposcopy clinic was added as a recruitment centre part way through the study, as it serves an ethnically diverse population and provided another means of trying to achieve the ethnic minority target samples. Testing for HPV is routinely carried out at the clinic. Women attending the clinic for colposcopy and HPV testing were given an information sheet about the interview study and invited to complete a short demographic questionnaire (including age, marital status, occupation and ethnic group, as well as contact details) if they were interested in taking part. Those who were subsequently found to have HPV, or had had it in the past, were contacted by telephone as before.

It should be noted that the women recruited from UCH (and from Guy's Hospital – see below) differed from those recruited at the other two sites as they had not had HPV testing as part of primary screening, but rather at their colposcopy appointment following an abnormal smear result, or a series of abnormal results.

2.3.4. Colposcopy Clinic, Guy's Hospital

As the study progressed, it proved increasingly difficult to identify and recruit African Caribbean women. The colposcopy clinic at Guy's hospital serves a large African Caribbean community and has computerised records of patients' ethnicity. A study of HPV testing was being carried out at Guy's and women who had taken part, tested positive, and came from an African Caribbean background were written to as before, and given the opportunity to opt out of the study. Some HPV negative African Caribbean women were also included to allow a better comparison with the South Asian group.

2.3.5. St Bartholomew's Hospital

It was originally planned to recruit women from a study of HPV testing being carried out at St Bartholomew's Hospital (the HART study - HPV in Addition to Routine Testing; Cuzick et al., 2003), but it subsequently transpired that the majority of women who were tested for HPV as part of the study were not given their results, so the trial was not suitable for recruitment for this study. However, one participant who had been given her HPV result was recruited from this trial.

Key demographic characteristics (age, education, occupation, relationship status and ethnic group) were ascertained during the recruitment phone call (see Appendix 4.6) or, in the case of the UCH patients, from the demographic questionnaires completed prior to contact (see Appendix 4.7). Women were selected for inclusion according to the demographic information provided, and information about their screening results provided by the recruitment centres. All women participating were provided with an information sheet about the study (see Appendix 4.4).

2.4. Information provided about HPV

All the women taking part in HPV testing were given information about HPV and the test. This varied between centres. Women taking part in the Margaret Pyke Centre self-test study were given a short leaflet informing them about HPV under the following headings:

- What is Human Papillomavirus?
- High risk HPVs
- How do you get HPV?

- If I have a high-risk HPV, does this mean that I will definitely get cervical cancer?
- What about HPV found on a biopsy or smear?
- Treatment of HPV

On the issue of sexual transmission, which is of key importance, women were told ‘Although there may be occasional exceptions, it is thought that HPV is caught during sex’.

Women taking part in the ARTISTIC trial were given minimal information at the time of recruitment. They were told ‘This new test would look for infection in the cervix by the human papillomavirus (HPV). Up to 70% of women have this infection in their cervix at some time but in most cases this clears itself up. However it has been shown that this virus can be associated with abnormal changes later on and so a study is needed to see whether HPV testing would improve screening’. Thus women were not informed about the sexually transmitted nature of the virus prior to participating in testing.

Women testing positive for the virus received a further leaflet with their results which was very similar to the Margaret Pyke leaflet. This included the sentence ‘Although there may be occasional exceptions, it is thought that Human Papillomavirus is sexually transmitted’.

At the UCH colposcopy clinic, women were given an information sheet on HPV and usually had the opportunity to discuss the test with a doctor or nurse while attending the clinic. The sheet contains the following information about transmission ‘HPV infections are spread through skin-to-skin contact. Genital warts are spread by having genital contact or sex with someone who has them already’. It is not made clear how high-risk HPV is contracted, although clinicians reported that sexual transmission was usually discussed during consultations.

Women taking part in HPV testing at the Guy’s colposcopy clinic received information about the trial explaining that HPV testing may help to predict which women with borderline or mildly abnormal smears will go on to develop more serious abnormalities. No further written information about the virus was provided but HPV was discussed during consultations.

2.5. Interview materials

Interviews were in-depth and were structured using a topic guide. The topic guide was developed to address the research questions of the study in a logical and sensitive order, leaving difficult and sensitive issues (e.g. sexual transmission) until later on in the interview, and finishing the interview with more neutral topics to do with future screening. A copy of the topic guide is shown in Figure 4.1. Topic guides have advantages over more structured interview guides. They can be used flexibly to guide the interview and to indicate the areas to be covered, without dictating the wording or the order of questions. This allows the interview to flow naturally, and enables the interviewer to tailor the wording of questions to the language used by respondents. Issues raised by respondents which are pertinent to the research questions can be explored, even if they are not covered by the topic guide.

The topic guide was developed with reference to the existing literature on cervical screening, STIs and HPV. An initial brainstorming session, attended by those involved with the study, as well as two experienced qualitative researchers, was used to generate ideas about what should be covered. I then structured this into a topic guide. Particular attention was paid to developing ways of allowing a discussion of sexual transmission, without telling women that HPV is an STI if they were unaware of this fact. Ways of doing this were developed and refined throughout the fieldwork process.

Figure 4.1 Topic guide for interviews in Study 3

CRC study: Psychosocial impact of screening for HPV - Topic guide
1. Introduction
<ul style="list-style-type: none"> • Thanks. • Introduce self (mention not from medical background) and that will give background about the study first... • Talking to women around the country about how they feel about the new Human Papillomavirus (HPV) test as part of cervical cancer screening. You might remember the last time you had a smear test, you were asked if you would mind taking part in a new HPV test. • Part of the trial is to see if the test improves cancer screening; would like to hear what you thought about the test; we also need to know how women feel about the HPV test results. • This is a study funded by the Cancer Research Campaign. The study will help decide if the screening should be introduced nationally. • Brief outline of the interview: background about you; past experiences of smear tests; what happened when you last had a smear test and the new HPV test; about an hour. • Consent form; Confidentiality; Tape recording
2. General background
Note: Ethnic background and class identity are important so probe for these.
<ul style="list-style-type: none"> • Can you tell me a bit about yourself • Age • Who lives with you (partner, children)? • Employment (current job; usual job if not working; other activities; always done same job?) • Partner's occupation and parents' occupations • Educational background (i.e. qualifications, age of leaving education) • Ethnic background (birthplace; parents birthplace; where educated). Suggested: We're interviewing women from a range of ethnic backgrounds; Can you describe yours? Probe: why? • Religious background
3. Screening history and background knowledge
<ul style="list-style-type: none"> • Can you tell me about the first time you had a smear test? • Age (if trouble remembering, probe with at school/college? Had children? Needed time off work?) • Where had it done (GP; GUM clinic; well-woman clinic); Why there. • How became aware of smear tests (invited to attend; opportunistically offered; part of family planning/contraceptive advice; asked clinic to provide test; given advice); What made respondent think that needed a smear test (e.g. became sexually active; reached certain age; any feelings of coercion; choice;); Why thought it was necessary then; who decided it should happen; What thought purpose of it was. • What information received before the test; informed consent; what is the test looking for? • Since then, what heard about recommended screening ages and frequency; Other sources of info. about cervical screening (leaflets; media; friends) • Screening history • How often been since then (what determines frequency; reasons for continuing with/missing tests; worries when miss test) • Links with other tests (e.g. sexual health check-ups; collecting oral contraceptives)

Figure 4.1 (cont.)

3. Screening history and background knowledge (cont.)
<ul style="list-style-type: none"> • Past experience of abnormal smear (management and impact); past problems with health (sexual; genital; reproductive) • Do friends/family go for smear tests (do they see it as important); Have friends/family ever had an abnormal smear (management and impact of result; how did the respondent find out about it) • Any changes in views about why have smear test; screening patterns • Use of clinic for other tests; treatment of infections; compare with cervical screening experience • Knowledge about cervical cancer • What else heard about cervical cancer? Risk factors; are some people more at risk than others; own perceptions of risk; symptoms; treatment; how common; where heard info from; pick up on STI issue if appropriate; stress no right or wrong answers; if sexual activity a risk factor, why might this be? • Role of smear test in prevention; perceptions of abnormal cells • Way in which cervical cancer is similar to or different from other cancers; beliefs about causes and risk factors for other types of cancer; beliefs/feelings about cancer in general
4. Recent test for HPV – Information and knowledge
Note: probe for previous knowledge about HPV and knowledge/ beliefs about HPV and cervical cancer.
<ul style="list-style-type: none"> • Now can you tell me about the most recent test you had as part of the HPV trial; first of all what you were told about HPV • What info was received before attending? (info about the trial; info about HPV; was info full enough?); what did it tell about the test; how understandable was it; aspects confusing or worrisome • What heard about HPV prior to receiving info about the trial; previous info with smear tests; what does HPV stand for; what is being investigated, looked for; how does it occur in the body; how do you get it • What heard about how HPV test relates to cervical cancer; compared with normal smear test; similarities/differences between the two tests • Why some people get HPV; own risk perceptions • How did respondent decide to have the test? (explore possible partner involvement; was it discussed with friends/family) • Who did respondent tell she was going
5. Recent test for HPV – the test itself
<ul style="list-style-type: none"> • Now I'd like you to tell me about the test itself and what happened when you went. • Where had the test • Who else went (explore issues of interpreters) • Who did the test? (doctor/nurse; man/woman). Explore impact and preferences. • What else happened at the test (explanations; reassurances; differences compared with previous smear tests) • Awareness of difference between the two tests had; differences from usual past test • Information provided about what happens next • Talked to anyone after the test?

Figure 4.1 (cont.)

6. Results – understanding
<ul style="list-style-type: none"> • Now I'd like to ask about the results of the tests you had. • How long waited for results • How results were given (letter; phone; did they come together, or separately?); What information was provided about the results? (written; from health professionals) • Results of the HPV & smear tests (understanding of results) • What does respondent think the results mean – how do they differ? • Reliability of results (reasons for confidence/lack of confidence; beliefs about accuracy of screening generally) • Beliefs about cause of respondent's HPV (specific info. And/or own beliefs about cause)
Note: it may be appropriate to include section 8 on the impact of results here if respondent starts to talk about this.
7. Results – disclosure
<ul style="list-style-type: none"> • Whether talked to anyone about the results (who?) • Reasons for disclosure or non-disclosure • Reactions to disclosure • Intentions to disclose to future sexual partners • Comparison with disclosure of previous smear results • If different, explore reasons (possible impact of STI information)
8. Results – impact
<ul style="list-style-type: none"> • In general, how did the results make you feel? What went through head when got results • Emotional reactions (explore reasons for feelings) • Perceptions of cancer risk (compared with after previous smears) • Impact on sex (even if STIs have not been mentioned); compared to any past experience of infections • Pick up on clues about knowledge of sexually transmitted nature of HPV and discuss if appropriate (disclosure issues; links between cervical cancer and sexual activity; screening in the context of being sexually active); compare, some people mention taboo associated with STIs, do abnormal cells / HPV attract the same taboo or not? • Feelings about the uncertainty of information about HPV
9. Treatment or follow-up
<ul style="list-style-type: none"> • Can you tell me about what happened after you got the results. • What treatment / follow-up was recommended; how felt about what was offered. • Whether attended (reasons why or why not) • What happened if did attend • How does respondent feel about HPV result now (and compared with smear test result; any anxieties, questions or concerns?)

Figure 4.1 (cont.)

10. Changes in self-identity, screening attitudes and intended behaviour
<ul style="list-style-type: none"> • Has having the HPV test changed the way you think about screening for cervical cancer? Explore changes in: • Perceptions of cancer risk (own risk and who is at risk in general) • Perception of well being (self-identity); effect of HPV positive status; perception of self as no longer healthy; vulnerability to illness; impact on other health behaviours • Impact of diagnosis of an STI (if this is understood) • Re-interpretation of smear results of friends/relatives in the past (if HPV is known to be sexually transmitted) • Would have the test again if offered?
11. Improvements to screening in the future
<ul style="list-style-type: none"> • Sort of ways the screening process could be improved (and features of screening that were helpful) • Additional information that would be useful before the test and with the results (enough info before decision to participate?). If results were upsetting, could info received before test have reduced this? • What info would you want a friend/relative who was going to have the test to be given? • Would you recommend the HPV test to friends/family? • Thoughts on the possibility of a national screening programme
12. Closing the interview
<ul style="list-style-type: none"> • How have you found the interview? • Any important issues that haven't been raised, extra comments about HPV or cervical screening in general • While tape still running, explain about possible follow-up study and ask if okay to call about another interview in a year's time. Stress – may not be called; can say no if asked to participate. • Give helpline numbers (as some people still have questions) • Have time to chat about other things after the interview • Reassure about confidentiality and repeat info provided at the beginning

Following an introduction to the study, the first section covered background information and demographic characteristics. As well as being important as a way of allowing the participant to begin talking about something familiar and non-threatening while a rapport was established, this section provided useful information to ensure that the sample was heterogeneous with respect to the characteristics mentioned in the section on sampling.

Participants were then asked about their screening history: when they first went for a smear test, what prompted them to go, what they understood about the test, whether friends and family go for cervical screening and any past experience of abnormal smear results. This provided background about any possible link between attending for

screening and becoming sexually active, social norms around attendance and disclosure of screening participation and results, and women's understanding of the current screening test used, to allow comparison with the HPV test. They were also asked what they knew or had heard about cervical cancer. This section of the topic guide related to the cognitive representations aspect of the CSM, although women were not explicitly asked about all the dimensions. Causal beliefs were explored in detail, as the sexually transmitted nature of HPV (and cervical cancer) was of key importance to the interview. Beliefs about cervical cancer were compared and contrasted with more general beliefs about cancer.

The next section covered HPV knowledge and beliefs, including awareness of the virus prior to participation in testing. Women were asked about the information they were given before taking part, how HPV relates to cervical cancer and what the purpose of the test is. This allowed women to describe their beliefs about HPV, as well as sources of information. This section also elicited their beliefs about the relationship between HPV and cervical cancer to allow an analysis of how the two sets of cognitive representations fitted together.

The fifth section covered women's actual experiences of having the test. This was included to allow women to tell their story in a sequential way, although most of the data are not of interest to the research questions being addressed here. With the South Asian women, it was anticipated that the presence of an interpreter might have had an impact on their experience but in fact none needed an interpreter to be present at their smear test.

Section 6 covered women's receipt and understanding of their HPV and smear results. Of particular interest in this chapter are women's explanations for their results. We were interested to find out whether women would acknowledge that HPV was sexually transmitted in their own case. This section was designed to shed more light on the way in which women's cognitive representations of HPV developed, and the links between their beliefs about HPV and about cervical cancer or abnormal smears.

Section 7 addressed the issue of disclosure of results. Reasons for disclosure or non-disclosure were explored, to try and find out whether HPV was perceived as carrying a stigma which might inhibit disclosure. Comparisons between disclosure of HPV and

smear results were made to find out whether HPV testing changed women's disclosure patterns. Possible implications in terms of, for example, mobilisation of social support were explored.

Section 8 covered the more general emotional impact of the HPV and smear results. The impact covered issues that have emerged in the literature on both STIs and CIN, including anxiety and concern, perceived cancer risk, and feelings about partners and sex. Once again, distinctions between the impact of the HPV result compared with the smear result were drawn out where possible.

Section 9 provided an opportunity for women to continue their narratives and give details about their follow-up recommendations and experiences where applicable. Any on-going concerns about HPV were elicited.

Section 10 attempted to find out whether having a positive HPV result changed the way women felt about themselves in terms of their cancer risk, but also in terms of having a diagnosis with an STI (if this was acknowledged). We also wanted to see whether information about HPV might make women re-interpret their own or others' past abnormal smear results, and see them as having arisen from an STI. Finally in this section, women were asked whether they would take part in HPV testing again.

The final section gave women the opportunity to make suggestions for improving HPV testing, if it is introduced nationally, and to say whether they would recommend the test to others.

The topic guide was revised slightly after the initial interviews. This included adding a section on cancer aetiology, which proved a useful way of accessing women's more specific beliefs about cervical cancer. Small changes were made to the topic guide to adapt it for each centre (e.g. women at the colposcopy clinics were asked to describe the events leading up to their referral). Further changes were made to adapt the guide for use with women who were HPV negative (see below).

The analyses in this and the next chapter focus on certain areas of the topic guide (particularly sections 3, 4 and 6-10).

2.6. Conduct of interviews

The majority of interviews were conducted in the respondents' homes, but some were carried out at UCL or at the respondent's place of work if this was more convenient. All participants signed a consent form to say that they had read the study information sheet and were willing to allow the interview to be tape recorded (see Appendix 4.8).

I carried out 30 interviews and Kirsten McCaffery, who was involved in the study and in the development of the topic guide, carried out seven. The rest were carried out by freelance interviewers. The interviewers were selected to reflect the broad ethnic make-up of the sample. Kirsten McCaffery and I are white British, two interviewers were Pakistani, and one was of Caribbean origin. When she was unable to complete the study, a black African interviewer took over. All the freelance interviewers attended a training session at which they were familiarised with the aims of the study and the topic guide. All interviewers were women. This was thought to be appropriate because of the sensitive nature of the area of research and was made clear to participants in the study information sheet.

A mixture of ethnic matching and mismatching was used, both of which have been argued to have advantages. Matching the ethnicity of the interviewer and participant might be expected to enhance the interviewer's understanding of the account, because of their familiarity with the language, cultural background and sub-texts involved. It can also be seen as reducing the perceived power imbalance of the interview situation. Ethnic matching may also be helpful in gaining access to particular communities (Lewis, 2003). However, mismatching also has advantages. It can reduce the assumptions made by the participant about the interviewer's understanding, leading to a more explicit explanation of the issues under discussion. It has also been found that in some situations, participants are more willing to discuss particular issues with an interviewer from a different ethnic group than they would be with someone from their own community (Rhodes, 1994). Given these different views, and the fact that characteristics like class and age might be just as important as ethnicity, it was felt that using a mixture of ethnic matching and mismatching was most appropriate to the research. The only exception to this was the case of Pakistani women whose first language was not English: these women were matched with Pakistani interviewers to ensure that they could express themselves in their first language.

The interview protocol was altered slightly for the HPV negative women participating in the study. As early interviews showed that they tended to lack any knowledge of HPV (especially those in the ARTISTIC trial who had not received a full information leaflet), these women were invited to read an information leaflet about HPV during the interview so that they could comment about it. The topic guide was amended accordingly.

All interviews were tape recorded and transcribed verbatim. Three interviews were carried out in non-English languages by the Pakistani interviewers. These were translated and transcribed by the interviewers.

All interviews were carried out between June 2001 and December 2003.

2.7. Analysis

Data were analysed using a method known as Framework Analysis which was developed by researchers at the National Centre for Social Research (formerly SCPR) (Ritchie & Spencer, 1994; Ritchie et al., 2003) (see Chapter 1 for more background on this approach and the reasons for using it). This is a matrix-based approach. A thematic framework is developed through familiarisation with a sub-set of transcripts. Emergent themes are arranged into higher order categories to form a series of thematic frameworks or charts, into which summaries from the transcripts are placed. This process is known as ‘charting’. Each case has a line in the framework so that analysis can be by case (by looking horizontally across the framework) or by theme (by looking vertically down a column).

Initial transcripts were read carefully and discussed between members of the team working on the study (Kirsten McCaffery, James Nazroo and myself). The thematic framework was developed in discussion between members of the team and was then tested against a number of transcripts to see whether all data could be summarised within the framework. An iterative process of development was used to make changes to the framework and re-evaluate it until everyone was happy with it. The thematic framework for the study is shown in Figure 4.2. Similarities can be seen between the framework and the topic guide as the broad areas covered in the interview obviously had an impact on the data that emerged.

Figure 4.2 Thematic framework for analysis of Study 3 data

<p>CHART 1: BACKGROUND</p> <p>Study ID number</p> <ol style="list-style-type: none"> 1. Age 2. Social class (education/occupation) 3. Partner status 4. Ethnicity/religion 5. Living arrangements (children) 6. Latest screening results 7. Previous smear results 8. General health status 9. Family health history 10. Misc/other <p>CHART 2: SCREENING TEST HISTORY</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. Circumstances & experience of 1st smear test 2. Decision to participate in first smear test 3. Subsequent participation in screening 4. Attitudes to procedure 5. General beliefs / feelings about screening 6. Friends'/family's experience of screening 7. Misc/other <p>CHART 3: CERVICAL CANCER</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. Understanding of cytology/smear test 2. Understanding of sexual activity as a risk factor 3. Beliefs about causes of CaCx & other beliefs about CaCx 4. Knowledge of screening programme 5. Perceived risk of CaCx 6. General beliefs about cancer 7. Misc/other <p>CHART 4: HPV</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. Prior knowledge of HPV (before test) 2. Understanding of mode of transmission 3. Perceived risk of HPV and STIs in general 4. Understanding of link with CaCx / abnormal cells 5. Impact of HPV info on perceptions of CaCx 6. Current understanding of HPV 7. Purpose of HPV testing 8. Unanswered questions 9. Comparison with other illnesses 10. Other/misc. 	<p>CHART 5: PROCESS AND RESULTS</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. How came to have test & decision to participate & expected outcome 2. Experience of HPV & smear tests 3. Results & how received 4. Understanding & meaning of results 5. Beliefs about cause of +ve results 6. Perceived severity of results & Ca risk 7. Emotional responses to results 8. Impact of results on relationships 9. Confidence in results & screening accuracy in general 10. Impact on perception of self as healthy 11. Misc/other <p>CHART 6: DISCLOSURE</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. Disclosure of previous screening participation & results 2. Disclosure of participation in recent test (prior to results) 3. Disclosure of results 4. Reasons for (non) disclosure 5. Other's reactions to disclosure 6. Friends'/family's disclosure of screening results 7. Misc/other <p>CHART 7: FOLLOW-UP, INFORMATION & FUTURE SCREENING</p> <p>Identifier</p> <ol style="list-style-type: none"> 1. Experience of follow-up/treatment 2. Perceptions of follow-up/recommendations 3. Sources of info (CaCx, smear, HPV, treatment) 4. Feelings about future HPV testing (self/others) 5. Improvements to screening process 6. Misc/other
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Once the thematic framework had been finalised, Microsoft Excel was used to draw up the matrices and to chart the data. Each of the seven thematic charts was laid out on a separate worksheet with a column for each theme and a row for each participant. Every transcript was carefully examined and summaries of each theme typed into the appropriate cell with quotes and page references so that relevant sections of the transcript could easily be re-visited (see Appendix 4.9 for an example). In summarising sections of the transcript, the language of the respondent is used as much as possible.

Once again, initial charting was discussed within the team to ensure that there was consensus about where to summarise particular aspects of the data, and to make sure that the charts would be useful in answering the research questions of the study. Charting was carried out by Kirsten McCaffery and myself. Where possible, we charted each other's interviews, so that we were both very familiar with all the transcripts. By reading back over each other's charts, we were then able to ensure that the summaries corresponded with our memories of the interviews, and that important information had not been missed. Where interviews had been carried out by freelance interviewers, both of us read the transcripts carefully and one of us carried out the charting. The input of more than one person at this stage of the process was essential to maximising the validity and reliability of the analysis.

Once all the data had been organised into charts, analysis began with descriptive accounts of themes, focusing on the data from particular columns of the framework. For example, the theme 'Understanding of sexual activity as a risk factor' in the 'Cervical cancer' chart was examined. Reading through the data in this column revealed a variety of levels of awareness of the link between cervical cancer and sex, from no awareness, through implied links and knowledge of sexual behavioural risk factors, to a conceptualisation of cervical cancer as an STI (see Section 3.3.1 below). Categories within the theme were developed and checked against the data from all the participants until all the data could be summarised within the categories. In some cases, the analysis was more fine-grained than a categorisation of all data from one column. For example, the theme 'Current understanding of HPV' in the 'HPV' chart was broken down into sub-themes relating to different aspects of beliefs about HPV (prevalence, symptoms etc.).

This process of describing the data proceeded to the development of associative and explanatory accounts where patterns in the data are identified and developed. This involved looking for patterns between columns, or between groups of participants (e.g. by HPV status or ethnic group). Excel allows cases to be sorted very easily, which facilitates this kind of examination of the data. Once the descriptive account had been developed, we had intuitive ideas about associations within the data, drawn from the interviews themselves, familiarisation with the transcripts and examination of the charts. For example, it seemed that women who believed that HPV is sexually transmitted experienced more negative emotional responses to testing positive. This intuitive

hypothesis was then tested systematically against the data by examining several columns of the charts together. When particular cases did not fit with the emerging pattern, explanations were sought, which led to the identification of moderating variables.

Typologies were developed to capture the variation within the data where appropriate. This was an iterative process where possible types were developed and then checked against cases, modified and re-checked until all participants could be placed within a type.

Throughout the analysis process, discussion took place between Kirsten McCaffery, James Nazroo and me, to ensure that there was agreement about emerging patterns and associations, and that typologies fit everyone's interpretation of the data. This helped to prevent anyone from misinterpreting the data, and reduced the tendency to focus on interviews which were memorable or which one had carried out oneself.

3. Results

3.1. Sample

The demographic characteristics of the sample are shown in Table 4.1. The target samples for each ethnic group were almost met, with 41 white British women, 17 South Asian and 16 African Caribbean women being interviewed. Two tapes were lost before being transcribed so could not be included in the analysis.

There was a reasonable distribution across age-groups, with women in their 20s, 30s and 40s well represented. The smaller number of women in their 50s and 60s reflects the much lower prevalence of HPV in this age group. Women came from a broad range of socio-economic backgrounds. Employment ranged from cleaners and shop workers to economists and doctors. Level of education ranged from no qualifications to PhDs. Forty-five women had taken part in HPV testing at the same time as their routine smear test, while the rest had had an HPV test while attending a colposcopy clinic following an abnormal smear result.

Demographic characteristics of each of the ethnic groups are shown in Table 4.2. It can be seen that there were some differences between the ethnic groups. Most notably, 10 of the 17 South Asian women tested negative for HPV and this has implications for the comparison of ethnic groups in terms of psychosocial impact (see Chapter 5). Some HPV negative women were recruited in each of the other groups to allow a degree of comparison. Three HPV negative white women were interviewed at the stage of piloting the topic guide and are included in the analyses, along with one woman who was mistakenly recruited for the follow-up study (Study 4), but turned out to have been HPV negative at the baseline of the ARTISTIC trial. Three HPV negative African Caribbean women were also included.

All groups were well-distributed across the age and relationship status groups, although a larger proportion of the South Asian women were married. The South Asian group included women of Pakistani, Indian and East African Asian background, some of whom were born in this country and some of whom were born in their country of origin. The African Caribbean women also varied as to whether they were first or second generation. The cytology results also showed different patterns across the groups – the white women were fairly evenly distributed between normal and abnormal results; the South Asian women mostly had normal smear results (because so many of them were HPV negative); the African Caribbean women mostly had abnormal results (because the majority were recruited through colposcopy clinics). The limitations imposed by these differences will be discussed in more detail later.

Table 4.1 Demographic characteristics of the Study 3 sample (n=74)

Demographic characteristics	n
Age	
20s	22
30s	27
40s	16
50 and over	9
Relationship status	
Single	19
In a relationship (not cohabiting)	11
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
Recruitment centre	
Manchester	30
UCH Colposcopy Clinic	21
Margaret Pyke Centre	14
St Bartholomew's	1
Guy's Colposcopy Clinic	8
HPV result	
Negative	17
Positive	57
Cytology result	
Normal	34
Borderline/mild	8
Moderate/severe	30
Inadequate	2
Interviewer	
Jo Waller	30
Kirsten McCaffery	7
Freelance interviewers	37
Ethnic group	
White British	41
South Asian	17
African Caribbean	16

Table 4.2 Demographic characteristics of the three ethnic groups in Study 3

Demographic characteristics	n		
	White British (n=41)	South Asian (n=17)	African Caribbean (n=16)
Age			
20s	11	6	5
30s	13	7	7
40s	10	3	3
50 and over	7	1	1
Relationship status			
Single	12	3	4
In a relationship (not cohabiting)	6	2	3
Cohabiting	7	2	2
Married	10	9	5
Divorced/separated/widowed	6	1	2
Education			
Left school before 16 / no qualifications	6	2	2
Left school at 16 (GCSEs, CSEs, O levels)	11	0	2
Further education (diploma, BTech etc)	5	3	4
Higher education (degree)	16	10	7
Missing data	3	2	1
Recruitment centre			
Manchester	17	11	2
UCH Colposcopy Clinic	13	3	5
Margaret Pyke Centre	10	3	1
St Bartholomew's	1	0	0
Guy's Colposcopy Clinic	0	0	8
HPV result			
Negative	4	10	3
Positive	37	7	13
Cytology result			
Normal	17	14	3
Borderline/mild	7	0	1
Moderate/severe	15	3	12
Inadequate	2	0	0
Interviewer			
Jo Waller	23	5	2
Kirsten McCaffery	7	0	0
Freelance interviewers	11	12	14
Country of birth			
UK	41	7	5
Elsewhere	0	10	9
Missing data	0	0	2

3.2. Beliefs about HPV

Very few women in the study had heard of HPV prior to participation in HPV testing. Those who had were generally health professionals themselves, or had experience of genital warts, or friends who had had HPV. The beliefs expressed in the interviews therefore related to information received at the time of testing, or that women had sought from other sources following their results.

3.2.1. *Causal beliefs*

Causal beliefs fell into two broad typologies: HPV as sexually transmitted, and HPV attributed to other causes.

The beliefs of women who were to some extent aware of the sexually transmitted nature of HPV can be divided into four sub-groups.

- 1) Sexually transmitted, but not in my case
- 2) Sexually transmitted, but how did I get it?
- 3) Sexually transmitted; I got it from X
- 4) Sexually transmitted; not interested in who it came from

The first group knew that HPV is generally regarded as an STI, but totally discounted this explanation in their own case. An example is a woman who believed herself to be in a life-long monogamous relationship with her husband, and who was certain that she could not have contracted an STI.

The only thing that sticks in my mind ... was it a sexually transmitted thing? ... I just thought well that's not true in my case. I just thought well not everybody that smokes gets lung cancer either, or people that do smoke don't always get it so although it may be that way it's not always going to be the case is it? (W23, age 41, married, HPV+, smear normal)¹⁴

This example illustrates that fact that there might be powerful reasons for women to deny the sexually transmitted nature of HPV, even if they have read the information about it. The ambiguous wording of the information about transmission (see section 2.4) allowed women to hold these beliefs without having to disregard reality completely, and allowed them to avoid dealing with potentially difficult questions about where the virus had come from. This will be discussed further in Chapter 5.

¹⁴ ID numbers are coded W for white, AC for African Caribbean and SA for South Asian

The second group knew that HPV was sexually transmitted but were unable to understand how this could be true in their own case because of their sexual history. These women frequently described feelings of confusion.

I couldn't understand that because I've not had sex in about 4 years. (W14, age 39, single, HPV+, smear normal)

I know that I wasn't sexually active with anybody else so... and with him I've always used condoms so it did worry me how I did get it. (SA9, age 38, separated, HPV+, moderate/severe smear)

The third group knew that they had contracted HPV through sexual contact and tried to establish who the infection came from, usually attributing it to a previous relationship or, in the case of monogamous women, assuming that their partner must have contracted the infection from a previous partner. In some cases, women suspected previous partners of infidelity, but none accused a current partner of this. Some women in this group were unable to work out who the virus had come from.

I've only ever had a relationship with my husband ... It could be that ... my husband had had it and passed it on to me ... it can just lie dormant in women and not give them a problem. (W9, age 42, married, HPV+, borderline/mild smear)

I'm not seeing the person any more...the person that I slept with so it was erm...it was like okay, it has to be him you know. (SA17, age 30, in a relationship, HPV+, moderate/severe smear)

Women in the final group knew that HPV was sexually transmitted but were not concerned about identifying the exact source of the infection. They showed evidence of making sense of their result within the context of their relationship status and history. These were usually women who had had several partners, so being HPV positive did not pose a threat to the integrity of a long-term monogamous relationship.

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. (W31, age 37, divorced, HPV+, borderline/mild smear)

The second typology (lack of awareness that HPV is sexually transmitted) can also be divided into distinct patterns of causal beliefs.

- 1) Cancer model
- 2) HPV is in some people and not others
- 3) Other specific causal beliefs
- 4) No causal beliefs

The first of these can be thought of as the ‘cancer model’. Cancer is commonly believed to be something that strikes out of the blue, without having a specific cause. As HPV is related to cancer, some women made sense of HPV within this model, believing that anyone could get it.

[I] just thought ... maybe just some people do and some people don't, like any type of ... like cancer I suppose, some people get it and some people don't. (W23, age 41, married, HPV+, smear normal)

I think it's like cervical cancer, it can hit you at a certain point in life or you're okay. (W25, age 40, married, HPV+, normal smear)

This integration of beliefs about HPV and cervical cancer will be discussed in more detail below.

A second model was of HPV as something which is either in all of us, or which some people have and some people do not, like a particular gene or characteristic. These women did not regard it as something that is caught, but rather as something that some people have and others do not.

Something in my brain says that she [the doctor] said to me it's not a transmitted thing, she said it's something that women have and don't. It's one of those things. (W37, age 30, cohabiting, HPV+, moderate/severe smear)

The third sub-group comprises other specific causal beliefs which included smoking, genetics, washing powder, tampons, altered immunity and stress. Some women also regarded HPV as something that sexual activity might ‘start up’; rather than being sexually transmitted, it was seen as something that the physical act of sex might cause.

Could be the washing powder, I mean, I don't know. You know [laughs]. You just don't know, do you? And then you get this toxic syndrome, don't you, if you're using tampons, and things like that. (W12, age 48, married, HPV+, borderline/mild smear)

Finally there were women who were unable to articulate any causal beliefs at all. These were generally women who were unaware that they had been found to have HPV, but this group also included a few women who knew that they were HPV positive.

It happens, but she [a friend with HPV] didn't know why. She didn't know whether it was like sometimes things happen, although there was a, that people know whether or not there is reasons for it. I don't know. (W10, age 24, in a relationship, HPV+, normal smear)

It should be noted that these beliefs were not always mutually exclusive. Some women held a series of concurrent causal beliefs, using different explanations to try to make sense of their HPV result in the context of their beliefs about HPV and about cancer, and their own sexual relationship history.

3.2.2. Other HPV beliefs

In addition to holding causal beliefs, many women built up a more sophisticated model of HPV, including a variety of other dimensions, many of which, unsurprisingly, corresponded with the kind of information women were given in the leaflets.

3.2.2.1. *What is HPV?*

HPV was commonly linked with warts or veruccas, but some women had other erroneous beliefs and related it to herpes, fungal infections and bacteria, or thought it was something that is 'produced' by the body rather than being caught. HPV was widely understood to be a virus, and this was often interpreted to mean that you can never get rid of it – cold sores often being given as an example of a virus the symptoms of which can come and go, but which remains in the body forever. For some, the infection was not seen as localised and HPV was thought to be in the blood or, because of its viral nature, to attack the whole body.

Like if you've got erm, a cold sore, herpes. It stays dormant but then now and again you're stressed and it comes up. (AC16, age 36, cohabiting, HPV-, moderate/severe smear)

3.2.2.2. *Prevalence*

Most women thought that HPV was 'common' or even 'normal'. However figures cited varied considerably e.g. 'everybody has HPV or lots of people have HPV'; 'seventy per cent of people have it'; 'I think it's only one in twenty people'. Only a few women

thought that it was rare, although often women were not aware of the high prevalence of HPV at the point of receiving their result.

3.2.2.3. *Symptoms*

There was widespread understanding of the lack of symptoms associated with HPV; however some women did attribute symptoms to the virus, linking it with something not feeling ‘quite right’ or with vaginal discharge. Some women took the lack of symptoms to be reassuring: ‘I’m not getting no symptoms. You don’t go to a doctor if you don’t have symptoms’ (W22).

3.2.2.4. *Dormancy, timeline and clearance*

Many women referred to the fact that the virus can lie dormant in the body and be undetected for many years: ‘it’s just there, dormant’ (AC11). Because of the lack of symptoms, you or your partner could have the virus without knowing about it: ‘there are thousands and thousands and thousands that are all walking about and nobody knows that they’ve got it’ (W15). The fact that it can be there for many years was viewed as reassuring, allowing women to attribute the infection to sexual contacts occurring before their current relationship, and preventing them from suspecting their partner of infidelity. While some women believed that the effects of the virus could take years to come out, others assumed that ‘it shows itself straightaway’ (W20).

