Recognizing Endometrial Cancer Risks in Perimenopausal and Postmenopausal Experiences: Insights From Community Qualitative Interviews and Workshop

Malak Ibrahim, MSc; Karman Johal, BSc; Madeline Dow, BSc; Mohamed Bedaiwy, MD, PhD; Andrea Neilson, MD; Jerilynn C. Prior, MD; Aline Talhouk, PhD

Department of Obstetrics and Gynaecology, University of British Columbia, Vancouver, BC

ABSTRACT

Objectives: To evaluate the experiences of perimenopausal and postmenopausal women in British Columbia, their perceptions of expected reproductive aging, and potential concerns about endometrial cancer (EC).

Methods: We interviewed 31 midlife community women of diverse backgrounds and hosted a workshop for more in-depth discussion. We summarized relayed experiences and beliefs through a thematic and descriptive analysis of participant stories and workshop feedback.

Results: Participants demonstrated a somewhat simplistic understanding of midlife changes, facing this phase of life with a "tough-it-out" attitude rather than seeking medical help for arising symptoms. Awareness of EC and EC-specific risk factors, such as obesity, was low. Confusion between cervical and EC was common. Although abnormal bleeding was seen as potentially of concern, many opted to wait before seeking medical help. Workshop participants stressed the need to include awareness about EC in a broader conversation about perimenopause and menopause and suggested strategies for disseminating EC awareness.

Conclusions: Community women in British Columbia demonstrated low awareness of EC-associated symptoms and risk factors. There is little information to help distinguish when perimenopausal abnormal uterine bleeding is of concern and when to seek help. This highlights the need to enhance knowledge of EC and its risk factors in perimenopause among the public and among health care providers.

Keywords: endometrial neoplasms; perimenopause; metrorrhagia; health services accessibility

Corresponding author: Aline Talhouk, a.talhouk@ubc.ca

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RÉSUMÉ

Objectif: Évaluer les expériences des femmes en périménopause ou en postménopause en Colombie-Britannique, leurs perceptions du vieillissement reproductif attendu et leurs préoccupations potentielles quant au cancer de l'endomètre (CE).

Méthodes: Nous avons interrogé 31 femmes de la communauté autour de la cinquantaine aux origines diverses et organisé un atelier pour mener une discussion approfondie. Nous avons résumé les expériences et les croyances dans une analyse thématique et descriptive des récits des participantes et des commentaires lors de l'atelier.

Résultats: Les participantes ont fait preuve d'une compréhension quelque peu simpliste des changements qui s'opèrent autour de la cinquantaine, en affrontant cette phase de la vie avec endurance au lieu de chercher de l'aide médicale pour gérer les symptômes. Elles étaient peu sensibilisées au CE et à ses facteurs de risque particuliers, tels que l'obésité. La confusion entre le cancer du col de l'utérus et le cancer de l'endomètre était répandue. Malgré la présence de saignements anormaux considérés comme potentiellement préoccupants, plusieurs participantes ont choisi d'attendre avant d'aller consulter. Les participants à l'atelier ont souligné la nécessité d'inclure la sensibilisation au CE dans la conversation générale entourant la périménopause et la ménopause. Elles ont aussi suggéré des stratégies pour sensibiliser la population au CE.

Conclusion: Les femmes de la Colombie-Britannique étaient peu sensibilisées aux symptômes et aux facteurs de risque associés au CE. Peu d'information est disponible pour les aider à déterminer quand les saignements utérins anormaux de la périménopause sont préoccupants et quand il faut consulter, ce qui souligne la nécessité d'améliorer la sensibilisation du public et des prestataires de soins au CE et à ses facteurs de risque pendant la périménopause.

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INTRODUCTION

7 ndometrial cancer (EC) is the most common gynecologic malignancy in high-income countries, with 420 242 new cases and 97 704 deaths in 2022 worldwide.¹ Increasing rates have been attributed to increased ECassociated risk factors and an aging population.² Obesity is thought to be responsible for over 40% of EC cases, with each 5 kg/m² increase in BMI associated with a 1.6fold increase in EC risk.³ Other risk factors include nulliparity, polycystic ovarian syndrome, and type 2 diabetes mellitus. EC is most commonly diagnosed after menopause, defined as the 'permanent cessation of menstrual periods determined retrospectively after a woman has experienced 12 months of amenorrhea without any other apparent pathologic or physiologic cause. However, EC is increasingly diagnosed in women who are not yet menopausal.6 Most ECs, if detected while confined to the uterus, are cured by surgical removal of the uterus (hysterectomy), with 5-year survival rates exceeding 95%. Conversely, only 20% survive EC if it is diagnosed after the cancer has metastasised, highlighting the importance of early detection.

