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Hong Kong Chinese women's responses to an abnormal cervical smear result

Key Messages

1. Hong Kong Chinese women's responses to and experiences of an abnormal smear are similar to those of women from other cultures.
2. Women referred for colposcopy or cytological surveillance experienced feelings of uncertainty and anxiety in part influenced by concerns about a diagnosis of cervical cancer.
3. The significance of information giving as a strategy for reducing anxiety is clearly demonstrated. Information giving, however, should be targeted at the specific needs of individual women.
4. Women need to be notified of the result of their abnormal smear in a way that does not contribute to their anxiety. Written notification, whether the smear is normal or abnormal appears to be the most appropriate method.
5. Women place significant trust in the practitioner to explain their abnormal result. Thus, practitioners must be skilled at information giving.

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Introduction

Well-organised population-based screening programmes effectively reduce cervical cancer rates.¹ A result of these programmes, however, is an increase in the number of women receiving an abnormal smear result requiring cytological surveillance or colposcopy. Research has demonstrated high levels of psychological morbidity associated with an abnormal smear result including anxiety, depression, and adverse effects on sexual relationships.² Women frequently misunderstand the result, believing they already have cancer.³ No such studies, however, have been undertaken with Hong Kong Chinese women and little is known about their response to an abnormal smear.

Aims and objectives

This study aimed to investigate the responses of Hong Kong Chinese women to an abnormal smear result. Three major objectives were: to investigate women's responses to an abnormal cervical screen result; to investigate the factors that may contribute to any distress and anxiety experienced by women with an abnormal smear result; and to investigate similarities and differences in their experiences of and responses to an abnormal smear result.

Methods

This study was conducted from September 2001 to December 2002. A qualitative research design consisting of face-to-face semi-structured interviews was selected. The setting was one centre of the Family Planning Association of Hong Kong (FPAHK). This setting was selected because previous research has demonstrated that the FPAHK is one of the major cervical screening service providers accessed by Hong Kong Chinese women.

Sampling

Three groups of women were selected: (1) women with an abnormal smear who require cytological surveillance; (2) women with vaginitis who required treatment but no cytological surveillance; and (3) women referred for colposcopy. Opportunistic sampling was used to recruit the 66 women who participated in the study: 22 women in group 1, 20 women in group 2, and 24 women in group 3. Recruitment of the colposcopy group continued longer to ensure saturation of data.

Data collection

A semi-structured interview guide was developed from a review of the literature and was designed to elicit women's experiences of and responses to receiving an abnormal smear result. The interview schedule allowed women to identify experiences and responses that were unique to them. The tape-recorded interviews ranged in length from 15 to 35 minutes. Interviews with women in the colposcopy group were generally longer and those with women in the vaginitis group were the shortest, lasting approximately 14 to 20 minutes. Thematic analysis of the translated interviews was done within each group to identify categories and themes illustrating women's experiences of and responses to an abnormal smear.

Results

Description of the participants

A total of 66 of 68 women agreed to participate in the study. Their ages ranged from 26 to 55 years with a mean age of 38 years in groups 1 and 2, and 36 years in group 3. Household monthly incomes ranged from below \$12 000 to over \$50 000 with 55% of women having an income of below \$18 000. A total of 89% of participants were married and 71% had one or more children. The majority (61%) had completed secondary education and 55% were employed outside the home. There were no statistically significant differences in the demographic characteristics of the three groups.

Group 1

Among the 22 women who had received an abnormal smear result requiring cytological surveillance, six had attended for their first cervical smear. Thematic analysis identified seven major categories illustrating the experiences and responses of this group of women to an abnormal smear result. These were anxiety, provision of information, use of knowledge, seeking other opinions, acceptance of results, association with sexuality, and sharing information. The association between anxiety and receiving the abnormal result was one of the most important results to emerge from the data analysis. Despite being told on the telephone that the abnormal result did not mean cancer, some women still described their fear that the abnormality was cancer. One woman described her feelings saying:

"... I am not such a nervous person but last time when I was told that there were cell changes I was so frightened. I guess cell changes are something really scary. But in fact after I calm down myself even if I were told today that I had it (ie cancer) I would still accept it if this was the fact..." (Int. 11:34)

These categories led to the development of three overarching themes emerging from this group: uncertainty, trust in practitioners, and the need for individualised information.

Group 2

Among those 20 women who received vaginitis as an abnormal result, four women had attended the FPAHK for cervical screening for the first time. All but three had vaginitis caused by *Candida albicans*. Five major categories were generated from the thematic analysis: repeated infections, perception of the problem, receiving results, sharing information, and presence of symptoms. The most important category to emerge from the data was the experience of repeated infections. One woman described her experience saying:

"I don't have any fear or anxiety since I know there is no other problem found out but an infection. It would only be a mild issue so I really don't have any special feeling." (Int.22.12)

Indeed, women usually said this was not the first time

that they had experienced a vaginal infection. When they received the results they were told they had an infection that needed treatment and described the result as "nothing special" or "a minor problem" as they knew the cause of the problem. The overarching theme emerging from this group was that their understanding of the cause of the abnormal smear minimised any feelings of anxiety or uncertainty associated with their result.