Beliefs about the timeline of infection varied. As a virus, HPV was assumed by some to be there forever, while others thought that it could come and go. This was linked with notions of clearance and persistence. Many women knew and took comfort in the fact that HPV could go away on its own, and that it would only cause problems if the infection was persistent. Others were concerned about whether they could ever get rid of HPV, or whether they would have it forever. The immune system was seen by some to play a role in whether the virus disappeared or not: ‘Other people tend to have the virus for longer and it gets a hold, and their immune system doesn’t deal with it’ (W26). Smoking was cited as something that might have a negative effect on the ability of the immune system to fight off the virus. These issues emerged much more strongly in Study 4 and will be discussed at greater length in Chapter 6.

3.2.2.5. *Treatment*

There was variation in beliefs about the possibility of treating HPV. Some women believed that there is no treatment for the virus; others thought that removing abnormal cells would also get rid of the HPV; some thought that there might be other treatment available, like antibiotics, which could be used if it did not clear up by itself.

3.2.2.6. *HPV and men*

The issue of whether men can have HPV was raised, and caused some confusion. Because cervical cancer is something that only women can get, some respondents thought that HPV would only affect women. There was a belief among some that men were carriers of the virus, but were not affected by it: 'But then the males are more carriers than actually ones that, um, the virus doesn't develop as much in them' (SA17). However some women wondered whether men could be tested, and concerns were expressed about transmitting the virus to male partners. These issues will be discussed at greater length in the next chapter.

3.2.2.7. *Links between HPV and abnormal cells and cancer*

Because of the context in which they had been tested, most participants were aware that HPV is causally linked to abnormal cells, having abnormal smear test results or developing cervical cancer. For some women, however, the link was unclear, and there was a relatively widespread belief that research was still being carried out to establish whether a link existed. Confusion was expressed about the fact that you might be able to have HPV without abnormal cells, or abnormal cells without HPV. Some women believed that you could not have HPV if you did not have an abnormal smear, regarding HPV as the next step in a progression of abnormality. There was wide variation in the extent to which women found the idea of a virus causing cancer plausible. These beliefs could be interpreted as being consistent with the coherence dimension of Leventhal's CSM (see section 3.5.3 below).

3.3. **Integration of causal beliefs about cervical cancer and HPV**

The next stage of analysis involved an investigation of women's causal beliefs for cervical cancer, and the way in which their beliefs about the aetiology of HPV were integrated into these existing beliefs. This involved careful examination of the themes relating to women's beliefs about HPV and cervical cancer, and the associations between the themes.

3.3.1. Link between cervical cancer and sex

As would be predicted from the findings of Study 2, there was huge variation in the extent to which women were aware of a link between cervical cancer and sex. Some did not mention any link and had other causal beliefs about cervical cancer, or showed no evidence of having conceptualised cause at all. Those who were aware of a link with sex can be divided into groups. For some, the link was merely implied and never explicit, but for others there was an explicit link between cervical cancer and sexual activity, with various mechanisms suggested, while others actually regarded cervical cancer as a sexually transmitted disease (STD) or STI. In some cases, women had not been aware of the link before participation in HPV screening. Each of these groups will be described in detail below.

3.3.1.1. Implied links

The relationship between starting to have smear tests and the becoming sexually active was commonly mentioned when women described their screening history. Having smears was often associated with early experiences of the contraceptive pill and this was sometimes seen as causally related. Many women expressing these views seemed not to have thought about the reason for the link between onset of sexual activity and cervical screening. But for a number of South Asian women attending for smear tests was clearly linked with becoming sexually active, and was seen as unacceptable for unmarried women. Young South Asian women who were in relationships without their parents' knowledge frequently hid their screening attendance from their parents (see Chapter 5 for a more detailed discussion of these issues in relation to the impact of HPV testing).

3.3.1.2. Sexual behavioural risk factors

Having many sexual partners is a long-established risk factor and one that women talked about. In some cases this was merely cited as something that might increase the chances of getting cervical cancer while other women went on to talk about possible mechanisms. These included STIs or diseases, bacteria transmitted through sex, sperm causing abnormal cells, and abnormal cells themselves being transmitted. It was also thought that the act of sex could make more cells, which could then develop into cancer. Condoms were seen as being protective and uncircumcised men were seen as more risky partners than those who had been circumcised. Sleeping with men who worked in

coal mines was cited as a risk factor, as the coal dust was thought to cause cancer.

Below are two quotes illustrating these kinds of causal mechanisms.

If you think that smoking provokes cancer, lung cancer, because there are foreign bodies [that] piss the cells off around there and that starts abnormal growth, then I suppose, foreign bodies of, you know um... somebody, some other human being's semen, their own bacteria, maybe not very nice, you know, foreskins [laughs] ... I suppose, it would be like smoking. (W7, age 39, single, HPV+, normal smear)

People that worked down the coal mines could give it you ... because of all the black dust if they didn't get showered and washed properly they could give it you. And you think you know well maybe they could if they've got black dust and it's putting it inside you. I mean a lot of that was going on years ago about oh if you worked in a chemical thing, you worked down the mines but nothing was proven. (W22, age 57, in a relationship, HPV+, normal smear)

Having sex at a young age was also cited as a risk factor. Causal mechanisms included having an immature or 'soft' cervix that was susceptible to infection, and young boys being rough during sex which might cause damage.

There was also scepticism about these risk factors. The idea of 'catching' cancer seemed to be at odds with generic beliefs about cancer aetiology and the feeling that anyone is at risk of cancer.

I don't think it can be caught, but I think you could be, you can heighten the risk. I don't know, I don't know exactly what I mean, but I know that I, I would never say that cervical cancer was something you could catch by having sex with somebody else. I don't think you could catch cervical cancer. (W6, age 29, single, HPV+, inadequate smear)

Different groups of women were cited as being more or less at risk of cervical cancer. Nuns and other women who are not sexually active were regarded as being at low risk, as were women who did not have male partners. Jewish women were thought not to get cervical cancer which was attributed to the practice of circumcision in the Jewish community. Muslim women were thought by some to be at low risk because they do not have sex before marriage. The view was also expressed that as Muslim men wash after going to the bathroom, this might reduce the risk among their partners.

I'll always remember her [TV presenter] saying that um that men could help women, it sounds ridiculous, but this is how she put it, by keeping their willies

clean [laughs]. So I often wonder if, I've often thought about that, if, if um the incidence of, of um cervical cancer, if it's lower in Asian women because, as um, Muslim, because when they go to the bathroom, they always have to, always have to wash themselves when they've been on the loo anyway, so I just wonder if, you know, if that's significant, if that would, if that's got anything to do with it. (W11, age 54, married, HPV+, inadequate smear)

'Promiscuity' was associated with cervical cancer, but views were also expressed that 'anyone' could get it, even married women, and that although sexual activity might be a risk factor, it was not the only cause. Even women who talked about the link between sexual activity and cervical cancer cited counter-examples of people getting cervical cancer without being promiscuous. The first of the examples below comes from a woman who had been diagnosed with CIN in the past.

I was quite young and I hadn't had a lot of sexual partners 'cause ... it's all quite a misconception really that it was something that happened if you slept around [laughs]. You know, it would happen to you if you had lots of partners and I hadn't had lots of partners I'd only had the one partner. (W24, age 32, single, HPV+, borderline/mild smear)

I don't think it's anything to do with to be honest how many partners you've had, really. I can't see where it can be. The only thing it can be is a man has got something and he gives it a woman and I'm talking about gonorrhoea syphilis and that kind of thing. Anything else I can't see because if you think a man and woman can be married years and she only has that one man and she gets cancer. So you can't put it down that you've had a lot of partners that cause it. (W22, age 57, in a relationship, HPV+, normal smear)

3.3.1.3. Cervical cancer as an STI

Some women talked about cervical cancer as being sexually transmitted, but this had usually been discovered in the course of taking part in HPV testing.

Until I asked to get involved with this research I never realised that cervical cancer is probably a sexually transmitted disease. Or that seems to be the way things are going. (W33, age 40, divorced, HPV+, normal smear)

A few women, however, had a long-standing awareness of the relationship between cervical cancer and genital warts or STIs. Some were health professionals who had learned about the aetiology of cervical cancer through their training; others were women with a long experience of abnormal smear results.

3.3.2. *Integrating HPV and cervical cancer beliefs*

A typology was developed to try to capture the way in which women integrated or failed to integrate information about HPV into their existing causal beliefs about cervical cancer. The typology is shown in Figure 4.3, and each type is described in detail below.

3.3.2.1. *Non-conceptualisers*

Women in this group did not talk about cause in relation either to cervical cancer or to HPV. They tended to know little about cervical cancer and had very little awareness of HPV. Testing negative for HPV, or having the test as part of the management of an abnormal smear, seemed to be associated with this lack of conceptualisation, although was also present among HPV positive women with serious abnormalities. One example was a South Asian woman who tested negative for HPV. When asked about what caused cervical cancer, she said:

Oh God. I don't know [laughs]. I don't think I've ever thought of it in that sense.
(SA4, age 34, married, HPV-, normal smear)

When asked why she thought some people might get HPV, she said 'I don't know'. Having always had clear smear results in the past, she seemed never to have thought about what might cause an abnormality, and had not read about HPV as her result was negative.

3.3.2.2. *Maintainers*

Women in this group had some level of awareness that HPV is linked to sexual activity. Although most were aware that it could be an STI, other causal explanations were given, and there was widespread belief that HPV was somehow different from other STIs. This group was characterised by a lack of awareness of the link between cervical cancer and sexual activity. Other models of cancer were put forward, with causes including bad luck, chance, family history and smoking. The link between HPV and cervical abnormalities or cancer was generally seen as being ambiguous, or unconfirmed, so women in this group were able to retain their model of cancer as not something that could be linked to sex.

Figure 4.3 Typology of beliefs about the relationship between cervical cancer, HPV and sex

Non-conceptualisers – did not hold causal beliefs about either cervical cancer or HPV, even if they recognised a link between the two.

Maintainers – did not believe cervical cancer to be related to sex. HPV was understood to be linked with sex, but the relationship between HPV and cervical cancer was not well understood so the existing model of cervical cancer was maintained.

Doubters – had some awareness of the link between cervical cancer and sexual activity, but doubted that the link was (always) true. HPV was understood to be linked to sex, but implications for the sexually transmitted nature of cervical cancer not drawn.

Non-integrators – were aware that both cervical cancer and HPV are linked to sexual activity, but did not integrate the two to form a coherent model. Implications for the sexually transmitted nature of cervical cancer were not explicitly recognised.

HPV agnostics – knew about the link between cervical cancer and sexual activity but had very few beliefs about HPV and its causes.

Re-conceptualisers – had not previously been aware of a link between cervical cancer and sexual activity, but since receiving information about HPV they had re-conceptualised cervical cancer as linked to sex.

Integrators – had a long-standing understanding of the link between sexual activity and cervical cancer, and were able to incorporate information about HPV into their existing causal model.

An example is a white woman who did not link cervical cancer risk with sexual activity. She had not been sexually active when she went for her first smear test, and when asked directly whether she believed that sex could affect the risk of cervical cancer, she said no; she thought it ‘just appeared’. She was uncertain about the sexually transmitted nature of HPV, and did not think that the link between HPV and cervical cancer had been established. When asked again about the link between cervical cancer and sexual activity, she said:

I have never thought that you catch cervical cancer through having too much sex. I don't know, that seems laughable because cancer is such a big word and sex is quite pleasurable so you wouldn't expect to get something like that from it.
(W16, age 24, cohabiting, HPV+, normal smear)

This illustrates the clash between the information about HPV and her existing beliefs about cervical cancer. By believing that HPV might not be sexually transmitted, she was able not only to manage her own response to her result (she said at another point in the interview 'if it is sexually transmitted I think I'd feel quite sick'), but also to maintain her current model of cancer as something which does not have easily identifiable causes.

Beliefs in this group were sometimes very complex. Another woman (W5) knew that attending for cervical screening was associated with the onset of sexual activity, but had a very clear model of cancer: 'I think everyone's got cancer in them and it takes ... something to set it off, to wake it up.' Although she had been told that HPV is sexually transmitted, she did not class it as being similar to other STIs. Because she understood that it was linked to cancer, which she did not see as being catching, she believed that you could get HPV in other ways: 'I think it wasn't like a specific thing to, to sex. ... I don't know, I suppose, with it being cancer ... I wouldn't ... associate it with [catching it from] anyone else'.

In some cases, women were clearly aware that HPV is an STI, but they did not conceptualise it as causally related to cervical cancer so, again, were able to maintain their model of cervical cancer separate from sexual transmission.

3.3.2.3. *Doubters*

All the women in this group mentioned the link between cervical cancer and some aspect of sexual activity, be it having many partners, having sex when young, or nuns having low rates of the disease. However, they did not see it as inevitably linked to sex (many doubted the veracity of the link), and held other concurrent causal beliefs. HPV was also linked with sex to some extent, but the causal relationship between the two was not recognised, or had not been thought through sufficiently to make the women reassess their beliefs about cervical cancer, and realise that it is effectively a sexually transmitted disease.

A nurse in this group cited having many sexual partners as an established risk factor for cervical cancer, but seemed unable to reconcile her model of cancer with her beliefs about sexually transmitted diseases. She knew that HPV is an STI, but regarded HPV as very different from cervical cancer.

Well, cervical cancer ... that's not just caused by a sexually transmitted disease. Anyone can, except that, well, no, you're not going to, you're not likely to get cervical cancer if you've never been sexually active, so it is, it is only in, in sexually active people but [Sighs] Well, I don't know, it is, it's just different. Because that's, I mean cervical cancer ... is a killer. The HPV is a, a nuisance, and not necessarily anything that's going to cause you any physical discomfort. (W9, age 42, married, HPV+, borderline/mild smear)

In this quote she seems to be struggling to bring together her medical knowledge about the risk factors for cervical cancer with her lay beliefs about cancer and STIs being very different things.

Other women talked about sexual activity not being the 'sole cause' of cervical cancer, or about knowing people who had had the disease, and it not being related to sex in their case.

The doctors used to say 'Oh if you have more than a certain amount of sexual partners' blah blah blah but ... I know that she was a virgin when she went with [boyfriend's name], so I know she wasn't one of those promiscuous women so then I thought that's a load of crap. (AC7, age 30, in a relationship, HPV+, moderate/severe smear)

These women did not conceptualise the relationship between HPV and cervical cancer clearly enough to necessitate a reassessment of their beliefs.

3.3.2.4. *Non-integrators*

This group was similar to the 'doubters' except that they held firmer beliefs about the causal relationship between sex and cervical cancer, often providing explanations for the mechanism through which this might operate. They were aware of the possibility that HPV could be sexually transmitted, although not all believed it. This uncertainty, together with uncertainties about the relationship between HPV and cervical cancer, prevented them from fully integrating their models of HPV and cervical cancer.

A Caribbean woman in this group held a variety of beliefs about how the relationship between cervical cancer and sex might operate: though ‘unprotected sex’, ‘infections’ and ‘lots of bashing’. She was aware that HPV could be transmitted by sexual partners, but had not fully understood the causal link between HPV and cervical cancer. She said she knew there was a connection between the two, but she didn’t know what it was. Despite knowing that both cervical cancer and HPV are related to sex, she did not apply this to her own abnormal smear and HPV positive result.

Did I think the whole thing was sex? [Pause] Not necessarily. I don’t know. I just thought cancer. [Pause] Yeah because you can get HPV it doesn’t necessarily affect guys as it does women in the same way and it can actually be transmitted through ... sexual partners and stuff. Hence the reason they ask about sexual partners [when you go for a smear] and blah-di-blah and protection and all that kind of stuff. ... I didn’t feel ‘Oh my God I feel dirty and unclean’ ‘cause I didn’t associate the HPV as much to the sexual thing. I was thinking more of the cancer thing. (AC4, age 32, cohabiting, HPV+, moderate/severe smear)

Throughout the interview she expressed as series of slightly contradictory beliefs, clearly trying to make sense of the information about HPV in the context of her pre-existing beliefs about cervical cancer. Ultimately, she did not manage to integrate the different models to give a coherent account of the causal relationships involved.

3.3.2.5. HPV agnostics

Women in this group described a variety of beliefs about the relationship between cervical cancer and sexual activity – some held sophisticated causal beliefs while others doubted the relationship was true. The group was characterised by a lack of understanding of HPV, and particularly by a lack of awareness that it is sexually transmitted. One reason for the lack of awareness of HPV was that women had tested negative for the virus, or had not received their results at the time of the interview, and so either had not received detailed information about HPV, or had not bothered to read it as their result was normal. For others, the HPV result was received at the same time as a smear result and was interpreted as being another test for the same thing.

An example of this was a woman who tested positive for HPV but had a normal smear result (W25). She had heard of a link between cervical cancer and number of sexual partners, but did not think that it could be true, believing that cancer ‘can hit anyone’.

She believed that HPV was ‘something connected with the smear’ and so thought that ‘it’s like cervical cancer; it can hit you at a certain point in life’. In the absence of any beliefs about HPV, she seemed to extrapolate from her beliefs about cervical cancer to construct causal attributions for the virus.

3.3.2.6. *Re-conceptualisers*

This group was characterised by a lack of previous understanding of the link between sexual activity and cervical cancer. Information about HPV was therefore incompatible with pre-existing beliefs about the aetiology of cervical cancer, and forced a change in women’s model of cancer, which was often associated with feelings of shock. Women in this group were different from those in previous groups, in that they had read and understood the information about HPV and had often sought additional information, frequently leading to a sophisticated understanding of the virus and its link with cervical cancer.

A white woman described her reaction when she realised that cervical cancer was caused by a sexually transmitted virus.

When I got the HPV I was horrified to discover that sex could lead to cancer. Yeah. So that was new information to me I remember the shock of discovering that and thinking everybody should know about this. It’s really shocking.
(W20, age 37, single, HPV+, moderate/severe smear)

A South Asian woman expressed similar views and wished that she had known sooner about the link, in order to make changes to her behaviour once she had HPV.

It was only a week before I was going to go for the treatment that I actually did a lot of research and it was only then that I realised that it is actually sexually related because I was under the impression that it was just my cells going crazy in me having cancer all of a sudden. ... The information about where it actually originates and how you can deal with it can help a lot. ... I would have ... insisted on, say, condoms ... so it would have made a world of difference. (SA17, age 30, in a relationship, HPV+, moderate/severe smear)

Many of these women expressed a sense of surprise and disbelief that they had never heard about the link between cervical cancer and sexual activity before. They were frequently well-educated women who took an interest in health issues, and were astonished that they had never heard of it. For some there was a sense of anger that doctors must have been aware of a link between cervical cancer and sex, but that this

information was not in the public domain, in what one woman described as a ‘conspiracy of silence’.

3.3.2.7. Integrators

This group was made up of women who had previous awareness of the link between sexual activity and cervical cancer, and who were able to integrate the new information about HPV into their existing causal framework. The extent to which cervical cancer was therefore seen as a sexually transmitted disease, and to which this was made explicit in the interview, varied.

A white woman described her longstanding belief that the incidence of cervical cancer is lower in ‘Jewish ladies’ and nuns. This made her think that ‘it’s obviously down to some kind of sexual preference and possibly foreskin’. However the information about HPV made this much more explicit, and caused a shift in her model of cervical cancer towards a sexually transmitted aetiology.

Before I heard about this [HPV] I would have just classed [cervical cancer] as the same form of cancer. Since I’ve heard about this and talked to people I would say it’s totally dissimilar to any other kind of cancer. ... It almost feels like it’s more of, like a sexual transmitted disease. It’s that, it’s picking up something off a sexual partner that’s causing the cancer where there’s no other kind of cancer that you can catch, basically, from somebody else. (W33, age 40, divorced, HPV+, normal smear)

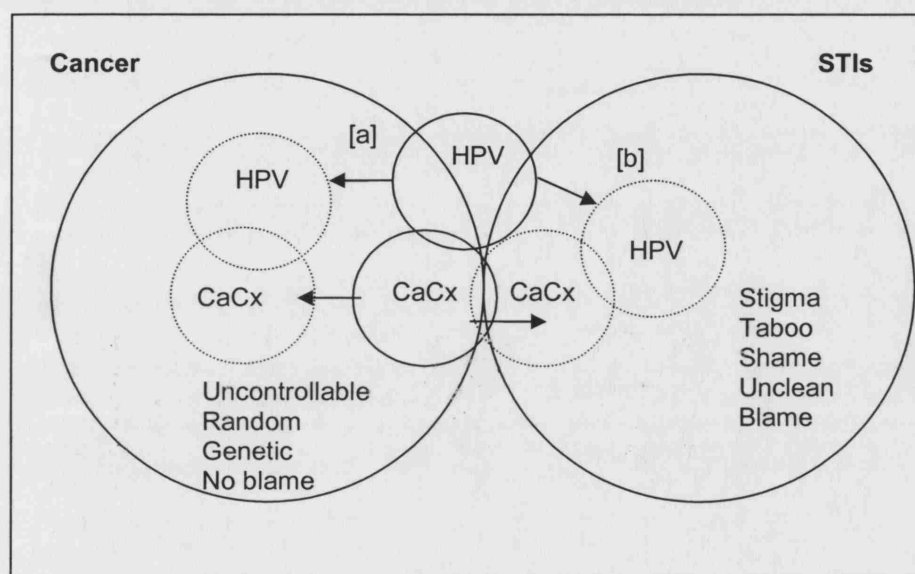
This account illustrates a shift in the conceptualisation of cervical cancer so that it is now thought to be more similar to a sexually transmitted disease than to other cancers.

Figure 4.4 illustrates the way in which conceptualisations of the relationship between cancer, cervical cancer, HPV and STIs might change with increasing awareness of, and information about HPV. At the moment, cancer and STIs are generally understood to be very separate spheres. Cancer is often seen as being uncontrollable and unpredictable, to be random or genetic, and people with cancer are not generally blamed or stigmatised. STIs, by contrast, are highly stigmatised. People with STIs are often regarded as having behaved in an unacceptable or deviant way which has led to the infection. Infections carry associations of being ‘unclean’ and of shame. Current uncertainty and lack of knowledge about HPV means that it is not conceptualised as being firmly within one sphere or the other. Cervical cancer is generally seen as falling

within the cancer sphere, although there may be a slight overlap into the field of STIs. This quote illustrates the difficulty women have in reconciling the two areas, and the desire for HPV to be clearly identified either as an STI, or as something to do with cancer.

There needs to be more definitive notion of it. Is it an STI? Is it to do with cervical cancer? Because it's kind of in between ... I don't know which people would find easier as an STI or to do with cervical cancer to be honest, but I think just having this kind of unknown thing makes it unnerving (AC11, age 21, in a relationship, HPV+, moderate/severe smear)

Figure 4.4 Models of cervical cancer, HPV and STIs



As perceptions shift, there are two possibilities, both of which are illustrated in the preceding typology. Firstly, HPV might be brought into the cancer sphere (see [a] in Figure 4.4) because of its link with cervical cancer, and the associations with other STIs could be played down. This is the case with the *Maintainers*, the *Doubters*, and the *Non-integrators*. Alternatively, HPV might be conceptualised as an STI (see [b] in Figure 4.4) and its relationship with cervical cancer might drag cervical cancer across into the sphere of STIs. This is illustrated by the *Re-conceptualisers* and to a certain extent by the *Integrators*. The pattern of perceptions is likely to be influenced by prior beliefs about the association between sexual activity and cervical cancer, as well as the extent to which information about HPV has been read, understood and thought through in the context of cervical cancer. We have also seen that women's sexual history may be a powerful factor in predicting the extent to which they are willing to acknowledge the sexually transmitted nature of HPV. If information is presented as ambiguous (e.g.

‘Although there may be occasional exceptions, it is *thought* that HPV is caught during sex’), women are able to interpret it in a number of ways. The degree to which the sexually transmitted nature of HPV is emphasised in public information is also likely to have an impact on the way in which it is conceptualised.

If cervical cancer comes to be perceived as a sexually transmitted disease, this has implications for the impact of abnormal smear results as well as positive HPV tests. This will be explored in the next chapter.

Most of the women who tested negative for HPV fell into the *Non-conceptualiser* and *HPV agnostic* categories. Interpreted within Leventhal’s CSM, this means that there was no illness threat for these women (i.e. no positive result), so they seemed not to build up a cognitive representation of HPV. It may therefore be that HPV testing only has an impact on beliefs about cervical cancer in women who test positive for the virus and are therefore motivated to attend to information about it.

3.4. Beliefs about STIs

The interviews were not specifically designed to elicit women’s beliefs about STIs but where HPV was recognised as sexually transmitted, and sometimes where it was not, more general beliefs about STIs were discussed.

Unlike cervical cancer, STIs were very widely perceived to be associated with ‘sleeping around’ or with ‘promiscuity’ and even if this slightly derogatory language was not used, women believed that those with many sexual partners were more at risk. This was the case even where women recognised the possibility of catching an STI from a single partner.

The image isn’t great. The reputation, association, isn’t great. Um... you know, and, and like all these things, I mean, you could get genital warts by having your very first sexual encounter with a person that you totally love, and never have another partner in your life and you can get, you know, AIDS, genital warts, you know, herpes, the whole lot, so realistically, you can’t make judgements (W7, age 39, single, HPV+, normal smear)

The association with promiscuity was linked to beliefs that STIs carry a stigma, are shameful, dirty and taboo.

In some cases, different STIs were seen to have different meanings and associations. Those which are untreatable were sometimes seen as being more stigmatised than those which can easily be treated.

HIV [is] a sexually transmitted thing and then there may be some stigma involved with it. Like I say if you've got thrush or something like that you just get the treatment and that's it but [HPV] sounds like, I don't know, like gonorrhoea sounds absolutely terrifying doesn't it? It just sounds terrible. Really does!
(W36, age 44, single, HPV+, moderate/severe smear)

3.5. HPV and illness representations

Some of the dimensions of the cognitive representation component of Leventhal's CSM emerged very strongly from the interviews and have been discussed in detail already (e.g. cause). After carrying out the initial inductive analyses described above, data about women's beliefs about HPV were explored explicitly to see whether they fit the dimensions of the cognitive representations component of the model (described in detail in Chapter 1). The emotional representations, coping and appraisal aspects of the model will be explored in the next chapter.

3.5.1. *Stimuli*

For the women in this study, the results letter was the stimulus providing information about the health threat, whether this was an HPV positive result, or an HPV positive result and an abnormal smear result. The combination of two results means that the parallel processing model must to some extent account for responses to both. This might involve developing illness representations for both HPV and cervical cancer.

Women who tested negative for HPV and had a normal smear result were not exposed to a health threat, and therefore tended not to develop any cognitive representation of HPV.

3.5.2. *Cognitive representation of health threat*

3.5.2.1. *Identity*

HPV is an example of an asymptomatic condition. Most women in the study were aware that there are no symptoms, but some were confused about the label – human papillomavirus was a difficult name to remember which often made the identity component of the representation weak.

As described earlier, some women believed that they had symptoms associated with HPV: ‘Even before I had my smear I knew I didn’t feel quite right down there anyway. ... Discharge. Bit smelly, you know, having a bath two or three times a day. I was thinking I’m not feeling right down there’ (W29). Others used the lack of symptoms to more or less dismiss anything being wrong. This woman did not develop any kind of model of HPV.

I’m not getting no symptoms. You don’t go to a doctor if you don’t have symptoms. I don’t go back and ask, I’ve got no symptoms but is this this? I don’t do that. If you had symptoms something was causing it yeah that’s when you go and see. But as I was getting nothing I thought I must be all right else my doctor would have wrote and said come back here quick! (W22, age 57, in a relationship, HPV+, normal smear)

It seems therefore, that being given in a label that they were not familiar with, in the absence of any symptoms, was confusing for some women, and that they dealt with it in different ways. For some women, the abstract label (HPV positive) was enough to trigger the development of illness cognitions but for others, the lack of concrete symptoms seemed to make the threat so insignificant that they hardly thought about it.

In the absence of a clear identity for HPV, some women seemed to try to link it with existing beliefs about other, similar, conditions. These included warts, herpes, verrucas, bacterial and fungal infections.

3.5.2.2. Cause

Women’s beliefs about the causes of HPV and of cervical cancer have been discussed in detail above. We have seen that many women developed causal beliefs for HPV, and these were integrated into their existing models of cervical cancer to a varying degree. In terms of the impact of results, the key distinction was between women who knew that HPV was an STI, and those who did not. This will be discussed at greater length in Chapter 5.

We have also seen that some women were unwilling or unable to acknowledge that HPV is an STI. This might indicate that the motivation to protect the integrity of their relationship (by believing in alternative aetiological pathways) was over-riding the desire to understand the health threat. This is will be discussed in more detail in the Discussion section below.

3.5.2.3. Control

This dimension captures beliefs about the extent to which a health threat or illness can be controlled or treated. As we have seen, women varied in whether they believed that HPV could be treated. Some were aware that there is no treatment for the virus itself. Others knew that there was effective treatment for abnormal cells if these developed. Some women wondered whether HPV could be treated with antibiotics.

In addition to treatment, the immune system was cited as a factor that might influence the course of the virus, and smoking was seen as something that might impair the ability of the immune system to fight off the virus. In general though, HPV was seen as quite uncontrollable – something that could clear up by itself but that could not be actively controlled.

I have got something, there is nothing that you can do about it, it [the leaflet] explains that there is nothing, there is no treatment so basically you've got something in your body that you weren't aware of before that you're not very happy about and there is no help and nothing can be done about it. (W15, age 56, divorced, HPV+, normal smear)

3.5.2.4. Timeline

The current medical understanding is that HPV is usually cleared within eight months of infection (Ho, Bierman, Beardsley, Chang, & Burk, 1998) but other aspects such as latency and whether the virus is ever truly eliminated are still unclear. Women's accounts seemed to reflect this lack of certainty. As described above, women had varying beliefs about dormancy, having the virus for a long time without knowing it, spontaneous clearance by the immune system and recurrence. Again, women frequently drew on their models of other viral infections like herpes, and concluded that HPV infections could come and go but would always be in the body. For those who knew that HPV is an STI, notions of sex and re-infection fed into their beliefs about the timeline of the virus. This example illustrates the confusion that was common.

From my O level biology, once you've got a virus you've got it forever. As I understand [HPV] once it's cleared up it won't come back unless I'm re-infected by a new strain of HPV virus with a new partner ... if my body's own immune system doesn't clear that up and it shows then I could have the whole process happen again. As I understand it if you have one sexual partner for a long period of time with no other partners then you might be exposed to HPV from them but if your body fights that HPV virus and gets rid of it then that's it, it's not going to ... show again. So it's sort of a bit confused in my head in that as I understand it if

you've got a virus it's always there in your body and can show again. But it seems from the information that I've had with this that once your body has fought it, it doesn't show again. (W20, age 37, single, HPV+, moderate/severe smear)

This illustrates the way in which information about HPV was sometimes inconsistent with the 'common sense' models on which women drew to understand the virus.

3.5.2.5. *Consequences*

The last component of the cognitive representation encompasses the consequences of the health threat. Most women understood that having HPV was associated to some degree with an increased risk of abnormal cervical cells or cancer. Beyond that, some felt that it had consequences for their sexual behaviour and relationships in terms of condom use, or disclosing their HPV status to their partner to avoid transmission. There was confusion about the consequences that HPV might have for men, with some believing that as it affects the cervix, only women were at risk, while others were concerned about whether it might have adverse health effects on men. Abnormal smear results seemed to have different consequences from HPV, generally being seen as more serious and not having the same implications for sexual health and relationships. The consequences and emotional impact of the results will be discussed in detail in Chapter 5.

3.5.3. *Sense of coherence*

Women in the study varied widely in the extent to which they appeared to understand HPV, and this understanding was dynamic, being affected by information seeking and other coping strategies which will be discussed in the next chapter. Some felt that they knew almost nothing about HPV, while others had a sophisticated understanding of the virus.

Women frequently expressed confusion about HPV and had unresolved questions about it. In some cases this was very distressing, and the lack of clear information regarding the virus was a cause of concern and frustration.

This conflict of information was diabolical. It wasn't that I was reading it out of Cosmopolitan. It was the fact that I was ringing STD clinics in hospitals, different hospitals and asking their opinion and they were all giving different information. ... I think that's quite a surprise 'cause you think that you trust people in that position, they're dealing with it every day. But I rang, I think, four

places and they all gave different information which suggests that maybe the information isn't there. (W20, age 37, single, HPV+, moderate/severe smear)

There was variation in women's need for coherence, though, and many seemed very happy knowing little about HPV.

3.5.4. Emotional representation of danger

Women's emotional representations of their HPV results are discussed in the next chapter.

3.6. Demographic differences

The data were examined for systematic demographic differences in beliefs. It seemed that, as has been noted in previous sections, relationship status and HPV status were important in explaining the way in which women made sense of HPV. These factors appeared to be more important than age, socio-economic status or ethnic group in explaining some of the differences in beliefs that emerged.

Making comparisons between ethnic groups was difficult. The majority of the South Asian women tested negative for HPV, and had not developed illness cognitions about the virus. Among the small number who tested positive, factors other than ethnicity, such as relationship status, seemed to have an impact on their beliefs. It was also difficult to compare the African Caribbean women's beliefs with those of other groups as many of them had been recruited at Guy's colposcopy clinic and had not received any written information about HPV. This, and the fact that they mostly had abnormal smear results, meant that their representations of HPV tended to be less well-developed than other groups.

4. Discussion

The aim of this chapter was to explore the way in which women participating in HPV testing make sense of information about the virus and reconcile this information with existing causal beliefs about cervical cancer. The analysis used data from in-depth interviews with 74 women who had taken part in HPV testing. The study has advantages over previous research on women's beliefs about HPV as it used in-depth interviewing, and the participants were women who had taken part in testing in the

context of cervical cancer screening, rather than women with genital warts or a mixture of symptomatic and asymptomatic HPV.

4.1. HPV beliefs

4.1.1. Causal beliefs

Women can broadly be divided into those who knew that HPV is sexually transmitted, and those who did not. However the variation was in fact much more subtle than this and some women held different causal attributions for the virus in general and for their own infection, the implications of which will be explored in the next chapter. There was evidence that most women were able to make sense of the presence of the virus within the context of their own beliefs and sexual history. For example a woman who was in a lifelong monogamous relationship believed that HPV could not be sexually transmitted in her case, even though she had heard that it was an STI. This is consistent with the findings of another study of women with STIs, some of whom believed that the infection had not necessarily been caught through sex (Redfern & Hutchinson, 1994). Others were able to draw on different aspects of their understanding of HPV (e.g. its ability to lie dormant) to attribute the infection to a previous relationship. The links between causal attributions and the emotional impact of testing positive for HPV are important, and will be addressed in the next chapter.

The tendency for women to reject the notion that HPV is an STI if this was not reconcilable with their own sexual history has not been discussed in the existing literature on HPV, and was not foreseen in this study. It could be interpreted within the literature on defensive denial and self-regulation (Wiebe & Korbel, 2003). Wiebe and Korbel argue that defensive mechanisms such as the minimisation of health threats and the use of self-serving comparisons are widespread, and may function as a means of regulating 'hot' emotional responses to health threats. In this study, in addition to regulating the health threat posed by HPV, women seemed to have other goals such as maintaining the integrity of their relationships. These goals might be well-served by using defensive denial to reject the notion that they have contracted an STI. Although there has been some suggestion that focusing on emotional issues relating to the threat, rather than the threat itself, may be maladaptive in maximising health outcomes, in the case of HPV, behavioural change is not required. Where the only behavioural recommendation is to re-attend for screening at some point in the future, using defensive mechanisms to minimise the emotional impact of the result might be a very

adaptive means of coping. These issues will be discussed in more detail in the next chapter, in relation to women's emotional responses to their results and their coping strategies.

4.1.2. Other beliefs

Other dimensions of women's beliefs about HPV related closely to the information with which they were provided. Women frequently talked about the prevalence of HPV, its link with warts and other viral infections, its symptoms and treatment, its timeline and dormancy and the impact that it can have on men. However the degree of knowledge varied widely; some women had a sophisticated understanding of the virus while others knew almost nothing about it. Many of the women who understood that HPV is an STI had unanswered questions about the virus. These often related to where it had come from and when, and issues to do with transmission to partners. This demonstrates that simply providing women with information about HPV does not guarantee understanding of the virus. It might also indicate that the leaflets that women in the clinical trials and colposcopy clinics were provided with may not be addressing their questions and concerns about HPV.

4.2. Integration of beliefs about HPV and cervical cancer

This study provided an opportunity to gain insight into the way in which women made sense of HPV in the context of their existing beliefs about cervical cancer. This was especially relevant for causal beliefs. As we saw in Study 2, a large proportion of the population is currently unaware of the sexual behavioural risk factors for cervical cancer, and very few know that HPV is the main causal agent. The women in this study were in the very unusual situation of being told that they had a virus that most of them had never heard of before, and of which those around them were largely unaware.