Abnormal uterine bleeding (AUB) and postmenopausal bleeding (PMB) are the primary presenting symptoms for EC. In perimenopause, the symptomatic period preceding menopause, AUB most commonly presents as irregular, heavy, or intermenstrual bleeding. Postmenopause, any vaginal bleeding may be abnormal and requires investigation. AUB is very common during perimenopause, with heavy and prolonged flow (menorrhagia) experienced by about up to a third of women. The key to early detection of EC is the awareness and recognition of symptoms and risk factors.

Recent trends highlight an increasing proportion of older women and individuals of South Asian and Black ethnicity being diagnosed with EC.¹⁰ The perspective of women in these demographics, as well as that of stigmatised and vulnerable populations with obesity, has not been adequately represented in research.^{11,12}

This study aimed to gain deeper insights into a broad and varied representative group of British Columbia (BC) midlife women. We used qualitative interviews and a workshop to learn what perimenopausal and postmenopausal women knew about EC risk factors and symptoms. Our goal was to understand commonly held beliefs among a diverse group of women in midlife, what is perceived as typical during these life stages and to note challenges encountered in seeking medical assistance for their concerns.

METHODS

Participants and Study Procedures

We recruited community individuals assigned female at birth who lived across BC, spoke different languages, were of various cultures and ethnicities, were over age 40 years, and had an intact uterus. Participants were approached using social media ads (Facebook, Instagram, and Twitter), the REACH BC Platform (https://reachbc.ca/), and in person at shopping centres and pharmacies. Participants with EC-lived experience (who were not required to have a uterus) were recruited through the BC Cancer registry, where a subset of EC patients were selected based on clinicopathological characteristics and their residential location and mailed recruitment letters. We strived for diversity in recruitment, by using quota sampling 13 to ensure adequate representation of various ethnic and racial backgrounds, rural and urban, chronic health conditions, history of EC or endometrial hyperplasia, and gender-diverse participants (Table 1). Participants consented to be interviewed and invited to a group workshop. Recruitment continued until interviews reached thematic saturation. This study was approved by the University of British Columbia Clinical Research Ethics Board (H21-02909).

Virtual Interviews and Workshop

A semi-structured interview guide, informed by a review of relevant literature, was used to direct the conversation toward predetermined topics (Supplementary Material 1). These topics included experiences of perimenopause, postmenopause, abnormal or postmenopausal uterine bleeding, and EC diagnosis. Questions were iteratively validated with the help of a patient partner and kept open-ended to reduce bias and capture participants' experiences in their own words. The interviews were conducted virtually between 21 July 2022, and 14 April 2023, lasted about an hour, and were

Table 1. Participant quotas		
Criteria	Target proportion	Obtained proportion
Various ethnic and racial backgrounds	30	35
Rural setting	20	23
Chronic health conditions ^a	20	23
History of EC or EH history	20	27
Gender diverse	10	0
Other	0	12

All values are given in %.

^aChronic health conditions such as obesity, diabetes, hypertension, PCOS, endometriosis, etc.

EC: endometrial cancer; EH: endometrial hyperplasia; PCOS: polycystic ovarian syndrome.

recorded and transcribed verbatim and reviewed by participants for accuracy. A preliminary analysis of the interviews informed 3 questions that guided the virtual community workshop on 11 May 2023. The workshop lasted one and a half hours and was recorded and transcribed. Suggestions from the workshop were summarized into an actionable list. After the workshop, participants were asked to rank the items on this list based on their perceived importance.

