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Knowledge and awareness of cervical cancer and screening among Malaysian women who have never had a Pap smear: a qualitative study

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ABSTRACT

Introduction: Cervical cancer is one of the commonest cancers in women worldwide. Despite the existence of effective screening using Pap smear, the uptake of screening is poor. A qualitative study was undertaken using face-to-face in-depth interviews to investigate knowledge, attitudes and beliefs on cervical cancer screening of Malaysian women.

Methods: In-depth interviews were conducted with 20 Malaysian women aged 21–56 years and who have never had a Pap smear test, with the aim to explore their knowledge and awareness of cervical cancer and its screening.

Results: A lack of knowledge on cervical cancer and the Pap smear test was found among the respondents. Many women did not have a clear understanding of the meaning of an abnormal cervical smear and the need for the early detection of cervical cancer. Many believe the purpose of the Pap smear test is to detect existing cervical cancer, leading to the belief that Pap smear screening is not required because the respondents had no symptoms. Despite considerable awareness of a link between cervical cancer and sexual activity, as well as the role of a sexually-transmitted infection, none of the respondents had heard of the human papillomavirus.

Conclusion: The findings highlight the importance of emphasising accurate information about cervical cancer and the purpose of Pap smear screening when designing interventions aimed at improving cervical cancer screening for Malaysian women.

Keywords: cervical cancer screening, health screening, Pap smear, qualitative study

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INTRODUCTION

Globally, cervical cancer is one of the most common cancers in women, with an estimate of 440,000 new cases annually, and 80% of these cases occurring in developing and undeveloped countries.[1] In Malaysia, cervical cancer is the second most common cancer in women.[2] According to the 2002 report of Malaysia's National Cancer Registry, there was an average of 2,000–3,000 hospital admissions of cervical cancer per year in Malaysia, with the majority of cases presenting at late stages of the disease. In the latest 2005 Social Statistic Bulletin of Malaysia, the death rate due to cervical cancer from 1996 to 2000 ranged from 0.29% to 0.41%.[3]

Studies have shown that human papillomavirus (HPV) infection is responsible for more than 90% of the cases of invasive cervical cancer worldwide, and it is related to 80% of pre-cancerous changes in the cervix.[4] Cervical cancer can be prevented by identifying pre-cancerous lesions early using repeated Pap smear screening and treating these lesions before they progress to cancer. Prevention, early diagnosis and treatment have been shown to reduce mortality due to cervical cancer. Many countries have significantly reduced their cervical cancer morbidity and mortality through cervical cancer screening and early treatment. In the United States, the introduction of the Pap smear has been responsible for a 90% decrease in deaths from cervical cancer.[5] Likewise in Australia, deaths from cervical cancer have steadily decreased, at about 2.8% a year, since the introduction of the National Cervical Cancer Screening Program in 1991.[6] In Australia, 85% of the women who die of cervical cancer have not had regular Pap smears and about 50% of them have never had a Pap smear at all. Similarly in the United States, half of women diagnosed with invasive cervical cancer have never had a Pap smear and 10% have not had Pap smears in the last five years.[7]

In Malaysia, the cervical cancer screening programme was established in 1969 to ensure early detection of cervical cancer among the target group of women aged 20–65 years through its network of state-level health centres, the National Population and Family Development Board clinics,

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Federation of Family Planning Association clinics, private clinics/hospitals and university/teaching hospitals. The Pap smear screening programme was planned, organised and evaluated by the Ministry of Health, Malaysia.[8] Nevertheless, no reduction in the prevalence of cervical cancer has been noted to date. The coverage and uptake of cervical cancer screening remains a major challenge. Pap smear coverage in the country is poor, i.e. 26% in 1996, as reported in the National Health and Morbidity Survey II (NHMS II).[9] It has also been reported that nearly 80% of patients with cervical cancer presented at advanced stages of the disease in 1989,[10] and 10.5% of deaths among women in government hospitals in 2002 were due to cancer of the cervix.[11] The recent 2003 Second Report of the National Cancer Registry of Cancer Incidence in Malaysia showed that cervical cancer constituted 12.9% of total female cancers.[12] There was a total of 1,557 cases of cervical cancer, with an age-specific incidence of 19.7 per 100,000 population.[12] These statistics are disheartening, given the wide availability of Pap smear screening programmes.