A typology was developed to describe the range of causal beliefs about cervical cancer and about HPV. There was variation in the extent to which women were already aware of a link between cervical cancer and sex, in women's understanding of the sexually transmitted nature of HPV, and in their conceptualisation of the relationship between HPV and cervical cancer. Some women were able to maintain their existing models of cervical cancer, but others were forced to re-conceptualise it as being caused by an STI. Where this link was recognised and was completely new, it was often found to be shocking and very surprising (see Chapter 5). This gives an indication of the impact

that widespread information about HPV might have on public understanding of cervical cancer. However the other typologies demonstrate that people's models of cancer may be resistant to change, especially where information about HPV is perceived as ambiguous or uncertain. Many women in the study retained their existing models of cervical cancer as being either linked to sex but not sexually transmitted, or as having other causes such as chance, bad luck or family history.

4.3. HPV and illness representations

Although the study was not designed explicitly to test Leventhal's CSM, women's accounts included detailed data on their beliefs about many aspects of HPV, and these lent themselves to interpretation within the framework of the CSM. The data appeared to provide a reasonably good fit for the model, with women talking about the dimensions of the cognitive representation component of the model (identity, cause, control, timeline, consequences and coherence). The receipt of an HPV positive result seemed to trigger the development of a cognitive representation along these dimensions, although women varied widely in the extent to which they had clear beliefs about HPV.

If the identity component of the representation was weak (with no symptoms, and a poorly understood label) women tended not to develop a sophisticated cognitive representation, perhaps because the abstract label of HPV was not sufficiently threatening to trigger a self-regulatory response. But if HPV was seen as a serious or threatening label, women seemed more motivated to attend to information about the virus and to develop a cognitive representation of it. This is consistent not only with the CSM but also with Lazarus and Folkman's notion of primary appraisal (Lazarus & Folkman, 1984); if HPV is evaluated as irrelevant or benign, self-regulatory processes to deal with stress are not necessary. Alternatively, the fact that some women knew next to nothing about HPV, despite having received a positive result, might be interpreted as a threat minimisation strategy, which could be adaptive in situations where no follow-up was required for a year.

'Sense of coherence', or having a clear perception of HPV, appeared to be important and will be explored more in the next chapter, in relation to the impact of results. It has been suggested that having a good sense of coherence is important for carrying out appropriate health behaviours. For example, women who understand how smoking is linked to cervical cancer may be more motivated to quit smoking than those who are

sceptical about the link (Hall et al., 2004). In the context of HPV, health behaviour change is not such an important issue, but having a sense of coherence about HPV, and about its link with cervical cancer, might be expected to help some women feel less anxious and confused about their results (see Chapter 5 for a discussion of emotional impact).

Two important aspects of beliefs about HPV are not explicitly included in the cognitive representation component of the CSM. The first is prevalence. Prevalence was very widely talked about, and as we will see in the next chapter, understanding that HPV is very common was associated with a marked reduction in the negative psychological consequences of a positive result. This is consistent with the experimental work of Croyle and colleagues (e.g. Croyle, 1992; Croyle, Yi-Chun, & Hart, 1997) which has found that manipulating the perceived prevalence of the invented condition ‘TAA enzyme deficiency’ was associated with variation in perceived seriousness of the condition. People who were told that the condition is very common perceived it as less serious than those who believed it to be relatively rare. Leventhal has also highlighted the importance of the so-called ‘prevalence rule’ as a means of evaluating illness indicators (Leventhal et al., 2003). He has argued that conditions seen as highly prevalent among others are usually regarded as less serious. Prevalence is used as a heuristic for processing information and forming appropriate illness representations.

Secondly, the impact of HPV on men emerged as an important theme. STIs are different from many other health threats in that they have the potential to affect people’s sexual partners, and future partners, and must often be dealt with in the context of an existing relationship. Although the CSM is primarily a model of individual adjustment to illness, and does not explicitly take into account the possible impact of the health threat on other people, it does acknowledge the importance of social context. The health impact on sexual partners could be conceptualised within the consequences dimension of the cognitive representation component of the model, and this might then be expected to feed into coping strategies (e.g. condom-use or disclosure to partners).

In general, therefore, the CSM provided a useful framework within which to interpret the data. In Chapter 5, the rest of the model will be examined to evaluate how useful the concepts of emotional representations, coping and appraisal are in this context, and

to investigate the links between particular illness representations and responses to the results.

4.4. Strengths and Limitations

The study benefited from a number of methodological strengths. Firstly the use of in-depth interviews and qualitative analysis allowed a thorough exploration of women's beliefs about HPV, and meant that women were not constrained by the closed questions used in most research about HPV knowledge carried out to date (Vail-Smith & White, 1992; Yacobi et al., 1999; Baer, Allen, & Braun, 2000; Dell et al., 2000; Pitts & Clarke, 2002; Philips et al., 2003; Waller et al., 2003). In addition, participants were women who had been tested for HPV in the context of cervical screening, or the management of cervical abnormalities, rather than in the context of STI clinics, or the management of genital warts. This allowed a better investigation of HPV testing in the screening context, which is not normally associated with testing for STIs.

The sample used was diverse, including women from a range of ethnic groups and a wide range of socioeconomic backgrounds and age groups. Although differences in beliefs about cervical cancer and HPV did not emerge between the groups, the inclusion of a diverse sample means that the findings are not limited to middle-class white women, or students, as has so often been the case in other research. The sample is also strengthened by the fact that women were recruited in a variety of settings (family planning clinics, GP practices and colposcopy clinics) and had a range of cytology results.

Unlike other studies of HPV beliefs, this study also investigated women's beliefs about cervical cancer, and because of the rich nature of the data, some light can be shed on the way in which beliefs about HPV and cervical cancer are integrated or not. This is important in trying to predict the way in which public understanding of cervical cancer might be affected by the introduction of HPV screening.

As mentioned above, the data from the study are very rich and detailed, thanks to the use of well-trained and experienced interviewers. The use of ethnically matched interviewers who were able to carry out interviews in non-English languages and translate them meant that women were included who might not usually be included in

such research. The interviews were successful in addressing the very sensitive issues involved in HPV testing, STIs and cancer.

The main methodological limitation of the study relates to the ethnic groups included. As noted in the Methods section, recruitment was far from straightforward and as a consequence, the different ethnic groups are limited in their comparability. The majority of the African Caribbean group were recruited at one centre (Guy's colposcopy clinic) and no white or South Asian women were recruited from this clinic. As a consequence, the majority of the women in the African Caribbean group had experience of abnormal smear results, and had not received the information leaflets about HPV provided in the other centres. They only received verbal information about HPV from clinicians, and it is difficult to establish exactly what they were told. They were certainly not able to refer back to HPV information leaflets as women in the other centres frequently reported doing. In contrast, the majority of the South Asian women were HPV negative and recruited through the ARTISTIC trial in Manchester. This meant that few of them had developed representations of HPV, as no health threat was present.

However, although the study was explicitly designed to include an ethnically diverse sample, investigating ethnic differences was not one of the main research aims of this thesis, and in this section of the analysis, differences between the accounts of ethnic groups were much less pronounced than differences within ethnic groups. Relationship status and HPV result seemed to be more important than ethnicity in explaining the variation in women's cognitive representations of HPV and cervical cancer.

A final possible limitation is the fact that the development of the topic guide for interviews was not driven explicitly by the CSM. The topic guide was developed to cover the issues of interest to the research questions, and was designed to allow women to talk about their beliefs and experiences without being constrained by pre-conceived theoretical constructs. This has the advantage that the data are grounded in the accounts of women, but limits the extent to which the utility of the CSM can be judged. However, the fact that the beliefs expressed by women seem consistent with the model despite the general nature of the questions asked perhaps provides stronger support for the model than if the dimensions of Leventhal's cognitive representations had been asked about more explicitly.

4.5. Conclusions

This first part of the analysis of the data from Study 3 has found that women who had participated in HPV testing varied widely in their cognitive representations of HPV. Those who tested negative, who did not regard their HPV positive result as serious or who had a very weak identity component in their cognitive representation, often had limited beliefs about the virus, while other women developed sophisticated representations along dimensions broadly consistent with the CSM. Crucially, causal beliefs varied widely, and even after taking part in testing and being given information about HPV, not all the participants understood or believed that HPV is sexually transmitted, particularly not in their own case.

Leventhal's CSM proved a useful framework within which to interpret the findings, although certain key elements of women's accounts did not fit neatly into the cognitive dimensions of the model and many women had not developed cognitive representations of HPV at all. In the next chapter, the usefulness of the model will be explored more fully, including an evaluation of the coping and appraisal elements.

CHAPTER 5 – IMPACT OF HPV RESULTS AMONG WOMEN PARTICIPATING IN HPV TESTING (STUDY 3)

1. Introduction

The focus of the previous chapter was on women's beliefs about human papillomavirus (HPV) and the way that they reconciled information about the virus with their existing causal beliefs about cervical cancer. Of key importance to this thesis is the finding that women varied in the extent to which they understood and believed that HPV is a sexually transmitted infection (STI). The implications of this will be discussed further in this chapter.

In this chapter, women's responses to HPV are explored to see whether testing positive for the virus imposes greater or different emotional and social burdens on women compared with having an abnormal smear result. Variation in response is explored and explanations for this variation are sought. Continuing from Chapter 4, this is carried out within the framework of Leventhal's Common Sense Model (CSM) (see Chapter 1).

1.1. Background

1.1.1. *Emotional impact of participation in cervical screening*

There is a large existing literature on women's responses to cervical cancer screening. Anxiety can be induced as early in the process as the receipt of a screening invitation (Nathoo, 1988), but most research has concentrated on women who receive an abnormal smear result. Between 5 and 10% of women are recalled after a smear test because an abnormality is detected (NHSCSP, 2002; Wright, Jr. et al., 2002a). The State Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, & Jacobs, 1983) is the instrument most commonly used to assess the emotional consequences of cervical screening. Levels of anxiety do not seem to be related to the seriousness of the initial screening result (Rogstad, 2002), although anxiety may be affected by the recommended follow-up. Among women with mildly abnormal smear results, those invited for colposcopy have been found to be more anxious than those recommended to attend for a repeat smear (Wardle, Pernet, & Stephens, 1995). Overall, the STAI scores of women waiting for colposcopy have typically been found to be elevated beyond the levels found in women awaiting surgery (Marteau, Kidd, Cuddeford, & Walker, 1996), and are exacerbated in women who have waited a long time for their smear result

(Wardle et al., 1995). Although anxiety usually decreases immediately after colposcopy, it is not certain whether it returns to pre-screening levels. One study found that anxiety remained raised in at least a fifth of women a week after colposcopy (Bell, Porter, Kitchener, Fraser, Fisher, & Mann, 1995), but it is unclear how many of the women in this study were waiting for treatment when anxiety was assessed. Anxiety has also been shown to be sustained in women who are managed by surveillance (Peters, Somerset, Baxter, & Wilkinson, 1999), although other studies have found that women receiving a smear result recommending surveillance are less anxious than those referred for colposcopy (Wardle et al., 1995; Jones, Singer, & Jenkins, 1996).

There is some evidence that women with mildly abnormal results prefer immediate colposcopy over cytological review (Jones et al., 1996; Meana, Stewart, Lickrish, Murphy, & Rosen, 1999). However, in a recent randomised trial testing the effect on psychological outcomes of giving women with mildly abnormal smear results a choice of management (Kitchener, Burns, Nelson et al., 2004), similar numbers of women chose colposcopy (56%) and surveillance (44%). Women in the two groups showed an almost identical reduction in General Health Questionnaire (GHQ) scores over 12 months. Women who opted for colposcopy tended to have higher anxiety at baseline, indicating that this might be a more appropriate management strategy for more anxious women. There was no reduction in anxiety associated with having a choice of management compared with being treated by surveillance without a choice.

In a study of longer-term impact, Ideström, Milsom and Andersson-Ellström (2003) surveyed women 5 years after receiving a mildly abnormal smear result. There was no evidence of any residual anxiety, but it should be noted that the study did not use validated measures.

There is some evidence that non-attendance at follow-up is predictive of negative psychological outcomes. Lerman and colleagues (1991) found that non-compliance with colposcopy was predictive of long-term negative psychological consequences, and Kitchener et al. (2004) also found that women who did not attend for follow-up after a mildly abnormal smear result had been more anxious following their smear result than women who did attend.

In addition to generalised anxiety, screening-specific worry has also been measured. Australian researchers developing a questionnaire to assess the concerns of women receiving an abnormal result (Bennetts, Irwig, Oldenburg et al., 1995) identified four areas of worry: medical procedures, beliefs/feelings about cervical cancer and changes to perception of self, worry about infectivity, and the effect on sexual relationships. Their questionnaire has recently been updated and adapted for use in North America (Shinn, Basen-Engquist, Le et al., 2004), and the new version includes two main components: anxiety about medical procedures (including embarrassment and discomfort) and anxiety about the perceived consequences of an abnormal smear (including concern about sexual/reproductive issues, and concern about health consequences). The Cervical Screening Questionnaire (CSQ) covers similar concerns (Wardle et al., 1995) and other studies have confirmed these domains, with women reporting fear about cancer, loss of sexual function, fear of medical procedures, loss of bodily integrity, sleep loss, and concerns about fertility (see Rogstad (2002) and Summers (1998) for reviews). These sorts of worries have been found even among women who show no increase in generalised anxiety (Wardle et al., 1995) and they may be longer-lasting than any increases in general anxiety (Ideström, Milsom, & Andersson-Ellstrom, 2003). The inherent ambiguity in cervical screening results has also been found to be distressing, as has the lack of information and emotional support received from physicians (Karasz et al., 2003).

Given the immediate negative emotional impact of an abnormal result, and the large numbers of women who are affected, attempts to develop interventions to reduce the confusion and anxiety experienced have been an important focus of research. Many women express the wish for more information about the meaning of the result (e.g. Kavanagh & Broom, 1997), and what to expect at colposcopy, so educational interventions have been the most commonly used as a means of trying to reduce anxiety. Wilkinson et al. (1990) found that an information leaflet sent with a personalised results letter reduced women's anxiety prior to medical consultation, although it made no difference to post-consultation anxiety levels. Freeman-Wang et al. (2001) found that women who were shown an educational video were significantly less anxious than those given only a leaflet prior to their 'see-and-treat' colposcopy appointment. The efficacy of video over written information has been supported by another study (Greimel, Gappmayer-Locker, Girardi, & Huber, 1997). A short booklet has also been shown to be more effective than a leaflet at reducing anxiety, although a

longer booklet was more effective at increasing knowledge (Marteau et al., 1996). Other studies have confirmed that increasing knowledge does not necessarily reduce anxiety (Somerset, Baxter, Wilkinson, & Peters, 1998; Tomaino-Brunner, Freda, Damus, & Runowicz, 1998) and one study found that women receiving a leaflet showed no benefit (Howells, Dunn, Isasi et al., 1999). Two studies of counselling interventions failed to achieve any reduction in anxiety (Wolfe, Doherty, Raju, Holtom, & Richardson, 1992; Richardson, Doherty, Wolfe et al., 1996). A recent review of colposcopy leaflets in the UK found that many do not contain the key pieces of information that women want to receive (Byrom, Dunn, Hughes et al., 2003). Anxiety among women under surveillance for mild abnormalities has been seen as a separate issue and one study developed an intervention for such women with no success; anxiety remained high over the course of the study (Peters et al., 1999). The variability of these results may be related to the time at which they were carried out, the service context in which they were delivered, or the measures of outcome.

1.1.2. Emotional impact of HPV

Anxiety associated with abnormal smear results seems to focus on cancer fear, loss of fertility and sexual function and the fear of medical procedures such as colposcopy and ablative or excision treatment. Lack of understanding of results also seems to raise anxiety and cause distress. Introducing HPV testing into cervical screening raises the possibility of additional and separate psychological consequences arising from the sexually transmitted nature of the virus. Research in this area has been dominated by US studies of patient samples with visible genital warts. Filiberti et al. (1993) studied women undergoing treatment for HPV infection. It is unclear from the methodology whether participants were suffering from genital warts or high-risk, asymptomatic HPV. They were, however, informed of the link between HPV and cervical intraepithelial neoplasia (CIN). Over 50% reported a worsening of their sexual relationship, but it is not clear how much of this was attributable to the treatment and how much to the HPV infection itself. Just under 30% of women were reported to experience fear that the HPV would develop into cancer, but it is not clear how this was measured and whether it was a result of information provided to participants as part of the study. Given the unclear methodology and the relatively small sample size (n=51), it is difficult to draw inferences from this study. In a multinational study of men and women with genital warts (Maw, Reitano, & Roy, 1998), fears centred on transmission and recurrence,

although people in Germany and the UK also reported high levels of disgust, shame and embarrassment. Just under 30% of women were concerned about cervical cancer.

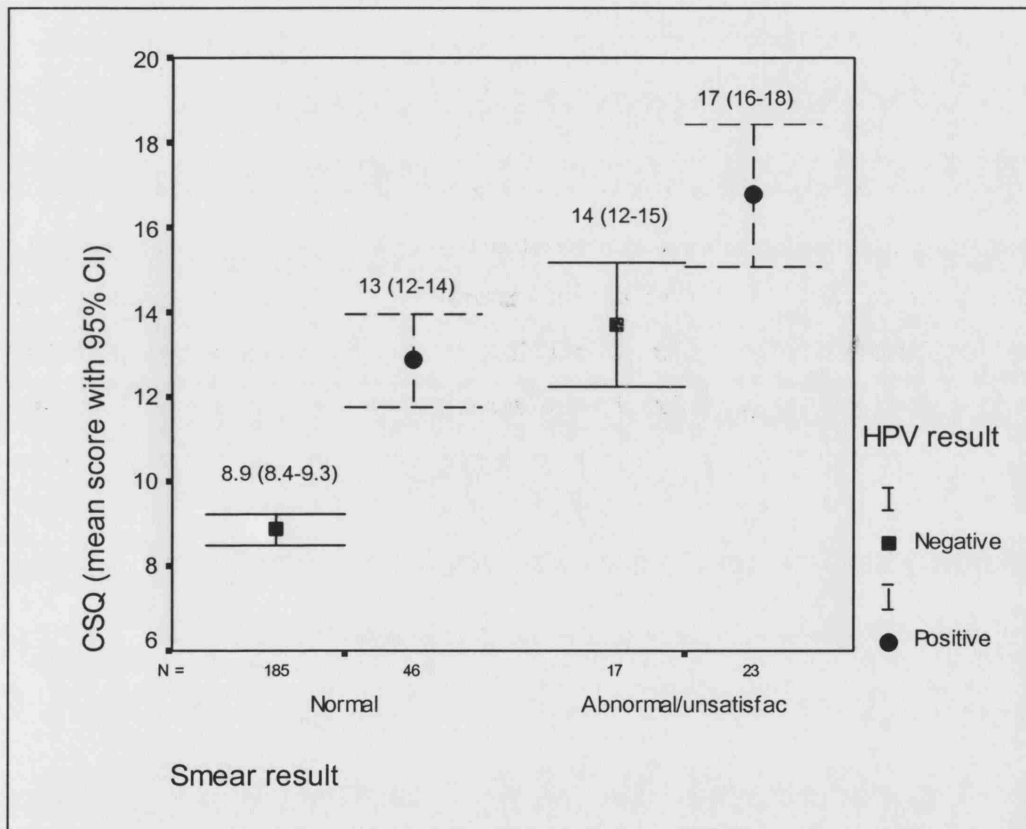
A study which included people with both genital warts and asymptomatic HPV infection identified emotional distress (anger, anxiety, depression, fear of rejection, shame and guilt), sexual problems, concerns about transmission, and negative impact on self-image (Clarke, Ebel, Catotti, & Stewart, 1996). However, the sample was drawn from an HPV support group, so is not representative of the general population. Another study asked female students to *imagine* testing positive for HPV (Ramirez et al., 1997). Their predicted emotions included fear, anxiety, regret, anger and confusion. In contrast, a study of women who had actually received positive HPV results (Reed, Ruffin, Gorenflo, & Zazove, 1999) found little impact on psychosexual outcomes, including physical intimacy, and sexual arousal and satisfaction. But the majority of the women in the study (both HPV positive and negative) were already suffering from symptoms of vaginitis which might have masked any differences between the groups. The study was relatively small and biased towards high social class white women, so the findings need to be replicated.

From these studies, it seems possible that testing positive for HPV in the context of cervical screening could be associated with wide-ranging concerns. While an abnormal smear can lead to fears about cancer, loss of fertility, treatment and loss of sexual function, HPV seems to carry the risk of greater psychosexual consequences, concerns about transmission, anger, regret and confusion. Conclusions must be drawn with caution, though, as there is a lack of clarity in the literature regarding the effects of visible warts compared with asymptomatic HPV infection.

A recent study in England measured anxiety among women who had taken part in HPV testing following a borderline or mildly abnormal smear result (Maissi et al., 2004). Women who had an abnormal smear and tested HPV positive had higher anxiety as measured by the STAI than those who tested negative, were not tested for HPV or had a normal smear result. These findings indicate that there is an additional negative psychological impact associated with testing positive for HPV, over and above the impact of having an abnormal smear result. However, the findings should be treated with some caution as the management strategy for women varied according to their results. Women with a normal smear received standard recall; those with an abnormal

smear who were HPV negative and those who had an abnormal smear and were not tested for HPV were recalled after six months; those with an abnormal smear who were HPV positive were referred for immediate colposcopy. Given this protocol, it is perhaps not surprising that women with HPV were more anxious since, as we have seen, colposcopy itself can induce anxiety. Lack of understanding of results and perceived risk of cervical cancer were found to be associated with increased anxiety. These findings would benefit from further investigation since the measures used were brief.

Figure 5.1 Mean Cervical Screening Questionnaire (CSQ) scores for women with normal and abnormal smear results who tested HPV positive and negative, from (McCaffery et al., 2004)



We have carried out another UK-based study in which women had an HPV test at the same time as their smear test (McCaffery et al., 2004). The study has not been included as a chapter of this thesis as Kirsten McCaffery took the lead in the research design and analysis. However, I was involved in the analysis and writing-up of the study, so a copy of the paper is included in Appendix 5.1. We found that both within the normal smear group (n=231) and the abnormal smear group (n=40), women who tested positive for HPV reported significantly more screening-related anxiety (measured by the CSQ) than

women who were HPV negative (see Figure 5.1). They also reported more negative feelings about their previous and future sexual partners, indicating that the psychological challenges associated with testing positive for HPV might be different from those associated with having an abnormal smear result. Feelings about sexual partners were measured with single items (e.g. *Since my HPV result, my feelings about my previous sexual partner are... better than usual/same as usual/worse than usual/much worse than usual*). This means that the reasons for changes in women's feelings are unknown and further research is needed to examine the factors involved.

1.1.3. HPV and stigma

A possible consequence of bringing public understanding of cervical cancer into closer alignment with the current medical view, which has not been addressed in the preceding literature on HPV, is an increase in the stigma associated with cervical abnormalities and cancer.

Someone who is stigmatised can be seen as 'devalued, spoiled or flawed in the eyes of others' (Crocker & Quinn, 2000). Goffman (1963) distinguished between 'discredited' stigma, which is visible and known-about, and 'discreditable' stigma, which is not immediately visible and need not be known about. Under this distinction, STIs would be 'discreditable', as they are not visible in most situations, and in the case of an asymptomatic infection like HPV, no one would know about the infection unless they were told. There is little doubt that diagnosis with an STI is associated with a feeling of stigma. This has been the case for thousands of years. Around 1000 AD, leprosy was believed to be sexually transmitted and carried a stigma. Syphilis was the main preoccupation in the late nineteenth century. Although the sexual revolution of the 1960s and 70s reduced the stigma associated with STIs, HIV is a clear example of another STI which carries a stigma and taboo (Gilman, 1999). Research on STIs and stigma has included people with herpes, HPV, HIV/AIDS, Chlamydia, and people attending for testing for gonorrhoea and HIV (Gilmore & Somerville, 1994; Redfern & Hutchinson, 1994; Holgate & Longman, 1998; Maw et al., 1998; Nack, 2000; Duncan et al., 2001; Fortenberry et al., 2002).

A few studies have suggested that an abnormal smear may also carry negative connotations of promiscuity and 'deviant' sexual behaviour (Gregory & McKie, 1992; Chavez et al., 1995; Box, 1998). These would certainly be very much exacerbated if the

transmission processes were better understood. In a review of women's knowledge and attitudes towards cervical screening, Fylan (1998) speculates that increasing awareness of the link between HPV and cervical abnormalities might cause women with abnormal smears to resent or distrust their partner, and to feel unable to disclose their test results for fear of stigma. Stigma in relation to asymptomatic HPV is not an issue that has been directly studied. One study of genital warts found that some people felt disgust, shame and embarrassment, all of which are indicative of stigma (Maw et al., 1998). Another study touches on stigma in relation to HPV, but the study sample was recruited from a sexual health clinic and it is not clear whether symptoms were always present (Nack, 2000). Some implications can be drawn from research on disclosure of HPV results.

Disclosure of HPV positive status has been explored by one US study, focusing on reducing transmission of the virus (Keller, von Sadoszky, Pankratz, & Hermesen, 2000). Reported disclosure to new sexual partners was lower than disclosure to the current sexual partner at the time of diagnosis. Fifty-two percent of the sample believed that they should disclose to all future sexual partners, but only 31% had disclosed to new partners prior to intercourse. It is difficult to draw any wider inferences from this study, as the HPV testing was not carried out in the context of cervical screening, and it is unclear what proportion of respondents had visible genital warts as opposed to high-risk, asymptomatic HPV. There are currently no clear guidelines for patients regarding the disclosure of HPV status to new partners, and advice to notify previous partners is not part of standard protocol.

In the absence of any other research on disclosure of HPV results, parallels can be drawn with the literature on Chlamydia, which is another prevalent, and usually asymptomatic, STI. A UK study (Duncan et al., 2001; Duncan, Hart, & Scoular, 2001) found that women with Chlamydia experienced anxiety about the way in which disclosure of their infection would be received by partners and others. Although disclosure was often motivated by a desire for information or support, fears about the impact of disclosure added to the anxiety of diagnosis.

It should be noted that HPV has different implications for women's partners compared with most other STIs: whereas other STIs affect men and need to be treated, HPV only has implications for men's future sexual partners, rather than for men themselves. This

might be perceived as reducing the immediate necessity of disclosure, especially for women who are in long-term relationships.

There is a surprising lack of research on women's disclosure of smear results, but anecdotal evidence suggests that discussion of these results does not generally carry the same taboos as does discussion of the results of tests for STIs.

1.1.4. HPV and cancer risk

There appears to have been little research investigating the effect of testing positive for HPV on perceived cancer risk, which one might expect to be a key area of concern if testing is introduced in the context of cancer screening. It may be especially important since HPV testing has the potential to identify large numbers of 'at risk' women who will never go on to develop cytological abnormalities. Filiberti et al. (1993) found cancer fear among about 30% of women with HPV but it is not clear how this was measured. Maissi et al. (2004) found that women with HPV rated their chances of developing cervical cancer as significantly higher than women with an abnormal smear who were either HPV negative or who had not been tested.

In their qualitative study, Kavanagh and Broom (1998) describe the impact of receiving an abnormal smear on women's feelings of risk. They argue that the 'embodied risk' identified by cervical screening poses particular challenges for women in terms of the threat of possible future disease, the need for medical surveillance, and an exacerbation of the self-body split (which has also been called 'bodily betrayal' (see Miller, Mischel, O'Leary, & Mills, 1996). It may be that an HPV positive result has a similar impact on perceived risk and self-perceptions. The high prevalence of the virus indicates that large numbers of women could be adversely affected, although the alternative is that an HPV diagnosis might become 'normalised' when its high prevalence is publicised. As the potential health threat associated with HPV is long-term, uncertain and uncontrollable, it has also been suggested that women with a monitoring coping style could be particularly susceptible to negative psychological outcomes (Miller, Rodolitz, Mangan, Schroeder, & Sedlacek, 1996). Once public understanding of HPV and the associated risk has been assessed, there will be a need for effective health education to ensure informed consent in screening. This might also reduce the anxiety associated with results as poor understanding has been found to increase distress (Kavanagh & Broom, 1997; Maissi et al., 2004). However other studies have found that information

provision alone is ineffective as a means of reducing anxiety about abnormal smear results (Tomaino-Brunner et al., 1998; Peters et al., 1999)

1.1.5. Common Sense Model

In the previous chapter, the cognitive representation component of Leventhal's CSM was found to provide a helpful framework within which to consider women's beliefs about HPV. As part of the analysis in this chapter, the data were examined in relation to the other components of the model: emotional representations, coping and appraisal (see Chapter 1). The model does not explicitly include a psychological impact component, but women's emotional responses to their HPV result could be conceptualised in terms of the emotional representation of the threat. Emotions such as anger, fear, depression or anxiety, which have been conceptualised as emotional representations within the CSM (Moss-Morris et al., 2002) have equally been used as measures of impact in the literature of abnormal smears and STIs described above. Research to date has tended to investigate the impact of abnormal smear and HPV results using standardised measures of anxiety, and has rarely been informed by a particular psychological model. The use of qualitative data in this study allowed emerging themes to be identified without the constraints of a questionnaire format, but meant that the analysis could be carried out with a particular theoretical approach in mind.

1.1.6. Concluding comments

From this fairly brief review of the literature it is clear that having an abnormal smear result has a negative emotional impact, at least in the short term, and is associated with anxiety about cancer, fertility, sexual functioning and medical interventions. However an abnormal smear does not generally seem to be associated with the kind of stigma and shame that is commonly reported by people with STIs. There has been little research on the psychological impact of testing positive for HPV in the context of cervical screening, rather than in the context of sexual health settings, but the few studies that have been done indicate that HPV adds to the anxiety experienced by women with an abnormal smear result. This anxiety might be associated with perceived cancer risk or negative emotions associated with an STI diagnosis.

1.2. The present study

The present study was designed to overcome the limitations of previous research and to build on the findings of other studies in a number of ways. Unlike most other research on the psychosocial impact of HPV testing, it uses participants who have been tested for high-risk HPV in the context of cervical screening. This means that the impact of an HPV diagnosis can be separated from the effects of having symptoms like warts.

Secondly, the study uses qualitative methods. This is a way of further exploring the negative consequences of HPV testing identified by our previous work and by other authors using quantitative methods (Maissi et al., 2004; McCaffery et al., 2004). It also allows issues which are important to the women taking part to emerge, regardless of whether they have been identified by the researchers in advance. Finally, women in the study received a variety of cytology results and management options, which means that the impact of the test result can be teased apart from the impact of the recommended management strategy and the accompanying smear test result.

2. Methodology

The data presented in this chapter also come from Study 3, the methodology for which is presented in Chapter 4. Seventy-four women took part in in-depth interviews following participation in HPV testing. The transcript data were analysed using Framework Analysis (Ritchie & Spencer, 1994).

3. Results

This chapter presents results from the same study as Chapter 4, so the demographic characteristics of the sample are shown in Tables 4.1 and 4.2, and are described in detail in the previous chapter. The majority of the analysis focuses on women who were HPV positive. A breakdown of women's HPV and smear test results is shown in Table 5.1.

The psychological impact of the results incorporates responses to the smear as well as the HPV result, and can be divided into two broad areas: i) impact associated with cancer and ii) impact associated with sexual transmission. These will be described in turn and then factors moderating the impact (beliefs about HPV, relationship status and

history, cultural factors and cytology result) will be explored to gain an understanding of why there was variation in impact.

Table 5.1 HPV and cytology results of women participating in Study 3 (n=74)

Cytology result	HPV positive (n=57)	HPV negative (n=17)
Normal	19	15
Borderline/mild	8	0
Moderate/severe	28	2
Inadequate	2	0

3.1. Emotional responses to the results

The first section of this analysis describes women's emotional responses to their HPV and smear results, with an emphasis on the differences between the two, and on the responses that appeared to be specific to HPV and its sexually transmitted nature.

3.1.1. *Impact associated with abnormal smear results*

3.1.1.1. *Cancer fear*

Many women, especially those with an abnormal smear result as well as an HPV positive result, described feelings of fear and worry about cancer, illness and death. This was especially true of women who were being treated for CIN. This woman had been undergoing treatment for CIN but described her response to her initial abnormal result, while she waited six months for follow-up.

I thought good God I could be dead in six months. But I knew I wouldn't be logically. But the other part of me I'd already picked a coffin almost ... And also trying to earn a living now I'm self employed ... I was thinking oh God I'm going to be not working, no work no pay so now what? So there were anxieties around those sorts of things. (W39, age 51, single, HPV+, moderate/severe smear)¹⁵

As illustrated by this quote, many women were worried about work and family responsibilities and how these might be compromised by prolonged illness or even death.

¹⁵ ID numbers are coded W for white, AC for African Caribbean and SA for South Asian

However some women with normal smear results were also extremely upset and frightened by their HPV positive result. One such woman described being ‘scared shitless’ while waiting for a colposcopy. Although her overall response was affected by the sexually transmitted nature of HPV, she described cancer as the ‘big thing’ and was more worried about this than anything else. This was associated with understanding that HPV is causally related to abnormal cells and cervical cancer.

3.1.1.2. Fears about treatment and waiting for treatment

In line with the extensive existing literature in this area, fears about cancer and progression of CIN were often compounded by uncertainty and apprehension about the colposcopy procedure and treatment. Women were particularly anxious during periods of waiting either for further investigation or treatment. Many described constant anxiety and sleepless nights while waiting for colposcopy appointments, although it is difficult to separate concerns about the procedure from concerns about cancer progression during the waiting period.

I was so stressed. ... And I stopped going out, I actually got skinny [laughs]. ... I wasn't sleeping very well. It was kind of nearly every day I was thinking about it. (W26, age 47, divorced, HPV+, moderate/severe smear)

3.1.1.3. Fertility

Some women, especially those who were young and did not yet have families, described concerns about future fertility. This woman raised the issue several times through the interview and was obviously concerned about the effect of treatment on her ability to have children in the future.

Being a woman you think about future babies. [laughs] Sounds funny just saying that but, I may not even want to have any but it's just a question, it's a bit more serious for women or for me at least it was. (SA17, age 30, in a relationship, HPV+, moderate/severe smear)

3.1.1.4. Sexual functioning and feelings about the body

Women with abnormal smear results sometimes reported altered feelings about sex, but this usually related to pain following treatment, or the fear of making abnormal cells worse. One woman described a combination of feelings. Having treatment for CIN had made her feel unattractive, but she was also concerned about having sex because she saw her vagina as ‘not working properly’ and wanted to wait until the cells had healed

fully. She also expressed anxiety about developing an infection which might exacerbate the abnormal cells.

So if you have sex you have an infection on top of your cells ... 'cause you've got the cells, they might cling on to the juices [laughs] ... 'Cause it's not working properly. Having sex is like a big function for your vagina to do isn't it really? So I'd just rather I didn't. ... And I know I could with a condom. I know I could but I keep making this excuse up, I'm not well yet, I'm not well yet. (W29, age 34, cohabiting, HPV+, moderate/severe smear)

3.1.2. Impact associated with HPV and sexual transmission

As we saw in Chapter 4, not all the women interviewed were aware that HPV is an STI. Among those who were aware, testing positive was associated with a set of responses that are not normally described among women with abnormal smear results, and which relate specifically to issues of sexual transmission.

3.1.2.1. Emotional response

Overall, many women described feeling 'shocked', 'astonished', 'horrified', 'scared' and 'confused' about their HPV result. These feelings were associated with having a low perceived risk of STIs and often with an inability to understand where the virus had come from and how they could possibly have it. Among women who did not realise that HPV is sexually transmitted, these feelings were absent. The typologies developed in Chapter 4 were useful in explaining this variation (see section on Moderators of Emotional Response below).

3.1.2.2. Stigma

In common with other STIs, HPV was frequently associated with stigma. Many women described feeling 'dirty', 'unclean' or 'cheap and nasty', or felt that HPV had a 'leper type deal about it'. They felt repulsed and disgusted to have something sexually transmitted and sometimes blamed themselves for behaving in what they perceived as an irresponsible way to have caught the infection. Others felt 'violated' or angry with the partner they thought had given it to them.