Group 3

Among the 24 women referred for a colposcopy, approximately one third were younger than 31 years and six attended the FPAHK for their first screening. Eight major categories were identified from the thematic analysis: fear, receiving the results, providing information, sharing information, seeking alternative opinions, association with sexuality, inevitability, and waiting time. The most important category emerging from this group was that of fear on receiving the result. Despite reassurance that the result did not mean cancer, women saw a direct association with the disease, and were frightened by the experience of having an abnormal smear and said lack of information contributed to their fears. One woman said:

"You know, she only asked me to come here during their office hour picking up the referral and I thought... (Client starts crying)... I thought I might have cervical cancer...ha...ha... You know, my understanding to having a Pap smear is to test for cervical cancer and a repeated test is only needed when there is a problem." (Int. 48.14)

How women received their results was another important category associated with the experience of an abnormal result. Although nearly all women said they were told on the telephone that the result did not mean cancer, they described feeling shocked, uncertain, and not knowing what to do. One woman described her feelings saying:

"Of course, I was not happy since the telephone call was too sudden to me. Since I know receiving a phone call from the FPAHK well before the scheduled day might indicate that I have had a serious disease. So I was worried about the result." (Int. 15.18)

The overarching themes emerging from the data in this group of women were of being scared and needing reassurance, uncertainty, and the importance of trust in the practitioner.

Discussion

Women's response to an abnormal smear

The data demonstrated that participant's responses to an abnormal cervical screen result were determined in part by the cause of the abnormal result. Those women whose abnormal results were a consequence of infection generally considered it a minor issue. Importantly, these women understood the reason for the abnormal result. The influence of comprehension on women's responses has

been demonstrated in other studies.⁴

Responses of women referred for colposcopy were similar to those receiving cytological surveillance. Women did not want to seek a second opinion in order to avoid confusion and described their feelings of lack of control over the result. Women used the word fear to describe their response to the result, frequently associating that fear with the fear of cancer. The findings suggest, however, that referral for colposcopy creates greater anxiety than cytological surveillance among these women, concurring with findings from the studies with non-Chinese populations.⁴ Women also described feelings of confusion, since they did not consider themselves at risk of cervical cancer, supporting findings from other studies.⁵

Factors contributing to distress and anxiety

Four major factors contributed to the levels of distress and anxiety experienced by women on receiving their result. Once again the underlying cause of the abnormal result contributed to the recipient's feelings. The first factor was being given an abnormal cervical screening result. Women within group 3 described themselves as 'shocked' and not knowing what to do. Those in group 1 described similar feelings, once again 'thinking the worst', concurring with findings from earlier studies in Caucasian women.⁶ Lack of information was the second factor. Women wanted answers to their questions but wanted that information to be specific to their needs. The third factor was the association with sexuality. Women in groups 1 and 3 described feelings of confusion, as they did not have multiple sexual partners. Waiting time was the final factor contributing to the anxiety and distress of women in the colposcopy group, concurring with studies in Caucasian women.²

Similarities and differences in responses

Women in all three groups expressed the need to ask questions about their results. Opportunities for asking questions were particularly important to women in groups 1 and 3. A belief in the association between an abnormal result and sexuality was also evident in all three groups. Women in group 2 appeared more accepting of this association whereas those in other groups frequently described confusion about their abnormal result. The final similarity was that of trust in the practitioner. An important outcome of this relationship of trust was satisfaction with the provision of services, preventing most women from 'doctor shopping' for alternative consultations and diagnoses.

Some important differences were also identified in the responses from women with vaginitis and the other two groups. In part, these differences may have been determined by the fact that many of the women with vaginitis had been prompted to attend for screening by an abnormal symptom such as a vaginal discharge. Such symptoms may have contributed to their response to the abnormal smear as well as contributing to their comprehension of the outcome. Indeed, the data found that women in group 2 accepted and understood their results whereas those in groups 1 and 3 had feelings of uncertainty, fear of cancer and anxiety. This suggests that a lack of readily available information explaining their result was a major reason for the difference in these women's responses to their result.

The second difference was that of sharing information. Most women in groups 1 and 3 shared their results with family members and close friends and valued the emotional support obtained by sharing this information. Women in group 2 usually only shared the information with their partner, particularly if the partner also needed treatment. This indicates women's recognition of the continuing stigma associated with sexually transmitted diseases.

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