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Gynaecologic cancer symptom awareness, concern and care seeking among US women: a multi-site qualitative study

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Abstract

Background—With limited screening options, early detection of gynaecologic cancers can depend on women recognizing the potential significance of symptoms and seeking care.

Objective—We investigated women's concern about symptoms that might be related to gynaecologic cancers, the underlying conditions they associated with symptoms and their actual and hypothetical response to symptoms.

Methods—Fifteen focus groups with women aged 40–60 years were conducted in Chicago, Los Angeles, Miami and New York City. Participants were given an untitled list of symptoms that could indicate various gynaecologic cancers and asked if any would concern them, what could cause each and what they would do if they experienced any of them.

Results—Overall, participants expressed greater concern about symptoms clearly gynaecologic in nature than other symptoms. Participants generally did not associate symptoms with any form of cancer. Some women who had experienced symptoms reported waiting an extended period before seeking care or not seeking care at all. The belief that a symptom indicated a benign condition was the most common reason given for delaying or foregoing care seeking. Strategies participants reported using to supplement or replace consultations with health care providers included Internet research and self-care.

Conclusion—Raising awareness of symptoms that can indicate gynaecologic cancers may lead to earlier detection and improved survival. In particular, women should be informed that gynaecologic cancers can cause symptoms that may not seem related to the reproductive organs (e.g. back pain) and that unusual vaginal bleeding should prompt them to seek care immediately.

Keywords

Neoplasms; women's health; early detection of cancer; qualitative research; focus groups

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Declaration

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Introduction

Of the five main gynaecologic cancers—cervical, ovarian, uterine, vaginal and vulvar—population-based screening is recommended only for cervical cancer, using the Papanicolaou (Pap) test.[1] As a result, early detection of most gynaecologic cancers can depend on women recognizing the potential significance of symptoms and seeking care.[2] Unfortunately, symptoms associated with gynaecologic cancers are often non-specific and associated with a variety of benign conditions[3,4] (Table 1). US women's awareness of gynaecologic cancer symptoms has been found to be low.[5–8] In the case of ovarian cancer, gastrointestinal symptoms were often unrecognized by patients as a serious concern,[9] and women were less likely to seek care for symptoms they perceived to be unrelated to the reproductive system, compared with those perceived to be gynaecologic in nature.[10]

To increase women's awareness of gynaecologic cancers, their symptoms and risk factors, the Centers for Disease Control and Prevention (CDC), in collaboration with the Department of Health and Human Services' Office on Women's Health, created the *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign.[11] Inside Knowledge supports the Gynecologic Cancer Education and Awareness Act of 2005,[12] or Johanna's Law, passed by Congress in 2006, and signed into law in 2007. The primary messages of this national, multimedia initiative include the following: pay attention to your body and know what is normal for you, gynaecologic cancers have warning signs and get a Pap test regularly to screen for cervical cancer. To date, *Inside Knowledge* has released public service announcements in several formats, including broadcast, print and out-of-home displays (e.g. on buses and in shopping malls), as well as a variety of patient education materials.

This focus group study was undertaken to supplement the limited available literature and inform the continued development of *Inside Knowledge* as well as other related public health initiatives. The analyses described here explored women's concern about symptoms that can indicate gynaecologic cancers, the underlying conditions they associated with symptoms and their actual and hypothetical responses to symptoms.

Methods

Fifteen focus groups with 132 women were conducted in 2009. Groups were held in Chicago (4 groups, 34 participants), Los Angeles (3 groups, 27 participants), Miami (4 groups, 36 participants) and New York City (4 groups, 35 participants). These cities were selected based on the diversity of their geographic region and demographic composition.

Participants

Participants were limited to women aged 40 to 60 years, the primary population initially targeted by the *Inside Knowledge* campaign. Women with a personal or family history of gynaecologic cancers were excluded; however, in a few instances participants divulged such history during groups, contradicting information they gave during enrolment in the study.