In a way you feel stupid. You think how could I be so stupid? Why didn't I know? But you wouldn't know necessarily, you can't tell. And you think he must have had me for a fool, what an idiot, I'm so stupid! You feel violated that you've let someone to that to you, infect you with something that does have such a huge impact on your life. (W34, age 21, in a relationship, HPV+, moderate/severe smear)

3.1.2.3. Relationship issues

In some cases, testing positive for HPV had an impact on women's relationships or their feelings about their partners. An example is a married woman in her forties who knew that her husband had previously had an affair. Having the HPV test and getting a positive result stirred up difficult issues about the affair and she said:

[The affair] had been a huge thing for me to get through, well us to get through ... really shook our marriage up and I never thought I'd be able to stay with him. And it was like this [the HPV] was something I hadn't even thought of coming out to get me just when I thought it had been dealt with. So that was really hard.
(W27, age 47, married, HPV+, normal smear)

Other women suspected their partners of infidelity, or worried that their partner would suspect them. Sometimes women concluded that a previous partner had been unfaithful. However these concerns seemed not to be sufficiently serious or long-lasting to pose a real threat to women's current relationships, and none reported the break-down of a relationship as a consequence of their HPV result. These findings are consistent with the findings of our earlier quantitative study in which women testing positive for HPV felt significantly worse about their past and future partners, but not about their present partners (McCaffery et al., 2004).

3.1.2.4. Impact on feelings about sex

The impact on feelings about sex was often markedly different for women who knew that HPV was sexually transmitted compared with those who did not. Transmission was a key issue for many women. They wondered whether they had given HPV to former partners and should therefore contact them to let them know so that their new partners could be tested: 'Have I given it to my partner, my ex-partner who's now got engaged to somebody else?' (W15). Women were also concerned about their current partners. Some assumed that they had given HPV to their partner already: 'I must have infected my boyfriend and how am I going to tell him? ... I've infected him and this is the man I want to spend the rest of my life with' (W34). Others were worried about infecting their current partner in the future, or about transmitting the virus to future partners. The fact that men cannot be tested for HPV added to these concerns. In extreme cases, women reported celibacy as a way of being responsible and making sure that they did not transmit the virus to anyone else. There was uncertainty among many about whether using condoms was a fail-safe method of preventing transmission, or not.

In addition to transmission issues, some women were put off sex by having something sexually transmitted which made them feel unclean or infected: ‘it did actually put me quite off having sex because I felt a bit unclean ... ‘Cause it wasn’t clear to me whether I could pass it on to anybody’ (W26). Women also worried that having HPV would make them unattractive to future partners, or would be associated with promiscuity.

For a few women, the HPV result had a direct impact on their sexual relationship with their current partner. One woman described not wanting to have sex with her husband because she assumed that he had given her the virus. She told her husband that she wasn’t ‘in the mood’ until she had read the leaflet again, and decided that HPV was not, in fact, sexually transmitted. This fits with the finding of the previous chapter, that women were able to (mis)interpret the information about transmission of HPV in order to maintain the status quo of their relationships.

Some women who were not in stable, long-term relationships, or who had had many partners in recent years, reported that having HPV had made them think again about safe sex and about their risk of STIs more generally. This was often associated with intentions to use condoms or be ‘more choosy’ in future.

3.1.3. Disclosure of results

Talking to women about their patterns of disclosure of results provided powerful insight into the way in which an HPV result is perceived to differ from a smear result. Women varied in their patterns of disclosure and their reasons for disclosing or non-disclosure.

3.1.3.1. Reasons for non-disclosure

A number of explanations for the non-disclosure of HPV results emerged.

3.1.3.1.1. Stigma, embarrassment and reputation management

Many women had not disclosed their HPV result, and this was frequently because they felt ashamed and embarrassed about their results, and were afraid of the stigma or censure associated with being diagnosed with an STI.

If it was something that you got through the water then I would be telling everyone ... But I’ve been told it’s sexually transmitted so I’m not going to tell everyone ‘cause obviously people, you feel that people are going to think ‘Oh you’re dirty’. (W30, age 31, single, HPV+, moderate/severe smear)

Women managed their reputations by telling people about their smear result but not about their HPV result, or by avoiding telling people that HPV is sexually transmitted. Feelings of embarrassment and shame were common, and women were fearful that they would be judged as promiscuous or that people would think differently of them if they disclosed their HPV positive result. For most women, having an abnormal smear result did not carry similar connotations of promiscuity and sexual transmission.

I lied even when I told them that ... I was going in for a colposcopy. I told them there was some irregular activity. I didn't say HPV. I only told my sister HPV when I knew I didn't have it. [Interviewer: Why?] Coz I didn't want to say someone's '[Name]'s got a genital wart problem'. Or '[Name]'s got some sort of weird STD thing'. ... Even when I said to my sister afterwards 'Actually what they thought it was, but it wasn't, was an HPV', she said 'Isn't that a genital warts thing?' And I thought 'Yeah, I'm glad I didn't say anything'. (W7, age 39, single, HPV+, normal smear)

Sometimes women found it particularly difficult to talk about HPV and its sexually transmitted nature with their partners. This was a way of avoiding a confrontation that might lead to difficult questions about where the virus had come from, and suspicions or accusations of infidelity. One woman had told her partner about having HPV but said that 'they don't know where it comes from'. If she had told him it was sexually transmitted she thought 'he'd be like 'Have I got it?' or 'Has she been with somebody else?' So I suppose I kept that to myself' (W16).

Some of the South Asian women reported that they could not talk to their families about HPV because they were unmarried and so should not have been sexually active: 'I mean nobody knows that I have a partner' (SA2).

In addition to the issue of sexual transmission, some women felt that because of the part of the body affected, having HPV or an abnormal smear result was very personal and not something that they wished to discuss with people.

3.1.3.1.2. Lack of understanding of HPV

Some women chose not to tell their partners or friends about their HPV result because they did not understand much about HPV, and did not feel able to explain it to someone else. Having to play the 'expert' and provide information about HPV was regarded by some as stressful and unnecessary. An example is this woman who told her husband

about her abnormal smear result, but chose not to talk to him about the sexually transmitted nature of HPV.

I just decided that rather than get into complicated explanations and all the rest of it, it wasn't anything that I needed to tell him, because it wasn't going to affect him physically, and I was undergoing tests, treatment, whatever, so it just seemed easier and less stressful for me [to] leave it out of the equation. (W9, age 42, married, HPV+, borderline/mild smear)

3.1.3.1.3. Protecting people

Some women described keeping their results to themselves to avoid worrying their family or friends. Women who perceived their results as being very serious and indicative of a high risk of cancer sometimes wanted to protect their family, or to wait for the results or further tests before disclosing. In some cases, women were worried that other people would assume that they had cancer, and would over-react which would, in turn, be distressing for them.

There's no point worrying them unnecessarily so the majority of them I didn't tell them, but my brother ... he'll just go around punching walls or something so, me and him were quite close and it would have been nice to be able to tell him but I just couldn't because I knew what his response would be and I felt that the whole time I was just judging people: 'Could you cope if I told you this?' and people that I knew couldn't, I just didn't tell. (AC11, age 21, in a relationship, HPV+, moderate/severe smear)

3.1.3.1.4. Not worth mentioning

For some women, the HPV result was seen as so trivial that it was not worth mentioning to anyone. These were women who had a normal smear test result and who assumed that HPV could not be serious since they were not being called for immediate follow-up.

Normally if I have a problem or something I'm worried about or something I'm concerned about I will go and discuss it with somebody. But it wasn't something that was worrying me or upsetting me or I didn't understand, so I didn't really feel the need to discuss it with anyone. (SA3, age 25, single, HPV+, normal smear)

3.1.3.2. Reasons for disclosure

Despite these barriers to disclosure, many women did talk to people about their results, and the reasons given for disclosure are described now.

3.1.3.2.1. Seeking reassurance

The main reason described for disclosing results was to seek information or reassurance from other people, or simply to ‘offload’ some of the anxiety associated with the result. Many women who were anxious about their results spoke to their partner, family or friends and were reassured. Sometimes friends, mothers or sisters had experience of abnormal smears themselves, and so were able to provide information and reassurances about the colposcopy procedure and treatment. Partners were often able to provide emotional support and reassurance that they did not judge their partners negatively for having an STI.

One woman described feeling ‘wretched’ and ‘ashamed’ about having to tell a relatively new partner that she had HPV and might have given it to him, but he responded very positively: ‘He was very supportive and wonderful about it and said it really matters so little. That’s what he said, and he knows nothing about it, he knows even less than I know about it, which I thought was very generous of him’ (W35). This is an example of the kind of psychological benefits associated with disclosure, which were not available to the women who felt unable to talk to anyone about the results.

As described above, some women chose not to disclose because they felt that they did not have sufficient information about HPV to explain the result to someone else. Other women were able to select ‘experts’ from whom to seek support. Examples of this included a nurse who talked to colleagues about her HPV result, but not her husband, and people who talked to friends in medical or scientific jobs who they felt would have an understanding of HPV and would therefore be well-placed to provide support.

I talked to [a girlfriend] about this HPV infection because she’s a biochemist so she knew about it and she goes ‘Oh that’s not a problem other women do suffer from it’. So she was aware of it. But otherwise I don’t think anybody else has heard of it. (W34, age 21, in a relationship, HPV+, moderate/severe smear)

3.1.3.2.2. Fears about transmission

Some women felt strongly that their partners had a right to know their HPV result, and were concerned about transmitting the virus to them. In some cases, this extended to previous partners, with women wondering whether they should disclose their results so that the new partner of an ex could be tested. In these cases, disclosure was often a stressful experience as the example below illustrates. This woman had experienced

slightly negative reactions to her HPV status from her mother and a friend, and was worried about telling her partner, although she felt she had to because she was sure she had given him HPV.

Well I didn't tell him I had HPV for a long while and he turned round to me one day and said 'How did your screening, you got your results back?' I went 'Yeah'. And he said 'So was it HPV?' And I just burst into tears and went 'Yeah it's HPV'. 'Well that's OK, that's not a problem. It's gone, they've taken it away and it's a viral thing you can't help that you've got it'. And I was like, 'I've infected you!' He was 'You haven't infected me, I would know if you'd infected me and I'd tell you!' (W34, age 21, in a relationship, HPV+, moderate/severe smear)

She commented that she felt that the fact that her partner was a medical doctor helped in the disclosure process: he felt well-informed about HPV and so was able to reassure her, and she did not need to explain it to him.

3.1.3.2.3. Spreading the word

The final reason for disclosure was an almost evangelistic desire to tell people about HPV and to try to ensure that friends were well-informed about the virus and the risks associated with it. This was frequently described by women who had previously been unaware of the link between cervical cancer and sex (the *Reconceptualisers* from Chapter 4) and who had themselves been shocked by the link with an STI.

At the moment I'm like a loud speaker; I'm telling everybody ... Apart from the embarrassing bit for me I'm, I've overlooked that bit just to communicate to people. (SA17, age 30, in a relationship, HPV+, moderate/severe smear)

3.1.4. Lack of negative impact

Not all women experienced the kinds of negative emotional and social responses described above, and some even interpreted their results in a positive way.

3.1.4.1. *Reassurance*

Some women described positive responses to their results as well as, or instead of, the concerns described above. A common theme was that of something being 'picked up early'. This was especially true for women who had received a normal smear result with a positive HPV result, and were therefore being monitored more closely on the basis of their HPV result. Some thought that anything that led to more frequent screening was a good thing, and in several cases, the HPV positive result had identified

underlying disease that needed treatment, which would have been missed by the smear test.

It's more sensitive than the smear, and it picked up a positive result, whereas the smear would have said a negative, and the big issue for me is that I would have not gone back for three years, so what if my cells had got worse in three years? I don't know how quickly they can get worse, you know, I don't know about the time period, but I just think it's obviously a better test. (W8, age 27, cohabiting, HPV+, borderline/mild smear)

Many women also expressed the view that if something was wrong, it was better to know than not to know. This was linked with the reassurance provided by regular monitoring and surveillance.

3.1.4.2. No negative impact

Other women described neither positive nor negative responses to their results. These women thought of it as 'just one of those things', HPV was seen as 'coming with the territory' of being sexually active, or the result was not seen as serious because there were no symptoms and the follow-up recommendation was the re-attend in a year. For some women who had HPV, the normal smear result was reassuring and prevented them from worrying about the HPV positive result.

3.2. Moderators of emotional responses to an HPV positive result

The preceding section has highlighted the variety of emotional responses to abnormal smear results and to HPV results, and has illustrated the additional emotional and social burdens that an HPV positive result can place on women. The next stage of the analysis aimed to identify the factors that are important in explaining which women had a negative response to HPV. This was done through familiarisation with the transcripts and developing hypotheses about the reasons for varying responses to a positive HPV result. Hypotheses were tested against the data using the appropriate columns of the frameworks and, where appropriate, sorting the data to explore between-group differences.

3.2.1. Cognitive representations of HPV and cervical cancer

As we saw in Chapter 4, women varied widely in their beliefs about HPV and cervical cancer, and analysis showed that several aspects of their cognitive representations of HPV were important in explaining women's emotional responses to testing positive.

3.2.1.1. Causal beliefs – sexual transmission of HPV

The most significant aspect of knowledge about HPV was its sexually transmitted nature. As we have seen above, women who knew that HPV was sexually transmitted were more likely to experience a sense of stigma or feeling ‘unclean’, to have fears about transmission to partners, and to have difficulties in disclosing their results. Lack of disclosure sometimes compounded anxiety as women were unable to mobilise social support and seek reassurance from others.

There's a sort of shame to it, there's a leper type deal about it ... I suppose because it's ... I don't know it's the feeling that you have to have got it from somebody else. And I suppose the shame for me would be that I haven't been with anybody else but if I suddenly got it where did I get it from sort of thing?
(W27, age 47, married, HPV+, normal smear)

Among the group who knew that HPV was an STI, those who had not previously been aware of the link between sexual activity and cervical cancer (the *Reconceptualisers* from Chapter 4) were most likely to report feelings of shock and distress. This related not only to having the HPV infection, but also to realising that their previous beliefs about cervical cancer were incorrect.

It was quite shocking to learn that. I mean I know about HIV and stuff but then I didn't associate cancer to be actually induced from say transmitted through sex. It was really interesting factor so it was quite shocking for me to hear that, to read that. (SA17, age 30, in a relationship, HPV+, moderate/severe smear)

The variation in emotions expressed among women who were to some extent aware that HPV is an STI can also be related to the first typology developed in Chapter 4:

- 1) Sexually transmitted, but not in my case
- 2) Sexually transmitted, but how did I get it?
- 3) Sexually transmitted; I got it from X
- 4) Sexually transmitted; not interested in who it came from

Women in the first group were able to avoid extreme emotional responses by attributing the infection to other causes. This woman was surprised to hear that HPV was sexually transmitted, but effectively reduced the emotional threat by denying this explanation in her case.

It surprised me really 'cause I've only ever had one partner so I thought well that's not true in my case 'cause he's only had one partner as well [laughs] ... maybe just ... some people get it and some people don't. (W23, age 41, married, HPV+, normal smear)

In the second group, women frequently reported shock and astonishment. As they accepted that HPV is an STI, they were unable to dismiss these feelings as easily as Group 1 and the on-going confusion about where the virus had come from seemed to compound their distress.

I am absolutely astonished that I have this thing and I just don't know where it's come from, you know. I am totally astonished ... The only thing I can think of is that probably my husband was unfaithful to me or somebody was obviously weren't they? (W15, age 56, divorced, HPV+, normal smear)

In the third group, women varied in their response. For some, having an STI was not shocking and came with the territory of being sexually active, or could be attributed to a previous relationship without distress. For others, the need to know who the infection had come from caused distress in itself.

Then went the most boring ... procedure of mentally going through all my boyfriends of the last twenty-something years ... I didn't know which one. And it was beginning to spoil my memories of some very nice years and relationships that I had. (W7, age 39, single, HPV+, normal smear)

The final group tended to be least distressed about the sexually transmitted aspect of the result, perhaps because their sexual history was easily reconcilable with having an STI (see section 3.2.3 below). Their responses were therefore fairly similar to the first group, but they showed no evidence of engaging in the kinds of defensive mechanisms that seemed to be used by Group 1.

Those who did not know that HPV is sexually transmitted did not experience these anxieties. Sometimes these women were explicit about the way in which their experience would have been different if HPV had been sexually transmitted. One woman said that she would feel 'quite sick' if she found out that HPV was an STI. Another had talked to her husband and friends about her HPV result, believing that it was not sexually transmitted, but she said she would not talk about STIs.

I think there's a lot of stigma attached to those diseases. I don't know, people I know just don't talk about it I suppose. (W25, age 40, married, HPV+, normal smear)

3.2.1.2. Timeline beliefs – dormancy of HPV

Understanding that HPV can lie dormant for a long time without causing any problems seemed to be key to maintaining the integrity of women's current sexual relationships if they were aware that HPV is an STI. Knowing that the virus could have come from a previous relationship, or that their partner could have given it to them when they first met, prevented women from drawing conclusions of infidelity based on their results. In some cases, women did not understand this at first, which exacerbated the initial distress and confusion associated with the result. Being told about the dormancy of the virus was then extremely reassuring. One woman described her initial shock and horror at the positive result: 'I'd only ever had a relationship with my husband and I just couldn't see how I would have got a sexually transmitted disease' (W9). She said that later she was told that the virus can 'just lie dormant in women and not give them a problem, so that obviously was quite reassuring'.

3.2.1.3. Prevalence of HPV

Also very reassuring to many women was the high prevalence of HPV. This seemed to normalise the infection and make it seem both less serious and less stigmatised. This woman found information about the high prevalence of HPV on the internet.

The research that I got back was like seventy five per cent of women have it and don't realise it. I suddenly thought why, why is it such a stigma then? (W34, age 21, in a relationship, HPV+, moderate/severe smear)

3.2.1.4. Identity – lack of symptoms

There was confusion about whether high-risk HPV has symptoms or not, and some women expected that they might develop genital warts. This added to the distress caused by a positive result. For some women who knew that there were no symptoms, this allowed them to 'go on with everyday life and not think about it' (W16).

3.2.1.5. Identity – the link between HPV and warts

Most of the leaflets women were given about HPV included the information that it is also linked to genital warts, other warts and veruccas. This seemed to have two possible effects. Some were reassured because warts and veruccas were something with which

they were familiar and which they did not see as serious or threatening. This woman was initially reassured that all she had was ‘wart virus’.

I’ve got a wart virus honestly and I’m thinking oh because it, I used to have warts on my hand when I was back home in Jamaica and I just used this stuff and it disappear so I’m just thinking it’s just a wart I’m not thinking wart internally.
(AC8, age 33, married, HPV+, moderate/severe smear)

However, once she realised that HPV was sexually transmitted, she felt silly and naïve for having disclosed her result so readily.

For other women, warts had negative connotations and genital warts especially were seen as repulsive and stigmatising: ‘the image, ... reputation, association isn’t great’ (W7). For these women, the term ‘wart virus’ was unhelpful and compounded feelings of stigma and anxiety.

3.2.1.6. Identity – confusion about HIV/AIDS

HPV was thought by many women to sound very similar to HIV, and this caused some confusion and additional distress. Although none of the women actually thought that they had HIV, the association often crossed their minds and seemed to cause some initial concern until they found out more about HPV.

I wasn’t thinking HIV but I was thinking God that sounds serious, what is that? ... It sounds scary! ... I think probably ‘cause it sounds like HIV. Um.. [pause] it’s like thrush, Candida sounds like harmless. Whereas that sounds really, oh I don’t know, it sounds awful. (W36, age 44, single, HPV+, moderate/severe smear)

3.2.1.7. Control beliefs – spontaneous clearance of HPV

Women were reassured by the fact that HPV can ‘clear up’ on its own and that treatment is not normally necessary. This allowed comparison with other trivial infections like colds: ‘in the majority of cases the system will clear, as in the common cold’ (SA3). Women who thought that treatment might be needed typically regarded the virus as more serious and were more concerned about it.

3.2.1.8. Beliefs about transmission

Among women who were aware that HPV is sexually transmitted, beliefs about transmission and the risks that the virus might pose for their partners were an additional source of anxiety and concern. Women were reassured if they knew that HPV does not

cause a problem for men and that transmission to a male partner need not be a cause for concern. Many women remained confused about this and had concerns about transmission of the virus in current or future relationships. They often wondered whether they should disclose their HPV positive status to future sexual partners.

What kind of precautions do I need to take in having this? And obviously I can give it to other people, and is that bad if I give it to other people? (W19, age 26, cohabiting, HPV+, moderate/severe smear)

There was also uncertainty about whether condoms are protective. For some, the fact that HPV cannot be fully prevented by condom-use reduced the stigma of the infection, but among others there was a sense of helplessness that the infection could not be prevented. Most distressing seemed to be the lack of clear information and advice available.

But nobody's actually sat down and said 'Look, you now have to be careful. You now have HPV' and I think if somebody said 'Look you really do have to either use condoms or inform future partners' I would do. If somebody actually said 'You need to start doing that'. But still nobody's really told me how serious or little of importance this virus is. (W33, age 40, divorced, HPV+, normal smear)

3.2.2. Lack of clear and consistent information – the need for coherence

In addition to the anxiety or reassurance associated with specific aspects of women's cognitive representations of HPV, women were frequently very upset and concerned about the general lack of clear information about HPV. This fits with the concept of coherence discussed in the previous chapter. Some women were unable to find answers to their questions about HPV, be it from their GP or consultant, the internet or their lay network. Conflicting information was also common, as this quotation illustrates.

What really, really bothered me was the lack of consistent clear information. And I wasn't just like reading this off the Internet I would speak to one health clinic in one hospital and 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. (W20, age 37, single, HPV+, moderate/severe smear)

Many women were left with unanswered questions relating to their HPV result, and these frequently involved concerns about where the virus had come from, how long it had been there, whether it would ever disappear, and issues to do with transmission to their current or future partners. Ongoing thoughts about these questions prolonged the negative psychosocial consequences associated with the result.

However there were also women for whom having a very limited understanding of HPV did not pose a problem. As described in the previous chapter, some women did not develop cognitive representations of HPV. The threat posed by their HPV positive result seemed insufficient to trigger the self-regulatory processes described by Leventhal's model, and these women did not experience negative emotional or social consequences. This woman was aware of having taken part in the ARTISTIC trial and of having had a new test, but hardly recognised the name 'HPV' and knew nothing about the virus. It seemed to be the absence of symptoms that prevented her from worrying, and she showed no signs of distress at having a diagnosis about which she understood very little.

And I thought well it's never bothered me so [laughs]. It ain't bothered me yet! I suppose that's it, it's something you get and you might have it and if they can treat it fair enough if they can't you just think well, it's not harming me, not doing anything to harm me so I don't bother. (W22, age 57, in a relationship, HPV+, normal smear)

This could be seen as an adaptive response to a threat that does not require any immediate action. By minimising the seriousness of the threat, the woman is able to regulate her emotional response to it without jeopardising her future health by failing to take appropriate action.

3.2.3. Relationship status and history, and perceived risk of STIs

Among women who understood that HPV is an STI, their current relationship status and previous relationship history played a significant role in explaining the impact of a positive result. Women's sexual histories were linked to their perceived risk of STIs, and this fed into their responses to the result. As has already been illustrated, the association also seemed to run in the opposite direction, with women's relationship status having an impact on the way in which HPV was conceptualised, and their willingness or ability to acknowledge its sexually transmitted nature.

3.2.3.1. *Lifelong monogamy*

At one extreme of the spectrum, there was a woman who was in a lifelong monogamous relationship with her husband: ‘I’ve only ever had one partner [and] he’s only had one partner as well’ (W23). Although she had read the information telling her that HPV was sexually transmitted, this was completely at odds with her risk perception and history, so she discounted this explanation in her case. Instead she tapped into her beliefs about cervical cancer and said that HPV was ‘like cancer I suppose, some people get it and some people don’t’. She was thus able to avoid potentially difficult questions about where the virus had come from, which might have threatened her relationship through accusations of infidelity or dishonesty. Her sexual history had an impact on her cognitive representation of the virus, which in turn eliminated the potentially negative emotional impact. It could be argued that this is a very adaptive defence mechanism and one which allowed her to maintain her relationship with her husband and regulate her emotional response to the result, while still responding appropriately to the health threat posed by HPV, by attending for follow-up testing.

Other women in similar relationships who did not regard themselves as being at risk of STIs seemed unaware of the sexually transmitted nature of HPV, and so also avoided having to confront potentially damaging questions about their relationship.

3.2.3.2. *Marriage or long-term relationships*

Within marriage or long-term relationships, women varied in the extent to which diagnosis with HPV was shocking or distressing, and this tended to show an interaction with their understanding of the timeline of infection and the possible long dormancy of HPV. Initial shock and disbelief often dissipated once women understood that they could have had the virus for a long time, and were thereby able to attribute it to a previous relationship or, in the case of women who had only ever had one partner, to a previous relationship of their partner. One woman (AC8) described being ‘really sad’ and ‘really upset’ when she first found out that she had HPV, because she had never ‘been about’ and so concluded that her husband must have been unfaithful. However when she found out more about HPV, she realised that her husband (who had ‘been about’ when he was younger) could have had the virus before he met her, and given it to her a long time ago.

For women who were with stable partners but where previous relationships were acknowledged on both sides, the diagnosis with HPV tended to pose less of a threat. This woman in her twenties did not find it difficult to talk to her partner or family about HPV, largely because she, as well as they, had had previous partners and this was something that was discussed quite openly. She did not, therefore, experience the feelings of stigma and taboo that were common among women who knew that HPV is sexually transmitted.

[Partner's name] himself and my sister and my mum have all had different sexual partners so I think that it's not something that's really a taboo thing and it's not something that's looked on as a bad thing. It's just one of those things that you've just caught, like you would catch verrucas or that type of thing. (W19, age 26, cohabiting, HPV+, moderate/severe smear)

In other cases, discussion of previous partners was much less easy; one example being a woman whose husband had had an affair. The HPV result stirred up many of the very difficult feelings that the couple had experienced while trying to rebuild their marriage following the affair.

I'd got myself into a real state. I thought well I'm definitely going to have to divorce my husband and I'm going to die and you know. Should I divorce him if I'm going to die? No, it wasn't dying so much. I think it was just the feeling that I was walking around with something that he probably gave me. Knowing where it came from. It just made me feel so dirty. (W27, age 47, married, HPV+, normal smear)

This is a vivid illustration of the way that the specific relationship context of the result can have a profound effect on the negative psychosocial consequences experienced by the individual.

3.2.3.3. Single or casual relationships

Some participants were not surprised to be diagnosed with an STI. If women had engaged in what they knew to be risky sexual behaviour or had had many partners, they were sometimes well aware of their risk of STIs. One woman (W33) described having been 'very promiscuous' since the breakdown of her long-term relationship two years previously. Rather than being shocked at her HPV result, she said she was 'surprised that I've not actually picked up something more severe'.

For other single women, the HPV result came as more of a shock. Some women were not sexually active at the time of the test, which made them wonder how they could have contracted the virus, especially if they were not aware that it could lie dormant for a long time. Others felt stupid for having had unprotected sex, and this contributed to the negative psychological consequences of testing positive.

Women in relatively new relationships, where trust and stability had not yet been established, often found the HPV result very difficult to cope with, and disclosure was a big issue. This was especially true where women had concerns about transmitting the virus to their partner. One woman (W35) who hadn't been with her partner for long, described feeling 'wretched' and 'ashamed' about her HPV infection, and found talking to her partner about the result 'pretty awkward', even though he turned out to be very understanding.

It is evident, then, that the specific relationship context within which women received their HPV positive result had a considerable impact on the way in which the results were understood and received. This affected how shocked or upset women were to have an STI, how threatened their relationship was, and the ease with which they were able to discuss the result with their partner. As is predicted by the CSM, the emotional and cognitive aspects of women's representations seem to influence each other in a bidirectional manner. But of key importance seems to be the social context in which these processes take place.

3.2.4. Religious and cultural context

Another important factor that appeared to moderate women's responses to testing positive for HPV was their religious and cultural background, and especially their social norms around sexual relationships and screening. This was one of the few areas in which clear differences between the ethnic groups emerged.

3.2.4.1. South Asian

Among the South Asian women interviewed, there was a strong perception of the link between attending for cervical screening and being sexually active. Many of the women in this group were married and had only begun to attend for screening after marriage. Some of the younger women were in relationships, often without the knowledge of their families, and frequently reported hiding their attendance for screening, especially from their parents. One woman aged 29 who was living with her boyfriend without her

parents' knowledge said: 'I couldn't tell [my parents] I was here tonight 'cause they'd be, like, why the hell are you having smears anyway? You shouldn't need them 'cause you've not been in a sexual relationship' (SA11). Since cervical screening was already associated with being sexually active among these women, the addition of HPV testing might make little difference to their feelings about attendance and disclosure.

Many of the South Asian women tested negative for HPV, and so did not have to confront a positive result. Among those who tested positive, reactions varied, but one woman who was in a relationship that her family did not know about described how her concern about the test result was compounded by her feelings of guilt about the relationship.

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, age 28, in a relationship, HPV+, normal smear)

Another woman described being unable to talk to her parents about her HPV positive result because they were arranging a marriage for her in India, and did not know that she had had sexual partners.

This kind of response was not universal. One South Asian woman was a medical doctor and took a very pragmatic approach to her infection, and another whose father was a doctor was able to talk to him about her results. Although this was uncomfortable for her, it was not associated with the same taboo as was described by others.

3.2.4.2. African Caribbean

In this group, the connotations of a link between sexual activity and screening were less widespread, but some women did talk about the link between having many sexual partners and cervical cancer, and said that this had an impact on perceptions of women who attend for screening. This women, whose parents were Jamaican but who was born in the UK, said:

Black people jump to conclusions quickly: 'Ah she must be a bad woman, hmm, that's why she's got that. She must have been sleeping around a lot'. (AC7, age 30, in a relationship, HPV+, moderate/severe smear)

She thought that this might be a reason why some black women are reluctant to attend for screening. Another women who was born in Jamaica thought that attending might imply sexual activity, and because of her Christian background, this worried her somewhat.

With the situation back home [in Jamaica] where maybe if I said to somebody 'I'm gonna do it' [go for a smear test] they might think I've been up to something you know. I would, I'm a Christian and they say 'Are you going to have a Pap smear?' (AC14, age 27, married, HPV-, moderate/severe smear)

However, when it came to discussing abnormal smears and HPV results, there seemed to be fewer cultural barriers for the black women interviewed than were described by the South Asian women.

3.2.4.3. *White British*

For most white British women, attending for screening did not have the same associations as were described by many of the South Asian women. This is perhaps because having sexual relationships before marriage is widely accepted as the norm, and young women frequently seem to discuss issues relating to contraception as well as screening with their mothers.

I first started to have sex when I was 16, so I talked, discussed it with my Mum and you know, we kind of discussed birth control, so we decided the Pill was the best option and obviously from then it just kind of followed on that smears would follow from that. (W6, age 29, single, HPV+, inadequate smear)

However, for some, having an abnormal result was associated with a sense of stigma and for many HPV, as an STI, was associated with promiscuity and a sense of being 'dirty'. In some cases, this was explicitly linked with 'catholic' beliefs about acceptable sexual behaviour.

I'm not promiscuous so I had this association in my head, an old catholic thing that promiscuity and cell changes would go together. (W20, age 37, single, HPV+, moderate/severe smear)

It seems therefore that beliefs about what is acceptable in terms of sexual behaviour within different religious and cultural groups has a potential impact on women's feelings about screening and about their results. This was most pronounced within the

South Asian group, but there was much variation within each of the ethnic groups as well as between them.

3.2.5. *Cytology result*

The final moderating factor identified was women's cytology result. This seemed to influence responses to the HPV result, although the pattern was not simple.

3.2.5.1. *Normal smear result*

Women with a normal result from their smear test seemed to respond to the HPV result in one of two ways. One response was to focus on the smear result, which was familiar and well-understood, and almost to discount the HPV positive result as irrelevant.

Women responding in this way often talked about the research context of the test, and thought about it in terms of helping with research rather than anything that had a direct impact for their own health. Many of these women were in the ARTISTIC trial where the recall for HPV positive women with a normal smear was one year. This management recommendation seemed to contribute to the downplaying of the severity of the HPV result. Many of these women were unaware that HPV is an STI.

The cervical smear was negative, that was a big relief, so I felt comforted by that. Um when the second set of results came back saying it was [HPV] positive, it didn't worry me that much. ... I think the feeling I got was if it was serious I wouldn't just be left. I've not signed anything that important that suggests that I'm willing to die for medical science! (W10, age 24, in a relationship, HPV+, normal smear)

An alternative response was to focus on the HPV result. This was more common among women who understood that it was sexually transmitted. In the absence of an abnormal smear result, these women tended to focus on the sexually transmitted nature of HPV and frequently had on-going concerns about where the virus had come from, as have been described in previous sections.

Only women in this group whose sexual histories were compatible with an STI diagnosis seemed able to accept the result without experiencing these negative emotions.

3.2.5.2. *Abnormal smear result*

Patterns of responses varied more widely within this group. As with the normal smear group, some women focused on their smear result and had little awareness of their HPV

result. This was the case with a woman who had treatment for CIN3, and reported knowing nothing about HPV at all. If extreme concern was raised by the smear result, and HPV was unfamiliar, some women seemed to ignore the issue of HPV, thereby avoiding the additional emotional challenges associated with having an STI. Other women with abnormal smear results were more aware of HPV, but reported that cancer was their major concern, so concerns about sexual transmission were minor by comparison.

By contrast, some women being treated for CIN were very aware and very concerned about HPV. The kinds of emotional issues discussed above clearly imposed a psychological burden on these women, over and above the concerns about cancer risk. They described having to cope with feelings of stigma and problems with disclosure, as well as dealing with anxiety about treatment procedures and cancer risk. One woman described her feelings ‘shock’ and ‘alarm’ about having CIN3 and her concern to have treatment quickly, but also experienced extreme anxiety and shame about having to tell her partner that she had an STI.

I felt embarrassed and very sorry ... about the HPV from the point of view of a fairly new boyfriend who I've only been seeing for a couple of months and have only known for a little bit longer than that. And just awful. I just felt this is just such an issue of trust really and this is just awful. (W35, age 38, in a relationship, HPV+, moderate/severe smear)

3.3. Coping responses

As has been shown in the foregoing sections, having an HPV positive result imposed a variety of cognitive, emotional and social burdens on women, from the cognitive task of integrating information about HPV into existing illness representations (described in Chapter 4), to dealing with the emotions engendered by having an STI. Women's coping strategies were contingent on their cognitive and emotional representations of the health threat. Depending on how they understood HPV, women had to deal with issues relating to having an STI and the emotions this evoked, possible transmission to partners, cancer risk, confusion or lack of understanding of the virus, and the ambiguity of the health threat. Coping strategies that emerged from the data are described below. Many of these have been mentioned in earlier sections, so the description here will be brief.

3.3.1. Focus on treatment, follow-up or future screening

As has been mentioned, some women coped with their result by focusing on the instructions they had received from health professionals regarding follow-up or treatment. Compliance with the medical recommendations was a practical step that women could take, and made many feel that they were doing what they could to minimise any perceived risk of the development of abnormal cells or cancer. Trust in the health profession enabled women to reduce their anxiety by complying with the recommendations. In some cases they were also able to interpret the recommendations as meaning that the result was not serious. This was especially true among women who were recalled after 12 months with a positive HPV result.

So when it came back that it was positive there was more of a feeling of oh that means I'm going to get tested yearly now rather than three years. So if something does occur I'm hopefully going to be one of the people at the forefront to be tested. (W33, age 40, divorced, HPV+, normal smear)

3.3.2. Trying not to worry

Many women described actively trying not to worry about their result. They tried to shut it out, put it to the back of their mind or not think about it. This strategy was often used in combination with compliance with the medical regimen.

The information I've been given has sort of made me feel that it, it's not something to worry about, but if you watch it you'll be alright. ... I think you can worry yourself into being ill, so [laughs], so I'm not going to worry about it. (W10, age 24, in a relationship, HPV+, normal smear)

3.3.3. Disclosure

Disclosure has already been extensively discussed in an earlier section, in the context of the emotional impact of an HPV positive result. This analysis will not be repeated, but it should be noted here that disclosure was commonly used by those who felt comfortable talking about their result as a means of mobilising social support and seeking information and reassurance from their partner, friends or family. Disclosure to a partner was also a way of coping with fears and concerns about transmission, or of confronting the guilt associated with having an STI.

For some women, non-disclosure was a preferred strategy. This was a way of avoiding the stress and the difficult issues that were perceived to be associated with disclosure, or

minimising anxiety in others, which itself would impose an additional emotional burden on women.

3.3.4. Information seeking

As many women knew little about HPV or the meaning of a positive result, seeking further information was a very common coping strategy to deal with confusion or uncertainty. For some this simply meant reading the leaflet that was provided, while others visited their GP, called the trial helpline, called genito-urinary medicine clinics, looked for information on the internet or in books, or talked to friends or family who knew about HPV.

I asked [the nurse] about it and she'd already given me the leaflet and found out things for myself like in the hospital with booklets and stuff in there, the manuals. I had a look. And of course in magazines. (W13, age 24, single, HPV+, normal smear)

The need for more information at the time of testing and afterwards was highlighted by many women as a way in which HPV testing could be improved.