Thematic Analysis

We explored and summarized participants' narratives during the interviews and workshop using qualitative descriptions and basic frequencies. The participants' stories were abstracted verbatim and provided a comprehensive account of their experiences. We did not make any prior theoretical assumptions. Team members independently read and coded all transcripts in N-Vivo (https://lumivero.com/products/nvivo/). A combination of inductive and deductive coding of the data relevant to the participant stories was completed using the method of constant comparison. ¹⁵ Iterative discussions between

authors verified emerging categories and themes until no new themes were found, thus indicating saturation.

RESULTS

Participant Characteristics

Thirty-one individuals, all identifying as cis-gender females, met the inclusion criteria and prespecified quota (Table 1). The median age was 56 years; 12 (39%) were previously diagnosed with EC or endometrial hyperplasia, 13 (42%) were of ethnically diverse backgrounds, 14 (45%) lived in rural BC, and 13 (42%) reported a chronic condition (polycystic ovary syndrome, obesity, hypertension, etc.) (Table 2). Of these participants, 12 participated in the workshop. Workshop participants were younger and less ethnically diverse than the interview participants.

Thematic Analysis of Interviews

A thematic analysis of the interviews revealed 3 themes: limited knowledge and awareness of EC, misconceptions about midlife experiences and interpretations of AUB/PMB, and unsatisfactory interactions with health care providers (HCPs).

Table 2. Demographics of community women in midlife participating in the study of risks and beliefs related to endometrial cancer

Demographic information	Interviews (n $=$ 31), n (%)	Workshop (n = 12), n (%)
Age		
40–50	7 (23)	2 (17)
51–60	12 (39)	8 (67)
61–70	10 (32)	2 (17)
≥71	2 (6)	0 (0)
Race		
White (European descent)	18 (58)	8 (67)
East Asian (Chinese, Korean, Japanese)	4 (13)	3 (25)
Indigenous (First Nations, Métis, Inuk/Inuit)	4 (13)	0 (0)
South Asian (Pakistan, India, other South Asian descent)	2 (6)	0 (0)
Middle Eastern (Arab, Persian, Turkish, West Asian descent)	1 (3)	1 (8)
Black (African, Afro-Caribbean, African Canadian descent)	0.5 (2)	0 (0)
Latino (Latin American, Hispanic descent)	0.5 (2)	0 (0)
Other	1 (3)	0 (0)
Personal EC or EH history		
Yes	12 (39)	3 (25)
No	19 (61)	9 (75)
Location		
Rural	14 (45)	5 (42)
Urban	17 (55)	7 (58)
Chronic illnesses		
Yes	13 (42)	6 (50)
No	18 (58)	6 (50)

EC: endometrial cancer; EH: endometrial hyperplasia.

LIMITED KNOWLEDGE AND AWARENESS OF EC

Although most participants expressed awareness of EC (almost 80%), one-third confused knowledge of screening and risk factors with those linked to cervical cancer (Pap test screening, human papilloma virus infections, etc.). Lack of differentiation between gynecologic cancers was also prevalent among some EC survivors who believed that their annual Pap test screened for all gynecologic cancers, only discovering that this was not the case after their EC diagnosis.

When asked about EC risk factors, one-fifth did not know any or were uncertain (Table 3). The most commonly cited risk factor was family history; those without a family history felt protected from EC. A few recognized obesity and often after their own EC diagnosis or through discussions with HCP. Age, reproductive factors, and hormonal exposures were speculated with great uncertainty. A minority (<25%) identified lifestyle factors like smoking and lack of exercise but often became aware of these factors after their EC diagnosis.

When queried about EC symptoms, participants guessed changes in vaginal bleeding most frequently, followed by pain (Table 4). Others guessed symptoms included weight changes, bloating, and fatigue. Participants' recognition and interpretation of AUB/PMB were heavily influenced

Table 3. Community midlife women's knowledge of endometrial cancer risk factors

Reported EC risk factors (total = 31 women)	n (%)
Family history	10 (32)
Sexual and medical history ^a	9 (29)
Lifestyle ^b	7 (23)
Obesity	5 (16)
Age	4 (13)
Hormonal issues and treatments ^c	4 (13)
Parity	3 (10)
Endometriosis	2 (7)
Environmental factors and carcinogens	2 (7)
Do not know/cannot recall	5 (16)

^aHormonal issues and treatments include hormone-related conditions, menopause therapies, infertility therapies, etc.

