

Screening for cervical cancer: a review of women's attitudes, knowledge, and behaviour

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SUMMARY

The United Kingdom (UK) cervical screening programme has been successful in securing participation of a high proportion of targeted women, and has seen a fall in mortality rates of those suffering from cervical cancer. There remains, however, a significant proportion of unscreened women and, of women in whom an abnormality is detected, many will not attend for colposcopy. The present work reviews the psychological consequences of receiving an abnormal cervical smear result and of secondary screening and treatment, and examines reasons for women's non-participation in the screening programme. Psychological theories of screening behaviour are used to elucidate women's reactions and to suggest methods of increasing participation, of improving the quality of the service, and of reducing women's anxiety. A literature search identified studies that examine factors influencing women's participation in the screening programme, their psychological reaction to the receipt of an abnormal cervical smear result, and experiences of colposcopy. Reasons for non-participation include administrative failures, unavailability of a female screener, inconvenient clinic times, lack of awareness of the test's indications and benefits, considering oneself not to be at risk of developing cervical cancer, and fear of embarrassment, pain, or the detection of cancer. The receipt of an abnormal result and referral for colposcopy cause high levels of distress owing to limited understanding of the meaning of the smear test; many women believe the test aims to detect existing cervical cancer. The quality of the cervical screening service can be enhanced by the provision of additional information, by improved quality of communication, and by consideration of women's health beliefs. This may result in increased participation in, and satisfaction with, the service.

Keywords: cervical cancer; CIN; screening; colposcopy; adherence; health; psychology.

Introduction

ALTHOUGH readily detectable in its premalignant stage, cervical cancer remains the second most common women's cancer worldwide¹ and the fifth most common in the UK.² In most countries with an established screening programme, the incidence of invasive cervical cancer has decreased,³⁻⁴ but increasing numbers of pre-invasive cervical intraepithelial neoplasias (CINs) have been registered in the UK^{5,6} and the USA,⁷⁻⁹ particularly in young women. It is unlikely that this increase in the number of abnormal cervical smear results can be accounted for either by the increase in numbers of women participating in the screening programme^{10,11} or by changes in diagnostic procedures or terminology.¹² It has been suggested that a reduction in the use

of barrier contraceptives may underlie the observed increase;¹³ if this is true, it is likely that this trend of increased incidence of CINs will continue.

It is therefore of prime importance that cervical cancer screening is effective in targeting at-risk populations, and that, once an abnormality has been identified, follow-up screening and treatment are provided with the minimum distress to women. Despite this, women in receipt of an abnormal smear result commonly experience extreme levels of distress.¹⁴⁻²³ The psychological consequences of the receipt of an abnormal cervical smear and colposcopy has attracted much interest in recent years but few studies suggest practical ways in which anxiety and distress can be reduced. This paper summarizes the results of studies that have examined factors that influence women's participation in the screening programme, their knowledge of cervical screening procedures, reactions to the receipt of an abnormal cervical smear result, and experiences of colposcopy. It also discusses ways in which general practitioners (GPs) can increase their patients' participation in the screening programme and minimize the distress experienced by women who require secondary screening and treatment.

Method

The English language research literature published between 1982 and 1997 was searched using the Bath Information and Data Services. Four searches were undertaken using keyword combinations: 'colposcopy'; 'cervical + cancer + screening'; 'anxiety + cervical + screening'; and 'psychological + cervical + screening'. Articles were selected for inclusion in this review if their title or on-line abstract included reference to women's knowledge of, or adherence to, the cervical screening programme, the distress, anxiety, or psychological reaction associated with the receipt of an abnormal cervical smear result, and subjective experience of colposcopy. Women's perceptions and behaviours are discussed with reference to psychological theories of health-related behaviours, and in this way methods of enhancing the quality of the screening service and of increasing women's participation are identified.

This paper is divided into five sections that consider different aspects of screening for cervical cancer. The first examines reasons why women do not participate in the cervical screening programme, both for regular Papanicolaou smears and, when necessary, colposcopy. Secondly, the results of studies that have investigated women's reactions to the receipt of an abnormal cervical smear result are summarized and the factors that underlie women's reactions are described. Thirdly, the implications of women's reactions for the management of mildly abnormal smears are discussed. A summary of the factors that can reduce women's participation in the cervical screening programme is then provided. Finally, the findings of previous sections are combined with the results of more general health-psychological research to identify ways in which women's participation in, and satisfaction with, the programme can be enhanced.

Obstacles to participation in cervical screening programmes

Despite increased efforts to encourage women to attend for regu-

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Submitted: 7 August 1997; accepted: 16 March 1998.

© British Journal of General Practice, 1998, 48, 1509-1514.

lar cervical smears, many have never been screened.²⁴ Since these women have an increased risk of developing invasive cervical cancer,⁶ it is important to identify the causes of their non-participation. For the purpose of this review, factors that influence screening behaviour can be classified as health service related, patient centred, or factors related to colposcopy, and are described below.