3.3.5. Changes in sexual behaviour

Some women felt differently about sex as a consequence of their results, whether this was related to feeling 'dirty' or 'infected' because of HPV, or feeling vulnerable and sore after having treatment for CIN. Reducing or even ceasing sexual activity was sometimes reported, at least in the short term, and intended changes in sexual practices to increase use of condoms or 'safe sex' in response to understanding that HPV is an STI were reported.

3.3.6. Changes in other health behaviours

A few women reported other changes in health behaviours. Quitting smoking was sometimes reported or attempted if smoking was known to be a risk factor for cervical cancer. Some women also reported trying to be healthier in general or to boost their immune system to help their bodies fight off the HPV virus.

Stopped smoking that day. ... Then I found out it was clear and I was smoking again within hours [laughs]. (W7, age 39, single, HPV+, normal smear)

3.3.7. *Benefit finding*

As we have seen, some women experienced positive responses to their HPV diagnosis in terms of feeling pleased that something had been picked up early, allowing them to have more regular surveillance than would have been indicated by their smear result.

3.3.8. *Avoidance*

In rare cases, women reported having initially responded to their HPV result in an avoidant way, denying that it could be positive.

I was gutted, when I saw that on the computer I was just like, I've not got HPV, don't know what they're talking about! 'Cause I don't have any genital warts or anything so it was just like how can they say? (W34, age 21, in a relationship, HPV+, moderate/severe smear)

3.3.9. *Defensive denial*

As we have seen in this chapter and the previous one, it seemed that some women engaged in defensive denial to cope with their HPV positive result. This seemed to be a way of coping not with the emotional representation of the threat itself but with the threat posed to their relationship or self-image by an STI diagnosis.

3.4. Appraisal

Appraisal did not emerge strongly as a theme in the data. As women were interviewed at a single time-point, it was necessary to rely on their accounts of changing illness representations and coping strategies over time and to infer the existence of an appraisal process, rather than tracking changes longitudinally. This provided some indication of an appraisal process going on. A common pattern seemed to be to use information seeking as a way of coping with the HPV result initially. Additional information altered the cognitive representation and caused a corresponding shift in the emotional representation (e.g. if HPV was now understood to lie dormant for a long time). This process is illustrated in the case studies below.

Two case studies have been chosen as a way of illustrating the way in which illness representations related to coping strategies, and how these were described as changing over time in a dynamic way. These are illustrated in Figures 5.2 and 5.3. The transcripts of the two interviews are in Appendices 5.2 and 5.3. They have been picked as contrasting examples of the impact of testing positive for HPV and as good

illustrations of the dynamic processes that seemed to be involved in responding to an HPV positive result.

3.4.1. Case study 1

The first woman is a 42 year-old nurse who is married, and has only ever had a sexual relationship with her husband. He had only had two girlfriends before meeting her, so she regards her risk of STIs as very low. In her capacity as a nurse, she is aware of the established risk factors associated with cervical cancer, including having many sexual partners, and smoking, although she is unaware that the link between HPV and cervical cancer has been firmly established. Her smear result is initially normal, but the HPV result means that she is called for colposcopy and biopsy, and is diagnosed with CIN1.

As shown in the ‘cognitive representation’ box in Figure 5.2, on receiving a positive HPV result, her representation of HPV centres on its sexually transmitted nature and its possible link with cancer. This representation is associated with a strong negative emotional representation of the threat. Her feelings include being ‘horrificed’ and ‘scared’, and the fact that HPV is sexually transmitted carries a stigma that has connotations of promiscuity. It also poses a threat to her relationship, as she is unable to reconcile her sexual history with an STI diagnosis.

In the next stage of the model, she responds to the emotional aspects of the result by seeking information from her health professional colleagues. At this stage, she finds out that the virus is very common, can lie dormant for a long time, and poses no threat to men. This feeds into a reappraisal of both her cognitive and emotional representations of HPV. She now has additional information in her cognitive representation, and this is associated with a reduction in the perceived stigma of the infection. Understanding the potential of the virus to lie dormant for many years allows her to attribute it to one of her husband’s previous relationships, thereby alleviating her concerns about where the virus has come from. Dealing with the emotional aspects of HPV involves concealing the result from her husband, on the basis that explaining the result to him is perceived to have the potential to cause additional stress and anxiety.

In parallel with dealing with the emotional aspects of HPV, she deals with the actual health threat by complying with recommendations to attend for colposcopy and subsequently for treatment of CIN. This reduces her perceived risk of cervical cancer,

and the on-going surveillance minimises the possible negative consequences associated with HPV.

The CSM seems to provide a useful framework within which to conceptualise the dynamic nature of this woman's response to her HPV result. What the model does not do, however, is allow an integration of responses to HPV and CIN, and the relationship between the two. Nor does it account for the social aspects of the HPV infection and the concerns about the implications the infection might have for her husband.

3.4.2. *Case study 2*

The second example is a 26 year old woman who lives with her partner. Both of them have had previous relationships, which are openly acknowledged. She tests positive for HPV and has an abnormal smear result.

Before having the HPV test, she has not heard of the virus and is given little information at the time of testing. She perceives her results as worrying (particularly the smear result) and her initial response is to read the leaflet about HPV. She discovers that there are hundreds of different types, some of which cause warts, and is concerned about whether she will develop symptoms. She also understands that abnormal cells are one of the possible consequences of HPV, and she knows that it is an 'STD'.

This representation is associated with an emotional response of concern about a) her risk of cancer and b) transmission of the virus. She copes with this by talking to her partner, mother and sister, all of whom have had previous partners. Her sexual history and the acceptability within her family of having more than one partner allow her to seek reassurance through disclosure. To gain more information, she consults her GP who reassures her that she will not develop symptoms, and need not worry about transmission of the virus to her current partner. This allays some of her concerns, and her coping strategy is then to attend for colposcopy as recommended. Her increased perceived risk of cervical cancer as a result of having HPV changes her perceptions of the importance of screening and makes her more determined to attend regularly in the future. However she also says that the HPV result is 'overshadowed' by the abnormal smear. This contextual factor might also contribute to the relatively low emotional impact of the HPV result.

Figure 5.2 Case-study 1

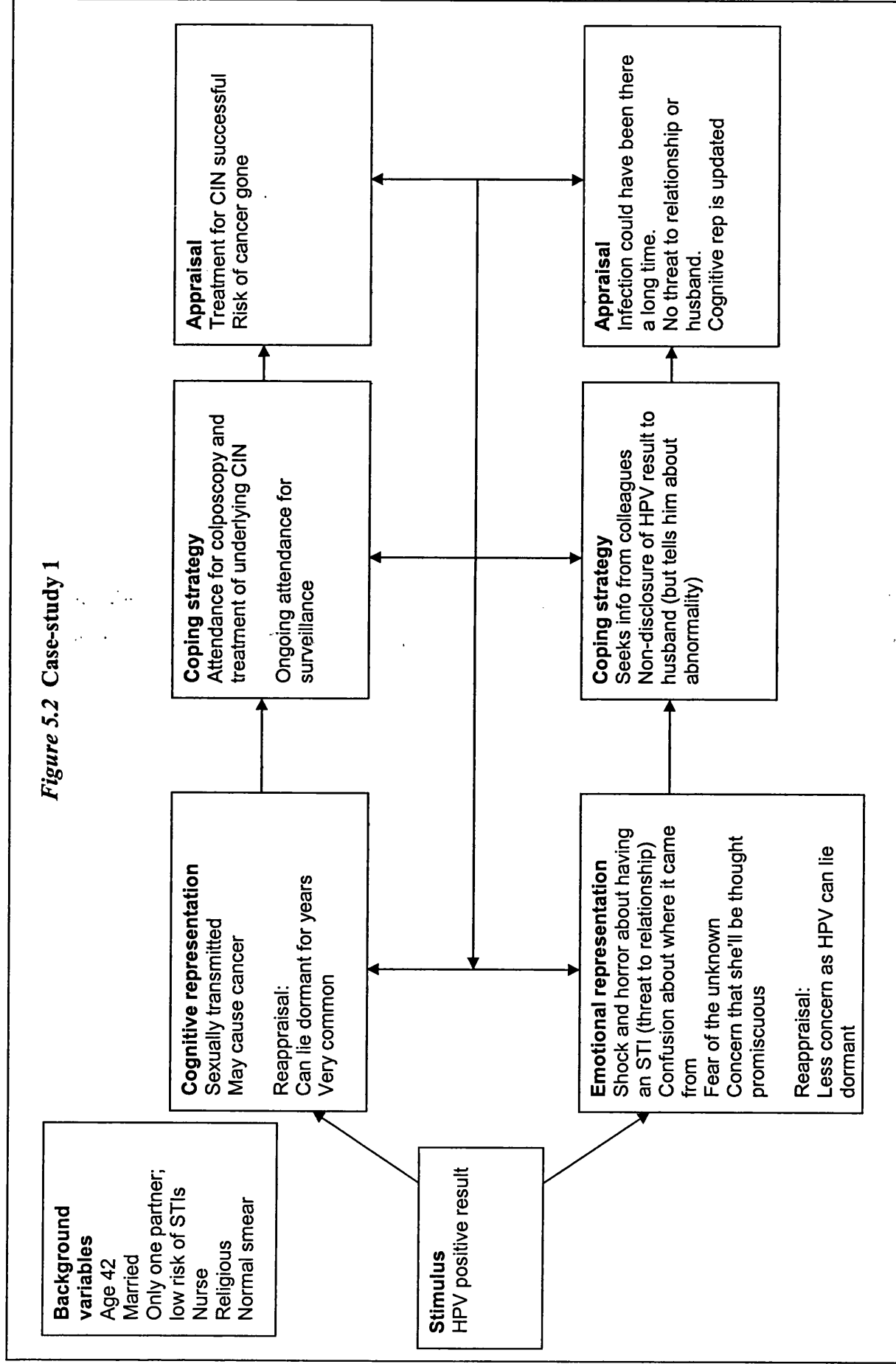
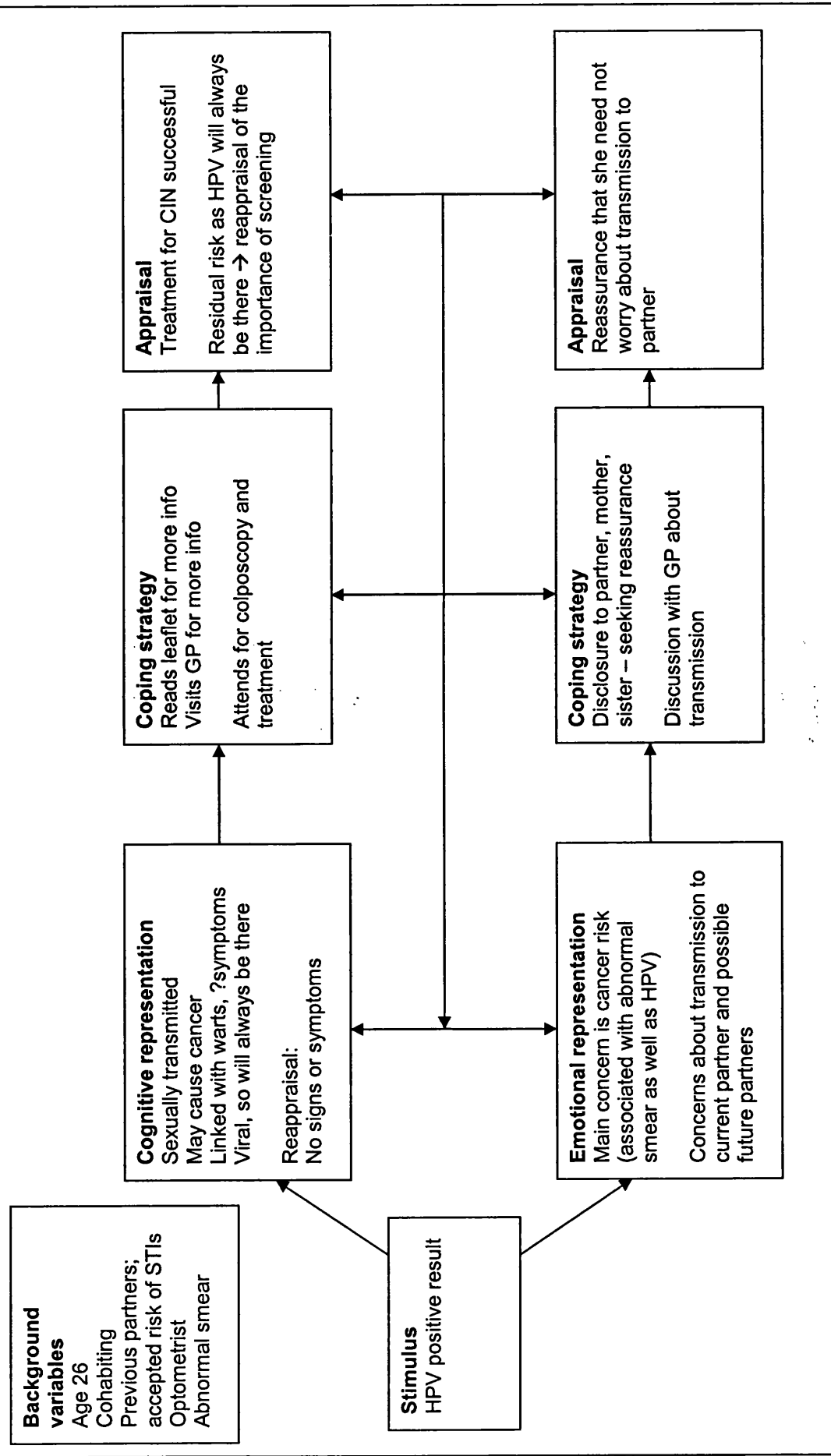


Figure 5.3 Case-study 2



By the time of the interview, her fears and concerns have been resolved. The only unanswered question is whether she would need to inform a future partner about her HPV status. This stems from the timeline dimension of her cognitive representation: she believes that now she has HPV, she will always have it. As changing partners is not an issue at the moment, it does not seem to worry her.

What these two case studies highlight is the importance of context in the model. Both women are aware of the sexually transmitted nature of HPV, but due to their different sexual histories and backgrounds, testing HPV positive poses a far greater emotional threat for the first woman than the second. Their disclosure patterns are influenced by their attitudes towards STIs and the second woman is more able to mobilise the support of her family. The dynamic nature of the model is indicated by the reported changes in illness representations and coping strategies used over time, although obviously this interpretation relies on women's self-reported retrospective accounts of the processes involved.

While these accounts seem to provide support for the utility of the CSM, it should be noted that for many women, HPV did not seem to constitute a sufficiently threatening stimulus for the development of multidimensional illness representations, and the model was much less helpful in thinking about these women's responses to HPV.

4. Discussion

This chapter has explored the impact of receiving an HPV positive result, and the moderators of that impact. It has used the CSM as a framework within which to interpret the way that women coped with a positive HPV result and appraised their coping strategies and their cognitive and emotional representations.

4.1. Emotional responses to results

In the first section, we saw very clearly that although women in the sample experienced the kinds of concerns about abnormal smear results that have been identified in the literature (Wardle et al., 1995; Bennetts et al., 1995; Rogstad, 2002), testing positive for HPV was also associated with responses that have not generally been reported in conventional cytology screening. Most of these related to the sexually transmitted

nature of HPV. As has been found in other studies of diagnosis with STIs (e.g. Gilmore & Somerville, 1994; Duncan et al., 2001; Cunningham et al., 2002; Fortenberry et al., 2002), women frequently reported feelings of stigma and shame, relationship difficulties, concerns about sex and transmission, and problems with disclosure of their results. The present findings are in line with our previous quantitative study (Kavanagh & Broom, 1997), which found that women who were HPV positive were more likely to have negative feelings about their past and future sexual partners. The data in this study take us forward in understanding these negative feelings, identifying specific issues of stigma, shame, blame, negative feelings about sex and problems with disclosure. It also identifies a pervasive feeling of shock among women who had not previously seen themselves to be at risk of an STI.

In addition to issues relating to HPV as an STI, the general lack of understanding of the virus was also a considerable cause of concern for many women. This is consistent with findings that poor understanding of smear results and the ambiguity of the meaning of the result compounds feelings of anxiety (Kavanagh & Broom, 1997; Karasz et al., 2003). It also fits with the finding of Maissi and colleagues (2004) that poor understanding was associated with increased anxiety among those taking part in HPV testing. However it should be noted that for some women, having an understanding of HPV seemed not to be necessary or even desirable, and they were happy to comply with the follow-up recommendations they had been given, knowing very little about the virus.

These findings suggest that introducing HPV testing into the national screening programme could impose emotional and social burdens on some of the women taking part, especially those who understand that HPV is an STI. Not all women were affected, though, and the study provides a first step towards understanding the variation in emotional response associated with a positive result.

4.2. Moderators of emotional response

The second step of the analysis aimed to explain the reasons for the variation in responses to an HPV positive result. Of key importance were women's cognitive representations of HPV, particularly awareness of its sexually transmitted nature. The way in which women were provided with information about HPV allowed some of them to remain unaware that it is an STI (see Chapter 4) and this was perhaps the most

powerful factor explaining emotional impact. This is consistent with one study of women with abnormal cytology results. Karasz et al. (2003) found that women who understood their abnormal cells to be caused by sexual activity experienced feelings of shame, which were not present among women with other causal attributions. The variation in beliefs may partly be due to women's information-seeking behaviour. Some women had called helplines, consulted their GPs, or searched for information on the internet or elsewhere, while others had barely read the leaflet that they had been given. However other studies have shown that women are able to attribute a variety of causes to infections that they know to be sexually transmitted diseases (STDs). Redfern and Hutchinson (1994) cite a respondent who says 'All STDs are not sexually transmitted – you can get them from almost anything'. This might be an indication of a defensive mechanism for avoiding the negative connotations of STI diagnoses, or maintaining the integrity of monogamous relationships. If this is the case, it suggests that women are not using self-regulation merely to deal with a health threat, as the CSM suggests, but may also be engaged in trying to regulate other aspects of their self-image, including their relationship with their partner. If one's positive self-image is closely linked to one's marital relationship, defensive denial might be an adaptive means of maintaining a positive self-perception (see Wiebe & Korbel, 2003).

Other aspects of women's cognitive representations were also important. Knowing that HPV i) is asymptomatic, ii) usually clears up on its own, iii) is highly prevalent, iv) can lie dormant for a long time, v) is not related to HIV, and iv) need not pose a threat to male partners all helped to reduce the negative impact of the result. These factors seemed to reduce the stigma associated with the infection, reduce the perceived seriousness and negative health consequences that might arise from it, and help women to address concerns about relationship issues and transmission of the virus. As noted in Chapter 4, these findings are consistent with those of Croyle and colleagues (1992). The link with warts and 'wart virus' had less clear implications; for some women it was reassuring while for others it was upsetting. Other studies have found the term 'wart virus' to be associated with feelings of stigma and confusion (Kavanagh & Broom, 1997; McCaffery et al., 2003b).

Also important in moderating emotional impact was relationship context. This was especially true for women who knew that HPV is an STI. The degree to which women were shocked and upset by their result depended very much on their history of sexual

relationships and their perceived risk of STIs. The two case studies in section 3.4 illustrate very clearly the way in which the same result can have different meanings for women, depending on their relationship history and social norms. The issue of relationship context has been neglected in the literature to date, and is conspicuously absent in most interpretations of the CSM.

The third moderating factor was cultural background. This was the one area in which differences between women in the three ethnic groups studied emerged. For many South Asian women, attending for cervical screening already conveyed messages about being sexually active. Some of the young South Asian women in the sample were in sexual relationships without the knowledge of their parents and so, unlike most of the white women, did not discuss screening with their mothers. Although these women tended to be HPV negative, they reported that discussing sex or STIs with their families was taboo. This would have definite implications for disclosure of results. Another study of similar ethnic groups (McCaffery et al., 2003b) identified concern among Pakistani and Indian women that the introduction of HPV testing would introduce connotations of sexual transmission into cervical screening. By contrast, the findings of the present study indicate that cervical screening is already linked to sexual activity by many in the South Asian community, so the introduction of HPV testing might have less of an impact than might be anticipated. Unfortunately our sample did not include any married South Asian women who tested HPV positive and were aware of its sexually transmitted nature, so we are unable to draw any conclusions about what the impact of this situation might be.

In the African Caribbean and white groups, cervical screening was less widely associated with taboo, although for some, attendance at screening was thought to go along with being sexually active. In these groups, sex before marriage seemed to be widely accepted and women were open about discussing screening with their families and friends. HPV, as an STI, could therefore be argued to have more of an impact on women in these groups since, for most, STIs were associated with negative connotations of stigma, shame, and being unclean. This was in contrast to their views about abnormal smear results, which were not associated with the same kind of stigma.

It should be noted, though, that there was wide variation within each of the ethnic groups as well as between them, so any firm conclusions about the likely impact of HPV testing on these different communities would need further investigation.

The final moderating factor was smear test result. Although women's beliefs and feelings about their smear result seemed to have an impact on the way in which they thought about their HPV result, the patterns were far from clear. Other factors including beliefs about HPV seemed to interact with the smear result to influence emotional responses.

4.3. Leventhal's Common Sense Model

4.3.1. Emotional representations

The CSM does not include a component that directly maps onto the notion of emotional impact. However, the emotional response to a health threat is conceptualised as being an 'emotional representation' of the threat. In this study, many of the emotional aspects of women's responses to their HPV positive result were not related directly to HPV as a health threat, but were linked to other aspects of self-identity. Although some women expressed fear and concern about the implications that HPV might have for their health, a much more dominant theme, as has been shown, related to the implications that HPV had for women's relationships. While this might not seem to fit neatly into the CSM, this may be due to the fact that the emotional side of the model is less well elaborated than the cognitive side. The findings can certainly be interpreted within self-regulation theory more generally, and are consistent with the idea that human beings strive to achieve multiple goals in a self-regulatory manner. For a married woman, maintaining the integrity of her relationship with her husband might be a very important goal and one that takes precedence over others (like having a clear understanding of HPV). If this is the case, the aim of the self-regulatory process will be to remove the discrepancy between her goal of a happy marriage and her current situation. This might involve dealing with the distress associated with testing positive for HPV by seeking information that is consistent with her being in a monogamous relationship.

Lazarus and Folkman (1984) have argued that in a situation where a health threat itself cannot be addressed (as is the case with HPV, in the absence of any treatment), coping

efforts may focus on dealing with the emotions engendered by the situation, and this seems to be consistent with the findings of the study.

4.3.2. Coping and appraisal

The study was not designed specifically to investigate women's coping responses or appraisal, but as the CSM appeared to be a useful framework within which to think about women's cognitive representations of HPV, the data were examined for evidence of these stages of the model as well.

Women showed evidence of employing a variety of coping strategies to deal with their confusion about the HPV result, the threat of cancer, their emotional responses to being diagnosed with an STI and the relationship issues this raised, and their fears about transmission of the virus to partners. As has been found elsewhere (Coyne & Gottlieb, 1996), identifying particular coping strategies that are universally successful was not possible. The ways in which women responded to their result were dependent (as the CSM predicts) on their beliefs about the virus, and the emotional impact that it had on them. This was in turn dependent on their relationship status and history and other aspects of their background. For example, many women found disclosure of their HPV result to their partner to be a good way of seeking support and reassurance. However for other women, this kind of disclosure would have raised stressful issues about where the virus had come from, and was therefore avoided using a non-disclosure strategy.

Evidence of appraisal processes also emerged from the data, to some extent. The CSM is consistent with the apparently dynamic processes involved in women's coping and adjustment over time. A common pattern was for women to seek information immediately after receiving a positive result, in order to address their confusion about what it meant. This caused a reappraisal of their cognitive representation of HPV, and a concurrent alteration in their emotional response. This frequently allayed women's fears and concerns about having an STI, and allowed them to focus on adhering to the medical recommendations for follow-up to deal with the threat itself, rather than the emotional responses to it. Unlike other more static or linear models, the CSM is able to capture this dynamic process.

4.4. Strengths and limitations

This study is the first to have carried out in-depth interviews with women who have taken part in HPV testing in the context of cervical cancer prevention. The methodological strengths of the study design have been outlined in Chapter 4.

The methodology also has several limitations that are particularly relevant to the questions being addressed in this chapter. Most of the women taking part in this study had their HPV tests in a research context, rather than as part of routine screening or care. This seems to have contributed to women's uncertainty about the link between HPV and cervical cancer, and may have had an influence on the way in which their results were perceived. In addition, they represent a group that is not only motivated to take part in screening, but also in research. We cannot therefore rule out the possibility that the consequences of having HPV might be different for women in routine screening, or for those who do not regularly attend for cervical screening at all.

As has been noted already, many of the South Asian women in the study tested negative for HPV. This has made it difficult to draw any conclusions about the impact of testing HPV positive in this group. Similarly, most of the African Caribbean women were recruited at a single centre, so it is impossible to tease apart the effect of having testing at that centre from any possible effect of ethnic background. In addition to these problems with the comparability of the samples, the majority of the interviews with South Asian and African Caribbean women were carried out by freelance interviewers. This may have affected the quality of the data, as they were less grounded in the aims of the research than Kirsten McCaffery and myself.

The study only provides a snap-shot of women's responses to HPV testing following one test. This could usefully be taken forward by investigating the impact of persistent HPV, as many women are likely to be managed using repeated HPV testing if it is introduced into the cervical screening programme. This issue will be addressed in Chapter 6.

4.5. Conclusions

The analysis in this chapter is consistent with other studies (Maissi et al., 2004; McCaffery et al., 2004) in finding that testing positive for HPV is associated with an increase in anxiety. However this study takes us forward in identifying the specific

concerns and worries that women experience as a result of testing HPV positive, and the ways in which these differ from responses to abnormal cytology results. It is clear that for most women, being diagnosed with an STI as part of cervical screening raises issues and concerns that are not normally associated with attending for a smear test.

Emotional impact varied widely, however, and was clearly linked with aspects of women's cognitive representations of HPV, their sexual relationship status and history, cultural background and cytology result. As cognitive representations are the most modifiable of these factors, providing information about HPV may prove key to minimising the potential negative psychological consequences of introducing HPV testing into the national screening programme.

CHAPTER 6 – IMPACT OF PARTICIPATION IN REPEAT HPV TESTING (STUDY 4)

1. Introduction

In Study 3, the beliefs and experiences of women having a single test for human papillomavirus (HPV) were investigated. This has provided insight into short-term responses to a single test, but does not tell us how women might respond to on-going surveillance using HPV testing. No matter how HPV testing is incorporated into the UK cervical screening programme, many women will be faced with repeated HPV tests, either in primary screening, or as a way of monitoring the risk of development of high-grade cervical intraepithelial neoplasia (CIN). If HPV testing is used to inform the management of women with borderline or mildly abnormal smear results, as is now recommended in the United States (Wright, Jr. et al., 2002a), women who are HPV positive will undergo regular surveillance by repeat HPV testing. If HPV testing is introduced as the primary screening modality, as has been suggested by some authors (Cuzick et al., 2003), women will take part in regular HPV testing as part of the screening programme. This raises questions about the impact of repeated HPV testing, in comparison to a one-off HPV test.

At present, mildly abnormal smear results are often managed conservatively by repeated cytology testing, so many women experience a series of smear tests with varying results. This kind of surveillance is the closest equivalent of repeated HPV testing currently being used, and women's responses to cytological surveillance could be indicative of the likely impact of surveillance with HPV testing. Few studies have directly addressed the question of how women understand and respond to persistent mildly abnormal smear results, but several shed some light on the issues involved. Wardle et al. (1995) found that women whose mildly abnormal smear results were followed up with surveillance rather than colposcopy were less anxious than those referred for colposcopy, but they did exhibit significantly more screening related concerns than women who had a normal smear result. Measures were only taken at one time-point (following a first abnormal result), so changes in anxiety over time and after subsequent smear tests were not investigated. In another cross-sectional study, Bell and colleagues (1995) found that women managed by cytological surveillance experienced less acute anxiety than women referred for colposcopy, but that women monitored by

repeated cytology (who had been under surveillance for an average of 22 months) displayed more serious social adjustment problems than those managed by immediate colposcopy. Although the psychological consequences of surveillance may be less acute, the authors suggest that they are more pervasive. Another study comparing surveillance with colposcopic management (Jones et al., 1996) found that women who had been referred for colposcopy were more likely than those receiving cytological surveillance to report retrospectively that they had believed their result to be indicative of cancer, but they also reported a clear preference for immediate colposcopy over waiting for repeated cytology. This reluctance to wait for follow-up is consistent with a small American study (Karasz et al., 2003) which found that women were fearful of cancer developing or spreading while they waited. It is, though, at odds with a recent UK study in which 56% of women with mildly abnormal smear results who were offered a choice of management opted for colposcopy, and 44% for six month surveillance (Kitchener et al., 2004). In this study, women's anxiety was found to decrease over time, regardless of the follow-up method.

In a retrospective study, questionnaires were sent to women who had received two consecutive mildly abnormal smear results, followed by a colposcopy and treatment where appropriate (Ideström et al., 2003). Women retrospectively reported their level of anxiety and concern between the first and second tests. A considerable proportion reported concerns about cancer, fertility and death, with 30% saying that anxiety had affected their daily lives. This indicates the potential for significant negative psychological consequences of waiting for further surveillance tests, although the retrospective methodology means that the findings should be treated with some caution.

One study has explicitly tried to explore women's understanding of a mildly abnormal smear result and the link between understanding and anxiety (Somerset et al., 1998). The methodology involved the analysis of free text responses to questions about knowledge and concerns following a mildly dyskaryotic result, and found a very weak (non-significant) association between higher knowledge and lower anxiety. However the authors judged knowledge by how 'accurate' or close to the medical model it was. They did not explore the possibility that specific beliefs might be associated with lower anxiety, regardless of their accuracy.

Taken together, these studies demonstrate the potential for anxiety and concern while waiting for a second test following a mildly abnormal smear result, although they tell us very little about women's responses to a second test, or their beliefs about the meaning of mild dyskaryosis and their understanding of the potential for spontaneous regression of CIN.

Study 3 (see Chapter 5) found that a first HPV positive result was associated with a variety of negative psychological sequelae including shock, distress and shame at being diagnosed with a sexually transmitted infection (STI), as well as concerns about cancer and future fertility. In light of these results, and the likelihood of women undergoing repeated HPV tests, it is important to know how these responses play out over time, whether women experience anxiety while waiting for a second HPV test and whether the second HPV result is associated with a different emotional and social impact. It is also important to investigate the way in which women make sense of viral persistence or clearance following a second HPV result. The ARTISTIC trial (A Randomised Trial of Screening To Improve Cytology) provided an ideal opportunity to do this, as women with a normal smear result who tested HPV positive at baseline were invited for a repeated HPV test 12 months later.

Another body of literature that might be expected to have a bearing on these kinds of questions is that relating to the psychosocial impact of other STIs. In fact, it is difficult to think of another STI that is comparable to HPV in terms of the need for repeated tests, and clearly none has the same implications for cancer risk. Bacterial infections such as Chlamydia, gonorrhoea and syphilis are usually treated successfully once diagnosed, and do not require follow-up testing. Other viral infections like herpes are always present, once diagnosed, so do not involve the kind of repeated surveillance that might be introduced for HPV. HIV infection has psychosocial consequences that are very different from HPV. Although monitoring of CD4 counts and viral load is routine for people with HIV, this is very different from monitoring HPV, in that there is no chance of viral clearance. The far greater severity of the health consequences associated with HIV make comparisons unhelpful.

In Study 3, Leventhal's (Leventhal et al., 1980) Common Sense Model (CSM) was found to be a useful framework for analysis of the data, and provided a way of interpreting the relationship between women's cognitive representations of HPV,

emotional responses to testing positive, and their coping strategies. This study used the same framework for analysis and aimed to address particular aspects of the CSM. The analysis focused on i) causal beliefs, which emerged as the most important aspect of women's cognitive representations in Study 3, ii) beliefs about the timeline and controllability of HPV infection, which relate to viral persistence /clearance and are important in investigating how women understand a second HPV result, iii) emotional responses to the results and iv) disclosure, which was found in Study 3 to be a common coping strategy and one that provided additional insight into the emotional impact that the HPV result had on women. The way in which each of these aspects changed over the year between the two tests, and varied between the first and second test, was investigated.

Since this is a very new area of research requiring exploration and description, qualitative methods were used to identify issues that were grounded in the perspectives of the respondents.

2. Methods

2.1. Study design

Study 4 consisted of 30 interviews with women who had had two HPV tests, a year apart, to investigate the changes in impact over a year, the impact of the second HPV result, and meanings attached to persistence or clearance of the virus. The group was selected to be homogeneous with respect their first smear and HPV results, so that the impact of repeated HPV testing could be investigated in women receiving the same management, without the 'noise' that would be introduced by variation in cytology results.

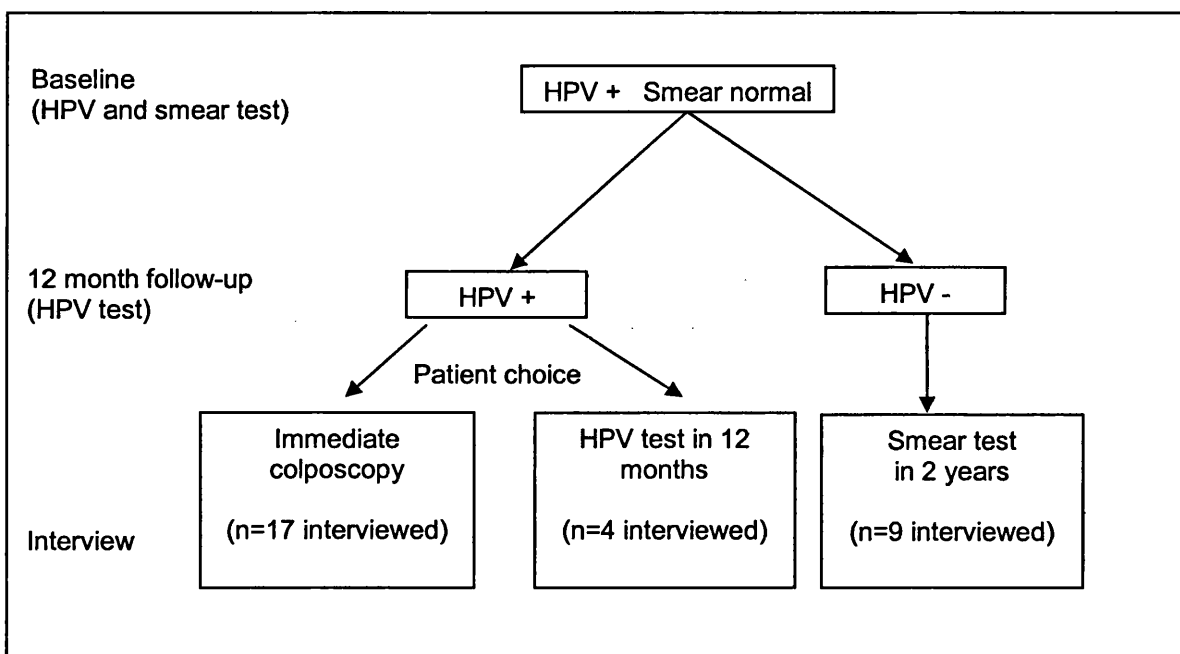
The study was designed as an extension to Study 3 and was approved by the North West Multi-centre Research Ethics Committee as before (see Appendix 6.1).

2.2. Sampling

All the women in the study were recruited from the ARTISTIC trial in Manchester (see Chapter 4 for a description of the trial). They all tested positive for HPV at baseline, but had a normal smear result. The trial protocol stipulated that these women be invited

back for a second HPV test, a year after the first. Those who were HPV negative at the second test were returned to routine screening (i.e. invited for their next smear in two years) while those testing positive were given the choice of a third HPV test after a further year, or an immediate colposcopy (see Figure 6.1 for the follow-up protocol). All the women from Study 3 who were eligible were invited to take part in this study, and additional women were recruited after their second HPV test to increase the sample size and to ensure that the findings were not the result of women having taken part in two interviews.

Figure 6.1 Protocol for ARTISTIC trial follow-up of women with a baseline result of HPV positive/smear normal



As with Study 3, the sample was purposively selected to be heterogeneous with respect to age, marital status and socio-economic background. In this study, the need to include women from the three outcome groups (see Figure 6.1), and the limited time and resources available, meant that ethnicity could not be included as a dimension on which to purposively sample. Given the difficulties with recruiting women from South Asian and African Caribbean backgrounds from the ARTISTIC trial for Study 3, it is perhaps not surprising that failure to purposively sample different ethnic groups resulted in a homogeneous white British sample.

