Journal of Cancer Education (2019) 34:1190–1197
https://doi.org/10.1007/s13187-018-1427-4

Increasing Awareness of Uterine Cancer Risks and Symptoms by Using Campaign Materials from *Inside Knowledge: Get the Facts About Gynecologic Cancer*

Daniel Novinson[1] · Mary Puckett[1] · Julie Townsend[1] · Guillermo Tortolero-Luna[2] · Jenny Rees Patterson[3] · Cynthia A. Gelb[1] · Sherri L. Stewart[1]

Abstract

Uterine cancer is the fourth most commonly diagnosed cancer among women in the USA. To increase knowledge among women and healthcare providers about uterine cancer, the Centers for Disease Control and Prevention's National Comprehensive Cancer Control Program (NCCCP) partnered with the *Inside Knowledge: Get The Facts About Gynecologic Cancer* campaign to present facilitated discussions about uterine cancer with women and providers. After standardized training, local NCCCP grantees developed and led community-based, tailored, facilitated discussions for public participants and providers. Pre- and post-session surveys were administered to assess knowledge of risk factors, symptoms, testing, and diagnostic options for uterine cancer. Following the facilitated sessions, significantly, more public respondents identified uterine cancer risk factors (e.g., advanced age, post-menopausal status). However, they also equally identified factors not associated with uterine cancer (e.g., smoking, HPV). Non-OB/GYN provider knowledge increased, significantly for some risks and symptoms, and their confidence with relaying uterine cancer information to patients significantly increased from 51.4 to 91.0% ($P < 0.0001$). Relatively low proportions of OB/GYNs (19.3%), other primary care providers (46.2%), and public participants (51.8%) knew post-session that genetic testing for Lynch syndrome can help stratify women for uterine cancer risk. Participant knowledge significantly increased for some risk factors and symptoms following *Inside Knowledge* educational sessions; however, some knowledge gaps remained. Overall, the *Inside Knowledge* materials are effective for increasing uterine cancer awareness among providers and women. Additional provider education could include specific resources related to uterine cancer genetic associations, as advancements in genetic testing for all uterine cancers are currently being made.

Keywords Uterine cancer · Health education · Cancer prevention · Comprehensive cancer control

Background

Uterine cancer is the fourth most common cancer overall among US women [8, 23]. Unlike for many other cancers, incidence of uterine cancer (specifically endometrial carcinomas) has been increasing recently [8, 23]. Numerous factors are associated with the recent increase, including increased prevalence of obesity, the aging population, and a decrease in the rate of hysterectomies in the USA [6, 14, 20–22]. In addition to increased incidence, uterine cancer survival rates are declining despite improved treatment protocols [12].

Studies have shown that many patients with gynecologic cancer symptoms do not know when to seek care, and patients and providers alike may misattribute symptoms of gynecologic cancer to more benign conditions, such as gastrointestinal upset [3, 10]. In addition, a 2011 study showed that many patients do not know how to assess their gynecologic cancer risk [3]. These factors could contribute to diagnostic delay, leading to increased morbidity and mortality from the disease.

✉ Mary Puckett
MPuckett1@cdc.gov

[1] Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Hwy, Mailstop F-76, Atlanta, GA 30341, USA

[2] Division of Cancer Control and Population Sciences, University of Puerto Rico Comprehensive Cancer Center, San Juan, Puerto Rico

[3] SciMetrika, Durham, NC, USA

Given the increasing evidence that many patients do not know risks, symptoms, or when to seek care for gynecologic cancers and the burden of uterine cancer, there is a need to increase knowledge and awareness of risk factors and symptoms of the disease among women and primary care providers. To do this, the Centers for Disease Control and Preventions' (CDC's) National Comprehensive Cancer Control Program (NCCCP) partnered with CDC's *Inside Knowledge*: *Get the Facts about Gynecologic Cancer* (*Inside Knowledge*) campaign [13, 19]. This national multimedia campaign develops and disseminates print, broadcast, display, and digital materials for women and providers, as well as provider continuing education curricula for providers. Materials address signs and symptoms, risk factors, testing, prevention strategies, and treatment for gynecologic cancers [18].

