

KNOWLEDGE OF THE RISK FACTORS AND SYMPTOMS ASSOCIATED WITH ENDOMETRIAL CANCER IN BRITISH SOUTH ASIAN AND BRITISH WHITE WOMEN

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ABSTRACT

Objective: To explore differences in the background knowledge of Endometrial Cancer (EC), its risk factors, symptoms and prognosis of Endometrial Cancer (EC) between British White (BW) and British South Asian (BSA) women who had undergone treatment for stage I endometrial cancer within the past 3-years.

Study design: Face-to-face, semi-structured interviews exploring knowledge; diagnosis; treatment; follow-up; and survivorship were undertaken and analysed using Thematic Analysis.

Results: Twenty-one women were interviewed (13 BW and 8 BSA). BW and BSA women reported similar views, experiences and concerns with regards to EC. Knowledge appeared to differ amongst the two groups with BSA women reporting being more aware that unscheduled vaginal bleeding could be associated with a malignancy but having lower levels of knowledge of the risk factors that can lead to EC, compared to BW women. There was a lack of understanding of the difference between cervical cancer and EC and as a result, many women reported taking reassurance from negative cervical cytology as excluding EC and there was also the misconception amongst some of the women that there was a link between sexual behaviour and EC. Women from both groups used the lay healthcare system to discuss their situation/symptoms, however BSA women reported to have specifically sought out women within their social network who had previously undergone treatment for EC.

Conclusions: Greater effort is needed to raise awareness in both the BW/BSA communities of the symptoms associated with EC that should prompt medical review. Educational efforts are required to overcome the reported perception that EC is synonymous with cervical cancer and cannot be detected by cervical screening.

INTRODUCTION

Improving the early detection of endometrial cancer (EC) is an important factor in improving overall survival. Media campaigns attempt to increase the awareness of symptoms associated with EC cancer that should prompt patients to seek a medical review, however, studies that have explored women's knowledge of suspicious symptoms have shown a low level of health education in women and a lack of knowledge of the different gynaecological malignancies and their risk factors [1, 2]. In particular, there appears to be a difference in the level of awareness amongst ethnic minority groups and there is concern that this could lead to a delay in the diagnosis of cancer and consequentially a poorer prognosis [3, 4].

Women from ethnic minority groups have been identified as having greater barriers to healthcare, for example language and mistrust of the medical services [5]. The use of 'community navigators' has shown to improve the health amongst different immigrant populations [6] and it is acknowledged that an understanding of the sociocultural factors of different populations can address specific barriers, which are commonly reported with cervical cancer screening [7].

In order to explore this topic and gain valuable information about the research topic a qualitative interview study was conducted with women of British White (BW) and British South Asian (BSA) ethnicity who had undergone treatment for endometrial cancer (EC), since it was felt that they may be called upon to give advice to women in their social network. The objective was to determine the level of background knowledge of EC, its risk factors, symptoms and prognosis in the two groups of women.

METHODS

Ethical approval was granted for the study (15/WM/0239). Women under follow up at the University Hospitals of Leicester for a FIGO stage I EC diagnosed between September 2011 and March 2016 were included in the study (n=174). Women were grouped according to their ethnicity British White (BW) (Group a) and British South Asian (BSA) (Group b) and randomly selected by hospital unit number for invitation. Twenty-one of the 52 patients contacted responded and consented to participate. A semi-structured interview guide was used to explore the domains of treatment journey, experiences, knowledge of risk factors and symptoms of EC, and views of the future. The interviews were audio recorded with participants' knowledge/consent and transcribed verbatim. Interviews were conducted until data saturation and lasted 20-58 minutes (median 35 minutes).

A hybrid inductive-deductive thematic analysis was used to analyse the interviews [8]. Codes were assigned by two coders (PK/HM) and were repeatedly modified in an iterative process in order to identify salient themes. A range of themes emerged from analysis of the interview transcripts and from these, thematic maps were created for each of the five topic areas: knowledge; diagnosis; treatment; follow-up; and survivorship.

RESULTS

A total of 21 semi-structured face-to-face interviews were conducted, median age 59 years (range 50-78 years). The 8 BSA women were all first generation migrants, however their duration living in the UK varied between less than 5 and over 40 years. All 13 BW women had been born in the UK. Five BSA and four BW women had either a family member or interpreter present during the interview (Table 1).

Awareness of endometrial cancer

The findings identified that although most participants from both groups had heard of EC prior to their diagnosis, their individual knowledge of the disease was poor (Table 2). Most of the women from both groups reported that their knowledge of EC prior to their diagnosis was predominantly gained from seeing a family member or friend having been given the same diagnosis; *“Yes, because my sister in law has had a similar operation in the summer. Although her symptoms were different and she was telling me about it but I’d obviously seen her before and afterwards.”* (BW, 56 years). Of the women who reported a close family member having EC, all but one reported that they felt reassured by having seen them during their treatment journey and their good quality of life post-treatment. In the other case the woman’s relative had had a poor prognosis and therefore this created feelings of dread and anxiety for that particular participant.

