| Awareness of symptoms and risk factors of ovarian cancer in a population of | | | | |
|--|--|--|--|--|
| women and health care providers | | | | |
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Precis

- A lack of awareness of the symptoms and risk factors for ovarian cancer is prevalent
- 32 among women and health care providers.

Abstract

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35 Objective: Despite ovarian cancer awareness campaigns, awareness among women 36 and health care providers is poor. The objective of this study was to determine the 37 level of awareness among a sample of women and providers and compare these two 38 populations. 39 *Methods*: Surveys were administered to women and health care providers attending 40 or volunteering at a community health fair. Survey questions were based on 41 previously published surveys. Survey responses and demographic information was 42 collected. SPSS, Chi-square test for independence and z-test were used for analysis. 43 Results: Over 2200 women and providers were surveyed and 857 women and 188 44 providers completed surveys. The majority of women were white, non-Hispanic 45 (80%) 40-59 years of age (50%) and had a college education (55%). The majority of 46 providers were nurse practitioners (48%) and under 40 years of age (33%). Health 47 care providers were significantly more likely to identify the symptoms and risk 48 factors for ovarian cancer (p<0.001). Forty percent of women reported being at 49 least slightly familiar with the symptoms of ovarian cancer. Women who were 50 familiar with symptoms were significantly more likely to identify symptoms and 51 risk factors correctly (p<0.001) and to report symptoms immediately to a provider 52 (p=0.011), although overall identification of symptoms was poor, ranging from 25-53 72%. Identification of symptoms among health care providers ranged from 59-93%. 54 Conclusions: Identification of ovarian cancer symptoms and risk factors is poor 55 among women and knowledge deficits are present are present in providers. 56 Increasing familiarity and awareness could lead to improvements in early diagnosis.

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Introduction

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Ovarian cancer is responsible for more deaths per year than all other gynecological cancers combined. The American Cancer Society estimates that 22,240 women will be diagnosed with ovarian cancer and 14, 230 are expected to die from it in 2013 [1]. In the U.S., the average five-year survival rate is 35% when diagnosed at stage IIIC, which accounts for 75% of initial diagnoses [1]. Women diagnosed at an early stage have a higher five-year survival rate, however, _because there is currently no accepted, reliable screening test, only 15% of women with ovarian cancer are diagnosed early ([2, 3]). Ovarian cancer has an insidious onset, and signs and symptoms are vague and nonspecific. Symptoms include bloating, pelvic or abdominal pain, frequent urination and early satiation or difficulty eating [[4]]. Women associate these symptoms with a variety of every day conditions and therefore often do not seek medical care ([5]). This results in the delay of diagnosis and most patients present with advanced disease ([6]). Nonetheless, most women recall having symptoms before diagnosis ([4]). When they consult their HCP, they report being prescribed medication for abdominal discomfort without thorough investigation of all complaints [[4, 7]]. Numerous national ovarian cancer organizations cite "raising awareness" in their mission statements. However, there have been few studies on the levels of awareness among women. Those that have been done have shown that women in

the general population are not aware of, or have low awareness of the symptoms of

81 ovarian cancer [[3, 8-10]]. There is also evidence that many primary care providers 82 do not follow up with patients who complain of these symptoms ([3], [8], [11], [12]). 83 Therefore, the importance of raising awareness and increasing knowledge of these 84 symptoms among women and primary care providers cannot be overstated. 85 86 The primary purpose of this study was to establish and compare the current level of 87 awareness of ovarian cancer symptoms and risk factors among 1) a population of 88 women seeking health care screening and 2) HCPs. We hypothesized that, in spite of 89 numerous efforts, women and HCPs continue to have knowledge deficits about the 90 signs and symptoms of ovarian cancer. 91 92 **Materials and Methods** 93 Survey Development 94 Surveys were developed for women and HCPs (see Appendix 1 & 2). Questions were 95 developed based on data from previously published studies [4, 9], with the addition 96 of a question inquiring a woman's ability to finish a meal, as this was frequently 97 observed in our practice. (Question 1m or 2m, see Appendix 1&2). Three incorrect 98 symptoms were added to examine possible response bias. Surveys were 99 administered in English and Spanish. 100 The survey for HCPs was similar to that distributed to women and contained 101 questions regarding their knowledge about the symptoms and risk factors for 102 ovarian cancer. General demographic information was collected from all 103 participants.