In this study, seven NCCCP grantees used *Inside Knowledge* uterine cancer materials in a community-based intervention to increase knowledge of this cancer. The intervention consisted of a facilitated discussion of these materials. The sessions were tailored to participants (both public and provider) in each of the seven areas. Knowledge, attitudes, and behaviors related to uterine cancer were measured before and after discussions.

Methods

Participants and Sessions

NCCCP awardees in Alaska, Michigan, New Jersey, Puerto Rico, Tennessee, West Virginia, and Wisconsin participated in this project. After undergoing standardized trainings designed in accordance with adult learning theory (the health belief model, the self-efficacy model, and the theory of planned behavior), these awardees were provided with standardized *Inside Knowledge* materials, and each was charged with planning public and provider-facilitated discussions and associated recruitment strategies best suited for their state or territory [1, 2, 7, 9]. Awardees used flyers, postcards, letters, e-mail, radio and newspaper ads, public service announcements, and social media to recruit participants. Participants received minimal tokens of appreciation for their time and attendance, and providers were eligible to earn continuing medical education (CME) credit. A total of 17 public and 11 provider sessions were held across the seven awardees. All participants were aged at least 18 years and provided informed consent. Public participants were limited to women only. Of the providers, only primary care providers, including internal medicine and family physicians, and obstetricians or gynecologists (OB/GYNs) were included. Other providers, including physician assistants, health assistants, and nurses, also participated in the provider sessions. All sessions and data collection were approved by the US Office of Management and Budget (approval number 0920-0800). Sessions and data collection were determined by the CDC Institutional Review Board to be public health practice and not research.

All discussion and materials were in English, with three exceptions. The Tennessee Foreign Language Institute translated the discussion, consent form, and questionnaires via earpiece for 11 Spanish-speaking attendees at the public session. In addition, Puerto Rico and New Jersey received Spanish-language *Inside Knowledge* materials upon request, and Puerto Rico conducted all sessions in Spanish.

Questionnaires

To measure changes in knowledge, attitudes, behaviors, and confidence concerning uterine cancer after facilitated discussions using *Inside Knowledge* uterine cancer materials, participants answered pre- and post-session questionnaires. Providers and public participants attended separate sessions and received separate questionnaires, and completed these questionnaires both pre- and post-session. Pre-session questionnaires were administered at the beginning of the educational sessions, prior to presentation of any *Inside Knowledge* related information, and post-session questionnaires were administered at the end of the educational sessions. All questionnaires were self-administered. Three leading health education theories drove the design of the questions: the self-efficacy model, health behavior model, and theory of planned behavior [1, 2, 7]. Questionnaires had successfully undergone usability testing and contained all close-ended questions that had either multiple choice, five-item Likert scales, or true/false responses. Usability testing for the provider and public questionnaires were performed with two primary care physicians, including an OB/GYN and an internal medicine physician and two women from different geographic locations, respectively. A protocol was developed for each questionnaire and usability testing interviews were conducted via telephone. Participants were sent the corresponding questionnaire in advance of the interview but were instructed not to open or look at the e-mail attachment until instructed to do so during the phone interview after instruction by the interviewer. Usability testing assessed the understanding of concepts in the questionnaire and wording of questions, as well as satisfaction with the overall length of the questionnaires. Revisions were made to the questionnaires based on feedback received during usability testing.

The questionnaire focused on the key uterine cancer facts and messages delivered in the training sessions, which included: knowledge of risk factors; signs and symptoms; health seeking behavior; screening and genetic testing; and confidence in providing information to patients among health care providers. Questions assessing respondents' basic demographic characteristics, public participants' educational history, and providers' practice characteristics were also included. At no time was any identifying information collected, such as name or address. All questionnaires were paper-based and filled out in the room where the discussion took place. Completed paper questionnaires were marked "pre" and "post" to distinguish the timing of the survey and for data analysis. All questionnaires were developed in English and translated into Spanish for Spanish-language sessions.

Statistical Analysis

All paper questionnaires were electronically entered into a database using Snap Survey Software (Snap Surveys; Thornbury, England), and then cross-checked to ensure data accuracy and quality. Pre-test knowledge was measured and compared with post-test knowledge. To maintain confidentiality, pre- and post-session questionnaires were not linked by individual.

In our analysis, we excluded participants who did not answer a question, answered "does not apply," or provided an invalid answer (e.g., by selecting multiple answers to a single-response question) from analysis of that particular questionnaire item. In those cases, the answers were coded as missing and excluded from the denominator in descriptive results and statistical testing. Given that nonresponse varied among questionnaire items, we chose to include surveys with partial responses, rather than excluding them entirely from the analysis. A dichotomous variable was created to bifurcate the five-point Likert scale question, with respondents either: (1) extremely or somewhat confident; or (2) neutral, or not very or not at all confident. Public and provider data were analyzed separately to assess outcomes of interest: correct knowledge of uterine cancer risk factors, signs, and symptoms; understanding that the Pap test does not screen for uterine cancer and that genetic testing can be done for risk assessment purposes; and among providers, confidence in providing information to patients about uterine cancer (Likert scale responses of extremely or somewhat confident). We hypothesized that OB/GYNs likely had increased general knowledge of uterine cancer compared to other primary care providers and nurses prior to discussions, given their specific training and practice; therefore, we dichotomized provider data into OB/GYNs and other (including all non-OB/GYN providers) for all analyses. Chi square tests or Fisher's exact test derived all P values, with all statistical tests using a significance level of alpha = 0.05. We used SAS 9.3 (SAS Institute, Inc.; Cary, NC) for all analyses. Given the small sample size at some sites, an analysis comparing sites was not attempted, nor were comparisons made between questionnaires administered in English versus Spanish.

Results

Table 1 highlights the demographic characteristics of the 499 public attendees of facilitated discussions. At least 20 public respondents came from each of the seven states or territories in the sample, with the most robust attendance in Puerto Rico (156, 31.3%) and West Virginia (146, 29.3%). Public attendees varied in age, with 32.6% under 45, 45.1% ages 45–64, and 22.3% age 65 or older. The public attendees were ethnically diverse, with 40.8% identifying as white, 37.2% identifying as Hispanic or Latino, and 14.7% identifying as black or African American. A total of 78.8% of public attendees completed some college or higher education.

Table 1 Characteristics of women attending public *Inside Knowledge* facilitated discussions

	Public, $n = 499$% (n)
Age	
< 45 years	32.6% (158)
45–54 years	21.7% (105)
55–64 years	23.4% (113)
65–74 years	16.1% (78)
75 years or older	6.2% (30)
Race/Ethnicity	
Hispanic/Latino	37.2% (177)
American Indian/Alaska Native	3.4% (16)
Asian/Native Hawaiian/Pacific Islander	1.9% (9)
Black/African American	14.7% (70)
White	40.8% (194)
Multiple race/Other	2.1% (10)
Educational level	
Some high school or less	4.7% (22)
High school graduate/GED	14.6% (68)
Some college	27.0% (126)
College graduate	20.2% (94)
Graduate studies	31.6% (147)
Other	1.9% (9)

Numbers in each category may add up to less than the total (499) due to missing responses. Participants with missing responses are excluded from the denominator

Table 2 describes the background characteristics of the 106 OB/GYNs and 259 other health care providers who attended facilitated discussions. OB/GYNs who participated were older ($P = 0.0002$) than other providers, with 20.4% aged 65 or older and 14.6% younger than 35, as compared to 4.7% and 20.1%, respectively for other providers. The OB/GYNs were 59.0% male, whereas other providers were 90.9% female ($P < 0.0001$). Nearly all OB/GYNs were Hispanic or Latino, whereas other providers identified mostly as white (58.4%) and Hispanic or Latino (20.6%, $P < 0.00001$). Other providers were mainly nurse practitioners or physician assistants, nurses or school nurses (61.4%), whereas an additional 21.6% of providers were family, general, or internal medicine doctors. The majority (68.0%) of OB/GYNs worked in both inpatient and outpatient settings, whereas most other providers (50.8%)

Table 2 Characteristics of providers attending *Inside Knowledge* facilitated discussions

	Providers		
	Obstetrician-gynecologist $n = 106$ % (n)	Other $n = 259$ % (n)	P value[a]
Age			0.0002
< 35 years	14.6% (15)	20.1% (51)	
35–44 years	12.6% (13)	18.1% (46)	
45–54 years	24.3% (25)	27.6% (70)	
55–64 years	28.2% (29)	29.5% (75)	
65+ years	20.4% (21)	4.7% (12)	
Gender			< 0.0001
Male	59.0% (62)	9.1% (23)	
Female	41.0% (43)	90.9% (229)	
Race/Ethnicity			< 0.0001
Hispanic/Latino	90.4% (94)	20.6% (53)	
Asian/Native Hawaiian/Pacific Islander	***	9.7% (25)	
Black/African American	***	9.3% (24)	
White	***	58.4% (150)	
Multiple race/Other	9.4% (10)	2.0% (5)	
Provider type			
OB/GYN	100% (100)	N/A	N/A
Family, internal, or general medicine	N/A	21.6% (56)	
Nurse practitioner/physician assistant	N/A	16.6% (43)	
Nurse	N/A	41.3% (107)	
School nurse	N/A	3.5% (9)	
Other	N/A	17.0% (44)	
Work environment			< 0.0001
Inpatient	***	8.9% (22)	
Outpatient	28.2% (29)	50.8% (125)	
Combination (inpatient/outpatient)	68.0% (70)	17.1% (42)	
School	***	11.0% (27)	
Other	3.9% (4)	12.2% (30)	
Patients seen per day			< 0.0001
< 10	6.8% (7)	24.0% (58)	
10–20	31.1% (32)	34.7% (84)	
21–30	35.9% (37)	19.0% (46)	
31–40	20.4% (21)	9.9% (24)	
41+	4.9% (5)	7.9% (19)	
Not sure	1.0% (1)	4.6% (11)	

Numbers in each category may add up to less than the total (499) due to missing responses. Participants with missing responses are excluded from the denominator. N/A: not applicable

[a] P values from chi-square tests or Fisher's exact test

*** Result reported within "other" to preserve confidentiality

worked exclusively in outpatient settings ($P < 0.0001$). OB/GYNs usually saw an average of 10–40 patients daily (87.4%), whereas 24.0% of other providers saw fewer than 10 patients daily.

Table 3 details public participants' knowledge and behaviors related to uterine cancer before and after facilitated discussions. Significantly, more public respondents (53.7% pre-session, 64.6% post-session, $P = 0.0010$) correctly identified peri- or post-menopausal status as the greatest risk factor for uterine cancer after facilitated discussion. However, significantly, more participants also identified factors not associated with increased risk for uterine cancer (smoking, having

Table 3 Public knowledge and behaviors related to uterine cancer

Question	Public, $n = 499$		
	Pre-session % (*n*)	Post-session % (*n*)	*P* value[a]
Risk factors			
Correct			
Most uterine cancers occur in women of peri-/post-menopausal status	53.7% (233)	64.6% (288)	0.0010
HPV does not cause uterine cancer	64.2% (296)	52.8% (237)	0.0005
Incorrect			
Most uterine cancers occur in women having never been pregnant	42.6% (185)	66.4% (296)	< 0.0001
Having multiple sexual partners	63.4% (275)	67.0% (299)	0.2523
Smoking	42.6% (185)	79.2% (353)	< 0.0001
Signs, symptoms, and behaviors			
Pelvic pain/pressure	73.3% (334)	89.4% (389)	< 0.0001
Abnormal bleeding or discharge	95.4% (435)	97.0% (422)	0.2080
Seek medical care if symptoms last for 2 weeks	25.1% (113)	69.2% (297)	< 0.0001
Seek immediate care for abnormal bleeding or discharge	97.6% (452)	97.9% (417)	0.7915
Screening/testing			
Pap test does not screen for uterine cancer	74.6% (353)	82.0% (365)	0.0067
Genetic testing for uterine cancer	48.2% (206)	51.8% (216)	0.3017

Numbers in each category may add up to less than the total (499) due to missing responses. Participants with missing responses are excluded from the denominator

[a] *P* values from chi-square tests or Fisher's exact test

multiple sex partners) as being associated, and fewer participants correctly identified that HPV does not cause uterine cancer post-session (64.2% pre-session, 52.8% post-session, $P < 0.0005$). With regard to symptoms, significantly, more women correctly identified pelvic pain or pressure as a symptom (73.3% pre-session, 89.4% post-session, $P < 0.0001$). After the facilitated discussion, there was also a large increase among those who said they would seek medical care for signs or symptoms lasting longer than 2 weeks (25.1% pre-session, 69.2% post-session, $P < 0.0001$). Significant increases were not observed for seeking care for abnormal bleeding or discharge as a symptom. However, knowledge was very high for these factors pre-session (> 95%) among participants, so only incremental increases were observed. With respect to screening and testing available for uterine cancer, increases were seen in the number of women who correctly identified that the Pap test does not screen for uterine cancer post-session (74.6% pre-session, 82.0% post-session, $P = 0.0067$), but the overall number of women aware that genetic testing for Lynch syndrome is available for uterine cancer remained low post-session (48.2% pre-session, 51.8% post-session, $P = 0.3017$).

Table 4 outlines providers' knowledge and attitudes related to uterine cancer pre- and post-session. OB/GYN knowledge did not significantly improve during the session for all factors measured; however, it was high (above 90%) pre-session for knowledge about abnormal bleeding and discharge symptoms, that HPV does not cause uterine cancer, and that the Pap test does not screen for uterine cancer. In addition, these participants noted a high level of confidence in their ability to inform patients about uterine cancer. Among these same participants, knowledge was relatively low pre-session (22.1%) and post-session (26.7%) for post-menopausal status as the single greatest risk factor. Knowledge remained low for Lynch syndrome genetic testing availability for uterine cancer regardless of session (22.1% and 19.3%, respectively).

In contrast, large and significant increases in knowledge were seen among non-OB/GYN providers. The proportion of non-OB/GYN providers correctly identifying that advanced age or post-menopausal status is the greatest uterine cancer risk factor (28.5% pre-session, 42.0% post-session, $P < 0.0001$) and that abnormal bleeding or discharge is an associated symptom (80.4% pre-session, 87.7% post-session, $P = 0.0248$) increased significantly. Knowledge that HPV does not cause uterine cancer and that the Pap test does not screen for uterine cancer remained unchanged. Knowledge that Lynch syndrome genetic testing is available for uterine cancer did increase significantly among non-OB/GYN providers, but still remained low post-session (32.0% pre-session, 46.2% post-session, $P = 0.0011$). In addition, many more non-OB/GYN providers expressed confidence that they had enough information to inform their patients about uterine

Table 4 Providers' knowledge and attitudes related to uterine cancer

Question	Provider					
	Obstetrician-gynecologist, *n* = 106			Other, *n* = 259		
	Pre-session % (*n*)	Post-session % (*n*)	*P* value[a]	Pre-session % (*n*)	Post-session % (*n*)	*P* value[a]
Risk factors[a]						
Correctly identified advanced age/post-menopausal status as greatest risk factor	22.1% (23)	26.7% (24)	0.1744	28.5% (72)	42.0%[b] (105)	< 0.0001
HPV does not cause uterine cancer	94.3% (99)	94.4% (84)	0.9769	77.0%[b] (198)	79.5%[c] (202)	0.4958
Signs and symptoms						
Pelvic pain/pressure	58.8% (60)	64.4% (58)	0.4245	70.1%[c] (176)	71.4% (180)	0.7469
Abnormal bleeding or discharge	91.4% (95)	93.3% (83)	0.6209	80.4%[c] (205)	87.7% (221)	0.0248
Screening/testing						
Pap test does not screen for uterine cancer	97.1% (102)	97.7% (84)	1.0000	88.3%[b] (227)	91.5% (227)	0.2320
Genetic testing for uterine cancer	22.1% (23)	19.3% (17)	0.6344	32.0% (80)	46.2%[c] (116)	0.0011
Confidence						
Confidence I have enough information to inform my patients about uterine cancer[d]	93.1% (94)	98.9% (89)	0.0682	51.4%[c] (130)	91.0%[b] (223)	< 0.0001

Numbers in each category may add up to less than the total (499) due to missing responses. Participants with missing responses are excluded from the denominator

[a] *P* values from chi-square tests or Fisher's exact test

[b] Significantly ($P < 0.05$) differs from percent of OB-GYNs with given post-session answer

[c] Significantly ($P < 0.05$) differs from percent of OB-GYNs with given pre-session answer

[d] % somewhat confident, extremely confident

cancer (51.4% pre-session, 91.0% post-session, $P < 0.0001$) post-session.

