

## Assessment of Women's Knowledge of Endometrial Cancer

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### Abstract

**Background:** The objective of our study was to assess women's awareness and knowledge of risk factors and symptoms associated with endometrial cancer.

**Methods:** A convenience sample of women waiting at clinics (general internal medicine, gynecology, and diabetes) was asked to complete a questionnaire focused on risk factors, symptoms, and concerns about endometrial cancer.

**Results:** A total of 161 women participated in this survey study (June 2010-January 2011). The majority of women (67.3%) did not know or did not perceive themselves to be at risk for endometrial cancer, and nearly two-thirds (62.7%) did not worry about developing endometrial cancer. Participants (n=45) with a self-reported history of diabetes mellitus (DM) were more likely to report not knowing symptoms of endometrial cancer (46.7% vs. 25.9%; p<0.05) and that they did not know any health behavior to reduce their risk of endometrial cancer compared to participants without a history of DM (20.0% vs. 6.0%; p<0.01). Women reported that their most trusted source of health information was from their physicians.

**Conclusions:** Women lack knowledge about risk factors and symptoms of endometrial cancer. Developing educational materials and programs focused on endometrial cancer risk factors and symptoms in addition to providing strategies to improve patient-provider communication about risk factors and symptoms is important, particularly for high-risk women.

**Keywords:** Endometrial cancer; Patient awareness; Risk factors

### Introduction

Endometrial cancer is the fourth most common cause of cancer among women in the United States (U.S.) [1]. It is estimated that in 2012, more than 47,000 women living in the U.S. will be diagnosed with endometrial cancer and more than 8,000 women will die from this disease of which a majority of cases will be endometrial cancer [2]. Although African American women compared to White women have lower endometrial cancer incidence rates (21.8 vs. 24.8 per 100,000 females), they have significantly higher mortality rates (7.3 vs. 3.9 per 100,000 females) and worse 5-year survival rates (58.9% vs. 84.7%) [3].

Although there are no screening tests to detect endometrial cancer, the majority of women (68%) present with abnormal bleeding, potentially allowing for early detection of the disease [2]. This is critical because the 5-year survival rate for endometrial cancer decreases with diagnosis at late stage (96%, 67%, or 16% for local, regional, or distant stage, respectively) [2]. Furthermore, the identification of risk factors for endometrial cancer are well-established and include: obesity, increased estrogen exposure because of late onset of menopause, diabetes, tamoxifen use, and family history/genetic predisposition [4,5]. Therefore, recognizing women at increased risk for endometrial cancer (e.g. women with diabetes) and

counseling women on symptoms and risk reduction may result in diagnosis at an earlier stage, improving survival rates.

Efforts to assess women's awareness and knowledge about gynecologic cancer have been documented; however, most studies have focused on cervical cancer. There is limited information about awareness and knowledge about endometrial cancer, including risk factors and symptoms [6]. Therefore, the objective of this study was to assess women's awareness and knowledge about gynecologic cancers, with an emphasis on endometrial cancer.

### Material and Methods

#### Setting and study participants

Female patients scheduled for a medical appointment in the general gynecology, internal medicine, or the diabetes clinic within one university medical system were asked to participate in the survey study. To be eligible, women had to be at least 18 years of age, speak and understand English or Spanish, and be able to provide verbal consent. The study was conducted from June 2010 to January 2011. Study protocol and informed consent procedures were approved by the Institutional Review Board of The Ohio State University.

## Measures

The survey used in this study was modified slightly for content and format from a survey used in a previous study by the Foundation for Women's Cancer (FWC), formerly known as the Gynecologic Cancer Foundation [7]. Modifications to the survey included: 1) the content focus was modified from ovarian to endometrial cancer; and 2) the format was revised to be self-administered vs. conducted over the telephone. Women who agreed to participate in the study completed a self-administered questionnaire that assessed: demographic characteristics; self-rated health, awareness and knowledge (risk factors and symptoms) about gynecologic cancers, particularly endometrial cancers; perceived risk for gynecological cancer, preventive health behaviors, and trusted sources for health information.

## Demographic characteristics

Socio-demographic information collected included age, race, education, marital status, employment, health insurance status, and household income.

## General health questions

Participants were asked to provide general health information, which included the following: self-rated health (poor, fair, good, very good, excellent), perceived risk of developing cancer (very low to very high) and history of medical conditions, and date of last regular check-up.