EC: endometrial cancer; HPV: human papilloma virus.

by their knowledge, awareness, and attitudes toward menstruation and menopause.

All participants expressed interest in learning more about what causes EC, its symptoms, and modifiable risk factors. They also wanted to know when to seek medical help and understand screening procedures and treatment options. Looking back on their experience, participants with an EC diagnosis wished they had taken their symptoms more seriously when they first appeared. They also wished they had known more about EC-related symptoms, risk factors, and reproductive health in general before their diagnosis.

MISCONCEPTION ABOUT MIDLIFE EXPERIENCES AND INTERPRETATIONS OF AUB/PMB

Participants had a simplistic understanding of the menopausal transition, often limited to the cessation of menstruation and the starting of hot flushes/night sweats (Figure 1). Many were unfamiliar with the term "perimenopause"; about two-thirds had either never heard it or had heard it but were unsure what it meant. About a third of participants thought that menopause occurred around age 50, and consequently, participants were caught off guard by symptoms of perimenopause that may have started over a decade prior and were often attributed to other factors. Even though they felt ill-informed about the experiences of midlife, over one-third expressed not wanting to bother their HCP with questions. Almost all participants drew their knowledge of midlife changes from discussions with female family members and friends, often comparing their experiences to those described by peers. This created preconceived expectations of homogenous perimenopausal symptoms, which caused distress when actual experiences differed from expectations. Almost half of the participants believed that they had to "tough it out"

Table 4. Knowledge of endometrial cancer-related symptoms among midlife community women

Reported EC Symptoms (n = 31 women)	n (%)
Unusual, unexplained, or unpredictable vaginal bleeding	25 (81)
Pain	15 (48)
Bloating	4 (13)
Weight loss/gain	2 (7)
Pelvic and vaginal pressure or tenderness	2 (7)
Other ^a	7 (23)
Did not know/could not guess	2 (7)

^aOther included unusual fatigue, high/low blood pressure, blood in urine, appetite changes, inflammation, difficulty urinating or defecating, and vaginal discharge. These were usually mentioned only by one participant.

EC: endometrial cancer.

^bSexual and medical history includes number of sexual partners, gynecologic infection history, sexually transmitted diseases, HPV, unprotected sex, miscarriages, previous cancer diagnosis etc.

^cLifestyle includes excessive alcohol consumption, smoking, lack of exercise, stress, poor work-life balance, etc.

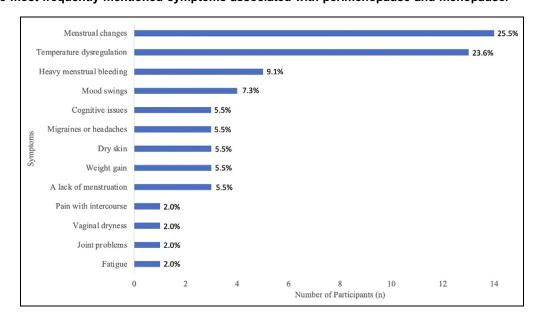


Figure 1. The most frequently mentioned symptoms associated with perimenopause and menopause.

when experiencing perimenopause. They were inclined to manage symptoms without seeking medical help, coping with the associated discomforts even though their quality of life was compromised. Many reported that they did not seek help because they were taught from a young age to be strong, self-reliant, and not complain about menstrual issues.

Almost half of the interviewed participants reported experiencing heavy menstrual bleeding during perimenopause; only one was diagnosed with EC. In contrast, 10 participants reported experiencing PMB, 8 of those had EC-lived experience, and one had received an endometrial hyperplasia diagnosis. The majority of participants who experienced abnormal bleeding attributed it to perimenopause or menopause. They were inclined to dismiss symptoms and did not seek help unless symptoms persisted. The type and severity of bleeding, the presence of accompanying pain or unusual symptoms, knowledge of warning signs for EC, and their personal experiences all played roles in shaping their decisions to seek medical help. Although many were correct in attributing bleeding changes to perimenopause, this was also observed among EC survivors who had initially presented with AUB (1/9) or PMB (8/9).