Little is known about the factors that hinder Malaysian women from taking up screening. Therefore, understanding the factors associated with the underutilisation of cervical cancer screening is important in order to increase overall cancer screening rates. Several barriers to cancer screening have been reported; these include a lack of awareness of the importance of screening, inadequate access to healthcare, aversion to the discomforts of screening, fear of finding cancer and logistic barriers such as having to take time off work for screening.[13-15] Studies have also revealed that knowledge, attitudes and beliefs about the Pap smear test appeared to be related to actual participation in cervical cancer screening.[16-18] In fact, women's knowledge[19] and beliefs[20] of the Pap smear test were shown to be the strongest predictors of repeated screening. Therefore, a qualitative study was undertaken using face-to-face in-depth interviews to investigate the knowledge, attitudes and beliefs on cervical cancer screening of Malaysian women. This article reports on the findings of the knowledge and awareness of cervical cancer and Pap smear of Malaysian women who have never had a Pap smear.

METHODS

In-depth interviews were conducted with 20 women who have never had a Pap smear test. These interviews were conducted in English, Bahasa Malaysia (the Malaysian national language) or the respondents' native language or dialect (Tamil, Cantonese or Mandarin) to cater to the multiethnic study population. A semi-structured interview guide was used to ensure consistency of data. The interview included questions on demographic characteristics, knowledge, attitudes and beliefs toward cancer in general, and about cervical cancer screening and barriers to screening.

The interviews took place between January and August 2005. Purposive and snowball sampling techniques were used to identify participants from the communities in Kuala Lumpur, the capital of Malaysia, to provide a good mix of socioeconomic and ethnic backgrounds. All interviews were recorded, with permission, using a digital audio recorder and were transcribed verbatim. The transcriptions served as the data for analysis. Data was conceptualised by analytic induction and the constant comparison approach. NVivo software (version 2) was used to code and manage all qualitative data. Ethics approval for this study was obtained from the University Malaya Medical Centre (UMMC) Ethics Committee, Kuala Lumpur. Written informed consent was also obtained from all respondents.

RESULTS

Respondents comprised six Malays, nine Chinese, four Indians and one of other ethnicity. The mean age of the respondents was 32.2 years, and the age ranged from 21 to 56 years. The educational level of respondents ranged from primary to tertiary level, but the majority had secondary education. About 45% of the respondents were single, 50% were married and one (5%) was divorced. The majority had technical jobs at a supervisory level.

Women in this study had poor knowledge and awareness of cervical cancer. When they were asked about cervical cancer, they often referred their knowledge to cancer in general. Most had heard of cervical cancer, but were not aware of how it could be prevented. Many respondents perceived cervical cancer as a deadly disease with absolutely no cure. They related the experiences of their friends or family members who had cervical cancer and had died from the disease. Cervical cancer was identified as a horrible disease and one that often incurred tremendous stress, emotions and physical suffering on both the patient and her family members. Only a few respondents, the majority of whom were older and married, were aware that early detection and treatment saves lives. For example, a 35-year-old respondent noted that, *"If [cervical cancer is] detected and take action* [sic]*, [there is a] great possibility she can recover."* Younger respondents had little knowledge of the role of the Pap smear test in the early detection of cervical cancer. When probed, most of them indicated that they have no understanding that early detection of cervical cancer might save one's life. Several had commented that there was nothing they could do if cervical cancer was

diagnosed. They would rather not know if they had the disease. Generally, the younger respondents lacked factual information about cervical cancer when compared to the older respondents. A few young respondents regarded cervical cancer as a sexually-transmitted disease.

Cervical cancer risk factors were recognised by less than half of the respondents. Those who were married had a higher recognition of cervical cancer risk factors than those who have never been married. Respondents had correctly cited several risk factors for cervical cancer that included being sexually active, having multiple sexual partners and having a partner who had multiple sexual partners. Many emphasised the influence of genetic inheritance, but the risks posed by HPV infection were unfamiliar to all the respondents. None of the respondents had heard of HPV or knew about its link with cervical cancer.