2.3. Recruitment

Women who had taken part in Study 3 had given consent to be re-contacted for a follow-up interview, so eligible women were contacted by phone and asked to take part. New recruits were sent the same letter with an opt-out slip as was used for Study 3 (see Appendix 4.3). Those who had not opted out were contacted by telephone and invited to take part.

Of the 11 eligible women from Study 3, four failed to attend for their repeat HPV test during the time period when the interviews were being carried out, and so were ineligible for the interview study (two of these subsequently attended for their second test). One had moved away, and one declined to take part in a second interview. The remaining five were interviewed. Of these, one had taken part in Study 3 but the tape had been lost prior to transcription, so she was not included in the Study 3 analyses. In addition, 27 women were recruited following their second HPV test, to represent different age groups and different outcomes (i.e. HPV negative, HPV positive/colposcopy and HPV positive/repeat test). These women were recruited using the same protocol as for Study 3 (see Chapter 4).

2.4. Interview materials

The interviews were structured using a topic guide as before. This was designed to recap briefly on women's experiences of the first HPV test, and to focus on changes between the first and second tests, the unfolding impact over the year, and the decision to take part in the second test. The impact of the second test was explored in detail, and differences between the first and second tests drawn out. Women who tested positive were asked about their follow-up choice and experience of colposcopy where appropriate. Beliefs about the meaning of the second result were explored, and women were asked about their perceptions of their future HPV status. The full topic guide is shown in Figure 6.2.

Figure 6.2 Topic guide for interviews in Study 4

Cancer Research UK – Psychosocial impact of HPV testing – study 2
Introduction
<ul style="list-style-type: none"> • Thanks. • Introduce self (mention not from medical background) and that will give background about the study first... • Have been talking to women around the country about how they feel about the new Human Papillomavirus (HPV) test as part of cervical cancer screening. Now talking to women who have had a follow-up HPV test. • Part of the trial is to see if the test improves cancer screening; would like to hear what you thought about the test; we also need to know how women feel about the HPV test results. • This is a study funded by the Cancer Research UK. The study will help decide if the screening should be introduced nationally and what sort of information women need about HPV. • Brief outline of the interview: background about you; first HPV test; what's happened in the year since then; what happened when you had your second HPV test; about an hour. • Consent form; Confidentiality; Tape recording
Background
<ul style="list-style-type: none"> • Can you tell me a bit about yourself (short recap if second interview) • Age • Who lives with you (partner, children)? • Employment (current job; usual job if not working; other activities; always done same job?) • Partner's occupation (or parents' occupation if live with them) • Educational background (i.e. qualifications, age of leaving education) • Ethnic background (birthplace; parents birthplace; where educated). Suggested: We're interviewing women from a range of ethnic backgrounds; Can you describe yours? Probe: why? • Religious background • Changes in circumstances over the last year (since 1st HPV test)
First HPV test and intervening year
<ul style="list-style-type: none"> • How got involved in ARTISTIC trial • What knew about HPV before first test (before recruitment to ARTISTIC trial) • Results of first test – understanding • Understanding of transmission, link to cervical cancer, how common, how serious • Perception of risk of cervical cancer • Emotional responses to results • Disclosure of results – include way that disclosure has unfolded over the year. • Way these things have unfolded and changed over the year (emotional responses, disclosure, understanding) • Impact of first interview on feelings about results and last 12 months (if this is the second interview)

Figure 6.2 (cont.)

Second (more recent) HPV test
<ul style="list-style-type: none"> Any info read/received on HPV between first and second tests (from health professionals, media, friends etc) How much thought about being HPV+ over the year (emotional responses, changes over the year) How felt about follow-up, waiting for 12 months Was invite for 2nd test expected? How invited? What understood about the 12 month follow-up Understanding of why second test being recommended Feelings about second test Reason for attending second test (thoughts about not attending?) Expectations about results
Results
<ul style="list-style-type: none"> How received What was the result Understanding of meaning of results (persistence, clearance, reinterpretation of first result) Awareness of factors affecting persistence/clearance Comparisons with first test (understanding; meaning) Confidence in results
Impact of results
<ul style="list-style-type: none"> In general, how did the results make you feel? What went through head when got results Emotional reactions (explore reasons for feelings) Perceptions of cancer risk (compared with after previous smears and first HPV test) Concerns/anxieties about having a persistent infection (feelings of being 'infected') or meaning of clearance Impact on sex (even if STIs have not been mentioned) in intervening year; compared to any past experience of infections Feelings towards partner Concerns about transmission to partner (if relevant) Pick up on clues about knowledge of sexually transmitted nature of HPV and discuss if appropriate (disclosure issues; links between cervical cancer and sexual activity; screening in the context of being sexually active); compare, some people mention taboo associated with STIs, do abnormal cells / HPV attract the same taboo or not? Feelings about the uncertainty of information about HPV Perception of well being (self-identity); effect of HPV positive or negative status; perception as self as healthy; vulnerability to illness; impact on other health behaviours Impact of diagnosis of an STI (if this is understood)
Disclosure
<ul style="list-style-type: none"> Whether talked to anyone about the results (who?) Reasons for disclosure or non-disclosure Reactions to disclosure Intentions to disclose to future sexual partners Comparison with disclosure of previous smear results If different, explore reasons (possible impact of STI information) Comparison with first HPV test and disclosure over the previous year

Figure 6.2 (cont.)

Follow-up
<ul style="list-style-type: none"> • What follow-up was recommended? What was chosen by respondent (if positive)? • Reasons for choosing repeat HPV vs. colp. • Why was other option NOT chosen • If chose HPV test, feelings about waiting a further 12 months • If chose colposcopy, experience of colposcopy, feelings about colposcopy results, (emotional impact, disclosure to others) • If HPV negative, feelings about returning to routine screening • Feelings about the whole series of follow-up tests/examinations (reassurance, over investigation, monitoring, surveillance)
Cervical cancer and HPV
<ul style="list-style-type: none"> • Causal beliefs about HPV infection (changes over year and since second test) • Causal beliefs about CaCx • Changes in beliefs about cause of CaCx (link with sexual activity) • Changes in beliefs/knowledge about HPV since first test (sources of info; reasons)
The future
<ul style="list-style-type: none"> • Risk perceptions (HPV persistence, cervical cancer) • Beliefs about future infection • Planned behaviour change (sexual behaviour; screening attendance, changes in other health behaviours – e.g. smoking, diet) • Thoughts about national screening programme & whether would recommend test to friends • Information that was useful or would have been useful before or after HPV tests
Closing the interview
<ul style="list-style-type: none"> • How have you found the interview? • Any important issues that haven't been raised, extra comments about HPV or cervical screening in general • Give help-line numbers (as some people still have questions) • Have time to chat about other things after the interview • Reassure about confidentiality and repeat info provided at the beginning • Thanks

2.5. Conduct of interviews

The majority of interviews were carried out in respondents' homes. In rare cases, the interview took place at the participant's place of work or at an office at St Mary's hospital if this was her preference. As in Study 3, women signed a consent form agreeing to the tape recording of the interview (see Appendix 4.8).

I carried out 12 of the interviews, Kirsten McCaffery did eight and 11 were carried out by one of the free-lance interviewers who had been trained to work on Study 3.

Additional training and familiarisation with the new topic guide were provided prior to

Study 4. One interview failed to record and is excluded from analyses, leaving a sample size of 30. All interviews were transcribed verbatim.

2.6. Analysis

Analysis used Framework Analysis (Ritchie & Spencer, 1994) as before. The thematic framework (derived from the transcripts) was similar to that used for Study 3, but also included new themes that emerged from this study (see Figure 6.3). The process of charting was the same as that described in Chapter 4, with themes making up the columns of the framework, and cases the rows. Data from all the interview transcripts were summarised in the matrix with quotations and references to pages in the transcripts, to facilitate referring back to the data. The processes involved were the same as those that have been described in Chapter 4.

3. Results

3.1. Sample

The demographic characteristics of the sample are shown in Table 6.1. The sample was well-distributed across the age groups, with roughly eight each in their 20s, 30s, 40s and 50s. Two-thirds were married or cohabiting, with the rest either being in a relationship (n=6), single (n=4) or divorced (n=1). Twelve women had educational qualifications equivalent to GCSEs/O levels or below; 10 had A levels or vocational qualifications; and 7 women had a degree. Seventeen of the 21 women who had persistent HPV opted to have an immediate colposcopy, rather than waiting for a repeat HPV test. This reflects the distribution in the full trial population, in which only a very small percentage of women opted for a repeat test (unpublished data).

Figure 6.3 Thematic framework for analysis of Study 4 data

<p>CHART 1: BACKGROUND</p> <p>Study ID number</p> <ol style="list-style-type: none"> 1 Age 2 Social class (education/occupation) 3 Partner status 4 Ethnicity/religion 5 Living arrangements (children) 6 1st and 2nd HPV results and follow-up chosen 7 Previous smear results 8 General health status 9 Family health history 10 Misc./other <p>CHART 2: SCREENING HISTORY & BELIEFS</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 Screening history and previous experiences 2 Beliefs/attitudes to screening 3 Beliefs about cervical cancer & cancer generally 4 Understanding of cytology/smear tests 5 Misc./other <p>CHART 3: HPV</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 Prior knowledge of HPV (before first test) 2 Understanding of mode of transmission 3 Perceived risk of HPV and STIs in general 4 Understanding of link with CaCx / abnormal cells 5 Impact of HPV info on perceptions of CaCx 6 Current understanding of HPV 7 Purpose of HPV testing 8 Changes in beliefs over year between tests 9 Unanswered questions 10 Misc./other <p>CHART 4: FIRST HPV TEST</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 How came to have test & decision to participate & expected outcome 2 First results & how received 3 Understanding & meaning of results 4 Beliefs about cause of +ve results 	<ol style="list-style-type: none"> 5 Perceived severity of results & Ca risk 6 Emotional responses to first results 7 Impact of results on relationships 8 Confidence in results & screening accuracy in general 9 Impact on perception of self as healthy 10 Misc./other <p>CHART 5: SECOND HPV TEST</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 Changes in feelings/beliefs about HPV over year 2 Invitation and decision to have second test 3 Expectations about results (reasons) 4 Results 5 Impact of result (emotional and relationship) 6 Perceived severity and risk of CaCx 7 Factors affecting persistence/clearance 8 Beliefs about future HPV status 9 Misc./other <p>CHART 6: DISCLOSURE</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 Own and friends' normal screening disclosure 2 Disclosure of participation in HPV test (prior to results) 3 Disclosure of results (both tests) 4 Reasons for (non) disclosure 5 Other's reactions to disclosure 6 Pattern of disclosure over year 7 Misc./other <p>CHART 7: FOLLOW-UP, INFORMATION & FUTURE SCREENING</p> <p>Identifier</p> <ol style="list-style-type: none"> 1 Decision about follow-up (if HPV+) 2 Experience of follow-up (colposcopy) 3 Perceptions of future screening 4 Sources of info (CaCx, smear, HPV, treatment) 5 Feelings about future HPV testing (self/others) 6 Improvements to screening process 7 Misc./other
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It should be noted that within the sample, three women did not remember having had two HPV tests, so their transcripts cannot be used to answer most of the questions addressed in this chapter. In addition, one woman with persistent HPV was not aware that she had tested positive at all, and believed annual HPV testing to be the standard trial protocol.

Table 6.1 Demographic characteristics of the Study 4 sample (n=30)

	HPV positive at follow-up (n=21)	HPV negative at follow-up (n=9)	All (n=30)
Age			
20s	7	1	8
30s	5	2	7
40s	6	3	9
50 and over	3	3	6
Relationship status			
Single	4	0	4
In relationship	4	2	6
Married/cohabiting	12	7	19
Divorced	1	0	1
Education			
Left school before 16 / no qualifications	1	2	3
Left school at 16 (GCSEs, CSEs, O levels)	7	2	9
A levels	3	0	3
Further education (diploma, BTech etc)	5	2	7
Higher education (degree)	4	3	7
Missing data	1	0	1
Ethnic group			
White British	21	9	30
Choice of follow-up			
Colposcopy	17	n/a	17
Repeat HPV test	4	n/a	4

3.2. Cognitive representations

3.2.1. *Causal beliefs about HPV*

In contrast to the Study 3 sample, all the women in Study 4 mentioned the sexual transmission of HPV at some point during the interview, perhaps because they had all tested positive on at least one occasion and had had longer to gather and assimilate information about HPV. The majority were aware that HPV was, unambiguously, an STI, but a significant proportion thought there were other ways you could get the virus.

A typology was developed, similar to the one used in Chapter 4, to describe the range of causal beliefs

- 1) Sexually transmitted, but there may be other causes
- 2) Sexually transmitted, but how did I get it?
- 3) Sexually transmitted; I got it from X
- 4) Sexually transmitted; not interested in who it came from
- 5) Other causal beliefs

3.2.1.1. Sexually transmitted, but there may be other causes

Women in the first group had heard that HPV is sexually transmitted, but believed that there were other ways of contracting it, or that it could just develop in the body.

I mean obviously it's not sexually transmitted so I shouldn't worry about passing it on to my husband um... When it was explained like what sort of a virus it was, it didn't worry me, it didn't worry me greatly because I know people just sometimes are more susceptible to cold sores or warts or things (F24, age 46, married, HPV+, colposcopy)¹⁶

There was a belief that some women might be more susceptible to infection, and that HPV could be linked to herpes or warts. Some quoted the leaflet which stated that there may be 'occasional exceptions' to the sexual transmission of HPV. Once again, this refusal to acknowledge that HPV is an STI provided a degree of protection against the negative consequences of testing positive, although some women held these beliefs in combination with others and did experience negative emotions associated with sexual transmission.

I felt quite dirty. But then I thought well it might not be sex, might be something else ... I thought well he's given me something. And I didn't like going near him then. (F13, age 21, in a relationship, HPV+, colposcopy)

3.2.1.2. Sexually transmitted, but how did I get it?

Those who knew that HPV is an STI but saw themselves as being at low risk, either because they had only had one partner, or because they had not been sexually active for a long time, expressed confusion about their result and about where the HPV might have come from.

I can't of caught anything. I haven't had sex in years ... and then I was with a regular partner, one partner and we split up and I haven't, I've not been in a sexual relationship since then. ... If it's a sexual disease I've not been playing around. (F25, age 41, single, HPV+, colposcopy)

3.2.1.3. Sexually transmitted, I got it from X

Many married women fell into this third group as either they or their partner had had previous relationships which were openly acknowledged, and to which HPV could be attributed. Awareness that HPV can lie dormant was, once again, key to these women's causal beliefs.

¹⁶ The HPV result refers to the result of the second test

[My husband] actually thinks that he was, if you like, the carrier of it. Because like I said when I looked on the Internet it said you could have it, you could actually catch it and then twenty years later it'll come through ... we've been married longer than that but you know. It's just not worth bothering about really. (F26, age 46, married, HPV+, colposcopy)

Other women whose sexual histories were consistent with contracting HPV also frequently attributed the infection to a particular partner.

I didn't tell the guy who I was sleeping with at the time. I presumed I caught it from him because, well I presumed it was him rather than my previous relationship with [name] for ten years. (F21, age 31, cohabiting, HPV+, colposcopy)

3.2.1.4. Sexually transmitted, not interested in who it came from

Some women who had had several partners felt that the infection could have come from anyone, and were not interested in trying to trace it to a particular person. Often this was associated with knowing that the man would have been unaware of carrying the infection, and a feeling that it was pointless to try and find someone to blame.

I think I'm more likely to just blame myself than somebody else really 'cause I mean you don't know, do you? I just don't see any point in looking back and trying to pinpoint something that I could have had for years. (F10, age 27, in a relationship, HPV+, colposcopy)

3.2.1.5. Other causal beliefs

A small number of women seemed totally to discount the idea that HPV is sexually transmitted. One reported that her husband had questioned whether HPV was an STI, but said that she had not thought so herself. Another claimed not to have been told about the cause of HPV (although at one point she said she wondered whether she had slept with someone). But after the end of the recorded interview her husband joined the conversation, and it transpired that sexual transmission was something that had been discussed between them. This highlights the difficult nature of eliciting beliefs about such a sensitive issue.

The women in this group cited other possible causes: problems with periods, something that just happens, or in one case, something related to an infection caused by a contraceptive coil.

Is it to do with my periods? ... I've not slept with anyone and I've not done this, I've not done that ... I don't think people can really tell you how you get things. I think they just appear don't they? (F9, age 31, married, HPV+, colposcopy)

3.2.2. Changes in causal beliefs over the year

One of the aims of the study was to investigate possible changes in causal beliefs about HPV over the course of the year in between the two tests. When the charts were examined, little emerged, perhaps because women found it easier to report on their current beliefs and were not able to remember how these might have changed over the year between tests. Many felt generally better informed by the time of the second test. Only three women had heard of HPV before participating in the trial, so levels of knowledge and awareness at the time of the first test were very low. Some had found information about HPV in magazines, on the internet or on TV during the year, as well as having information about it as part of the trial. A few had spoken to one of the nurses on the ARTISTIC trial helpline.

In a few cases, information gathered during the year seemed to change women's beliefs about the sexually transmitted nature of HPV. One woman seemed not to have taken in much information about HPV when she received her first positive result. Later, she realised she was HPV positive and phoned the helpline. This was the first time that she realised that it might be sexually transmitted.

I didn't actually read that properly either, what was going on. So I haven't actually took it all in ... [Later she said] I spoke to a nurse who sort of explained they might think it's like a sexual problem from young, from being young. They sort of indicated that it might be like sexually transmitted but they didn't know: it was something that it could be. But something that could have been from years ago. (F8, age 27, single, HPV+, colposcopy)

Later in the interviews she said: 'But I think I didn't know it was sexually transmitted until I got [to the hospital] for the biopsy, I didn't know'.

Another woman began by assuming that HPV was sexually transmitted, but then when she looked it up on the internet, she decided that that was not necessarily the case.

In my own mind I thought it was just a sexually transmitted disease and I didn't think that I could have it 'cause I've been with [my husband] since I was sixteen and I've never had another sexual partner since I was, well never anyway in my life. ... But then I had a look on the computer and it said that in most cases but it didn't explain what it meant by in most cases it was sexually transmitted. And then I just sort of dismissed it to the back of my mind and never thought any more

about it until I got this letter to say would I go back for another test. (F3, age 54, married, HPV-)

These two examples illustrate the way in which women's beliefs could change over the course of the year, but suggests that some may have had difficulty in remembering at what point they acquired their current beliefs about particular aspects of HPV.

3.2.3. Timeline and control beliefs relating to viral persistence or clearance

Women were also asked about why they thought the HPV was still there after the second test (in the case of HPV positive women), or had gone (in the case of HPV negative women). The beliefs expressed fell into five broad themes which encompass aspects of both the timeline and control dimension's of Leventhal's CSM.

3.2.3.1. Psycho-immune explanations

Many women talked about HPV persistence in terms of immune functioning and attributed the persistent infection to their body's inability to fight it off. This is consistent with the information given to women in the trial which stated: 'In the majority of cases the body's immune system will clear the infection as it would a common cold'. In addition to this basic model, women believed that a number of psychological or behavioural factors could have an effect on their immune functioning. These included stress, depression, smoking, taking vitamins and getting enough sleep.

I don't think stress does you any favours because if HPV is linked to your immune system as in your immune system getting rid of it which most women do, then if stress affects your immune system which it does, then you're less likely to get rid of it maybe. (F18, age 26, single, HPV+, colposcopy)

Women who tested positive at follow-up and held this model often attributed the persistence of the virus in their case to stress. These beliefs emerged strongly in this study compared with Study 3 and indicate that participation in repeated HPV testing might be associated with the development of a more sophisticated cognitive representation of HPV than a single result.

3.2.3.2. Medical intervention

Some women believed that without treatment or some other kind of medical intervention, the virus would remain present. These women seemed unaware of the

possibility that the virus could spontaneously clear, and had expected the second test to be positive.

I don't know how this thing works, whether it would clear itself up or not but I can't see that there's anything else that I could do that would make any difference one way or the other without some sort of medical intervention. (F2, age 56, married, HPV+, colposcopy)

Women with this model may have been drawing on their beliefs about other STIs like Chlamydia, which need treatment in order to be resolved. This is consistent with the distinction that is now drawn between treatment control and personal control in the CSM (Moss-Morris et al., 2002) – these women had a low sense of personal control over the course of the infection, but believed that treatment might be effective in clearing it.

3.2.3.3. Model of viruses

There was evidence that some women held a model of a virus as something that can come and go on its own, without the influence of any other factors, corresponding with a cyclical view of the timeline of the infection. Women drew comparisons with other illnesses and conditions which appear to come and go spontaneously, and assumed that HPV could behave in the same way.

I think viruses come and go, viruses can leave your body as quick as they come to your body, like if you have a tummy bug, you might be ill for two, three days maybe four days, maybe a week when you're out of it but after that you feel fine so therefore to me that virus has left your body, doesn't come back. (F25, age 41, single, HPV+, colposcopy)

This model was in contrast to beliefs about herpes and other viruses which, once there, stay in the body forever.

Like herpes, how that can lay dormant and then come. And shingles and things like that. (F15, age 55, cohabiting, HPV+, repeat test)

3.2.3.4. Sexual activity

The fourth explanation for the persistence or clearance of HPV related to sexual behaviour. Some women believed that if the infection had come from their current partner, they would be re-infected every time they had sex so the virus would never clear.

If I have it and then maybe my partner had it and every time we have sex is it just going to carry on going and I'm never going to get rid of it? (F10, age 27, in a relationship, HPV+, colposcopy)

In this case, there is a close relationship between causal beliefs relating to sexual transmission, and timeline and control beliefs. The timeline is seen as being chronic and this is related to the cause (i.e. the on-going relationship with the sexual partner from whom the virus came). In the example above, there was a sense of lack of control over the infection, as the woman was not going to end her relationship in order to get rid of the virus.

3.2.3.5. *No explanation*

Finally, there were women who were not able to articulate any explanation for the persistence or clearance of HPV. They did not seem to believe that anything in particular would affect their future HPV status. Often, these were women who did not hold a coherent cognitive representation of HPV and were confused about the cause of the virus as well as the reasons for persistence or clearance.

3.3. Emotional impact

Women's emotional responses to the first test, the interval between the two tests, and the emotional impact of the second test were explored, with particular attention paid to changes over time and differences between the first and second tests.

3.3.1. Emotional impact of the first HPV test

In line with the findings from Study 3, women generally recalled feelings of shock and surprise in response to their first HPV positive result. Anxiety, distress and even panic were felt, and centred on the idea of 'something being wrong', diagnosis with an STI, perceived risk of cancer, and concerns about the implications of HPV for future fertility. This 27 year-old woman expressed her feeling of panic, and was concerned about her ability to have children.

Yeah I panicked. 'Cause at first it was like God how long has this been going on? And I've not really read what I should have read. You do immediately panic 'cause you don't know, do you? It's like a woman's nightmare. Especially when I'm twenty seven, I've got no children and I do want children in the future, I don't want to have a problem. (F8, age 27, single, HPV+, colposcopy)

As in Study 3, particular issues emerged relating to the sexually transmitted nature of HPV. Many women reported feeling ‘unclean’ or ‘dirty’, having been diagnosed with an STI, and talked about the stigma associated with the infection. Genital warts were often mentioned as being unpleasant, and some women were concerned about whether they would develop warts in the future as a result of the HPV infection. Relationship issues were raised, with some women feeling anger towards their partner for giving them the infection, expressing concerns about their partner’s fidelity, and about future transmission of the virus, either to their existing long-term partner, or to future partners. One woman reported having started to use condoms with her regular partner after her first positive HPV result.

Often, women’s own sexual relationship history was inconsistent with their views about the kinds of people who have STIs, as this quotation illustrates.

I felt quite dirty ‘cause I’ve only ever had two relationships, sexual relationships ... And I thought I was quite good, I’m not a sort of casual one night stand type of person. Always been quite careful and obviously yeah I was quite upset.
(F21, age 31, cohabiting, HPV+, colposcopy)

Consistent with Study 3, some women did not report having experienced this kind of negative impact. In many cases, the normal smear result was cited as a reason for lack of concern. If the smear test was seen as familiar and trusted, then having a normal smear seemed to mitigate these feelings of anxiety. As before, certain pieces of information about HPV were key in reducing anxiety, namely that it is very common and can clear spontaneously. Some women were also reassured that something had been picked up earlier than it would have been with only a smear test, and that this entitled them to more frequent monitoring and surveillance with an annual recall. The belief that HPV could lie dormant for a long time was also important in allowing women to acknowledge the sexually transmitted nature of the virus without feeling that their relationship had been undermined.

3.3.2. Emotional impact over the year between the two tests

One of the aims of this study was to examine the way in which anxiety and concern about being HPV positive changed over the course of the 12 months between the two tests. Three main patterns of anxiety were described.

3.3.2.1. Initial anxiety that was resolved

It was common for women to describe initial feelings of shock, confusion and distress. This was often followed by seeking further information about HPV from the trial information leaflet, the internet, the ARTISTIC trial helpline, or a GP. Once some of the confusion had been resolved, women seemed able to put the result to the back of their mind until the next test. This pattern is illustrated by the following quotation from a woman who was initially upset to be diagnosed with an STI, but whose distress lessened after receiving reassurances from the ARTISTIC trial helpline.

I was quite annoyed, couldn't really believe it that it happened to me. And because it was sexually transmitted and because I haven't had a lot of partners. Yeah wasn't very happy at all really. ... I spoke to my sister who's like my best friend, yeah. And she was sort of with me when I phoned the helpline and they reassured me, they really did reassure me so I felt quite happy after talking with them. ... I would say it [the anxiety] lessened over the year because of the chat I had with the helpline and because they said to me look if you hadn't taken part in this you wouldn't have even known you had it. With reading the literature it says people have it and don't realise they have it. So I thought it's quite common. ... that's how I handled it really, I thought well if I hadn't taken part in that test I would never have known I had it and I knew I was going to have further tests. (F21, age 31, cohabiting, HPV+, colposcopy)

As was discussed in Chapter 5, this pattern is consistent with Leventhal's CSM, involving a reappraisal of the cognitive representation of HPV in light of subsequent information. The new representation was then associated with a less anxious emotional response.

3.3.2.2. On-going anxiety

Women describing this second pattern of anxiety thought about their HPV on and off throughout the year, and these thoughts seemed to focus on unanswered questions about the virus. These women had not usually sought additional information about HPV, or had not found satisfactory answers to their questions, and so seemed to dwell on the confusing and worrying aspects of the virus, unable to resolve their concerns. For example, one woman had phoned the ARTISTIC trial helpline, but still had questions about HPV which she reported thinking about on a weekly basis.

Like I say the only thing that I do go back on is like what is it? If I keep carrying on how long will I have it? What will they do for it? What will the long-term effects be for me? They're the questions that go over a lot. The other things are just fleeting thoughts like now I sit and think about it. Could it be that? Could it

be this? ... Every now and again I'll think about it for whatever the reason and they're my thoughts that I always have. (F9, age 31, married, HPV+, colposcopy)

In this example, the woman was unable to employ effective coping strategies to deal with her anxieties, so the worry associated with her unanswered questions had yet to be resolved fully.

3.3.2.3. *No anxiety*

Thirdly, there were women who were unconcerned about their HPV positive result and claimed to have forgotten about it completely between the two tests. Even some of the women who had strong initial emotional reactions then forgot about HPV until they were recalled for the second test. This response seemed to be associated with understanding that HPV could clear up on its own over the year, that it was not serious or life-threatening, and that the smear test was normal. The asymptomatic nature of HPV was also cited as a reason for being able to forget all about it. Sometimes anxiety increased immediately prior to the second test, as women wondered what the result would be.

I think to be honest I probably forgot about it most of the time until, I think, August when I realised I had to go for another one [test]. Then I got a bit anxious. How will it go? Will I still be positive? (F10, age 27, in a relationship, HPV+, colposcopy)

3.3.3. Expectations about results

The majority of women hoped or expected that the result of their second HPV test would be negative. This was associated with timeline and control beliefs that the virus could clear on its own, without treatment. Some women drew on previous experience of having warts on other parts of the body that had cleared up without medical intervention. Others thought that their bodies would get rid of a virus, as would be the case with a cold or another infection. A common reason for hoping to be negative was the avoidance of further tests and possible treatment.

I remember having a kind of wart on my arm that was like a virus or lots of little ones, when I was about twelve and they disappeared after about three years. ... So in my mind I thought ... it would just go away. (F15, age 55, cohabiting, HPV+, repeat test)

Some women did not seem to understand that HPV could clear on its own, so expected their second result to be positive as they had done nothing to make it disappear during the intervening year. Some thought that medical treatment would be needed to clear it, while others thought that once there, you would have the virus forever, or that most women have HPV most of the time.

I suppose I expected it to be positive because I'd not done anything in between, I'd not had any medication, I'd not changed my lifestyle at all. So I didn't think that there would be any reason, unless I was just one of these people where it cleared up on its own, I didn't see any reason why it wouldn't be. (F2, age 56, married, HPV+, colposcopy)

Finally there were women who had no expectations about the results. Some knew that it could clear up on its own but did not know whether it would have done in their case, and others felt that they had not known enough about HPV to have any sense of what the second result might be.

3.3.4. Emotional responses to result

3.3.4.1. *HPV positive at follow-up*

Many of the women in this study who tested HPV positive at follow-up described similar feelings on receiving their second HPV result as have been described for the first result. These included fear and anxiety about cancer and becoming ill, concerns about fertility, feelings of being unclean because of the sexually transmitted nature of HPV, concerns about transmission and sexual relationships, an impact on feelings about sex, and relationship issues including blaming a partner for the infection.

There was some variation from responses to the initial result though, with many participants reporting greater concern after the second test. This was partly related to having a greater understanding of HPV the second time around, and may also have been linked to the fact that a colposcopy was offered after the second test, making it seem more serious.

The first one you don't know what it's about whereas with the second one it's important to you. When you find out you're positive again ... you're like ahh..!
(F18, age 26, single, HPV+, colposcopy)

Some women also felt that something that ‘isn’t going away’ must be more serious and more of a threat to health than the first result. After the second test, fears about cancer and progression seemed to be more salient than they had been initially.

As well as a generally higher level of concern, many women who had hoped or expected that their result would be negative reported feelings of disappointment that their body had not cleared the virus. In some cases, this seemed to be experienced as a sense of failure, or of one’s body letting one down.

You know, when you’re thinking oh God my body can’t fight it off itself, my body can’t get rid of it itself, it’s not good. (F18, age 26, single, HPV+, colposcopy)

Not everyone experienced a negative impact though. Some women reported that they felt reassured to be offered a colposcopy and additional monitoring. This was especially true if women knew that cervical abnormalities could be treated easily if they developed. Another response was to regard the test as part of research, and not something that was of personal relevance.

I just understood that it was one of these things that women get and that’s what the whole research was about trying to find out how and why and why some clear up and some don’t and all the rest of it. That it was really just a piece of research rather than anything that was threatening to me personally. (F2, age 56, married, HPV+, colposcopy)

3.3.4.2. HPV negative at follow-up

Most women testing negative described feeling ‘pleased’, ‘glad’ or relieved, as if a ‘big weight [had been] lifted off your shoulders’. The relief was associated with not needing further tests or treatment and, for some, with a reduced risk of cervical cancer.

[HPV] was something that was gone that was possibly some kind of a risk, I don’t know. If it’s something that it’s better not to have than to have, then I’m glad I haven’t got it. (F6, age 64, in a relationship, HPV-)

One woman was especially pleased about her negative result as she interpreted it as meaning that the HPV could not have come from her current partner. She believed that if it had come from him, he would have re-infected her during the year, so her result would still have been positive.

Some had lingering concerns about future fertility or about recurrence of the infection. There was uncertainty about whether a negative test could be an indication that the virus was still lying dormant and might reappear at a later date, and these concerns were linked with cyclical timeline beliefs that the virus could come and go.

Among the women who had expected still to be positive, there was shock and surprise about the negative result, but this was usually associated with feelings of gladness as well.

I just had a feeling it would still be there. I was quite surprised when it said it was negative. I was glad but ... I was just surprised that it would have just gone on its own. (F7, age 42, married, HPV-)

The negative result was also welcomed as evidence of the body having fought it off.

I thought oh my body must be working then because it's fought it off now, it's disappeared for now. (F29, age 56, married, HPV-)

3.4. Disclosure

Women's patterns of disclosure following each HPV result were explored. This provided additional insight into the emotional impact of an HPV positive result and the way in which women coped with it.

3.4.1. Disclosure of the first result

Women reported similar reasons for disclosure and non-disclosure as were found in Study 3, with feelings of stigma and embarrassment common reasons for non-disclosure. One additional reason for non-disclosure emerged, which related to the management of one's partner's reputation. Some women did not want their family or friends to think badly of their partner for giving them HPV, and therefore did not discuss the result, or avoided talking about the sexually transmitted nature of HPV.

I think at the very first I think it was more, like I said, my husband feeling a bit guilty. I don't think he'd have liked me to do it [talk to friends about the result] so I didn't do it. (F26, age 46, married, HPV+, colposcopy)

3.4.2. Pattern of disclosure over the year

Talking about the HPV result over the course of the year between tests did not seem to be common. Most women described disclosing their first result when they received it

and discussing it initially, but then not talking about it until the second test. However some women did disclose to new people a long time after receiving the first result, and this was usually triggered by a relevant conversation, someone else taking part in the trial or, in one case, seeing a television programme about HPV. For one woman, the ARTISTIC trial had come up in conversation with friends during the year.

Just that I spoke to a couple of friends and they just mentioned that, I think one had been asked to go on the [ARTISTIC] programme and had said no they didn't want to. And somebody else was on it as well. So we had a bit of a chat about it. I can't remember how it came up in conversation but then when I was telling them that I did have the virus they went, the other one said I didn't have it. (F7, age 42, married, HPV-)

3.4.3. Disclosure of the second result

Most women reported a consistent pattern of disclosure across the two results, talking to the same people about their second as their first result. Some, though, did not talk to anyone about their first result, but were so upset or worried about their second result that they either felt the need to seek support and reassurance, or were forced to explain to work colleagues or their family what they were upset about. This woman described telling her father about her second positive result.

I think I wouldn't have bothered if it wasn't for the fact that I was so upset 'cause I didn't bother the first time round but second time I was so upset and needed to get it off my chest that I told him. It was quite difficult! (F10, age 27, in a relationship, HPV+, colposcopy)

In addition, some women chose to disclose following a second positive result because they wanted information or support about the colposcopy procedure and possible treatment. This provides further evidence that the emotional impact of the second test could be more negative and severe than the first result, and that some women were motivated to overcome feelings of embarrassment about the sexually transmitted nature of HPV in order to gain support through disclosure.

One woman had only told her partner about the tests on the day of the interview, to explain about the study that she was taking part in. In this case, disclosure was not chosen as a way of coping with the result, but was seen as necessary to explain the interviewer's visit to the house.

3.5. Decisions about follow-up among women with persistent HPV

As shown in Table 6.1, the majority of women interviewed opted to have a colposcopy rather than waiting another 12 months for a third HPV test. Only four women in the sample decided to wait, which reflected the strong tendency to opt for colposcopy in the trial population as a whole. Three women were unaware of having been offered a choice. Among those who had actively chosen a particular management option, the reasons for the choice were explored.

3.5.1. *Reasons for choosing colposcopy*

Anxiety was one reason for choosing to have a colposcopy immediately. Some women were worried and upset by their second HPV positive result and were not prepared to continue to worry for another 12 months.

[The practice nurse] also said do you want this sort of anxiety for twelve months or would you rather know now what your cervix is like? And I would rather know I couldn't have coped with that level of anxiety. (F10, age 27, in a relationship, HPV+, colposcopy)

Well I thought maybe there was something a bit wrong, I don't know. To have two tests come back that say positive I think then you start thinking well what is it? What is wrong? I just would rather if there was something wrong for it to be found really. ... I'd prefer to be looked at and examined and be told everything's fine rather than for another year to worry about yeah I'm positive again, what does that mean to me? I'd rather be checked really. (F9, age 31, married, HPV+, colposcopy)

As the second example demonstrates, this was associated with concerns about the second positive result, and fears about what might be wrong. Other women exhibited less anxiety, but nevertheless expressed a desire for immediate resolution and reassurance, rather than a further period of uncertainty. This was often associated with an understanding that treatment might be offered if abnormalities were picked up during the colposcopy.