## Cancer questions

Questions focusing on cancer included cancer worry (rarely or never to all the time) and risk of developing specific cancers (very low to very high). Questions regarding risk factors (not at all to a lot), and identification of preventative behaviors and awareness of symptoms of endometrial cancer were also included in the questionnaire.

## Statistical analysis

Descriptive statistics (counts/percentages) were used to summarize characteristics and responses of women by group. Differences between groups were compared using t-test and Pearson's Chi-Square when appropriate. Statistical analyses were conducted using IBM SPSS Statistics Version 20.

## Results

A total of 207 women were offered participation and 161 women (78%) agreed to participate in the study and completed the questionnaire. The main reason for refusal to participate was time. Of these, 45 participants self-reported having a history of diabetes mellitus (DM) and 116 participants reported not having a history of DM. No women reported a prior or current diagnosis of uterine/endometrial cancer. Demographic characteristics of the participants are listed in Table 1.

The participants had a mean age of 49.9 years, almost two-thirds (64.6%) were non-Hispanic Whites, slightly over half (51.6%) were married or living with a partner, 45.3% had at least a college education, almost half (47.8%) were employed full- or part-time, and 96.3% had some form of health insurance.

	n (%)
Age (mean years+SD)	49.9+16.5
<b>Race</b>	
White	105 (65.2%)
Black	39 (24.2%)
Other	14 (8.7%)
<b>Ethnicity</b>	
Non-Hispanic	155 (96.3%)
Hispanic	3 (1.9%)
<b>Marital status</b>	
Single	31 (19.3%)
Married	83 (51.6%)
Divorced/Widowed	47 (29.2%)
<b>Education</b>	
<College	88 (54.7%)
College+	73 (45.3%)
<b>Household income</b>	
<\$20,000	38 (23.6%)
\$20,000-\$59,999	46 (28.6%)
≥\$60,000	52 (32.3%)
<b>Employment status</b>	
Part/full time	77 (47.8%)
Unemployed	21 (13.0%)
Retired	34 (21.1%)
Disabled	29 (18.0%)
<b>Health Insurance</b>	
None	6 (3.7%)
Employer/HMO	73 (45.3%)
Medicare/Medicaid	52 (32.3%)
Employer and Medicare	9 (5.6%)
<b>Self-Rated Health</b>	
Poor/Fair	53 (32.9%)
Good/Very Good/Excellent	108 (67.1%)
†Not all variables sum to total because of missing data	

**Table 1:** Demographic characteristics of participants (n=161)<sup>†</sup>.

Demographic characteristics did not differ among participants who reported a history of DM compared to participants without a history of DM, however participants with DM were more likely to report fair

or poor health status compared to participants without DM ( $p < 0.05$ ). Prior to the current medical visit, 132 (82.0%) participants had a regular check-up within the previous year and 153 (95.0%) had a check-up in the past two years.

More participants (69.0%) without a history of DM indicated that they had heard of "gynecologic cancer" prior to participating in the study compared to participants (46.7%) with a history of DM ( $p < 0.01$ ). Five participants reported they had a history of a gynecologic cancer, and the majority (67.3%) of remaining participants either reported that they did not know if they were at risk or were not at risk for developing a gynecological cancer. Among participants who had no previous diagnosis of endometrial cancer, nearly two thirds (62.7%) stated that they rarely or never worry about developing endometrial cancer compared to only 29.2% of the participants without a history of breast cancer who reported that they never worry about developing breast cancer.

Risk factors for endometrial cancer reported by participants are listed in Table 2. Participants most frequently indicated that family history ( $n=132$ ; 82.0%) and obesity ( $n=99$ ; 61.5%) were risk factors for endometrial cancer. Furthermore, the participants incorrectly identified smoking ( $n=109$ ; 67.7%) and stress ( $n=103$ ; 64.0%) as risk factors. There were no significant differences between participants with or without a history of DM except that participants with DM were less likely than participants without DM to report that smoking (60.0% vs. 74.5%) and high blood pressure (24.4% vs. 44.1%) were risk factors for endometrial cancer ( $p < 0.05$ ).