Health service related problems

Until recently, one of the major obstacles to women participating in the cervical screening programme was administrative errors, particularly incorrect addresses.²⁵⁻²⁹ Although many GPs made use of opportunistic screening, this was often performed during contraceptive or obstetric consultations and resulted in postmenopausal women being overlooked.^{27,30}

The introduction of the GP's target payment scheme has meant that it is in the interests of both GPs and patients to ensure that regular cervical screening is achieved. The scheme provides a sliding scale of remuneration with payment depending on the proportion of women aged 20-64 years registered with the practice and screened within the previous five years; enhanced payments are made when 80% are screened and lower payments when 50% are screened.

The introduction of computerized records by many GPs has alleviated many administrative problems such as screening history and changes in address. Many women, however, do not participate due to the unavailability of a female screener^{29,31} and due to appointments available only inside working hours.³¹

Patient-centred problems

Reasons women give for not participating in a cervical screening programme include lack of knowledge about the test and its indications;^{29,32,33} considering the test unnecessary or of no benefit, or considering oneself not to be at risk of developing cervical cancer;^{6,25,27,30-36} and fear of embarrassment or pain.^{29,31-34,37-39} In addition, certain groups of women may experience particular problems. Women of low socio-economic status may be less likely to have been screened.^{32,36} There is some evidence that ethnic-minority women, particularly those of Asian origin, are less likely to participate.^{40,41} Finally, postmenopausal women are less likely to be screened regularly,^{26,30} and non-participation may be a result of uncertainty as to whether the smear test is appropriate for their age group.^{29,34}

Obstacles to attending for colposcopy

Estimates of the percentage of women who do not attend for colposcopy varies widely, between around 12% and 50%,⁴²⁻⁴⁷ depending on centre and patient population. There are two likely explanations of this non-compliance. First, as compliance is related to the patient's perception of the severity of the disorder,⁴⁸ women may not consider the receipt of an abnormal smear as sufficiently serious to comply with health advice. Alternatively, women may be too distressed to attend. Support for the latter explanation comes from studies that examine women's understandings of, and reactions to, an abnormal cervical smear result. Many women believe they have cancer^{14-16,20,21,42,49,50} and the fear of cancer remains high throughout subsequent investigations.^{14,15,21,42,49} Indeed, those women who do not attend for colposcopy show higher levels of anxiety and greater impairment in daily activities than women who do attend.⁴² To gain an understanding of possible reasons for non-compliance, the psychological consequences of an abnormal cervical smear result will be examined.

Reactions to the receipt of an abnormal cervical smear result

The receipt of an abnormal cervical smear result, and of referral for colposcopy, causes anxiety and distress in a large number of women,^{14-23,42,49-53} although the degree of anxiety experienced varies.^{17,51,52} The most distressing period appears to be the receipt of the abnormal smear result;¹⁶ women's anxieties diminish following colposcopy and treatment.^{14,18,21,22,51} The primary cause of distress appears to be fear. Many women are frightened of medical procedures,^{14,17,19,23,52} believe that the abnormal smear is indicative of cancer,^{14-16,20,21,42,49,50} and that their reproductive ability will be threatened.^{14,17,20,21,52} The resulting anxiety can have severe effects on day-to-day functioning; for example, depressed mood^{18,42,51} and decreased libido.^{14,16,21,42,51} The result can cause changes in self-perception, including impaired body image^{14,16,18,20,49} and lowered self-esteem;^{14,16,18} women report feeling 'less attractive', 'tarnished', 'let down by their bodies',¹⁸ 'defiled', 'contaminated', and 'dirty'.¹⁶

As the majority of abnormalities will be borderline or indicative of mild dyskaryosis,⁵⁴ both of which carry a relatively low risk of progression to invasive cervical cancer,^{55,56} the above reactions could be considered inappropriate. It may be that women react in this way as they do not understand the meaning of their result. In order to identify information that women require it is important to examine their understanding of cervical screening procedures.

Understanding of cervical screening procedures

Women tend to demonstrate very little understanding of the meaning of an abnormal cervical smear result or the reason for colposcopy. Many women do not have a clear understanding of the meaning of an abnormal cervical smear,⁵⁷ or the concept of precancer,⁴⁹ and many believe the purpose of the smear test to be the detection of existing cervical cancer.⁵⁸ This misconception may explain the high numbers of women who, on receiving notification of an abnormal smear result, believe they have cancer.^{14-23,42,49-53} This lack of understanding persists in women referred for colposcopy, with many women unaware of the main reason for colposcopy.^{57,59}