UNSATISFACTORY INTERACTIONS WITH HCPs

Participants reported systemic barriers to accessing health care, such as a lack of family doctors, long wait times, and not wanting to burden their HCP and the health care system. Many felt that menstrual cycle and perimenopausal issues were not significant enough to discuss during the precious time they had with their HCP. Participants avoided or delayed medical consultations for months or years because they perceived their symptoms were insufficient to warrant medical attention. They were also worried about the embarrassment and the stigma of being labelled as complainers, sickly, or whiny; they feared being overprescribed medications and hormones. Prior dismissal of symptoms and the lack of solutions offered by HCPs also contributed to their hesitation to seek help.

Almost two-thirds of EC survivors wished their doctors took them more seriously. They discussed a need for more awareness in the community and by HCP and the desire for less invasive diagnostic tests, as ultrasounds were inconclusive, and endometrial biopsies were painful and even described as "inhumane."

Supporting quotes from participants can be found in Table 5.

COMMUNITY WORKSHOP

In the workshop, participants expressed a need to include EC discussions within broader conversations about perimenopause and menopause. They highlighted a desire to receive comprehensive information from HCPs about reproductive health and aging at significant age milestones (e.g., ages 35–40 years) coinciding with mammography and cervical cancer screening

Theme	Supporting quotes		
Misconceptions about period	menopause/menopause		
Age	"When I started actually menopause, like you know at first I would bleed then stop then bleed then stop then have spotting again but I did, I said no I'm young and I never thought that I was menopausing at the time" — 67°		
Expected experiences	"I had assumptions based on what was commonly spoken about by women in my family and cohort." — 31 "It wasn't till like a few years later or not that long ago, actually, that I, reading about menopause, hearing other people say, yeah that anxiety was a big symptom for them. But I'd never heard that before. So that was why didn't really associate it with that." — 111		
Recognising abnormal uter	rine bleeding in perimenopause		
	"I had like one drop of blood. It was just minimal. It was like easily ignoredBut a month later, same thing, just a tiny like, like, I don't know if it was 2 drops or if it was less, it was just minimal. But then I Googled it, and it said to see your doctor, and that's the first time I had ever heard of, you know, like that it could be a problem, really." — 33		
Attitudes and barriers to se	eeking medical care		
	"I soldiered on it was stacked against me as a woman who was trying to do her best just to maintain a certain level of function." – 49 "I'm not a doctor, I can only tell him this is what I'm having so every time you go, they send you back, you don' want to be like a fool keep asking the same questions." – 67 "Aside from doctors taking you more seriously and not treating you like idiots that would help. But. Who's going to change that?" – 99		
Endometrial cancer knowledge			
Misconceptions	"I usually had my Pap tests regularly and I always thought that that was like my security blanket. I thought that had all that covered you know it's not. So cervical cancer it's different of uterine cancer, different than ovariar cancer, different than you know, vulvar cancer etc., etc" — 138		
Knowledge gaps			
	"I don't know if I realized, or if I understood, maybe that extra weight was um, you know, detrimental, and possibly a precursor to the cancer." $-$ 76		
Experiences with EC			
	"I know a biopsy is a test. But a biopsy is barbaric." – 99		

EC: endometrial cancer; ID: identification.

appointments. They felt this would enable them to be proactive about their health. They also believed that their HCP did not offer holistic information about reproductive health and lacked sufficient awareness of EC. They expressed interest in understanding the various stages of the menopausal transition or perimenopause, what to expect at different times, clarity around when to seek help, and the characteristics of vaginal bleeding associated with EC risk. Specifically, they wanted to learn more about EC symptoms and risk factors, including predictive tools for EC risk, genetic predisposition and available screening and testing. To avoid being dismissed, they wanted to learn how to talk with their physician about reproductive health in general and their perimenopausal and EC-associated symptoms specifically.

Participants stressed the importance of providing information on expected perimenopausal bleeding changes and EC risk factors. Visual aids, including guides to help them recognize patterns of change in bleeding patterns in perimenopause, measure menstrual flow, and knowing when to seek information or medical help, were among the many suggestions. Those diagnosed with EC emphasized that anyone with PMB needed to have EC excluded. Participants were also interested in monitoring the menstrual cycle, tracking flow, and increasing screening for related gynecologic issues. Figure 2 reports key strategies ranked by participants.