The women felt that EC or womb cancer was less well known amongst the general public and less reported by the media than other gynaecological cancers, such as cervical and ovarian cancer. Both BW and BSA women reported not understanding the distinction between the womb and the cervix and as a result were not aware that EC was a separate disease entity: *“I don’t think I’d ever heard of endometrial, just heard of ovaries and all that sort of thing”* (BW, 69 years). This reinforces the lack of knowledge about this disease.

Awareness of suspicious symptoms

Although participants from both groups reported that they were aware that their symptoms of bleeding were abnormal, the knowledge that bleeding could be associated with a malignancy was greater amongst BSA women, compared to BW women. The specific association with

endometrial cancer was less well known but again the BSA women appeared to have greater knowledge of this association than the BW women.

For all the women, what they perceived as abnormal bleeding prompted them to contact their General Practitioner. Several women from both groups reported delaying seeing their doctor as they attributed their bleeding to a post menopausal 'residual period' and it was only after symptoms persisted that they sought a medical review.

Barriers to medical review

The reported barriers to seeking a medical review among women in both groups were normalisation of symptoms, choosing to ignore symptoms and difficulty accessing primary care. Having a personal knowledge of EC, especially through a relative, appeared to make women more aware of the associated symptoms. Both groups reported asking advice from female friends/relatives before consulting their doctor, however, BSA women mentioned specifically seeking out peers with a previous EC diagnosis. BW women however did express that they suspected a cancer diagnosis due to the investigations conducted and researching the consultant they had been referred to on the internet prior to their hospital appointment.

Knowledge of risk factors

Knowledge of risk factors associated with EC was less among BSA women compared to BW women. Those that were not aware of risk factors suggested 'smoking', 'drinking' and 'unhealthy lifestyle' as possibly being associated with EC. A common misconception reported by participants was that EC was associated with promiscuous sexual behaviour and was mentioned particularly by three BSA women as compared to two BW women; *"I wasn't [aware of EC risk factors]. I just think it's pot luck [...] I've done everything healthily, lived*

a healthy lifestyle, I've only ever had one partner in my life [...] I think you're unlucky if you're gonna get it no matter what" (BSA, 53 years). "My sister had it. She's not married but still got it." (BSA, 55 years).

A negative smear test was taken as a reassuring sign of not having a cancer and women who had participated in cervical screening and received negative results reported feeling shocked when they were given their EC diagnosis. Women felt that they had been responsible in looking after their health by attending for screening and as a result reported feelings of being misled by the information they had been given about cervical screening because it did not confer the protection against cancer they thought. *"Now I had just had a smear test done but it only shows cervical cancer. If you've had a clear from a smear, it doesn't mean to say you haven't got endometrial cancer" (BW, 63 years).*

Almost all of the women that demonstrated an awareness of risk factors associated with EC stated 'obesity' as a risk. The next common answer was 'age', followed by nulliparity. There was however, poor knowledge of the link between diabetes and EC even amongst the women who were diabetic. *"Well for my point I think my weight was a factor because yes that is a factor, being overweight [...] I mean there's other factors isn't there? There's genetic factors but I think for me that was a factor" (BW, 62 years).*

DISCUSSION

Our study has shown that the BW and BSA women have similar knowledge levels and share many of the same views, experiences and concerns with regards to EC. Many women were aware of EC prior to their diagnosis however, despite knowing that symptoms such as unexpected bleeding were abnormal, do not link this to a sinister pathology. There also

appears to be a lack of understanding amongst women from both BW and BSW ethnic backgrounds as to the difference between cervical and endometrial cancer with women taking false reassurance from negative cervical cytology having excluded EC and incorrectly assuming that sexual behaviour is an aetiological factor.

We have shown that there is a lack of symptom awareness, especially of the association between symptoms of abnormal bleeding and a diagnosis of malignancy. In our cohort, knowledge appeared to differ amongst the two groups with BSA women reporting being more aware that unscheduled vaginal bleeding could be associated with a malignancy but having lower levels of knowledge of the risk factors that can lead to EC, as compared to BW women. Despite sustained media campaigns, studies have shown that there is a difference between different ethnic groups and their perception of cancer and its symptoms. This can lead to delay in diagnosis and as a consequence poorer prognosis, especially in ethnic minority groups. Studies have found that women tend to 'normalise' their symptoms, and often would consult their friends and family, the 'lay healthcare system' [1, 2] or self-medicate. In our study although women from both groups reported using the lay healthcare system, BSA participants reported seeking out women within their social network who had previously undergone treatment for EC in order to discuss their symptoms. Reasons for this could include a wish to validate the importance or severity of their symptoms and the need for medical review. This does highlight the need to increase awareness of symptoms that could be due to malignancy in women who are diagnosed with EC since they may be seen as sources of advice for other women in their social network. Every year large numbers of women experience postmenopausal bleeding and are referred for investigations to exclude EC. Educating these women on the key risk factors and symptoms, for example obesity and postmenopausal bleeding, may help increase the awareness of EC amongst the lay

community and enable women to make lifestyle modifications and potentially reduce their future risk. It is therefore imperative that health professionals treating EC give clear, understandable information in order to raise the baseline knowledge levels in all populations. For women whose first language is not English, thought needs to be given as to how best to deliver this information since providing written resources such as leaflets in many languages has resource implications and women may not be literate in their first language [9]. Consideration should be given to visual/oral information to facilitate understanding.

The barriers already known to help-seeking behaviour have been reported as previous unpleasant experiences with the healthcare system, wasting the GP's time, lack of concern about their symptoms, the GP's gender and difficulty in finding time for and booking appointments [1, 4]. In our study difficulty accessing primary care and, having seen a doctor, securing referral to secondary care was reported by a number of women from both groups, which subsequently had a negative impact on their future doctor-patient relationship. It has been shown that patients typically report visiting their doctor if they feel that their symptoms are persistent and debilitating or if they are aware of the seriousness of their symptoms. However, when the possibility was raised of the cause of symptoms being cancer the participants dismissed it as being unlikely [1]. This has also been shown to be the case in South Asian ethnic minority groups where the majority reported they would see their GP in less than two weeks for unexplained bleeding or pain [4]. Our study found that the majority of women realised that postmenopausal bleeding was abnormal but did not associate it with a possible malignancy. A greater number of the BW women were alerted to the possibility of a cancer due to the referral pathway process and investigations they were undergoing compared BSA women, which may indicate a greater awareness of the suspected cancer referral process and familiarity with the NHS healthcare system. The lack of awareness of EC specifically

and that bleeding post menopause could be a sign of EC is concerning, especially because of the dramatic rise in EC incidence over the past 30 years and therefore the greater prevalence in the community.

Our results identified that there was a lack of knowledge as to the differences between the different gynaecological malignancies and their associated risk factors [10]. In particular, EC was thought to be the synonymous with cervical cancer by women from both ethnic groups. Cervical cancer was viewed negatively due to its association with promiscuous sexual behaviour, a finding that has been reported previously [11]. Barriers to cervical cancer screening amongst ethnic minority women have been identified as a lack of awareness of cervical cancer and 'smear tests' with emotional barriers such as fear, embarrassment and shame due to the association with sexual behaviour [12, 13]. The opinion that sexual activity and having more than one sexual partner was linked to a diagnosis of EC was more common amongst the BSA women in our study, and therefore by inference EC was associated with the negative social stigma of cervical cancer.

Several women held the view that since they had been proactive in looking after their gynaecological health by attending for cervical smear test they felt misled by the reported benefits of screening because it had not detected their EC. The coverage of cervical screening is the low in Leicester and is falling, down to 66.4% in 2015-16 compared to 67.7% in 2014-15 [14]. Many potential reasons have been identified but practical barriers are the most commonly cited cause with the majority of women not endorsing the statement '*I do not trust the smear test*' [15]. It is possible that this feeling of trust may result from misplaced confidence in the ability of cervical screening to detect a greater range of disease than it is designed for, since the women in our study thought that a negative cervical smear result

indicated an 'all clear' from all gynaecological disease. This also suggests that women may not be aware of or have little understanding of gynaecological anatomy and the difference between cervical and endometrial cancer. The perception that all gynaecological malignancies are as a result of sexual behaviour needs to be countered since the negative emotions and perceptions associated with cervical cancer appear to be extended to the EC population, which may have an impact on women seeking timely medical review.

Study limitations.

This study compared the views of a group of women of BSA ethnicity, only one of the many ethnic groups in the UK. Recruiting ethnic minority patients to cancer trials is acknowledged to be challenging [9] with language difficulties reported as being the main issue, often resulted in such patients being excluded from research because of the language barrier [16]. As a result these populations and their views are under represented in trials leading to a calls for research that gives minority groups a voice [17], therefore the use of interpreters is necessary in order to access this population. Qualitative studies, such as this, may not be representative of the population as a whole but are able to engage with patients who would not participate in quantitative studies therefore enabling their voices and opinions to be heard.

In conclusion, greater effort is needed to raise awareness in both the BW and BSA communities of the symptoms associated with EC that should prompt medical review and to overcome the perception that a diagnosis of EC synonymous with cervical cancer and cannot be detected by cervical screening.

AUTHOR CONTRIBUTIONS

EM, LB and NP designed the study. EM and PK conducted the interviews. PK and HM performed the analysis. PK and EM wrote the manuscript and all authors contributed to the final draft.

CONFLICT OF INTEREST

None of the authors report a conflict of interest.

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