Knowledge of the risk factors associated with cervical cancer

Women also have little knowledge of the risk factors associated with cervical cancer.^{16,29} The accumulation of evidence of a causative link between human papillomavirus (HPV) and cervical cancer may serve to increase women's feelings of resentment towards their partner and of being tarnished. Indeed, the fear of moral judgement may result in some women being unable to tell anyone of their abnormal smear; the resulting lack of social support may lead to increased distress.^{18,51}

Requirement for additional information

Women report a need for additional information on the meaning of both the cervical smear result and the colposcopy.^{15,16,29,49-51,59,60} Women who perceive the information provided to be adequate are less distressed,^{18,50} less likely to fear they have cancer, and more likely to attend for future cervical screening.⁵⁰ The most common source of information used by women was a friend who had previously experienced a colposcopy, although, given that knowledge does not appear to increase following colposcopy,⁵⁹ it is unlikely that women receive correct information by this route.

Box 1: Methods of increasing participation and reducing anxiety

- Provide more information,
- improve the quality of communication,
- increase women's satisfaction, and
- consider women's health beliefs.

Management of mildly abnormal smears

The high levels of distress experienced by women referred for colposcopy have resulted in considerable debate as to the optimal management strategy for mildly abnormal smears. Two approaches are commonly taken: immediate colposcopy, or cytological surveillance. As only a small proportion of low-grade CINs are likely to progress to invasive carcinoma,^{55,56} it is argued that colposcopic investigation of CIN I causes an avoidable financial burden on the National Health Service and unnecessary distress to women. This approach is supported by suggestions that instead of CIN I being a precursor of CIN III, CIN I may represent a discrete manifestation of HPV;⁶¹ a distinction supported by the Bethesda System⁶² of low- and high-grade squamous intraepithelial lesions. If this distinction is substantiated, CIN I may be used as a marker of exposure to HPV⁶³ rather than being treated directly.

A number of studies have compared women's responses to an abnormal smear result as a sequela of cytological surveillance with those in response to a sequela of colposcopy. Women told to return for a repeat smear to monitor borderline abnormalities report less anxiety than women referred for colposcopy^{18,20} but, as the latter are more likely to have higher-grade CINs, these studies are unable to disconfound anxiety owing to cytological status from anxiety owing to management approach. One study used differing recommendations of cytology laboratories to assess the psychological consequences of these two approaches.²¹ Women referred for colposcopy experienced more anxiety, more marked loss of libido, greater resentment of their partner, and were more likely to believe they had cancer. The women who were kept under surveillance, on the other hand, experienced anxiety while awaiting the result of the repeat smear, and if the abnormality persisted, anxiety increased further. Women referred for early colposcopy expressed greater satisfaction with their management approach, and both groups of women preferred the option of immediate colposcopy. There is an apparent conflict, therefore, between management that minimizes distress and that which increases satisfaction. Considering women's individual management preferences may decrease women's anxiety and increase attendance for subsequent screening or colposcopy.

Summary of factors reducing women's participation in the cervical screening programme

The factors reducing the participation of women in the cervical screening programme are:

- poor awareness of the indications and benefits of the cervical smear test;
- lack of knowledge of cervical cancer and its risk factors;
- fear of embarrassment, pain, or cancer;
- lack of female screeners or convenient clinic times;
- anxiety caused by receiving an abnormal cervical smear result;
- poor understanding of cervical screening procedures; and
- a need for additional information.

Determining ways of overcoming these problems is a prerequisite for improving adherence to the screening programme. The

following sections will examine methods of addressing these problems.

Issues affecting women's participation in the cervical screening programme*Provision of information*

Women have reported a need for information on the indications, benefits, and procedures of cervical screening; such information is effective in increasing attendance for primary screening.^{26,29,31,41} The section above suggests that women's high levels of anxiety on the receipt of an abnormal smear result may originate in a lack of understanding of the meaning of cervical abnormalities, and that the provision of information may reduce anxiety. Although women have different coping strategies, and as a consequence require different amounts of information,^{17,49,52,60} unwanted written information tends to remain unread²⁵ so that it is unlikely that excess information increases anxiety or decreases attendance. Indeed, increased information is associated with increased confidence in the service provision,⁶⁰ reduced anxiety,^{15,53} and improved attendance for colposcopy.^{45,47}

Quality of communication

Women may be highly anxious during consultations and so unable to absorb fully what is being said or to ask questions;⁴⁹ information should be provided clearly so that women do not misunderstand or forget what they have been told.⁶⁴ Although information leaflets are provided by many colposcopy clinics, some leaflets may be difficult to read,⁶⁵ particularly as there may be a preponderance of women with low educational attainment among the women with abnormal smears.^{66,67} Indeed, information leaflets do not generally take into account that English may not be the first language of many women.