Participants were recruited using public information (e.g. published telephone numbers) and proprietary lists by the private research facilities where the groups were conducted. A

minimum of seven and a maximum of nine participants were included in each focus group. To allow for participants who failed to report as scheduled, up to 12 participants were invited to each focus group. When more participants reported than were needed, decisions about which individuals to retain were based primarily on maximizing demographic diversity.

Procedure

Each focus group lasted 1½ to 2 hours and was led by a professional moderator using a semi-structured discussion guide. Three or more investigators monitored each group from behind a one-way mirror. Before taking part in the study, each woman signed a consent form disclosing the rights of participants, data handling and reporting procedures and the use of audio recording. During her introductory remarks, the moderator reiterated the voluntary nature of participation and informed participants of the presence of investigators behind the one-way mirror. To ensure anonymity, only first names were displayed on participants' name cards; participants were instructed to use only their first names during the groups; and identifying information was not provided to investigators. To defray the costs associated with attendance, participants received a small honorarium, the amount of which was consistent with federally sponsored research. Participants also received a packet of *Inside Knowledge* educational materials.

At the beginning of each group, participants were given a list of symptoms associated with cervical, ovarian, uterine, vaginal and vulvar cancers. The list was not titled, and the moderator was instructed not to use the term 'symptom' during the discussion. To mitigate any order effects, the sequence in which symptoms were listed was rotated midway through the study, after the eighth focus group. The symptoms listed were drawn from CDC's *Inside Knowledge* campaign materials,[13] which are based on expert recommendations and existing scientific evidence: (1) 'bleeding or discharge from your vagina that is not normal for you'; (2) 'changes in the color of the skin of the vulva or a rash, sores, or warts on the vulva' (as reported elsewhere,[8] participants' understanding of the term 'vulva' was evaluated); (3) 'itching or burning in the genital area that does not go away'; (4) 'pain or pressure in the pelvic area (the area below your stomach and between your hip bones)'; (5) 'back or abdominal pain'; (6) 'being tired all the time'; (7) 'a change in your bathroom habits, such as having to pass urine very badly or very often'; and (8) 'bloating, which is when the area below your stomach swells or feels full'.

In response to the symptoms list, participants indicated in writing which would most concern them. Next, the moderator asked participants to discuss why the symptoms they selected would be of concern and what could cause symptoms. Then, the moderator asked participants about their actual response to symptoms they had experienced and their hypothetical response to symptoms they had not experienced.

Analysis

An inductive (data-driven) thematic approach was primarily used to develop the codes included in the analysis. In addition, several codes were suggested by the existing literature,

investigators' interest and social cognitive theory,[14] which is the guiding theoretical framework of CDC's *Inside Knowledge* campaign.

Verbatim transcripts of focus groups were compiled using the audio recordings. After reviewing several transcripts and the notes of the investigators who observed the groups, the lead investigator drafted the initial codebook, which listed code names (e.g. 'symptom is concerning because it may signify a serious underlying condition'), definitions and coding instructions. A companion coding form with codes organized by theme was developed using Microsoft Word. A participant utterance or unbroken unit of speech was the coding segmentation unit analysed, and participant utterances were numbered in sequential order in each transcript. Moderator utterances were not numbered or coded but were included on the coding form if needed for context. Transcripts were coded by electronically 'cutting' a section of text with utterance numbers and 'pasting' it onto the coding form next to all relevant codes.

The initial codebook and coding form were refined through an iterative process in which four investigators—two primary coders and two consultants—independently coded the same three randomly selected transcripts, compared coding forms, clarified code definitions and revised the codebook accordingly. Then, the two primary coders independently coded the 12 remaining transcripts in random order. After coding each transcript, the primary coders reconciled all coding discrepancies, the vast majority of which were the result of one coder missing a valid code detected by the other. In rare instances in which the primary coders could not resolve a coding dispute (<1% of coding discrepancies), one of the consultants cast the deciding vote. No new codes were added or other major revisions made to the codebook after the seventh transcript. The final codebook included 85 codes related to the topics reported here. The coding forms of the first six transcripts coded were updated to reflect the final codebook. Intercoder reliability between the two primary coders was evaluated using Cohen's Kappa[15] for the 12 transcripts coded after the initial codebook development process and ranged from 0.79 (standard error [SE] = 0.0061) to 0.90 (SE = 0.0057) with a median of 0.89.

As recommended by Krueger and Casey,[16] the frequency of responses is described here using general terms rather than actual counts. Analyses of response frequencies revealed natural clusters of codes in terms of the number of participants who mentioned them and the number of groups in which they were identified. A code attributed to 'many' participants indicates it was mentioned in at least half of the groups by 22 to 40 women, the modifier 'some' indicates a code was mentioned in at least a quarter of the groups by 12 to 18 women, 'few' indicates a code was mentioned by 3 to 10 women and 'very few' indicates that a code was mentioned by 1 or 2 women. The consistency of findings across cities was evaluated, and no differences were noted (data not shown).

Cohesion refers to participants' comfort and engagement in group activities[17] and is an indicator of focus group data quality.[18] Five interaction scenarios were monitored as proxies of cohesion: a participant sharing personal health experiences, agreeing with another, disagreeing with another, interacting directly with another (without the moderator's involvement) and referring to another by name. In every focus group, the majority of

participants shared personal health experiences and two or more agreed with the opinions of another, disagreed with the opinions of another and interacted with each other directly without the moderator intervening. In 14 of the 15 groups, one or more participants referred to another by name.

Results

Participant characteristics

Participants included a diverse group of women aged 40–60 years (Table 2). All participants said they had at least one Pap test in the past, and most (87.1%) reported they had a Pap test within the past 3 years.

Symptom concern

Of the symptoms tested, participants reported the greatest concern about unusual vaginal bleeding, changes in the skin of the vulva, and vaginal itching or burning (Table 3). Participants said they were least concerned about bloating, having to pass urine very badly or more often than usual and being tired all the time. Many women reported that concern about a specific symptom was related to their perception of the seriousness of the underlying conditions they associated with it, the severity of the symptom, the pain and discomfort it caused and its impact on their day-to-day lives. Their comments reflected these associations:

- With the bleeding, I would think cancer, and I would go to the doctor immediately.
- You could spot for several reasons, and it wouldn't be that big of an issue. But heavy bleeding would concern me.
- If I feel pain, it's time to call somebody immediately.
- New York is not the friendliest bathroom place in the whole wide world so the fact that I'd need to go to bathroom frequently or badly while I was out and about would really upset me.

Underlying conditions associated with symptoms

Most participants did not report specific causes associated with symptoms, despite probes from the moderator. These participants often attributed symptoms to 'something serious' or 'nothing serious'. However, the specific causes mentioned by the minority of participants were generally accurate.

Unusual vaginal bleeding was the only symptom tested that participants attributed to cancer with any consistency, with some noting it could indicate cervical cancer. A few participants specifically stated that they did not associate the symptoms with any form of cancer ('None of these would make me think cancer'). However, many participants recognized that unusual vaginal bleeding and changes in the skin of the vulva could suggest 'something serious'. Recognition that other symptoms could signal a significant health issue was not as widespread.

Actual and hypothetical care seeking

In response to symptoms they had actually experienced, some reported not seeking care at all or waiting for an extended period, even years, before seeking care. Others reported that they sought care after a few days, and several said they sought immediate care due to severe pain resulting from symptoms.

Hypothetical care seeking for the symptoms studied also varied. Changes in the skin of the vulva elicited the most consistent and timely predicted response of the symptoms tested, with no women reporting that they would wait more than ‘a couple of weeks’ to seek care. However, a few participants qualified their response, noting they probably would not notice this symptom, as their genitals are not readily visible. For the other symptoms tested, the timing of predicted care seeking ranged from immediate (‘I would go as soon as possible’) to never (‘I would just live with that’).

The most commonly reported factor prompting timely care seeking in response to both actual and hypothetical symptoms was concern that a symptom signalled a serious underlying condition (Table 4). When women said they had waited longer or would wait longer to seek care than the intervals suggested in Table 1, they attributed their delay to belief that the symptom was related to a benign cause, a personal tendency to delay or avoid care seeking in general, cost concerns and the absence of discomfort or tolerable discomfort.

In response to symptoms associated with the reproductive organs, such as unusual vaginal bleeding and changes in the skin of the vulva, participants typically said they had consulted or would consult a gynaecologist or primary care physician. Most who mentioned consulting a primary care physician for such symptoms explained that they received gynaecologic care from their primary care physician or that their insurance plan required that a primary care physician make specialist referrals.

For the remaining symptoms, participants generally said they had consulted or would consult a primary care physician. However, a few participants reported they would consult specialists (e.g. a urologist, for the condition of having to urinate more often than usual).

Also, a few participants reported that they had sought or would seek treatment in a hospital emergency room in response to a symptom (gynaecologic or other). Typically, participants reported that severe pain would prompt them to seek emergency care. Others said they would go to the emergency room because getting an appointment with their doctor would take too long.

Other care-seeking strategies

To supplement or replace consultation with a health care provider, participants discussed several strategies they had or would use in response to symptoms (Table 5). The most commonly mentioned were Internet research (typically using Google searches or WebMD), self-care and discussion with family members or friends. Many participants said they used such strategies before contacting health care providers. Use of Internet research and consultations with friends and family were also reported after scheduling a visit with a

health care provider in order to prepare questions. A few participants reported using the Internet after an appointment to research diagnoses.

Not all participants endorsed use of the supplemental strategies mentioned. A minority said that they would not research symptoms on the Internet ('The Internet is too scary'), use self-care ('I would take the wrong medicine and make things worse'), or discuss symptoms with family members or friends ('It's best not to discuss that kind of intimate information with friends').

Discussion

Our findings suggest several factors that may impede care seeking for symptoms associated with gynaecologic cancers. First, women in our study were largely unaware of the symptoms related to gynaecologic cancers, and many said they would not seek timely care if they experienced the symptoms studied. In addition, we found that a personal tendency to delay or avoid care seeking in general, cost concerns and an ability to tolerate discomfort or pain may represent additional barriers to early detection of gynaecologic cancers.

Consistent with prior research,[9] participants were most concerned about symptoms clearly related to their reproductive organs, such as unusual vaginal bleeding or vaginal itching or burning. Participants more often associated these symptoms with serious underlying conditions, compared with other symptoms discussed. However, unusual vaginal bleeding was the only symptom that participants consistently associated with any form of cancer. Many participants were unaware that some symptoms, such as back pain, bloating and urinating more often than usual, could be associated with any serious underlying conditions.

Some participants who reported experiencing symptoms never sought care, and others delayed seeking care for extended periods, even years. However, women who were aware that the symptoms studied could be associated with a gynaecologic cancer tended to report that they did or would seek timely care. For instance, a participant reported she did not seek care for persistent, severe back pain for several months; then she learned that it could indicate ovarian cancer and sought care immediately.

Our study is subject to the limitations and strengths intrinsic to all qualitative methods. Given the low number of participants and use of convenience sampling, inferences about qualitative results cannot be made in the same way as with quantitative data. Although a diverse group of women participated in this study, they are not necessarily representative of all US women. Also, qualitative methods cannot produce firm counts or percentages to characterize response volume, as not every participant responds to every point of discussion.[16] One notable advantage of focus groups is that the open-ended interaction among participants facilitates the collection of data with nuances and depth that are not possible to obtain through quantitative methods.

Clearly, efforts are needed to educate women about gynaecologic cancer symptoms and when to seek care. At the same time, it is important to emphasize that some symptoms associated with gynaecologic cancers may result from many benign conditions. Routine medical examinations and Pap tests provide opportunities to educate women about the

absence of population-based screening tests for ovarian, uterine, vaginal and vulvar cancers and the symptoms that may be associated with gynaecologic cancers—particularly those seemingly unrelated to the reproductive organs and unusual vaginal bleeding, which should prompt immediate care seeking.

Significant decreases in gynaecologic cancer morbidity and mortality may ultimately depend on the development and uptake of population-based prevention and screening modalities and improved treatments. The human papillomavirus vaccine, now available for males as well as females, offers protection against cervical, vulvar, vaginal and anal cancers.[19] Ongoing investigations of ovarian cancer markers may result in a viable population-based screening modality in the future.[20] In the meantime, educating women about gynaecologic cancer symptoms offers a potential pathway to earlier diagnosis and improved survival.

Human Subjects Review

Compliant with Code of Federal Regulations, Title 45, Part 46, The Public Health Service Act as amended by the Health Research Extension Act of 1985, Public Law 99–158,[21] the protocol of this study was submitted to the Institutional Review Board for CDC's National Center for Chronic Diseases Prevention and Health Promotion and was determined to be a public health practice activity on 20 June 2008. This determination was applied because the primary purpose of the study was to inform development of, and improve, a public health program, CDC's *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign. The US Office of Management and Budget reviewed the burden to participants taking part in focus group studies supporting cancer prevention and control communication campaigns and approved the study protocol on 9 January 2009.

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Table 1

Gynaecologic cancer symptoms and appropriate timing of care seeking

Cancer	Symptoms	When care should be sought
Cervical	• Unusual vaginal bleeding or discharge	Two weeks after onset for all symptoms, except unusual vaginal bleeding, for which immediate care should be sought
Ovarian	• Pelvic or abdominal pain or pressure • Back pain • Bloating • Having to urinate more frequently or urgently than usual • Unusual vaginal bleeding (especially post-menopause) or discharge	
Uterine	• Unusual vaginal bleeding (especially post-menopause or bleeding between periods, periods that are either longer or heavier than normal) • Pelvic or abdominal pain.	
Vaginal	• Unusual vaginal bleeding (especially after sex) • Having to urinate more frequently or urgently than usual	
Vulvar	• Itching of the vulva that does not go away • Changes in the colour of the vulva, so that it looks redder or whiter than usual • A rash or sore on the vulva that does not go away	

Source: Centers for Disease Control and Prevention. Gynecologic cancer symptoms. Atlanta, Georgia: US Department of Health and Human Services. Available at: http://www.cdc.gov/cancer/gynecologic/basic_info/symptoms.htm

Table 2

Participant demographics (N = 132)

		%
Metropolitan area of residence	Chicago	25.8
	Los Angeles	20.5
	Miami	27.3
	New York City	26.5
Age*	40–44 years	20.5
	45–49 years	25.8
	50–54 years	31.1
	55–60 years	22.7
Race/ethnicity	White	40.2
	Black	32.6
	Hispanic	18.9
	Asian	8.3
Highest level of education attained	Did not complete high school	7.6
	High school graduate/GED	21.2
	2-year college program graduate/technical school graduate	12.9
	Some college (less than 4-year degree)	15.9
	4-year college degree graduate	35.6
	Advanced degree	6.8
Employment	Full time	56.1
	Part time	22.0
	Not employed	19.7
	Retired	2.3
Annual household income	Less than $25 000	15.2
	$25 000–$39 999	19.7
	$40 000–$64 999	28.8
	$65 000–$99 999	25.0
	$100 000 or more	11.4
Marital status	Married	44.7
	Single	33.3
	Divorced	15.2
	Separated	3.0
	Widowed	3.1
	Other	0.8
Health insurance for routine care	Yes	81.8
	No	18.2
Pap test within last 3 years	Yes	87.1

	%
No	11.4
Not sure	1.5

* Participants were limited to women aged 40–60 years.

Table 3

Underlying causes that participants associated with symptoms*

Symptoms in descending order of concern	Participants who mentioned†					
	Many	Some	Few		Very few	
Unusual vaginal bleeding or discharge	• Unspecified cause of concern/ ‘something serious’	• Cervical cancer • Fibroid tumour/cyst	• Ovarian cancer • Uterine cancer • Unspecified cancer • Perimenopause • Unspecified cause of no concern/ ‘nothing serious’		• Fallopian tube cancer • Vaginal cancer • Pelvic cancer • Stomach cancer • Throat cancer • Endometriosis • Sexually transmitted disease (STD) • Kidney stones • Gallstones • ‘Rupture’ • Laceration (‘cut’) • Bladder infection • Yeast infection • Menstruation • Normal aging • ‘Not cancer’	
Changes in the skin of the vulva	• Unspecified cause of concern/ ‘something serious’	• Unspecified STD	• Herpes • Allergic reaction to antibiotic or detergent • Unspecified cancer • Unspecified cause of no concern/ ‘nothing serious’ • ‘Not cancer’		• Cervical cancer • Ovarian cancer • Uterine cancer • Vaginal cancer • Breast cancer • Skin cancer • Throat cancer • Stomach cancer • Human papillomavirus/ ‘papilloma cancer’ • Chlamydia • Genital warts • Fibroid tumour/ cyst • Jaundice/kidney problems • Hypertension • Yeast infection • Bladder infection	

Symptoms in descending order of concern	Participants who mentioned†				
	Many	Some	Few	Very few	
					• Diet • Insect bite • Normal aging
Vaginal itching or burning	—	• Yeast infection/ infection • Unspecified cause of concern/ ‘something serious’	• Herpes • Allergic reaction to detergent or perfume • Unspecified STD • Unspecified cause of no concern/’nothing serious’ • ‘Not cancer’	• Ovarian cancer • Unspecified cancer • Diabetes • Urinary tract infection • Premenstrual syndrome • Poor hygiene • Normal aging	
Pain or pressure in the pelvic area	—	• Unspecified cause of concern/ ‘something serious’	• Cervical cancer • Ovarian cancer • Unspecified STD • Unspecified cause of no concern/ ‘nothing serious’	• Uterine cancer • Colon cancer • Breast cancer • Throat cancer • Tubal pregnancy • Arthritis • Fibroid tumour/ cyst • Appendicitis • Gallstones • Hypertension • Sciatica • Urinary tract infection • Premenstrual syndrome • Perimenopause • Menstruation • Exercise/ overexertion • ‘Gas’ • Normal aging • ‘Not cancer’	
Back or abdominal pain	—	• Unspecified cause of concern/ ‘something serious’	• Injury/ overexertion • Appendicitis • Menstruation • Normal aging • Unspecified cancer	• Cervical cancer • Ovarian cancer • Uterine cancer • Pancreatic cancer • Breast cancer • Colon cancer	

Symptoms in descending order of concern	Participants who mentioned†									
	Many		Some		Few		Very few			
					•	Unspecified cause of no concern/ ‘nothing serious’	•	Stomach cancer • Arthritis • Diabetes • Ovarian cyst • Kidney stones • Kidney disorder/ infection • Fibroid tumour/ cyst • Herniated disc • Hypertension • Premenstrual syndrome • Perimenopause • Curvature of the spine • ‘Gas’ • Diet • Lack of exercise • Pregnancy/labour • ‘Not cancer’	
Being tired all the time	—		•	Fatigue/not sleeping enough • Unspecified cause of no concern/ ‘nothing serious’	•	Diet/vitamin deficiency • Unspecified cause of concern/ ‘something serious’ • ‘Not cancer’	•	Ovarian cancer • Prostate cancer • Colon cancer • Esophageal cancer • Throat cancer • Unspecified cancer • Heart disease • Kidney stones • Anaemia • Premenstrual syndrome • Common cold • Medication side effect	
Having to pass urine very badly or more often than usual	—		—		•	Urinary tract infection • Kidney disorder/ problem • Unspecified cause of concern/ ‘something serious’	•	Ovarian cancer • Vaginal cancer • Colon cancer • Diabetes • Liver disease • Hypertension		

Symptoms in descending order of concern	Participants who mentioned†			
	Many	Some	Few	Very few
			• Unspecified cause of no concern/ ‘nothing serious’	• ‘Cyst’ • Premenstrual syndrome • Menopause • Consuming a lot of fluids • Diet • Normal aging • ‘Not cancer’
Bloating	—	—	• Ovarian cancer • Menstruation • Diet • Unspecified cancer • Unspecified cause of concern/ ‘something serious’ • Unspecified cause of no concern/ ‘nothing serious’	• Uterine cancer • Cervical cancer • Colon cancer • Stomach cancer • Fibroid tumour/ cyst • Premenstrual syndrome • Normal aging • ‘Gas’ • Pregnancy • ‘Not cancer’

*Reported underlying causes that are not generally associated with symptoms are italicized. When interpreting this table, it is important to consider that topics of less concern were the subject of fewer comments during focus groups.

†Because focus group results are not generalizable and not every participant voices an opinion on every topic discussed, the frequency of responses is described using modifiers such as ‘many’, ‘some’ and ‘few’, rather than counts or percentages.[16]

Note: — indicates there are no responses in this cell.

Table 4

Factors influencing timing of actual and hypothetical care seeking in response to symptoms

	Factor	Participants who mentioned*	Example
Care seeking within appropriate interval†	Concern that symptom indicates a serious underlying condition	Many	If I had bleeding, if I had itching or burning, if I had to go to the bathroom a lot, I'd call my gynecologist. To me, these are all the symptoms of ovarian cancer.
	Personal tendency to seek care promptly	Some	When I find something wrong, I call the doctor and I go. I don't second guess. I don't go to Google. I'm going to a doctor.
	Pain	Some	In the past I have gone to the emergency room for unbearable pain.
	Concern that symptom indicates worsening of an existing condition or the recurrence of a past condition	Few	Bloating, that would probably be number one [the most concerning symptom] because, you know, of a condition I do have. I have fibroids.
Delayed care seeking and failure to seek care	Belief that symptom is associated with a benign cause	Many	A lot of these things are normal, based on like everyday things, like what you ate or what you did. I am not concerned about those.
	Personal tendency to delay or avoid care seeking	Some	Well, I've had the bleeding after my period, and I guess because I don't like doctors, I didn't go. I just waited to see. And then I waited and waited until it finally went away.
	Cost concerns	Some	I have insurance, but my deductible is $6,000. … That affects my decision [whether or not to seek care].
	Lack of discomfort/tolerable discomfort	Few	If something is bothering me, then I am going to go [to the doctor]. If it is not it's not painful, I don't.

*Because focus group results are not generalizable and not every participant voices an opinion on every topic discussed, the frequency of responses is described using modifiers such as 'many', 'some' and 'few', rather than counts or percentages.[16]

†'Appropriate interval' was defined as 2 weeks after symptom onset for all symptoms, with the exception of unusual vaginal bleeding for which immediate care should be sought.[5]

Table 5

Strategies used to supplement or replace consultations with health care providers

Strategy	Participants who mentioned*			
	Before contacting provider	In preparation of scheduled visit	After visit	Would not use
Internet research	Many	Some	Few	Some
Self-care, including over-the-counter medication	Many	—	—	Few
Consultation with lay family members or friends	Many	Few	—	Few
Consultation with family members or friends who are medical professionals	Some	Few	—	—
Consultation with pharmacist	Few	—	—	—

*Because focus group results are not generalizable and not every participant voices an opinion on every topic discussed, the frequency of responses is described using modifiers such as ‘many’, ‘some’ and ‘few’, rather than counts or percentages.[16]

Note: — indicates there are no responses in this cell.