Respondents also believed that failure to maintain hygiene or "dirtiness" was a factor for cervical cancer development. These referred to keeping the vaginal area clean, proper hygiene especially during menstruation and washing away the partner's semen after sexual intercourse. A young respondent had associated masturbation with cervical cancer. Some respondents believed that certain types of food, such as deep-fried food, canned food, preserved eggs and salted/dried fish, might trigger the development of cervical cancer. Other risk factors of cervical cancer, such as early onset of sexual intercourse, parity and cigarette smoking, were not identified by the respondents. None of the respondents mentioned that cervical cancer was usually asymptomatic. Only about half of them were able to correctly list other signs and symptoms of cervical cancer, such as irregular or abnormal bleeding and foul smelling and excessive vaginal discharge. However, the respondents' knowledge of the treatment of cervical cancer was fairly good. The three most commonly-identified treatment options for cervical cancer were hysterectomy, chemotherapy and radiotherapy.

Three respondents asserted that they had no knowledge of the Pap smear test, and one of them had never even heard of this term. Some could not explain what a Pap smear test was, despite saying that they knew about it. Of those who knew of the existence of the Pap smear, their understanding of the purpose of the test was poor. Although many associated the Pap smear test with the detection of cervical cancer, some respondents erroneously thought that the test screens for sexually-transmitted infections, the human immunodeficiency virus or a growth in the uterus: *"I have heard of Pap smear, it is for….whether is normal or you got any cancer* [sic]*…got anything….got any problem with your uterus."*

The main misconception was that Pap smear is a diagnostic test used to detect existing cervical cancer and other reproductive health problems. Most women failed to realise that the Pap smear is a cervical screening procedure. None, however, understood the concept of pre-cancerous lesions and cervical abnormalities. Neither did they know that the Pap smear can detect abnormal or precancerous cells and that early detection of such abnormalities could be treated easily and effectively. A few of them indicated that the purpose of the Pap smear test is *"to check everything is ok, whether got cancer or not"*. Most respondents were unsure of how the test was performed. Most common replies were either *"Don't know exactly, I only know something taken out from vagina area and send for testing"* or *"I think they take out liquid from down part* [sic]*"*; these replies reflect a lack of factual and accurate information about the Pap smear procedure.

When they were asked about the frequency of screening, none of the respondents could answer with confidence. Most respondents guessed that screening should be conducted every one to two years. One respondent thought that the test must be repeated every six months: *"I don't know, I would guess a woman should have Pap test every six months."* Some even thought that the test should only be done when there were symptoms. Respondents were unsure who should be screened. A few of them correctly identified that women above 18 years of age or those who are sexually active (whichever is earlier) should go for regular Pap smear tests. Many believed that the Pap smear is only for married women. Two women aged 50 years and above noted that since they were never married or sexually active, they did not need to go for Pap smear tests.

Lack of recommendation by healthcare providers prevented women from taking the Pap smear test. One respondent who was married and had three children said, *"Nobody ever advised me; I have no understanding about it. The doctor did not advise me."* Another married respondent who had just delivered a child claimed that a Pap smear test was not suggested to her by her gynaecologist because she was not on contraceptives: *"I go for regular check-up after delivery, but doctor never does Pap smear on* [sic] *me. Doctor said I am not taking contraceptive pill, so no need [to] do Pap smear."*

DISCUSSION

In this study, the knowledge of Pap smear screening and cervical cancer, attitudes and beliefs pertaining to cervical cancer screening, and reasons for not doing cervical screening were identified. It concurred with other studies that women's knowledge, attitudes and beliefs influenced

their screening behaviour.[21-26] The study found that women were poorly aware of the indications and benefits of cervical cancer screening. Many believed that Pap smear is performed only on women who are symptomatic. Women were not aware that the Pap test is for the early detection of cervical cancer. They did not see the need for a Pap smear test because they perceived themselves as not at risk of developing cervical cancer. Many thought that the purpose of a Pap smear test is to detect existing cervical cancer. Such misconceptions require extensive public education, with a new emphasis on the crucial fact that Pap smear screening is targeted primarily at detecting precursor lesions that occur early in the course of the disease, and subsequent timely treatment would thus impede progress towards invasive cancer.