'Cause I'm the sort of person that I need to get things sorted now. I'm a bit of a fix it person, if there is anything that needs fixing I'll do it. So in that way I would have gone as far down the line as I could have done before people said there's nothing more we can do. That was why I chose the colposcopy. (F20, age 36, in a relationship, HPV+, colposcopy)

I wanted to know basically really. I mean I haven't heard of HPV before and I thought well whatever it is I'd like to know what I've got and what treatment is available to me. (F25, age 41, single, HPV+, colposcopy)

There was a widespread belief that the colposcopy was a more 'thorough' test, and many women welcomed the opportunity to have further investigation, even if they were not concerned about anything being wrong.

I think because that was the next piece in the jigsaw. It was OK I've been here and it's still showing up as positive, a colposcopy now so we'll investigate it a bit further. Well go along and make sure that there's nothing there untoward. ... I saw it more as an investigation and quite probably nothing would show up. ... I suppose it didn't occur to me that something would show up. (F19, age 32, cohabiting, HPV+, colposcopy)

There was a sense among some women that waiting 12 months might allow something to develop which could otherwise be dealt with now. This was associated with the notion of the importance of early detection in cancer prevention.

I think with anything if you let, with cancer especially you're always reading and hearing that if you think, like with breast cancer if you've got a lump, you go straightaway. ... You nip things in the bud with cancer. The sooner you get treatment the better it is. (F5, age 35, married, HPV+, colposcopy)

Despite the general feeling that a colposcopy was preferable to waiting for a year, many women had concerns about the procedure itself, as has been found in the literature on conventional cervical screening.

I was more worried about the procedure I think. At that moment in time I was worried about the procedure, I hadn't thought past the result. I thought more about how much it was going to hurt and whether I'd have to take time off work all that kind of stuff. (F1, age 25, married, HPV+, colposcopy)

In one case, a woman who was pregnant was concerned about the colposcopy jeopardising her pregnancy, and decided to wait until after delivery to have the procedure.

3.5.2. Reasons for choosing a repeat HPV test

Of the four women who opted for a repeat test, only three were aware of having done so. The fourth woman was, in fact, unaware of having tested positive for HPV, and thought that annual screening for HPV was the standard trial protocol. Among the other three women, one decided not to go for the colposcopy because this was the easiest

option, and she was not concerned about her HPV result. Practical barriers to attending for colposcopy outweighed any perceived benefit to attending.

If anyone gives me a choice of having treatment or not if it's not necessary... I mean if they said oh yes it is necessary you have to go then I would go. But if you're giving me an easy way out then I'll take the easy way out. It's the convenience I think. I wasn't quite sure how I would have it done, how I'd get there. (F15, age 55, cohabiting, HPV+, repeat test)

The second took a similar view, describing herself as too busy to go, but having subsequently acquired additional information about HPV, regretted her decision.

When I was offered the colposcopy and I thought oh I haven't got time I'm too busy with work. [Later, after having realised more fully the link between HPV and cervical cancer, she said] I think I made the wrong decision. (F33, age 40, divorced, HPV+, repeat test)

Once again, a trade-off seems to have been taking place between the perceived risk associated with HPV and not attending for further investigation, and the practical barriers to attendance. As women were offered a choice, those who were not worried about their result were able to interpret the colposcopy as being unnecessary and therefore to avoid this additional procedure.

The third woman in this group had a different attitude towards the colposcopy, and described fear about what might be found. She preferred to wait, and hoped that it might go away.

I was quite tempted to go for the examination but then I think fear and... I'm a bit scared about what might be found and it got the better of me. That sounds awful ... but I think it's a lot of case of just ignore it, it might go away. (F23, age 23, in a relationship, HPV+, repeat test)

4. Discussion

To my knowledge, this is the first study to investigate women's responses to repeated HPV testing in the context of cervical screening. It used in-depth interviews to explore the beliefs, experiences and concerns of 30 women who had had two HPV tests.

4.1. Cognitive representations

Most women in this study had heard that HPV might be sexually transmitted but, as in Study 3, some were able to interpret the information in a way that allowed them to believe that they had contracted the virus in another way, in order to avoid impugning their partners. Others were able to reconcile testing positive for HPV with their own and their partner's sexual relationship history, and did not interpret it as threatening to their relationship.

The study was of limited value in exploring changes in causal beliefs over time. As women were interviewed at a single time-point, following their second HPV test, their self-reported changes in beliefs had to be relied on. Some described changes in beliefs in response to additional information or conversations with health professionals over the year, but in many cases, it was impossible to gain a sense of the way in which beliefs had changed over time. There was, however, a fairly pervasive sense that women felt better informed about HPV at the time of their second test compared with the first.

Women expressed a variety of beliefs about the reasons for the persistence or clearance of their HPV infection. These could be interpreted as falling into the 'control' dimension of Leventhal's CSM (see Chapter 1). Some women felt that they had a degree of control over the infection through health behaviours that have an impact on immune functioning: eating healthily, not smoking and reducing stress. Others felt that there was nothing that they could do, or that medical intervention would be necessary to treat the infection. For some women, the means of controlling the persistence of HPV infection was linked with their notions of cause: they knew that it was sexually transmitted and felt that having unprotected sex could lead to re-infection from an existing partner.

4.2. Emotional impact

Evidence from the study suggested that women tended not to experience on-going negative emotions about having HPV over the course of the year between the two tests. This is in line with the findings from Chapter 5, in which most women described initial feelings of shock and concern about being HPV positive, but frequently had their main concerns allayed by further information about the virus. The findings indicate that most women were able to develop a cognitive representation of HPV that minimised the negative emotions experienced. Some women were able to focus on the normal smear result and discount the importance of having tested positive for HPV. A minority of

women reported on-going concern, often associated with an inability to find satisfactory answers to their questions about the virus. This indicates that for some women, having a coherent cognitive representation of HPV was important in reducing the negative emotions associated with their positive result. This is consistent with the coherence construct in the latest version of the CSM (Moss-Morris et al., 2002).

Responses to a second HPV positive result were often more negative than were reported for the first test. Although STI-related responses were described, there seemed to be more concern about the health implications of persistent HPV. The offer of an immediate colposcopy often made women feel that the result was more serious than the first one, and they were concerned about the implications for cancer risk and future fertility. There was a strong desire to have the problem investigated further, and to have treatment if necessary.

In line with the findings of Study 3, which found some women to be unconcerned about their first HPV positive result, there were women who were not concerned by their second HPV positive result. Some interpreted the option of waiting a further year as meaning that the result could not be serious, while others were happy to go for a colposcopy but did not feel any immediate sense of anxiety about it.

4.3. Disclosure

The study explored the pattern of disclosure of the HPV positive result over the course of the year between tests and any differences in disclosure after the second test compared with the first. For the most part, women reported similar reasons for disclosure on non-disclosure as were identified in Chapter 5 among women who had had a single HPV test. An additional reason for non-disclosure was the desire to protect one's partner from being judged negatively by others. Women did not want their friends or family to think that their partner had given them an STI. This fits with the finding from Study 3 that women seemed very motivated to preserve the integrity and status quo of their relationships. Negative censure from other people might have threatened this.

In general, women talked to the same people following their first and second HPV tests. However, some women who had not talked to anyone following their first positive result did disclose after a second one. This was usually because the second result was

more upsetting, and the need to mobilise social support seemed to out-weigh the embarrassment and unwillingness to disclose an STI diagnosis. This indicates the way in which women were able to modify their coping strategies in response to different emotional representations of the results.

4.4. Follow-up decision among women with persistent HPV

In the ARTISTIC trial as a whole, the vast majority of women with persistent HPV opted for an immediate colposcopy over waiting a further year for another HPV test (unpublished data). This is in contrast to a recent trial of management of mild dyskaryosis (Kitchener et al., 2004) but is in line with other studies that have found a preference for colposcopy over more conservative management of mildly abnormal smear results (Jones et al., 1996; Karasz et al., 2003). Because of the small numbers of women who opted for repeat testing in the trial as a whole, most women in this study had chosen management by colposcopy. Reasons given centred on the desire to resolve the uncertainty associated with the meaning of a positive HPV result, to have further investigations and, if necessary, treatment, and to have a speedy resolution to the problem, rather than another period of waiting. Women who opted for repeat HPV testing were generally unconcerned about their result and perceived that the practical barriers to attendance at colposcopy out-weighted the benefits. In one case, fear of what would be found seemed to motivate the decision, and the woman hoped that the HPV would have gone away in another year. This kind of fearful attitude has been associated with non-attendance at screening (McCaffery, Borril, Williamson et al., 2001), but is perhaps unusual in someone who participates in screening. A larger study would be needed to see which of these patterns are pervasive in the wider population.

4.5. Strengths and limitations

As with Study 3, the use of in-depth interviews in this study allowed women's beliefs, experiences and concerns to be explored without the constraints imposed by the use of questionnaires.

The main limitation is that although the study aimed to explore changes in beliefs and emotions over time, due to the constraints of time and funding, interviews could only be carried out at a single time-point. When the study was designed, it had been hoped that more women from Study 3 would participate, but due to women moving away, declining to take part, or not attending for follow-up, only four were included in this

study. This was deemed to be too few to analyse separately, although an in-depth analysis of the four pairs of transcripts from these women might be a way to take forward the analysis presented here. A more in-depth analysis of this sub-set of transcripts might provide greater insight into the way in which women's beliefs, emotional responses and coping change over time and the way in which the different elements of Leventhal's CSM relate to each other. This would move beyond the fairly descriptive account provided in the current analysis, and allow more sophisticated explanations for the findings to be developed. Although this was beyond the scope of this thesis, post-doctoral funding will be used to build on this work and continue to analyse the data.

Women seemed to have difficulty in remembering how their emotional responses and particularly their beliefs had changed over time. This may have been exacerbated by a tendency for the interviewers to fall into the more familiar topic guide from Study 3, and not to cover the issues of change over time and differences between the two tests, which were of interest to this study, as thoroughly as they could have done. Evidence that this sometimes happened comes from gaps in certain areas of the charts for some interviews. A further problem was the fact that some women were unaware of having had two HPV tests. This raises interesting questions about informed participation in the clinical trial.

The relatively homogeneous nature of the sample is a further limitation. The findings must be interpreted within the context of the clinical trial from which participants were recruited. It is likely that the findings are, at least in part, a product of the context in which women were tested for HPV, the information they were given as part of the trial, and their interactions with the health professionals involved. The sample is also limited by the lack of women from non-white ethnic groups, and the findings need to be replicated in other settings and with other groups.

4.6. Implications

The findings of this study indicate that most women did not experience on-going anxiety following a first HPV positive result, while waiting for a second test a year later. This suggests that annual recall could be an acceptable form of management for HPV positive women with normal smear results. However, the more serious negative impact of a second HPV positive test compared with the first, and the overwhelming

desire for an immediate colposcopy, indicates that on-going monitoring using HPV testing might be less acceptable to women than immediate referral for colposcopy if the infection is persistent. This finding needs to be replicated in other settings, but if found to be robust, might have an impact on the development of screening policy for HPV testing.

In terms of using Leventhal's CSM as a framework within which to explore women's beliefs and responses to HPV, this study demonstrates the difficulty of investigating the dynamic processes involved using cross-sectional methodology. As has been noted above, analysis of the transcripts of women who were interviewed twice, or further research using longitudinal methodology, would be needed to provide a better analysis of on-going processes and changes.

4.7. Conclusions

This study provides a first step towards understanding the impact of participation in repeated HPV testing. The findings indicate that the negative impact of a second HPV positive result may be greater than the first result, with women reporting more concerns about the threat that HPV posed to their health, and about their future cancer risk following their second result. More research, using a prospective design, is needed to investigate the way in which women's beliefs and emotions about HPV play out over the time between tests, but the results indicate that most women do not experience high levels of anxiety while waiting for the second HPV test.

CHAPTER 7 – CONCLUSIONS

The research in this thesis was prompted by the dramatic changes that are currently taking place to the way in which cervical cancer is prevented. The identification of human papillomavirus (HPV) as the main aetiological agent in the process of carcinogenesis in the cervix brings with it a potential for significant reductions in morbidity and mortality from the disease through HPV screening and vaccination. Clinical and economic evaluations of HPV testing and vaccination are well under way, but evaluation of the psychosocial impact of linking cervical cancer with a sexually transmitted infection (STI) has lagged behind (Division of STD Prevention, 1999; IARC, 2004). Because of the sexually transmitted nature of HPV, raising public awareness about the medically accepted aetiology of cervical cancer and introducing HPV testing and vaccination has the potential to affect people's models of cervical cancer aetiology, and the experience of women who take part in screening. The research described in this thesis has taken a first step towards addressing these issues.

1. Summary of findings

In Chapter 1, the aims of the thesis were set out as five questions, each of which has been addressed in subsequent chapters. The findings will be summarised in relation to each of the original questions.

1.1. What is currently known about HPV by women eligible to take part in cervical cancer screening?

Study 1 used a sample of women attending a well-woman clinic to assess levels of awareness of HPV and knowledge about the virus in women who are eligible for participation in cervical screening and who might therefore be expected to take part in HPV testing if it is introduced in the UK. Just over 1,000 women completed a written survey, of whom 30% reported having heard of HPV. This is in line with previous survey studies in the UK (Pitts & Clarke, 2002; Philips et al., 2003) but, due to the relatively affluent clinic population surveyed, may represent an over-estimate of true levels of awareness in this country. Causal knowledge about HPV was also measured using a series of true/false statements. Of the women who had heard of HPV, two thirds thought that it was sexually transmitted, carried by men and that condoms are protective

against infection. This indicates that most women were thinking about HPV as an STI. In contrast, well under half of these women were aware of the link between HPV and cervical cancer.

The study suggests that the majority of women have not heard of HPV, and that those who are aware of it have probably heard of it in the context of sexual health rather than cervical cancer. This is of concern, as these are the women who would be eligible for HPV testing were it to be introduced in cervical cancer screening. These findings indicate that a huge public education programme will be necessary to raise levels of knowledge to meet the criteria for informed participation in screening (General Medical Council, 1998; Marteau et al., 2001; Michie et al., 2002). It could also be argued that women participating in conventional cytology screening should be informed about HPV, since the smear test aims to identify cell changes associated with HPV infection and in the UK, HPV is frequently mentioned on cytology laboratory reports.

1.2. What is the current public understanding of the aetiology of cervical cancer?

Study 2 approached the question of HPV awareness from a different direction – by investigating beliefs about the causes or risk factors for cervical cancer. In order to overcome the sampling limitations of Study 1, it used a representative population sample of men and women to survey people on their beliefs about the aetiology of cervical cancer.

Responding to an open-ended (i.e. unprompted) question in a face-to-face interview, less than 1% of people surveyed cited HPV as a cause of cervical cancer. This indicates that although some people recognise the name ‘HPV’ when prompted (as shown in Study 1), very few are able to retrieve it as a cause of cervical cancer. Awareness of a link between cervical cancer and some aspect of sexual activity (having many partners, young age of first intercourse, STIs, not using condoms) was higher, with 46% of women and 35% of men mentioning at least one of these factors. But this still means that over half of the population appears not know that there is a link between sexual activity and cervical cancer. Awareness was lowest among men, in the youngest and oldest age groups, and in people with fewer years of education.

The findings from this study indicate that raising public awareness of HPV, its sexually transmitted nature, and its link with cervical cancer, could drastically change the way in

which the public conceptualises cervical cancer, just as the identification of smoking as a risk factor for lung cancer has changed the way that this type of cancer is viewed. Introducing HPV testing and/or vaccination will force a change from the protectionist discourse surrounding cervical cancer, in which the role of sexual transmission has traditionally been down-played to minimise possible stigma or victim-blaming (Braun & Gavey, 1999b). This raises questions about the impact that this will have on the women taking part in screening, and particularly on those who test positive for HPV.

1.3. How do women participating in HPV testing make sense of information about the virus and incorporate this into their existing beliefs about cervical cancer?

The third study was designed to explore the potential impact of participation in HPV testing in the context of cervical cancer screening. The sample was drawn from clinical trials of HPV testing currently taking place in the UK, and from a colposcopy clinic where HPV testing is a routine part of the management of women with abnormal smear results. As this is a new and potentially sensitive area of research, qualitative methods were used to explore women's experiences and beliefs so that the findings would be grounded in women's accounts.

The first stage of the analysis investigated the way in which women developed cognitive representations of HPV in response to participation in testing, and how information about HPV was incorporated (or not) into their pre-existing causal beliefs about cervical cancer. Aetiological beliefs were of particular interest, given the negative psychological consequences that are known to be associated with STI diagnoses.

Women held a variety of aetiological beliefs about HPV. Some were aware that it is an STI, but others believed that there were different ways of contracting or developing the infection, and some demonstrated no awareness at all of the sexually transmitted nature of the virus. There was also a variety of beliefs about the causes of cervical cancer, as would have been predicted from Study 2. Some women were able to maintain their existing models of cancer in the face of information about HPV but for others, awareness of the sexually transmitted nature of HPV and its causal relationship with cervical cancer, forced a significant shift in their beliefs about cervical cancer. For some women, the notion that cancer could be linked with an STI was new and shocking.

The causal beliefs of women who tested positive for HPV seemed to be influenced by the extent to which their own sexual relationship histories were reconcilable with an STI diagnosis. Self-regulation theory was a useful way of conceptualising this. Women in this study often seemed to be acting to regulate the integrity of their relationships, and to be engaging in defensive strategies to minimise the threat that might be posed by implications of infidelity or dishonesty. This sometimes involved rejecting the notion that HPV is an STI, and the ambiguity of the information that women were given about the virus allowed them to do this. This is consistent with Lazarus and Folkman's notion of emotion-focused coping (Lazarus & Folkman, 1984). Rather than dealing with the health threat of HPV itself, they were acting in a way that minimised the negative emotions engendered by being diagnosed with an STI. Scheier and Carver (Scheier & Carver, 2003a) have emphasised the fact that self-regulation involves multiple goals and that people act in different ways to attain different goals. For some women, the most important goal seemed to be to protect the integrity of their relationship with a partner, and the causal components of their illness representations were constructed in a way that allowed them to do this.

In addition to causal beliefs, women expressed a variety of other beliefs about HPV that were broadly consistent with the cognitive representations component of Leventhal's Common Sense Model (CSM). Again, there was huge variation not only in the content of the beliefs, but also in the extent to which women appeared motivated to understand the infection or, in other words, in their need for a coherent model of HPV. For some women, HPV did not seem to pose enough of a threat to trigger the development of a cognitive representation. This is consistent with the concept of primary appraisal (Lazarus & Folkman, 1984) – if HPV is evaluated as being benign or irrelevant, a self-regulatory response is not required.

1.4. What are the emotional and social consequences of testing positive for HPV in the context of cervical screening?

This question was also addressed using the qualitative data from Study 3. The emotional impact of a positive HPV result was found to vary widely. Women who were unaware that HPV is sexually transmitted usually reported little negative impact of the result. Those who were aware that HPV is an STI frequently expressed strong negative emotions and had different concerns from those identified in the literature on abnormal smear test results. Feelings of shock, anxiety and being 'dirty' or 'unclean' were

common and for many women these feelings were compounded by confusion about where the virus had come from. This was especially the case for those who had had few sexual partners, or who were not currently in a sexual relationship. Women were also concerned about the implications that HPV might have for their partners, or for the current female partners of their previous partners. There was confusion about the impact that HPV has on men, and about the need for disclosure or the use of condoms.

Disclosure emerged as a difficult issue for many women. Fears of being judged negatively for having an STI were expressed and women often managed this by disclosing only their smear result, or by omitting to tell people that HPV is an STI. Disclosure patterns demonstrated very clearly that HPV was seen as embarrassing and stigmatised, whereas this was generally not the case for abnormal smear results.

Although many women described having experienced these negative consequences, they were not universal. Women's cognitive representations of HPV, their relationship status and history, their cultural norms around sex and screening, and their smear results all had an impact on the way in which an HPV positive result was perceived and responded to.

Women's responses to testing HPV positive appeared to change over time, especially if additional information received about the virus changed their cognitive representations of HPV (for example if they learned that it could lie dormant for a long time and so the infection did not imply that their partner had been unfaithful). The dynamic processes involved were consistent with Leventhal's CSM.

1.5. How do women make sense of and respond to results of repeated HPV testing?

The final study, Study 4, used the same qualitative methodology to investigate women's responses to participation in a second HPV test following an initial positive result. The findings were similar to those of Study 3. Women varied in the level of anxiety they reported during the year between the two tests, but few seemed to have experienced severe and on-going concerns about HPV. Beliefs about why HPV had persisted or cleared between the two tests fell into five groups, and related to the control and timeline dimensions of the CSM. The dominant model was a psycho-immune explanation, with stress seen as important in determining whether the immune system

was able to fight off the virus. Women who tested HPV negative at follow-up described feelings of happiness and relief. Those who had a persistent infection reported experiencing more anxiety following their second HPV positive result than their first, and there was an overwhelming preference for immediate colposcopy over continued surveillance with HPV testing. Disclosure was a more common coping strategy following the second positive result as women's need for support and comfort over-rode their embarrassment about having an STI. The cross-sectional nature of the study meant that exploration of changes in illness representations, emotional responses and coping over time relied on women's self-reports, and was therefore limited.

1.6. Overview

Taken together, these studies begin to paint a picture of the possible implications of raising awareness of HPV as the cause of cervical cancer and of introducing HPV testing into the national screening programme for the prevention of cervical cancer. There seems little doubt that very few people are currently aware that HPV is the main cause of cervical cancer and although some may know of the link between sexual activity and cervical cancer risk, for most this does not seem to be well-understood or clearly conceptualised; very few seem aware of the role of sexual transmission. Many other causal beliefs are held, and there is a tendency to regard cancer and STIs as very different kinds of disease. Raising public awareness of HPV could therefore have a dramatic impact on the way in which cervical cancer is conceptualised.

There are also likely to be implications for the women who take part in HPV testing. For many, information about HPV is at odds with existing beliefs about cervical cancer aetiology and women in Study 3 who had read and understood the information they had been given often described a change in their beliefs about cervical cancer that was both dramatic and shocking.

Testing positive for HPV appears to be associated with different emotional and social consequences from those that are reported by women with an abnormal smear result. Women reported feelings of shock, embarrassment and being 'unclean' in response to being diagnosed with an STI. These are different from the feelings of anxiety, cancer fear and concerns about fertility that are usually found among women with abnormal cytology results. Maintaining the integrity of current relationships seemed to be an important goal for women, and they sought information about HPV that allowed them

to develop cognitive representations that were consistent with their own sexual and relationship histories. However, if information about HPV is in the public domain and it is clearly understood to be an STI, the defensive mechanisms employed by women may be more difficult to maintain in the face of contradictory evidence. Ways of communicating with the public about HPV in order to minimise the negative consequences for women participating in screening must be developed. The findings presented in this thesis begin to identify some of the key characteristics of HPV that are reassuring to women testing positive (see section 4.1 below).

2. Strengths and limitations

2.1. Combining quantitative and qualitative methodologies

The mixed methods approach taken in this thesis allowed a variety of questions to be addressed, using methods appropriate to answering each question. Although the different studies sought to answer different questions, the overall results were broadly consistent, which lends credence to the findings and adds to the validity of the research. The quantitative studies provide an indication of levels of knowledge on a wide, population scale, while the qualitative work allowed an in-depth analysis of the impact of participation in HPV testing from the perspectives of the women taking part.

2.2. Sampling

As has been noted in each chapter, the sampling in the studies had some limitations. In Study 1, the sample was drawn from an affluent clinic population and differed from the general population in being of higher socioeconomic status and more likely to be white. This limits the extent to which the findings are generalisable.

Study 2 overcame these limitations by using a population representative sample. But the cost of this meant that the number of questions that could be asked was very limited. Future work could usefully expand on this study to ask more questions about HPV and cervical cancer aetiology to a representative sample.

The samples in Studies 3 and 4 had the advantage of having taken part in HPV testing in the context of cervical cancer screening. The study design overcame many of the

limitations of previous studies on the psychosocial impact of HPV testing, particularly those that have included people both with and without visible genital warts.

One of the priorities of the research was to include an ethnically diverse sample to explore responses to HPV in contrasting cultural groups. Great efforts were made to recruit women from South Asian and African Caribbean backgrounds, but this proved very difficult and the samples are of limited comparability, as detailed in Chapters 4 and 5. One barrier to carrying out this kind of research is the necessity of recruiting from clinical trials where South Asians have been found to be under-represented (Mason, Hussain-Gambles, Leese, Atkin, & Brown, 2003). In the case of this research, problems were compounded further by the failure of the ARTISTIC trial to collect data on the ethnicity of its participants.

Notwithstanding these limitations, Study 3 benefited from the inclusion of women from different ethnic backgrounds, and from a variety of age, marital status and socioeconomic groups. It is regrettable that time and funding constraints did not allow for purposive sampling by ethnicity in Study 4, but women varied on the other dimensions of interest.

2.3. Theoretical approach

The work in this thesis involved a very new area of study and, as noted in the Chapter 1, it was difficult to know in advance which theories might be useful in addressing the questions of interest. The questions addressed were therefore pragmatically rather than theoretically driven, aiming to provide findings that would usefully feed into the policy debate about HPV testing. Although Leventhal's CSM has been used in this thesis, particularly as a framework within which to interpret the qualitative data, it is likely that other theories could usefully be brought to bear on the issues arising from the work. In particular, it seemed that women receiving an HPV positive result were engaging in self-regulation in a broader sense than merely dealing with the health threat imposed by the virus. This included maintaining the status quo of their relationships, and ensuring that HPV would not affect their partners' health. Although this broader notion of self-regulation is implicit in Leventhal's model, other self-regulation theories such as that of Scheier and Carver (Scheier & Carver, 2003a) were useful in interpreting the data. Future research might investigate more explicitly the goals guiding women's self-regulatory behaviour following an HPV positive result.

The qualitative studies are limited by the fact that the CSM was not explicitly used to drive the development of the interview topic guide. In order to test the utility of the model more thoroughly, the topic guide should have been structured around the model to make sure that all aspects were covered. This would have facilitated an analysis structured around the dimensions of the model, and would not necessarily have precluded the exploration of other issues that were of relevance to the women taking part, allowing the data to remain grounded in the accounts of participants. However, when the topic guide was developed, it was decided that using a particular theory to structure the interview might constrain women's accounts, so the components of the CSM were explored where they emerged but did not explicitly guide questioning.

3. Implications of the findings

3.1. Implications for theory

As has been discussed above, self-regulation, and specifically Leventhal's CSM, provided the theoretical framework for interpreting the results of Studies 3 and 4. Data emerging from the qualitative studies mapped onto the dimensions of the cognitive representation component of the CSM and provided support for Leventhal's elaboration of the content of illness representations. Emotional representations are less well described in the model, but women experienced a variety of emotional responses to testing positive for HPV which are consistent with an emotional processing pathway. A clear link was found between certain cognitive representations and emotional responses to testing HPV positive. Some specific beliefs about HPV were associated with less serious emotional responses to testing positive, especially its high prevalence, lack of symptoms, ability to clear spontaneously, and the tendency for the virus to lie dormant for long periods of time. However, the relationships between the cognitive and emotional pathways of the model were mediated by other factors like relationship status and cultural background. These social factors seemed to be of key importance because of the sexually transmitted nature of HPV and the implications that testing positive has for sexual relationships. Although Leventhal has stressed the importance of social context in the self-regulation of health and illness (Leventhal et al., 2003), social factors are not well elaborated within the model. The impact of an HPV diagnosis on sexual relationships could be conceptualised within the 'consequences' dimension of the cognitive representation component, but beyond this, it is difficult to see how social

context fits explicitly into the model. Leventhal has argued that the whole process of self-regulation is rooted in social context, and that social processes are important in shaping cognitive representations. He has acknowledged, though, that the processes involved need further investigation (Leventhal et al., 2003).

The CSM is described by Leventhal as a model of ‘self-regulation of health and illness’ and most applications of the model assume that individuals are acting in a way that aims to promote good health. Health therefore seems to be the implicit goal of the self-regulation process. However, other self-regulation models emphasise the fact that individuals are motivated to achieve multiple different goals (e.g. Scheier & Carver, 2003b). This certainly seemed to be the case among women responding to an HPV diagnosis, and these multiple goals were not always easy to interpret within the CSM.

While the CSM could be criticised on the basis that only the cognitive representations component is clearly elaborated and lends itself to rigorous testing, it could also be said that the model is so general that almost any data could be interpreted within it. The qualitative data in Studies 3 and 4 lent themselves to interpretation within the framework of the CSM, but it is difficult to imagine data that could not be conceptualised within the model. The dynamic processes described in the model are particularly difficult to test, and while some of the interview data appeared consistent with the notion of appraisal and re-evaluation of cognitive representations and coping, the cross-sectional nature of the methods used did not lend themselves to an evaluation of this aspect of the model. In Study 4, women appeared to have changed their illness representations and coping strategies over time but they seemed to have difficulty in remembering and reporting the way in which this had happened. This points to a need for longitudinal research to track changes as they happen and build up a clearer picture of the dynamic processes involved.

3.2. Implications for policy and practice

The findings in this thesis highlight the need for psychosocial issues to be taken into account in decisions about the implementation of HPV testing and vaccination programmes. If the clinical benefits of HPV testing prove to be marginal, the psychological distress and the negative impact on women’s relationships may outweigh the advantages of introducing the testing. This is perhaps unlikely, but serious consideration must be given to the way in which information about HPV is

communicated to the public to avoid i) potential stigmatisation and negative consequences for women taking part in testing and ii) a possible reduction in attendance for screening if women do not regard themselves to be at risk of an STI, or do not want to be seen to be attending for STI testing. Although the work in this thesis has found that the desire for information about HPV is not universal among women testing positive, the distress experienced by some women who were unable to access enough information to develop a coherent cognitive representation of HPV and its consequences points to the need for clear and consistent information to be made available to those who want it. Information will also be essential to ensure that women are able to make an informed choice about participating in HPV testing.

The final study showed that women with persistent HPV expressed an overwhelming preference for colposcopy over continued annual monitoring. While being consistent with some of the literature on the management of abnormal smear results (Jones et al., 1996; Karasz et al., 2003), the preference for colposcopy was far greater than was found in a recent study of patient choice in the management of mildly abnormal smears (Kitchener et al., 2004). If HPV testing is to be used as a long-term surveillance test, ways of making this acceptable to women will need to be developed.

4. Future research

4.1. Development and provision of HPV information

Despite the sampling limitations of the first study, Studies 1 and 2 add to a growing body of evidence for the low awareness of HPV in the UK population. As has been noted, this has implications for the provision of information about HPV to ensure that women who participate in HPV testing are able to provide informed consent for the test, and to minimise the negative emotional and social consequences of testing HPV positive that were identified in Chapter 5.

The work in this thesis has begun to identify specific pieces of information that appear to provide reassurance to women: the high prevalence of HPV, its potential to lie to dormant for long periods of time, its lack of symptoms, the likelihood that it will clear spontaneously without the need for treatment and the fact that it does not have health consequences for men. This work could be taken forward by developing information

leaflets and investigating their impact on women's beliefs about HPV, and on the emotional impact of testing positive for the virus. Experimental studies using implicit association tasks could be used to investigate the impact of leaflets framed in different ways on the extent to which people perceive HPV and cervical cancer as stigmatised.

4.2. Development of measures of HPV knowledge

In order to evaluate information provided about HPV, it might be useful to develop and validate a measure of HPV knowledge. The items used in Study 1 were developed with reference to the existing literature, but most studies currently develop new measures of HPV knowledge which makes comparison across studies difficult. Given that the cognitive representations component of the CSM proved useful in thinking about women's HPV beliefs in Chapter 4, the Revised Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002) might be a useful starting point for developing such a measure. However, if it were to be used among women who had not tested positive for HPV, it would need to be modified, as the IPQ-R is designed to assess beliefs about an existing health threat rather than an illness in general.

A first step must be to reach a consensus among experts on what aspects of HPV knowledge are important, and what women must know in order to provide informed consent for the test. Aspects of knowledge that have been identified in this thesis as reducing the anxiety associated with an HPV positive result should certainly be included.

4.3. Quantitative evaluation of the emotional impact of testing HPV positive

The qualitative studies in this thesis provide insight into women's experience of HPV testing, and into their concerns about testing positive. However, as the samples were not designed to be statistically representative, the studies are not very informative about the likely distribution of different responses across the wider population. The findings from these studies could now be used to develop appropriate quantitative measures to assess the emotional impact of HPV testing on a larger scale. This would contribute to the small existing body of literature that has aimed to quantify the psychological impact of testing positive for HPV (e.g. Maissi et al., 2004; McCaffery et al., 2004; Maissi, Marteau, Hankins, Moss, Legood, & Gray, 2005). These studies have measured generalised anxiety as well as specific concerns that might be experienced among women with HPV (e.g. feelings about sexual partners). The qualitative work in this

thesis provides evidence about the wide range of issues that cause anxiety and confusion among women who are HPV positive, and could be used as the basis for developing detailed quantitative measures of anxiety in different domains.

4.4. Further exploration of the implications of HPV for sexual relationships

In Studies 3 and 4, it was found that a diagnosis with HPV had the potential to have a significant impact on women's relationships with their partners. For some women, an STI diagnosis raised the possibility that their partner might have been unfaithful, and had implications for trust within the relationship. Although at the time of the interviews none of the women in the study believed that their partner had actually been unfaithful, some described a period of suspicion, perhaps before they gained a better understanding of the natural history of the virus. Other women were concerned about transmitting the virus to their partners, and even initiated condom-use within long-standing relationships. Trust between partners was of critical importance in explaining responses to an HPV diagnosis and its implications for the relationship.

The issue of trust within sexual relationships is one that has been explored in the context of other STIs, particularly in relation to HIV/Aids. This is an area of research where qualitative methods have been used very successfully to uncover complex and sometimes counter-intuitive processes operating within relationships. Work by Flowers and colleagues (Flowers, Smith, Sheeran, & Beail, 1997; Smith et al., 1997) has found explanations for what is usually seen as risky sexual behaviour within male homosexual couples where one partner is HIV positive. In-depth interviews revealed the importance of unprotected sex as a sign of trust and commitment, and found that in long-term relationships, men were willing to run the risk of infection with HIV in order to have the intimacy of sex without a condom.

A qualitative study of heterosexual men in Australia has also highlighted the importance of trust in relation to condom use. As among the homosexual men in Flowers' study, sex without a condom was seen as a sign of intimacy, and as being preferable to sex with a condom. These men frequently described cessation of condom use once a casual sexual encounter developed into a 'relationship'. The study found that relationships were frequently regarded as signifying 'trust and monogamy ... rendering condom use redundant' (Flood, 2003). This has serious implications for the spread of STIs, especially as participants sometimes described establishing a sense of trust within a first

sexual encounter, and not discussing STI status before abandoning condom use in favour of other forms of contraception.

HPV poses slightly different challenges to relationships compared with other STIs, as the health risks associated with the virus are specific to women, and there is uncertainty about the utility of condoms in preventing transmission. However, issues of trust, monogamy and condom use were mentioned frequently during the interviews in Studies 3 and 4, and are worthy of further exploration.

4.5. HPV vaccination

As was mentioned in Chapter 1, phase III trials of HPV vaccines are now under way and policy interest in vaccine programmes is likely to increase over the next few years as the vaccine becomes commercially available. A handful of studies have begun to investigate the acceptability of HPV vaccines in a number of settings (Hoover, Carfioli, & Moench, 2000; Zimet, Mays, Winston, Kee, Dickes, & Su, 2000; Lazcano-Ponce, Rivera, Arillo-Santillan, Salmeron, Hernandez-Avila, & Munoz, 2001; Boehner, Howe, Bernstein, & Rosenthal, 2003; Kahn, Rosenthal, Hamann, & Bernstein, 2003; Gudmundsdottir, Tryggvadottir, Allende, Mast, Briem, & Sigurdsson, 2003; Mays, Sturm, & Zimet, 2004) but none has been carried out in the UK. Studies that have been carried out elsewhere have generally found the vaccine to be highly acceptable, although most were designed to assess the feasibility of vaccine *trials* rather than population-based vaccination programmes. There are many issues that need to be addressed, particularly the acceptability of vaccinating young adolescents against an STI and the possible impact this might have on sexual behaviour. In one study, parents taking part in interviews about vaccines for a variety of STIs, including HPV, thought that the vaccine might be seen as a *carte blanche* for risky sexual behaviour among adolescents (Mays et al., 2004). It is also important to find out how people respond to information about HPV vaccines and the different effects of placing emphasis on cancer prevention, sexual transmission, or genital warts. Research in this area is urgently needed in the UK to inform the policy debate about vaccination programmes.