Women's fears and misconceptions can be addressed by health professionals either in person or by telephone; both methods significantly increase attendance.^{31,44} Alternatively, the provision of audio-visual educational material in women's preferred language has been shown to improve attendance among ethnic-minority women.^{41,68}

Limited communication between doctor and patient may underlie the reports of poor participation of women from ethnic minorities, particularly of Asian origin.^{40,41} This is supported by findings of unscreened Mexican-American women being less likely to speak English or to be aware of cancer signs, symptoms, risk factors, and screening guidelines than Mexican-American women who are screened regularly.^{69,70} Indeed, non-English speaking women are enthusiastic about the cervical screening programme when the nature of the test is explained in their own language.⁷¹ It is of particular importance to determine ethnicity-related reasons for non-participation in the screening programme. Although compliance decreases when cultural norms contradict health advice, this can be countered if health care providers are aware, and show understanding, of possible health care and cultural conflicts.⁷²

Patient satisfaction

The research described suggests that individual preferences exist among women in respect of both the treatment they receive and the amount of information they require, and that concordance with these preferences leads to increased satisfaction. Since it is well established that satisfaction is a predictor of compliance,^{73,74} it is important to examine ways of increasing women's satisfaction with the cervical cancer screening service provided. Where women express a preference for a female screener, an assurance

that this will be possible can be effective in increasing the number of women who participate in screening programmes.^{31,75} Furthermore, as patients are considered to be service users, they should, in consultation with their clinician, be able to choose their preferred treatment — adapting the service to meet users' needs may act to increase attendance.⁷⁶ Studies of medical treatment have generally shown patient satisfaction to be influenced by factors such as the time interval between referral and appointment, the time spent waiting in the clinic,⁷⁷ and the patient's confidence in the clinician's ability.⁷⁸ Few studies have examined women's satisfaction with the service they receive from cervical screening programmes, although examination of women's views and behaviour suggest that the availability of a female screener^{26,29} and more information^{29,45,58} may increase compliance.

Consideration of health beliefs

The health belief model^{79,80} predicts that screening behaviour depends on motivation, beliefs about susceptibility to illness and the severity of the illness, and beliefs that the benefits of screening outweigh the costs of participation. Women's perceived susceptibility to cervical cancer, and perceived obstacles to participation, have been found to predict cervical screening behaviour.³⁷ Furthermore, patients with a high health-locus-of-control; i.e. those who believe their health is controlled by themselves rather than by others or by chance,⁸¹ are more likely to participate in the screening programme.³⁴ These models of health behaviour suggest that informing women of their susceptibility to cervical cancer, and encouraging a belief that active participation can minimize the likelihood of developing invasive cervical cancer, will be effective in increasing attendance. Women should therefore be encouraged to take responsibility for their own health and be an active participant in the cervical smear programme rather than a passive attender on the bequest of their GP. This shift from a model of patient compliance⁸² (passive attendance) to one of patient adherence⁷³ (active participation) involves a change in the way in which health care is provided, with the clinician and patient establishing a health care plan to which the patient can readily adhere.

Reduction of anxiety in women with abnormal cervical smear results

It has been suggested that those women who do not attend colposcopy appointments may be those who are most anxious about their abnormal result.^{42,83} To increase attendance, methods of reducing anxiety in women receiving abnormal smear results must be considered. Not all women receiving abnormal smear results experience severe levels of anxiety.⁵¹ Women's initial reactions and subsequent concerns are related to the adequacy of the explanation of the meaning of their result — women who consider the explanation to be inadequate are more likely to be shocked upon receipt of the result and to have enduring concerns and higher levels of anxiety than women who perceive the explanation to be adequate.^{18,50}

Conclusion

This paper has discussed the reasons why some women do not participate in the cervical cancer screening programme, and has highlighted how low levels of information, coupled with poor communication, contribute to high levels of distress in women with abnormal cervical smear results and may lead to non-attendance for colposcopy. The research summarized here suggests that maximizing patient compliance will require changes to the way in which both patients and clinicians approach health care. Changes that might be made by GPs and may be beneficial in

increasing attendance and in reducing women's anxiety are summarized in Box 1. Changes in screening practice, such as the provision of evening clinics, the availability of a female practitioner, and an increase in educational information, may remove many of the obstacles that prevent women participating in the screening programme. Women's lack of knowledge of the purpose and indications of the cervical smear suggest that information must be provided at the primary health care level, particularly since those women who have the most negative preconceptions may be those who do not attend for colposcopy. Care should be exercised when advising patients of the risk factors associated with cervical cancer: if women are not made aware of the high prevalence of HPV, information on the link between cervical cancer and HPV may result in women being unable to disclose the receipt of an abnormal cervical smear. The subsequent lack of social support and resulting increase in distress may impede attendance for colposcopy. A clear understanding of the meaning of an abnormal cervical smear result *before* such a result is received would certainly decrease the high levels of anxiety commonly experienced. This may improve attendance and increase women's satisfaction in this vital screening service.

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