Discussion

Knowledge and behaviors related to uterine cancer increased overall after participation in *Inside Knowledge* facilitated discussions. However, there were some differences noted between participant groups. Public participant knowledge of signs and symptoms of uterine cancer and related behavioral intentions increased post-session, but incorrect identification of uterine cancer risk factors increased, as well. In addition, knowledge of select uterine cancer risk factors remained low for both OB/GYNs and other providers' post-session, and OB/GYNs did not significantly improve their knowledge of uterine cancer signs and symptoms following facilitated discussions. OB/GYN confidence with information related to uterine cancer was high pre- and post-session, and confidence in ability to discuss uterine cancers significantly increased among other providers post-session.

Although knowledge among the public of signs and symptoms and positive behavioral intentions increased after attending facilitated discussions, knowledge of select risk factors did not. In addition, with respect to risk factors, more participants reported incorrect risk factors, such as smoking, after participating in facilitated discussions than they did pre-session, highlighting areas of confusion that may need to be addressed with additional and more specific educational efforts in the future. Communities may also consider tailoring messages around uterine cancer risk to their particular populations so that accurate information is conveyed in a clear, understandable way. Because uterine cancer is increasing, resources that clearly define factors that increase risk may be helpful. One such area communities may consider addressing is obesity because of the association of obesity with uterine cancer risk, and there are many evidence-based strategies available that communities can consider on the basis of their specific needs and resources available [16, 24].

Non-OB/GYN providers demonstrated increased knowledge and confidence after participating in facilitated discussions, indicating that the *Inside Knowledge* materials were effective for them. These gains seen among non-OB/GYN providers are particularly encouraging given that often they are the first providers women see for symptoms potentially related to uterine cancer. Although OB/GYN providers have higher knowledge in general, they could benefit from specific additional educational resources, particularly on Lynch syndrome.

A low proportion of all participants (public and providers) knew post-session that genetic testing can stratify women's uterine cancer risk, indicating that both women and providers may need more education on this particular topic. Lynch syndrome, a genetic syndrome that can be identified through genetic testing, is found among approximately 2.3% of women presenting with uterine or colon cancer [17]. Because of the hereditary nature of Lynch syndrome, screening of high-risk individuals and cancer patients for genetic conditions predisposing to cancer is important not only for the patient with known cancer, who may be able to prevent cancers in other organs, but also for unaffected relatives, who can become aware of the benefits of genetic testing themselves. Screening for Lynch syndrome among colorectal cancer patients and their family members has been shown to be cost-effective [11]. Further, Lynch syndrome screening among endometrial cancer patients up to 70 years of age has also been shown to be cost-effective for the purpose of preventing colorectal cancer in patients and their relatives, and universal screening is recommended by some groups [4, 5, 15]. Although there are no government recommendations yet around Lynch syndrome screening for uterine cancer, evidence is growing about its effectiveness, and NCCCP programs need to be aware of the associations of Lynch syndrome and uterine cancer so they are prepared to support screening practices if and when recommendations are made.

Our analysis was subject to several limitations. Participants completed questionnaires immediately after sessions, and thus any measured knowledge gains may reflect immediate recall, as opposed to longer-term retained knowledge. In addition, social desirability bias could have affected answers of participants to questions related to their behavioral intentions and confidence, causing them to overstate agreement with statements presented. Finally, because missing data varied among awardee data sets, our results could have been potentially biased if non-respondents would have answered items differently than respondents who answered all survey items.

The results of this study point to several key opportunities for NCCCP programs and state and local public health practitioners in their communities. The *Inside Knowledge* campaign materials were effective in increasing knowledge around many aspects of uterine cancer, and can serve as a resource to improve uterine cancer knowledge in the community. However, to increase their effectiveness, public health programs may need to look at their unique populations to identify how best to educate their communities. NCCCP awardees have ample knowledge of the needs of their communities and experience in providing tailored outreach for cancer prevention and control [13, 19]. With this expertise, awardees can create educational resources for their particular populations. Further, programs can identify ways to present specific information on uterine cancer to the women and providers in their communities to increase knowledge and awareness of this common cancer among all.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Financial Disclosure No financial disclosures were reported by the authors of this paper.

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