5. Final remarks

Technological advances in the development of HPV testing and vaccination herald a new era in the prevention of cervical cancer, and provide hope of reductions in

morbidity and mortality worldwide. Alongside the clinical and economic evaluations of these new technologies, this thesis has argued that it is essential to take psychosocial factors into account. Evidence has been found of a huge discrepancy between public understanding of cervical cancer and the current medical model, and this must be considered in the evaluation and implementation of screening and vaccination programmes. It seems that there exists the potential for cervical cancer to become stigmatised, and for women testing positive for HPV to experience negative emotional and social consequences unless steps are taken to ensure that information about HPV is disseminated in a sensitive and evidence-based way.

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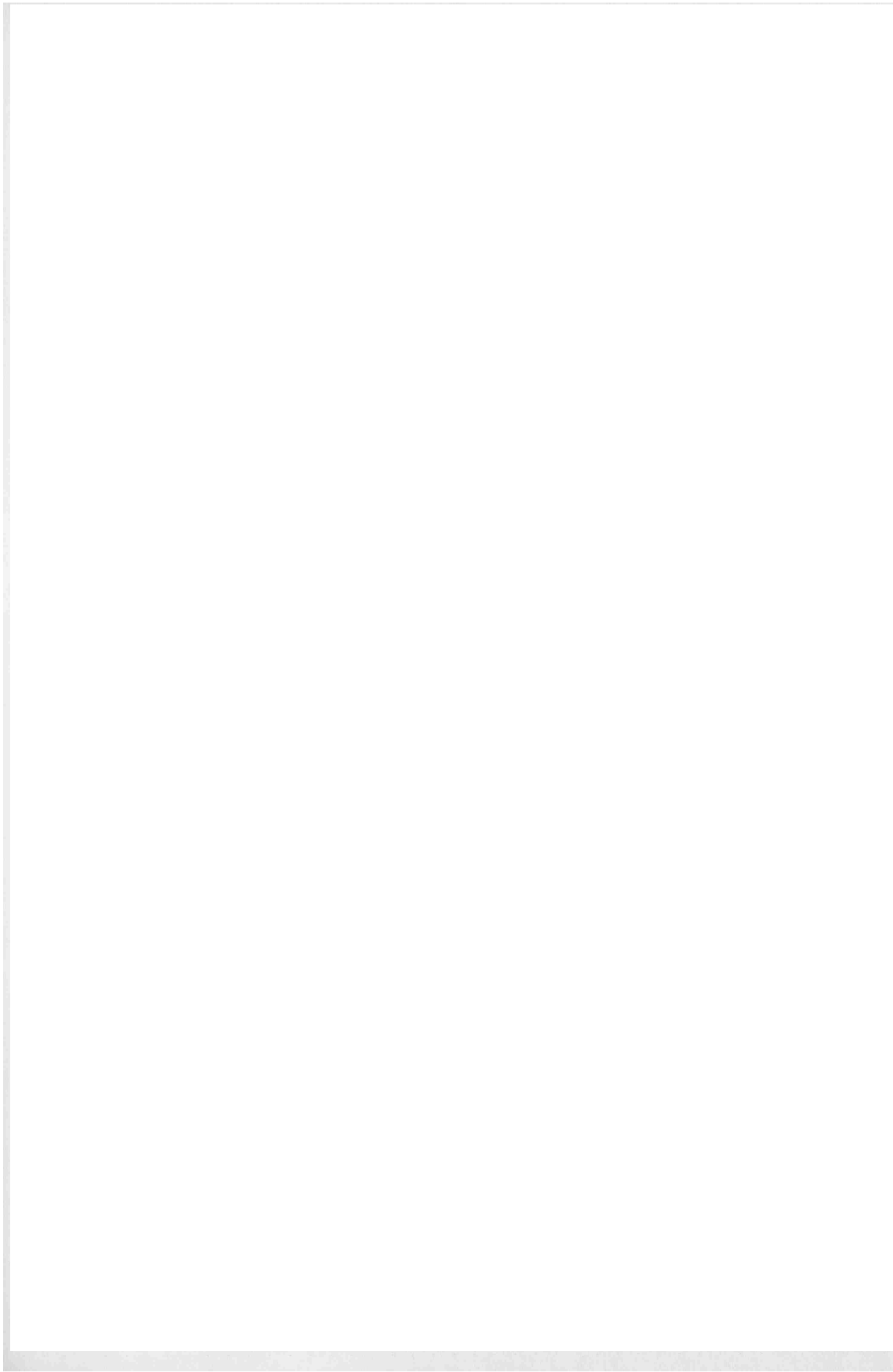
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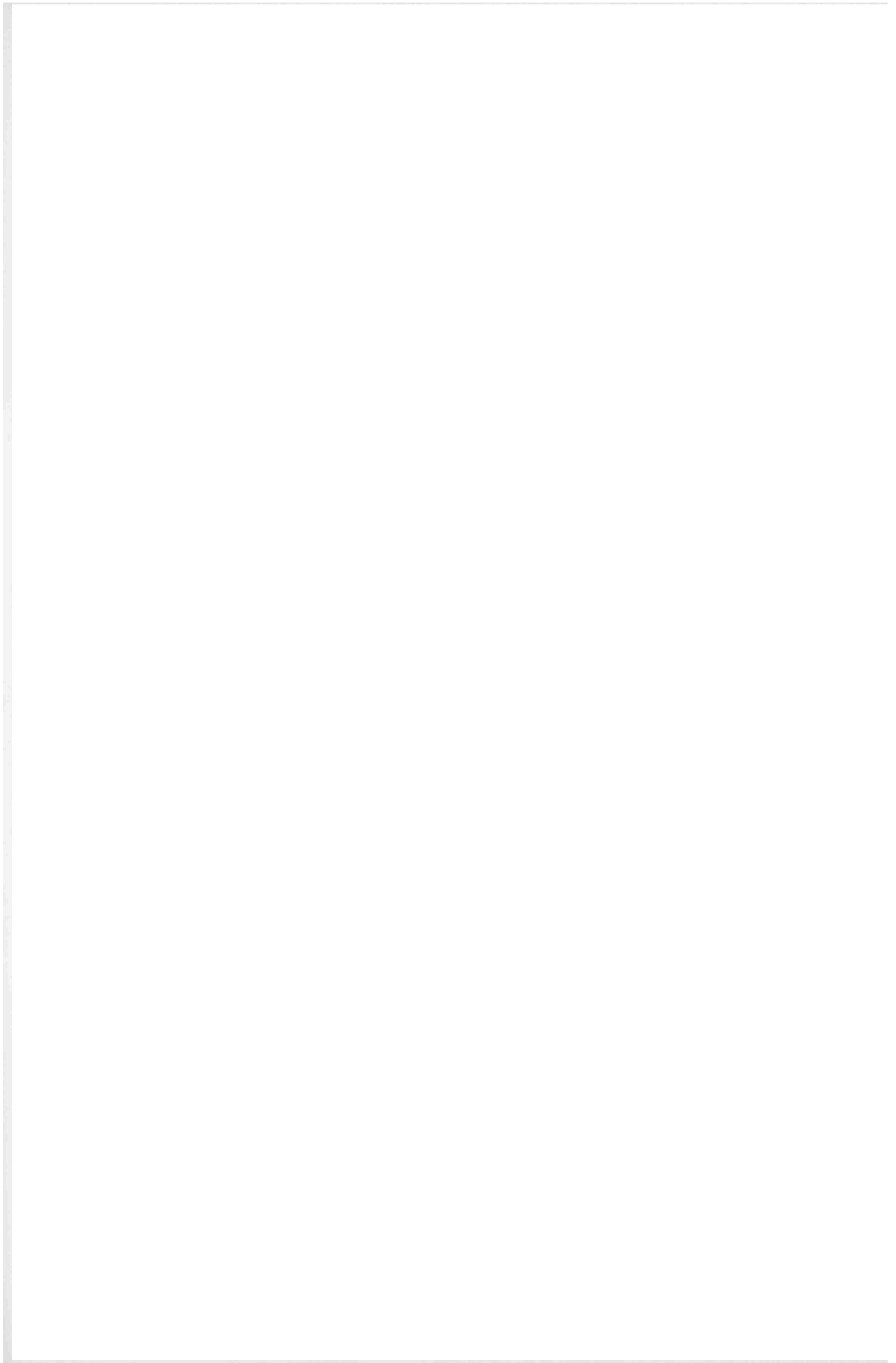
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APPENDICES





Appendix 2.2 Questionnaire used in Study 1

CANCER RESEARCH UK 

Date / /

Clinic number (if known)

Date of birth / /

Initials -
 (take 1st 2 letters from 1st name
 and 1st 2 letters from 2nd name
 e.g. Anne Smith → AN-SM)

A Cervical Screening Self-sampling Study – Questionnaire 1a (baseline)

This is a questionnaire looking at how you feel about smear tests and tests for the human papillomavirus (i.e. HPV virus). We would be grateful if, while you are waiting to see the doctor or nurse, you would fill in the following questionnaire. Please put your completed questionnaire in the envelope provided and hand in to the receptionist.

Please read each statement and then mark in the appropriate box for each question to indicate how you feel right now, at this moment:

	Somewhat	Not at all	Moderately	Very much
➤ I feel calm.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
➤ I am tense.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
➤ I feel upset.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
➤ I am relaxed.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
➤ I feel content.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
➤ I am worried.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The following questions are about cervical screening ie, smear tests. Please answer every question to the best of your knowledge

➤ How many smear tests have you had?.....

➤ When was your last cervical smear test? Never had one before ☐ Over 5 years ago ☐
 Over 3 years ago ☐ Within last 3 years ☐
 1 year ago ☐ Less than 1 year ago ☐

➤ What are you attending for today? _____



PLEASE DO NOT
WRITE IN THIS
SECTION

/ /

/ /

- In your opinion, out of 100 women of your age coming for a test, about how many do you think will have an abnormal smear?

- Compared to other women of your age, do you think your chance of having an abnormal smear test result is:

Much lower ☐ A little lower ☐ About the same ☐ A little higher ☐ Much higher ☐

Which of the following do you think increase a woman's chance of having an abnormal smear?

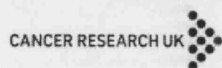
	Yes	No
➤ Being aged over 50 years	<input type="checkbox"/>	<input type="checkbox"/>
➤ Family history of cervical cancer	<input type="checkbox"/>	<input type="checkbox"/>
➤ Late age of first childbearing	<input type="checkbox"/>	<input type="checkbox"/>
➤ HPV infection	<input type="checkbox"/>	<input type="checkbox"/>
➤ Starting periods early	<input type="checkbox"/>	<input type="checkbox"/>
➤ Genital warts	<input type="checkbox"/>	<input type="checkbox"/>
➤ Obesity	<input type="checkbox"/>	<input type="checkbox"/>
➤ Contraceptive Pill	<input type="checkbox"/>	<input type="checkbox"/>
➤ Alcohol	<input type="checkbox"/>	<input type="checkbox"/>
➤ Many sexual partners	<input type="checkbox"/>	<input type="checkbox"/>
➤ Smoking	<input type="checkbox"/>	<input type="checkbox"/>
➤ Stress	<input type="checkbox"/>	<input type="checkbox"/>
➤ Food additives	<input type="checkbox"/>	<input type="checkbox"/>
➤ Having had a sexually transmitted infection (STD)	<input type="checkbox"/>	<input type="checkbox"/>
➤ Illnesses which affect the immune system	<input type="checkbox"/>	<input type="checkbox"/>

- At what age do you think women are most at risk of developing cervical cancer?

20-29 yrs ☐ 30-39 yrs ☐ 40-49 yrs ☐ 50-59 yrs ☐ 60-69 yrs ☐ 70-79 yrs ☐ over 80 yrs ☐

- Have you ever had an abnormal smear result? Yes ☐ No ☐

- Have you ever had treatment (e.g. laser, loop, LLETZ, diathermy, freezing) for abnormal cells in your cervix? Yes ☐ No ☐



PLEASE DO NOT
WRITE IN THIS
SECTION

 / /

 / /

Have you ever been diagnosed with any of the following sexually transmitted infections?

- | | Yes | No |
|--|--------------------------|--------------------------|
| ➤ Candida (thrush)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Herpes simplex virus..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Genital warts..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Trichomonas vaginalis (TV)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Chlamydia..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Gonorrhoea (GC)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Anaerobic vaginosis..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Pelvic inflammatory disease (PID)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Non-specific urethritis (NSU)..... | <input type="checkbox"/> | <input type="checkbox"/> |

- Do you personally know anyone who has had an abnormal smear result (e.g. family member, friend or colleague)? Yes ☐ No ☐

- If yes, how many people? Only 1 ☐ 2 or 3 ☐ 4 or more ☐

If you are attending for a smear test today, please indicate if you told any of the following people that you are attending for it:

- | | Yes | No |
|-------------------------------------|--------------------------|--------------------------|
| ➤ A friend..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Someone in your family..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Your partner (if applicable)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Other (e.g. your boss)..... | <input type="checkbox"/> | <input type="checkbox"/> |

If you are attending for a smear test today and if your smear result is abnormal, how likely will you be to discuss it with:

- | | Very likely | Fairly likely | Not sure | Fairly unlikely | Very unlikely |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ A friend..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Someone in your family..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Your partner (if applicable)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

CANCER RESEARCH UK



PLEASE DO NOT
WRITE IN THIS
SECTION

 / /

 / /

Please indicate how much you agree or disagree with the following statements about abnormal smear results

- | | Very
likely | Fairly
likely | Not
sure | Fairly
unlikely | Very
unlikely |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ Having an abnormal smear result would interfere with my sex life..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ If I had an abnormal smear result I would have problems which would last a long time..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ If I had an abnormal smear result my whole life would change..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ My feelings about myself would change if I had an abnormal smear result..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Having an abnormal smear result would be a problem for me..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- To what extent do you think that having an abnormal smear is a serious medical condition?

Not at all
serious ☐

Somewhat
serious ☐

Not
sure ☐

Quite
serious ☐

Very
serious ☐

These are similar questions about the Human Papillomavirus (HPV). Please answer every question to the best of your knowledge.

- Have you ever heard of HPV Yes ☐ No ☐

- If yes, how did you hear about it?

GP ☐

Friend ☐

Family member ☐

Internet ☐

TV / Magazine / Newspaper ☐

Other (please specify below) ☐

- If you have heard of HPV, what information do you know?

- In your opinion, out of 100 women of your age coming for a test, about how many will test positive for HPV?.....

CANCER RESEARCH UK



PLEASE DO NOT
WRITE IN THIS
SECTION

□/□/□

□

□/□/□

□ □

- Compared to other women of your age, do you think that your chance of having a positive HPV test is:

Much
lower ☐

A little
lower ☐

About
the same ☐

A little
higher ☐

Much
higher ☐

Please tick the appropriate box to indicate whether you believe the following statements are true or false

- | | True | False | Not sure |
|---|--------------------------|--------------------------|--------------------------|
| ➤ HPV is transmitted during sexual intercourse..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ HPV infection is the main cause of cervical cancer..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Men can carry HPV..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Genital warts cause cervical cancer..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ The contraceptive pill can protect against HPV..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Condoms protect against HPV..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- Do you personally know anyone who has had a positive HPV result (e.g. family member, friend or colleague)? Yes ☐ No ☐

- If yes, how many people? Only 1 ☐ 2 or 3 ☐ 4 or more ☐

If you had an HPV test and the result was positive, how likely would you be to discuss it with:

- | | Very
likely | Fairly
likely | Not
sure | Fairly
unlikely | Very
unlikely |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ A friend..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Someone in your family..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Your partner (if applicable)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- To what extent do you think that having a positive HPV result is a serious medical condition?

Not at all
serious ☐

Somewhat
serious ☐

Not sure ☐

Quite
serious ☐

Very
serious ☐

CANCER RESEARCH UK



PLEASE DO NOT
WRITE IN THIS
SECTION

 / /

 / /

Please indicate how much you agree or disagree with the following statements about HPV.

- | | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| ➤ Having a positive HPV test result would interfere with my sex life..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ If I had a positive HPV test result I would have problems which would last a long time..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ If I had a positive HPV test result my whole life would change..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ My feelings about myself would change if I had a positive HPV test result..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ➤ Having a positive HPV test result would be a problem for me..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- On a scale of 1-10, where 1 is not serious at all and 10 is very serious, please rate how serious you think it is to test positive for HPV.

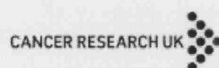
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	6	7	8	9	10

Not serious
(can be ignored)

Very serious
(life threatening)

The following are some general questions about you

- How old are you?..... years
- What is your marital status?
- Married / Living with partner ☐ Single ☐ Divorced ☐ Separated ☐ Widowed ☐
- Do you smoke cigarettes at all nowadays? Yes ☐ No ☐
- If yes, how many do you smoke a day?
- 0-5 ☐ 6-10 ☐ 11-20 ☐ 21-30 ☐ over 30 ☐



PLEASE DO NOT
WRITE IN THIS
SECTION

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 / /

- About how many partners have you had sexual intercourse with (*not including just oral sex*) in the past year?

None ☐ 1 ☐ 2 ☐ 3 ☐ 4-5 ☐ 6-9 ☐ 10 or over ☐

- How many servings of vegetables (fresh, frozen or tinned, NOT INCLUDING POTATOES) do you usually eat per day? (e.g., about a handful of carrots counts as one serving)

Less than 1 ☐ 1-2 ☐ 3-4 ☐ 5 or more ☐ I never eat vegetables or salad ☐

- About how many servings of fruit do you eat per day (including fresh, frozen or canned fruit)? (e.g., one apple counts as one serving).

Less than 1 ☐ 1-2 ☐ 3-4 ☐ 5 or more ☐ I never eat fruit ☐

- How old were you when you left full time education?..... years

Or still in full time education?.....

- Please indicate which of the following best describes your work status:

Working full time ☐ Working part time ☐ Not working at present ☐ Student ☐

- Please tick the box which best describes your living arrangement:

Rent from local authority ☐ Rent from private landlord ☐ Own/buying home ☐ Live with parents ☐ Other ☐

- Do you have a car Yes ☐ No ☐

- Which of these best describes your ethnic background?

White ☐ Black ☐ Asian ☐ Other ☐ Do not wish to answer ☐

Thank you very much for filling out this questionnaire.

Please check that you have answered every question and then put it in the envelope provided and hand over to the receptionist.

Appendix 2.3 Ethical approval letter for Study 1

Camden and Islington 
Community Health Services NHS Trust

LOCAL RESEARCH ETHICS COMMITTEE

Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NW1 0PE
tel: 020 7530 3376 fax: 020 7530 3235
e-mail: research.office@dial.pipex.com
Chair: Stephanie Ellis Administrator: Michael Peat

Tuesday, 03 October 2000

Dr Anne Szarewski
Imperial Cancer Research Fund
London WC2A 3PX

Dear Dr Szarewski

Ref: 00/ 71 (please quote in all further correspondence)

Title: HPV (Human Papilloma Virus) testing by self-sampling: Assessment of methodology and acceptability

Thank you for your correspondence dated 31st August 2000. I am pleased to inform you on behalf of the Local Research Ethics Committee that you have ethical approval to proceed with your study. Please would you write and inform Angela Williams of the start date of your project, at the above address.

Please note that the following conditions of approval apply:

- ♦ It is the responsibility of the investigators to ensure that all associated staff including nursing staff are informed of research projects and are told that they have the approval of the Ethics Committee.
- ♦ If data are to be stored on a computer in such a way as to make it possible to identify individuals then the project must be registered under the Data Protection Act 1998. Please consult your department data protection officer for advice.
- ♦ The Committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.
- ♦ The Committee must receive notification: a) when the study is complete; b) if it fails to start or is abandoned; c) if the investigator/s change and d) if any amendments to the study are made.



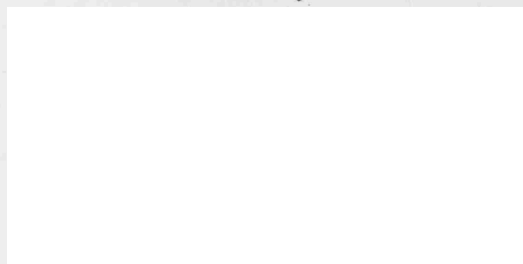
Page 1 of 2

USMAN KHAN: Chair
ROB LARKMAN: Chief Executive

- ♦ The Committee will request details of the progress of the research project periodically (i.e. annually), and require a copy of the report on completion of the project.

Please forward any additional information/amendments regarding your study to contact the Local Research Ethics Committee Administrator or myself at the above address. If you have any queries, please do not hesitate to contact the Ethics Committee Administrator at the Research & Development Unit.

Yours sincerely



Appendix 4.2 Ethical approval letter for Study 3

Our ref: MREC 01/8/20

1st May 2001

Professor Jane Wardle
Imperial Cancer Research Fund Health Behaviour Unit
Department of Epidemiology & Public Health
University College London
2-16 Torrington Place
London
WC1E 6BT



North West

MREC
Gateway House
Piccadilly South
Manchester
M60 7LP

Chairman
Mrs Jennifer Blunt OBE

Tel 0161 237 2394
Fax 0161 237 2383

e-mail
alison.forbes@mchester-
ha.nwest.nhs.uk

Dear Professor Wardle

MREC 01/8/20 Please quote this number on all correspondence

Psychosocial impact of human papilloma virus (HPV) screening

The Chairman of the North West MREC has considered the amendments submitted in response to the Committee's earlier review of your application on 13th March 2001 as set out in our letter dated 26th March 2001. The documents considered were as follows:

MREC Application Form dated 9/2/01
Information sheet, version 3, dated 6th April 2001
Consent form, version 3, dated 6th April 2001
Letter to accompany demographic questionnaire
HPV study questionnaire
Interview recruitment letter: White and African Caribbean women
Interview recruitment letter: Pakistani women
Interviewer confidentiality form
Interview topic guide
Protocol - undated

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set out below. A full record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.



INVESTOR IN PEOPLE

Conditions of Approval

- No research subject is to be admitted into the trial until agreement has been obtained from the appropriate local research ethics committees.
- You must follow the protocol agreed and any changes to the protocol will require prior MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of any final questionnaire before it is used.
- You must promptly inform the MREC and appropriate LRECs of:
 - (i) deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects;
 - (ii) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
 - (iii) all adverse drug reactions that are both serious and unexpected;
 - (iv) new information that may affect adversely the safety of the subjects or the conduct of the trial.
- You must complete and return the standard progress report form to the MREC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the MREC when your research is completed.

While the MREC has given approval for the study on ethical grounds, it is still necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/HAs) in which the work will be done.

Local Submissions

It is your responsibility to ensure that any local researcher seeks the approval of the relevant LREC before starting their research. To do this you should submit the appropriate number of copies of the following to the relevant LRECs:

- this letter
- the MREC Application Form (including copies of any questionnaires)
- the attached MREC response form
- Annex D of the Application Form
- **one** copy of the protocol
- the final approved version of the Patient Information Sheet and Consent Form

It is important to check with the respective LRECs the precise numbers of copies required as this will vary and failure to supply sufficient copies could lead to a delay. In addition, you should submit to LRECs only the revised paperwork reflecting the requirements of the MREC as referenced in the response form.

Local Sites

Whilst the MREC would like as much information as possible about local sites at the time you apply for ethical approval it is understood that this is not always possible. You are asked, however, to send details of local sites as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at <http://dSPACE.dial.pipex.com/mrec>.

Yours sincerely

Alison Forbes
Manager, MREC North West

Enclosures MREC response form
 Progress report form

Appendix 4.3 Recruitment letter used for Studies 3 and 4 (ARTISTIC trial version)



ARTISTIC
A Randomised Trial In Screening To Improve Cytology



CONFIDENTIAL

Dear Patient

Re: ARTISTIC – A Randomised Trial In Screening To Improve Cytology

As part of the ARTISTIC study, you recently had the new human papillomavirus (HPV) test when you attended for your last cervical smear. Our colleagues at University College London (UCL) would like to interview some women to find out how they felt about the new test. The aim of the study is to help improve screening services for women in the future.

An information sheet is enclosed to tell you more about what is involved. Please read it carefully. Over the next few weeks, one of the researchers from UCL may telephone you or write to you to see if you are willing to take part in the study. You will be able to say no if you do not want to take part.

If you would rather not be contacted about the study, please complete the slip at the bottom of this letter and return it in the stamped, addressed envelope provided in the next week. If you would like further information on the study, you can call Ms Jo Waller at UCL on 020 7679 6639. She will be happy to talk to you about the study.

If you decide not to take part in the study, your medical care will not be affected in any way.

Yours sincerely

HENRY C KITCHENER
Professor of Gynaecological Oncology

✂-----

I would rather not be contacted by researchers from UCL.

Name: _____

Address: _____

Appendix 4.4 Information sheet for participants in Study 3 (UCH version)**Royal Free and University College Medical School**

UNIVERSITY COLLEGE LONDON
HEALTH BEHAVIOUR UNIT
DEPARTMENT OF EPIDEMIOLOGY AND PUBLIC HEALTH



Gower Street Campus
2-16 Torrington Place
London WC1E 6BT

Telephone 44 (0) 20 7679 6642
Direct Line 44 (0) 20 7679 6639
Fax 44 (0) 20 7813 2848

Version 5

Date: 18 June 2002

The HPV Screening Study

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London, N16 0BW.

Thank you for reading this.

Why have you been chosen?

At your colposcopy appointment at Elizabeth Garrett Anderson and Obstetrics Hospital at UCH, you recently had a test for human papillomavirus (HPV). We are interested in finding out about women's views on HPV testing and cervical screening and we would like to invite you to take part in an interview. The research will help us understand women's concerns about HPV and screening, and will help us work out ways to make screening more sensitive to women's needs. It will help us provide important information to women who attend HPV screening in the future.

What is the purpose of the study?

New tests have been developed which can show if HPV is present in women and as part of your colposcopy appointment, you have been tested for HPV. Since HPV testing is new, it is important to find out women's views on it. That is why we are interested in your attitudes to HPV screening.

What will the study involve?

The study will involve a one-to-one interview with a female researcher. The interview will last about an hour and will cover your views about HPV and your feelings about your screening results. Because of

the nature of cervical smears and HPV screening, some of the questions will be of a personal nature. You will not have to answer any questions you are not comfortable with. If you agree, the interview will be tape recorded so that the interviewer does not have to make notes during the interview and can concentrate fully on listening to you. You can ask for the tape to be stopped at any time.

The interview can take place at your home or at the research office, whichever you would prefer and all travel expenses will be refunded.

Confidentiality

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/ surgery will have your name and address removed so that you *cannot* be recognised from it. All tapes will be kept in a locked cabinet in the research office and will only be accessible to members of the research team. Your name will not be on the tape. Notes will be taken from the tape-recording of the interview but your name will be removed. We will not be able to identify any individuals from the recordings. Once notes have been taken, the tape will be destroyed. This process will take us between 2 and 8 weeks.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

What do I do now?

Please think about the study. If you are interested in taking part, please fill in the attached form and place it in the Freepost envelope provided. You can either put the envelope in the box at the clinic reception, or send it by post to Jo at UCL. No stamp is needed.

Further information about the study

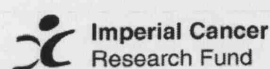
If you would like to obtain further information about the study please contact:

Ms Jo Waller
Health Behaviour Unit
UCL
Tel: 020 7679 6639

This study is funded by Cancer Research UK. It is intended that the results of the research will be published in a medical journal in about 2-3 years time. It is important to point out that no volunteers included in the research will be able to be identified from any report or publication. However, if you would like a copy of the published results of the research please contact us at the address given above and we will be happy to send them to you.

**The aim of this research is to improve screening services
for women in the future**

All proposals for research using human subject are reviewed by an ethics committee before they can proceed. This proposal was reviewed by North West Multi-centre Research Ethics Committee.

Appendix 4.5 Recruitment letter used for Study 3 (Margaret Pyke Centre version)

Department of Mathematics, Statistics and Epidemiology

Head: Jack Cuzick, PhD

P.O. Box No. 123
Lincoln's Inn Fields
London, WC2A 3PX

Direct Line: 020 7269 3160
Fax: 020 7269 3429
e-mail: a.szarewski@icrf.icnet.uk

CONFIDENTIAL

22 June 2001

Dear Patient

Re: A Cervical Screening Self-Sampling Study

As part of the Cervical Screening Self-Sampling Study, you recently had the new human papillomavirus (HPV) test. Our colleagues at University College London (UCL) would like to interview some women to find out how they felt about the new test. The aim of the study is to help improve screening services for women in the future.

An information sheet is enclosed to tell you more about what is involved. Please read it carefully. Over the next few weeks, one of the researchers from UCL may telephone you or write to you to see if you are willing to take part in the study. You will be able to say no if you do not want to take part.

If you would rather not be contacted about the study, please complete the slip at the bottom of this letter and return it to me in the Freepost envelope provided in the next week. If you would like further information on the study, you can call Ms Jo Waller at UCL on 020 7679 6639. She will be happy to talk to you about the study.

If you decide not to take part in the study, your medical care will not be affected in any way.

Yours sincerely

Dr Anne Szarewski

✂-----

I would rather not be contacted by researchers from UCL.

Name: _____

Address: _____

**Appendix 4.6 Sheet used to record telephone contact with participants in Study 3
(ARTISTIC trial version)**

HPV + / - Cytology: normal / borderline / mild / moderate / severe

Study ID number

Contact sheet

Patient name

Patient address

Phone number

Date of telephone call / /

Outcome of call
 Interview booked ☐ Interview refused ☐ Left message ☐
 Wrong number ☐ No reply ☐ Didn't meet quota ☐

Occupation/partner's occupation

Marital status
 Not cohabiting ☐ Married/cohab ☐ Separated/divorced/widowed ☐

Ethnic group

Age

Meets quota?
 Yes ☐ No ☐

Date of interview Time :

Name of interviewer

Address checked ☐

Notes

Comments/problems

Sheet copied to Paula ☐

Appendix 4.7 Demographic questionnaire completed by patients at UCH for Study 3

CONFIDENTIAL

HPV Screening Study



Please fill in this form if you are interested in taking part in the HPV interview study.

Date of appointment: _____

Name: _____

Phone number: _____

Best time/day to call: _____

We are keen to interview women from a range of different age-groups and backgrounds, so we would be grateful if you could fill in a few questions about yourself.

All your answers are totally confidential.

How old are you? _____ years

Please tick the box which best describes your ethnic group:

White <input type="checkbox"/>	Black Caribbean <input type="checkbox"/>	Black African <input type="checkbox"/>	Black other <input type="checkbox"/>
Indian <input type="checkbox"/>	Pakistani <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	Chinese <input type="checkbox"/>
Asian other <input type="checkbox"/>	Other (please specify) _____		

Are you:

Single <input type="checkbox"/>	Living with a partner <input type="checkbox"/>	Married <input type="checkbox"/>	Divorced <input type="checkbox"/>
Separated <input type="checkbox"/>	Widowed <input type="checkbox"/>		



Now please place this form in the envelope provided. Either put it in the box at the clinic reception or send it to Jo Waller at UCL. No stamp is needed.



THANK YOU FOR YOUR TIME

Health Behaviour Unit, Department of Epidemiology & Public Health, University College London, 2-16 Torrington Place, London WC1E 6BT. Telephone: 020 7679 6639.

Appendix 4.8 Consent form for participants in Studies 3 and 4**Royal Free and University College Medical School**

UNIVERSITY COLLEGE LONDON

DEPARTMENT OF EPIDEMIOLOGY AND PUBLIC HEALTH

Gower Street Campus
1-19 Torrington Place
London WC1E 6BT

Telephone 44 (0) 020 7679 2000
Direct Line 44 (0) 020 7679
Fax 44 (0) 020 7813 0242



Centre Number:.....
Study Number:.....
Patient Identification Number for this trial:.....
Version 6

Date: 6 April 2001

Title of Project: The HPV Screening Study**Name of Researcher: Ms Jo Waller/ Dr Kirsten McCaffery****CONSENT FORM**

Please initial box

1. I confirm that I have read and understand the information sheet dated 6 April 2001 (version 3) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the above study.
4. I agree to the interview being tape-recorded.

☐
☐
☐
☐

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix 4.9 Example of charted data from Study 3

CHART 5: PROCESS AND RESULTS

Identifier	1 How came to have test & decision to participate & expected outcome	2 Experience of HPV & smear tests	3 Results & how received	4 Understanding & meaning of results	5 Beliefs about cause of +ve results
MPC5, age 23, boyfriend, white, ?SES, HPV+, borderline smear	Attended clinic for injectable pill, received leaflet about study (p2). Has been a student so knows importance of research, was willing to take part (p3). Just took part & didn't think that it would 'affect me'. Took part to help without considering outcome (p4).	Positive experience of doing the self-test (p7). Found the doctors very helpful and reassuring (p10).	Smear was 'borderline changes' and 'HPV was abnormal cells'. Hadn't received letter so got results at next clinic visit. Pleased that results were given that way as it was reassuring. Would have had lots of questions had it been a letter (p4).	Told that it was abnormal changes but not cancer. Not clear what it was & what had caused it (p3). Minor changes which could go on to cause cancer if not monitored (p3). Told they were very mild changes but 'it's still not 100% right' (p4). Abnormal changes are the 'start of the stages that can eventually lead to CaCx'. Can take 10 yrs. (p5).	Not too clear. Wondered if had done something to cause it, or if it could be prevented (p3). Didn't think she's got it from boyfriend. It's something that can just happen (p8). Doesn't really matter how she got it because 'I didn't know enough to prevent myself getting it, if there was anything I could do' (p11).
M013, age 56, widow, white, low SES, HPV+ mildly abnormal smear	Returned to GP for repeat smear, recruited for trial. Just wanted to get it over with. Trial didn't require doing anything different. Wanted to be of help, no harm to herself. 'Didn't think I would have a problem' (p5).	Test done by practice nurse at GP practice. Just like normal smear test, just like a normal appointment. Didn't ask about the HPV test - assumed would get s'thing through the post - case of wait and see what the results are.	Was told would have results in 8 wks - letter through post as normal. HPV was positive, smear 'mild'. Has to wait 6 mths for repeat smear.	Understood abnormal cells were lowest grade 'slight', and often cleared itself by next smear. Confused about implications with sexual partner - prevention - 'must be sort of things you can do'. 'I find it very difficult that side of it'. 'I am still a bit ignorant about it all' (p7-8). Questions how to avoid it in the first place. 'Forewarned is forearmed' but doesn't understand how much of a danger HPV is (QQ), and if Drs know or not. Feels women should know and now many women already do.	Blamed it on recent relationship. Started a relationship - first since husband died.
M007, age 39, single White, low SES, HPV + smear normal	Attended for routine smear, invited to participate in trial. Understood she was going to have another test which looked to see if there was 'anything wrong' and felt 'if there's anything wrong I'll find out' (p7). Didn't really understand the info (p7).	Done by practice nurse. Didn't notice it was 2 difference tests. Nurse very good explained about the research, no pressure to take part. Told she might be in revealed or non revealed arm and not to worry about waiting for the results. No different from previous smears (p9)	Had to wait a couple of months 'it wasn't long' (p9). 'I had a virus thing' (p8). 'Wart virus'. Smear result came first. Needs repeat smear in 12 months.	Understands HPV test as a further test for CaCx. Not aware if what HPV stood for. Did not understand the difference between the smear test and the HPV test. 'I have a virus thing.....they said tests again in 12 months time' (p8) the information said that 90% of the time it is sexually transmitted. Information said the virus can go away on its own or you might have to have treatment. Understood HPV could lie dormant but she wasn't sure if it had been dormant or had just been there undetected.	90% of the time it's sexually transmitted (p10). Doesn't know or understand. Finds it 'weird'.. 'I haven't had a partner for at least 4 years, I just think why has it happened to me?' QQ (p13) Thought that you got STDs from sleeping with lots of people. It could have 'been there for years and never been picked up on' (p10).

Appendix 6.1 Ethical approval letter for Study 4**North West Multi-centre Research Ethics Committee**

Our ref: MREC 01/8/20

27th November 2002

Gateway House
Piccadilly South
Manchester
M60 7LP

Professor Jane Wardle
Imperial Cancer Research Fund Health Behaviour Unit
Department of Epidemiology & Public Health
University College London
2-16 Torrington Place
London
WC1E 6BT

Dear Professor Wardle

MREC 01/8/20 Please quote this number on all correspondence

Psychosocial impact of human papilloma virus (HPV) screening

- **Revised protocol no version no. undated**

The North West MREC reviewed the proposed amendment to the above application at its meeting on the 11th June 2002.

The amendment sought approval for an additional interview of participants following the second HPV test

The members of the Committee present agreed that there is no objection on ethical grounds to the proposed amendment to the study. I am therefore happy to give you our approval on the understanding that you will follow the protocol as agreed.

A copy of the amendment together with this letter should be sent to LRECs for information.

Yours sincerely

Alison Forbes
Manager, MREC North West

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees