



## Full length article

## 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. 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.

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## 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

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**Table 1**  
Demographic characteristics of women interviewed (n = 21).

	Number (percentage)
<b>Age (years)</b>	
50–59 years	11 (52.4%)
60–69 years	5 (23.8%)
>70 years	5 (23.8%)
<b>Ethnicity</b>	
British White	13 (61.9%)
British South Asian	8 (38.1%)
<b>Residence</b>	
Urban	16 (76.2%)
Rural	5 (23.8%)
<b>English as first language</b>	
Yes	15 (71.4%)
No	6 (28.6%)

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 min (median 35 min).

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 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

**Table 2**  
Common and differentially expressed themes between British White and South Asian women.

Themes	Common themes	British White	British South Asian
Awareness of endometrial cancer	- Previous diagnosis in family/friend		
Awareness of suspicious symptoms	- False reassurance from cervical screening	- Diagnosis suspected from referral pathway	- Association with cancer
Barriers to medical review	- Normalising of symptoms - Difficulty accessing primary care		- Use of 'expert patients' in the lay healthcare system
Knowledge of risk factors	- Obesity - Age		- Sexual behaviour

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