	n (%)
<b>Family history</b>	132 (82.0%)
<b>Smoking</b>	109 (67.7%)
<b>Stress</b>	103 (64.0%)
<b>Obesity</b>	99 (61.5%)
<b>Older age</b>	93 (57.8%)
<b>Post-Menopause</b>	88 (54.7%)
<b>Pollution</b>	75 (46.6%)
<b>Alcohol</b>	72 (44.7%)
<b>Diabetes</b>	67 (41.6%)
<b>High blood pressure</b>	59 (36.6%)

**Table 2:** Risk factors for endometrial cancer reported by participants (N=161)

Common symptoms of endometrial cancer reported by participants are presented in Table 3. Participants most often reported pelvic pain ( $n=89$ ; 55.3%), abnormal vaginal bleeding ( $n=89$ ; 55.3%), fatigue ( $n=72$ ; 44.7%), and vaginal discharge ( $n=71$ ; 44.1%) as symptoms of endometrial cancer. Participants with a history of DM were less likely than those without DM to report abnormal vaginal bleeding (37.8% vs. 62.1%) and vaginal discharge (26.7% vs. 50.9%) as symptoms of endometrial cancer ( $p < 0.05$ ). Additionally, participants with DM compared to participants without DM were more likely to report that they did not know the symptoms of endometrial cancer (46.7% vs. 25.9%;  $p < 0.01$ ).

	n (%)
<b>Pelvic pain</b>	89 (55.3%)
<b>Abnormal vaginal bleeding</b>	89 (55.3%)
<b>Fatigue</b>	72 (44.7%)
<b>Vaginal discharge</b>	71 (44.1%)
<b>Swelling</b>	63 (39.1%)
<b>Do not know</b>	51 (31.7%)
<b>Loss of appetite</b>	50 (31.1%)
<b>Constipation</b>	25 (15.5%)
<b>Other (excessive urination; belly pain; bloating)</b>	5 (3.1%)

**Table 3:** Symptoms of endometrial cancer reported by participants (N=161)

Health behaviors to reduce their risk of developing endometrial cancer reported by the participants are listed in Table 4. Participants indicated most frequently that having annual checkups ( $n=136$ ; 84.5%), eating a healthy diet ( $n=118$ ; 73.3%), maintaining a healthy weight ( $n=114$ ; 70.8%), and exercising ( $n=111$ ; 68.9%) as behaviors individuals can do to reduce their chances of being diagnosed with endometrial cancer. Participants with DM differed from participants without DM in two ways regarding behaviors to reduce their risk of endometrial cancer; they were more likely to indicate that they did not know what to do to reduce their chances of getting endometrial cancer (20.0% vs. 6.0%;  $p < 0.01$ ) and they were less likely to indicate that having an annual check-up would reduce their risk of getting endometrial cancer (73.3% vs. 88.8%;  $p < 0.05$ ).

	n (%)
<b>Have annual check-ups</b>	136 (84.5%)
<b>Eat a healthy diet</b>	118 (73.3%)
<b>Maintain a healthy weight</b>	114 (70.8%)
<b>Exercise</b>	111 (68.9%)
<b>Reduce stress</b>	97 (60.3%)
<b>Do not smoke</b>	94 (58.4%)
<b>Do not drink alcohol</b>	63 (39.1%)
<b>Use birth control pills</b>	20 (12.4%)
<b>Do not know</b>	16 (9.9%)
<b>Other (safe sexual behaviors; be happy; aloe gel; vitamins)</b>	7 (4.4%)

**Table 4:** Health behaviors to reduce risk of endometrial cancer reported by participants (N=161)

Participants listed that they trusted health information the most from following three sources: physicians ( $n=127$ ; 78.9%), health organizations like the American Cancer Society ( $n=102$ ; 63.4%), and nurses ( $n=93$ ; 57.8%). There were no significant differences between groups with respect to their trust in these information sources.

## Comment

Improving awareness of risk factors for endometrial cancer is important and may result in modification of behaviors. Since there is not a currently recommended population-based screening test for endometrial cancer, knowledge of symptoms is important to improve early detection and thus reduce endometrial cancer mortality rates. This study demonstrated that almost a third of participants reported not knowing the symptoms of endometrial cancer, and a majority of participants incorrectly reported smoking and stress to be risk factors. Although diabetes is a risk factor for endometrial cancer, diabetic patients were more likely to state that they did not know symptoms of endometrial cancer and were less likely to identify abnormal vaginal bleeding as a symptom of endometrial cancer. Though the discrepancy in knowledge of symptoms between diabetics and non-diabetics is not readily apparent, it highlights the importance of education in this subgroup. As the majority of endometrial cancer cases (68%) present with abnormal bleeding, patient identification of this symptom is especially important [2]. Women who lack knowledge that abnormal vaginal bleeding may be a symptom of endometrial cancer may be less likely to report this symptom to their doctor, possibly delaying their diagnosis.