DISCUSSION

Our interviews with 31 diverse midlife women from BC, highlighted themes similar to the literature, emphasizing the lack of knowledge regarding EC, its risk factors, and its relationship with perimenopausal experiences. ^{16,17} Participants made guesses and confused EC with cervical cancer, such as mistakenly believing that the Pap test could exclude EC. and falsely associated EC with sexual behaviours such

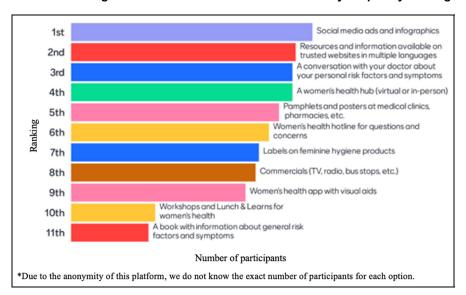


Figure 2. Strategies for disseminating information about endometrial cancer by frequency ranking.

as having multiple sexual partners. This may decrease willingness to seek medical assistance, particularly among ethnic minorities with unique cultural influences. 18,19

Obesity plays a significant role in EC carcinogenesis by amplifying estrogen bioavailability and inducing inflammation, hyperinsulinemia, and insulin resistance.²⁰ It is estimated that over 60% of ECs can be prevented through risk factor modifications and progesterone or progestin therapy.²¹ Increasing awareness may empower lifestyles that promote increasing physical activity to avoid obesity and reduce not only EC risk but also their overall cancer risk and other comorbidities.²²

Although AUB/PMB is the presenting symptom in the majority of EC patients, about half postpone seeking medical assistance, potentially delaying diagnoses.²³ In some ethnic communities, these delays may be exacerbated by embarrassment and taboos related to menstruation and menopause.²⁴ Currently, AUB/PMB is investigated with an endometrial biopsy, to rule out EC²⁵; it is an invasive and painful test some women wish to avoid. EC is found in < 3% of perimenopausal AUB and < 10% PMB, 26,27 highlighting the lack of specificity of these symptoms. The low specificity of AUB and its universality in perimenopause necessitates the development of less invasive, accurate diagnostic methods (NCT06268626). While it is essential not to overmedicalize perimenopause and menopause, individuals with EC risk factors, such as obesity, nulliparity, or polycystic ovarian syndrome, must seek medical help to rule out cancer upon presentation of any symptoms.

People with obesity are at the highest EC risk and face negative health care experiences, fat bias, and stigma, which significantly decrease appropriate help-seeking behaviour. Lack of HCP awareness and physician delays in recognising symptoms of EC, especially AUB, are the main reasons for failure to appropriately refer and diagnose EC early. This highlights a critical need to direct knowledge campaigns to women in midlife and their HCPs. 29,30

It is a limitation that, despite a concerted effort, our study could not recruit gender-diverse participants who may be at risk for EC, with added barriers to care, and whose perspective is often missing from research. This group can face additional stigmas and barriers to accessing care.³¹ Our recruitment efforts produced a lower workshop representation of different races/ethnicities and age groups. The criteria used for eligibility were self-reported and relied on the memory and assumptions of participants, which may be biased. The SARS-CoV-2 pandemic may have influenced the experiences of some women accessing care and should be considered in future research and this was not accounted for. A strength of this study is the representation of diverse racial/ethnic participants, as well as older women, both of which are typically underrepresented in research. However, experiences did not significantly differ between races/ethnicities in this study. 11,12

This community-based information we have collected highlights the lack of clarity among women about the risks of EC and the changes to be expected in normal perimenopause and menopause. HCPs were not available to assist them when they experienced heavy flow or other disturbing symptoms in perimenopause. A connection point with the health system at this critical juncture can help correct misconceptions and prompt timely reporting of EC-suspicious symptoms. Since there are currently no specific and acceptable to women screening tools for EC for women having PMB, more population-based as well as genetic and physiological research is urgently needed to develop strategies to prevent the increasing rates of EC.

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ETHICS

This study was approved by the University of British Columbia Clinical Research Ethics Board (H21-02909).

SUPPLEMENTARY DATA

Supplementary data related to this article can be found at https://doi.org/10.1016/j.jogc.2024.102707.

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