The perception of one's susceptibility to cervical cancer can affect screening behaviour. Many women expressed a lack of personal susceptibility to cervical cancer and therefore believed it was unnecessary for them to have a Pap smear test done. This concurs with a study which found that women's perceived susceptibility to cervical cancer predicts their cervical screening behaviour.[27] Thus, efforts to promote cervical cancer screening uptake among women should focus on informing women of their susceptibility to cervical cancer, challenging beliefs of vulnerability to the disease and encouraging a belief that active and regular screening can detect cervical cancer at the pre-cancerous stage, hence enabling the early treatment and prevention of cancer development. Women should be encouraged to take responsibility for their own health and be active participants in the screening programme rather than relying on the provider's recommendation for Pap smear screening.

Women's knowledge of who should receive cervical cancer screening was poor. Unmarried and non-sexually active women of an appropriate age group for screening did not perceive themselves to be at risk and hence did not see the need to undergo testing. Married women were convinced that they were not at risk because neither they nor their spouses were involved in promiscuous sexual behaviours, and hence did not need to have a Pap smear test. Therefore, health promotion campaigns should target both sexually active and non-sexually active women to increase their knowledge and awareness of personal risks and encourage them to have regular cervical cancer screening.

Respondents were ignorant about HPV infection and its link to cervical cancer. This is consistent with findings in the United States and the United Kingdom. According to the National Cancer Institute's 2005 Health Information National Trends Survey in the United States, 40% of American women aged 18–75 years have heard about HPV, and of these women, only 20% were aware that it can cause cervical cancer.[28] There is a need to educate Malaysian women on the role of HPV in the aetiology of cervical cancer and its prevention. The mass media plays an important role in this context and its function should be optimised. In addition, effective delivery methods, such as the use of local celebrities as role models to champion the uptake of Pap smear screening, can increase public attention as well as effect behavioural change in screening practices among women.

The need for information about Pap smear screening and cervical cancer detection emerges as a strong issue from the results. Many perceived cervical cancer as a terminal illness with no hope for a cure, even when detected in the early stages. The pessimistic attitude towards cancer and death needs to be addressed. The belief that death is inevitable when cancer is present has been identified as a barrier to participation in cancer screening, detection and treatment.[29-31] This finding was similar to a study conducted in Singapore that revealed fatalism as a social barrier to screening behaviour.[31] Women need to be demystified about these misconceptions via health education and promotion.

Healthcare providers influence women's screening behaviours. It was found that the under-utilisation of cervical cancer screening might be due in part to a lack of physicians' recommendation. There appears to be a need to improve health education by healthcare providers, as women reported that they had never been informed of the existence and importance of Pap smears by healthcare professionals. Opportunistic screening was noted to increase screening rates.[32] However, most respondents said they had never been approached for cervical cancer screening during their visits to healthcare professionals. Many respondents also said that they would agree to be screened if this was recommended by their healthcare provider. A woman undergoing gynaecological examination or seeking reproductive healthcare is more likely to receive a recommendation for a Pap smear test by her doctor. At the same time, healthcare providers such as general practitioners and gynaecologists need to do their part in promoting cervical cancer screening. They should disseminate educational materials that focus on educating the women about cervical cancer risks, prevention and early detection to enhance uptake of screening practices.

This study was not without its limitations. As is inherent in qualitative study designs, its purpose was not to generalise the present findings to the larger Malaysian women population. Instead, this qualitative method provided an in-depth meaning of the knowledge, attitudes and beliefs

of Malaysian women towards Pap smear screening. These findings could be augmented by conducting a quantitative random survey on Malaysian women.

In conclusion, this study revealed the limited knowledge about the susceptibility of cervical cancer and the necessity for cervical cancer screening among the women in the study population. The findings highlighted the poor dissemination of knowledge, information and communication by healthcare providers as factors that may have contributed to women's non-attendance at Pap smear screenings. It is not surprising that the women's reluctance to undergo cervical cancer screening appears to be based on a lack of knowledge about the natural history of cervical cancer, the effectiveness of screening and the risk factors of cervical cancer. Education, communication and reassurance are required to overcome such resistance. Therefore, efforts to reduce cervical cancer mortality should focus on reaching out to the women who have never had a Pap smear test within the target age group. In summary, health education, barrier-specific counselling as well as community-based interventions would provide an opportunity to increase cervical screening rates among Malaysian women.

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