Similar to the findings in the current study, previous studies found that women were not aware or had limited knowledge about gynecologic cancers [6-9]. The FWC conducted a national telephone survey of 800 women and found that 46% of the participants were not aware of risk factors for developing a gynecological cancer [7]. An on-line internet study of 235 women conducted in 2006 found that a low percentage of participants from the general population were aware of risks and symptoms of ovarian cancer and that most participants had never discussed symptoms with their physician [8]. A focus group study that included 132 women from four U.S. cities conducted in 2009 found limited knowledge of risk factors and symptoms of gynecologic cancers and in a convenience sample of women (n=0.545), 58% of the women were not aware obesity was a risk factor for endometrial cancer [6,9]. With the currently low level of gynecologic cancer knowledge, women may be less likely to view their symptoms as important and report them to their physician.

In addition to lacking knowledge about the signs and symptoms of gynecologic cancer, the majority of women (63%) believe that by completing a Pap test they have screened for all gynecological cancers in addition to cervical cancer [10]. Women completing cervical cancer screening who incorrectly believe they are being screened for numerous gynecologic cancers may be less likely to report gynecologic symptoms to their physician. This problem may be further complicated by the decreased frequency of cervical cancer screening recommended in the new screening guidelines [11,12]. Without undergoing an annual gynecological examination, women may delay reporting gynecologic symptoms to health care providers, possibly delaying diagnosis and treatment of a gynecologic cancer. By increasing awareness and improving knowledge of endometrial cancer symptoms, more women will most likely report symptoms earlier potentially improving endometrial mortality rates.

The lack of awareness and limited knowledge about gynecological cancers may also be a contributing factor to the disparities associated with endometrial cancer in addition to other factors including biology (e.g. genetics, obesity), individual risk factors (e.g. education, socioeconomic status), social/physical context (e.g. access to resources), institutional context (e.g. health care systems), and social conditions (e.g. cultural attitudes) [13,14].

To reduce cancer disparities and to improve patient outcomes, a concerted effort must be made to develop effective educational materials and programs focused on gynecologic cancer. These educational efforts should not only include information for patients but should also include strategies to improve communication of information between patients and health care providers. When active educational efforts are available compliance with recommendations may improve. For example, women with knowledge of risk factors for cervical cancer and awareness of the importance of screening for the early detection and successful treatment of cervical cancer were more likely to complete recommended Pap tests [15]. Along these same lines, additional studies have shown that when women are informed and understand the estimated risk of developing hereditary breast and/or ovarian cancer, there are notable improvements in recommended screening tests and compliance with medical care [16-18]. Therefore, by improving patient knowledge, and patient-provider communication, appropriate medical consultation for symptoms may be sought.

Our study has a few limitations. First, women self-reported a history of diabetes and other medical conditions and we did not confirm any diagnosis by medical record review. It is possible that women may not accurately report their medical history but we thought this would not occur with great frequency. In addition, this study included a convenience sample of female patients waiting for a medical appointment and these women may not be representative of women in the general population or women living in other regions of the U.S.

Despite the fact that endometrial cancer is one of the common cancers among women, our study suggests that 40-60% of women lack knowledge of the most common risk factors (e.g. obesity, diabetes, and hypertension) and symptoms of endometrial cancer. The development of educational materials and programs to increase awareness of risk factors and symptoms of endometrial cancer may help improve detection and ultimately, endometrial cancer mortality rates. Though the earlier diagnosis of endometrial cancer based on abnormal uterine bleeding has not been definitively shown to result in improved survival outcomes; awareness of risk factors in asymptomatic women may prompt earlier recognition and/or evaluation which may impact prognosis [19,20]. Therefore, health care providers should be counseling women about symptoms of endometrial cancer and providing this important information should be a priority for high-risk patients. Improving women's awareness of risk factors for endometrial cancer may result in the potential to offer risk-reducing behavioral strategies (weight loss programs, diabetes management, etc.) as well as risk assessment (genetic predisposition) through a trusted communication channel for health information.

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