Recruitment

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The 9Health Fair, a not-for-profit organization in the state of Colorado, performs free health screenings annually. These events take place at over 140 sites in rural and urban areas, with over 87,000 attendees and 14,000 volunteers annually. Approximately one-half of the volunteers are health care professionals. Of those seeking screening in 2013, approximately 59% were women (Personal communication, C. Belz, 2013). Eleven sites were selected based on projected high attendance and a representative sample of counties across the state of Colorado. The first 200 women and all HCPs presenting at each selected site were surveyed. In addition, one primary care clinic and all providers in two women's health clinics were asked to complete the survey. The 9Health Fair Medical Advisory Board and the institutional review board at the University of Colorado approved the study. StatisticsThe data were analyzed using SPSS Ver.21. Chi square tests for independence was performed on speed of reporting symptoms by the presence or absence of having a regular health care provider. Z-tests were performed for comparisons of women's awareness of symptoms to HCP's knowledge and for the comparison of women familiar with symptoms to those who were not. Ninety-five percent confidence intervals were also computed for each difference between the women's and HCP's proportions._A power analysis was not performed due to the exploratory nature of

Results

this study.

| 127 | Demographics |
|-----|--|
| 128 | Women |
| 129 | There were 857 women who completed the survey. However, two questions were |
| 130 | inadvertently omitted on 256 surveys. Therefore, the results for these two |
| 131 | questions are reported for 601 women. Based on attendance, approximately 2200 |
| 132 | women received the survey with a response rate of approximately 39%. |
| 133 | |
| 134 | The women's demographic information is presented in Table 1Most women were |
| 135 | 40-59 years of age (50%) self-identified as white, non-Hispanic (80%) and were |
| 136 | college educated_(55%). More than a third (37%) of respondents said they knew |
| 137 | someone with ovarian cancer and 1% reported being_diagnosed with ovarian cancer_ |
| 138 | |
| 139 | Health Care Providers |
| 140 | For Health Care Providers (HCP), 188 completed the survey with 40 of these self- |
| 141 | described as family practice physicians, 52 as nurses, 34 as nurse practitioners and |
| 142 | six obstetricians/gynecologists. The largest group of HCPs was under 40 years of age |
| 143 | (33%). |
| 144 | |
| 145 | Comparison of awareness of symptoms_and risk factors |
| 146 | The ability to recognize the signs and symptoms of ovarian cancer for both HCPs |
| 147 | and women is presented in Table 2. For each symptom presented, HCPs were |
| 148 | significantly more knowledgeable than the women_Pelvic or abdominal pain, along |
| 149 | with bloating or abdominal swelling was recognized as indicative of ovarian cancer |
| | |

150 more than any other symptoms. The inability to finish a meal was the least correctly 151 identified symptom with only 59.5% of HCPs and 25.1% of women indicating this as 152 a symptom of ovarian cancer._There was no significant difference between the two 153 groups for frequent headaches and continuous fever. HCPs were more accurate in 154 indicating that an abnormal Papanicolaou (Pap) test was not a symptom of ovarian 155 cancer compared to the women (p<0.001). 156 157 Identification of risk factors is listed in Table 3. Five of the six factors are known risk 158 factors for ovarian cancer ([13], [14], [15], [16], [17]) with the effect of high dose 159 estrogen without progesterone on ovarian cancer unknown [[18]]. Personal or 160 family history of ovarian, breast or colon cancer was identified as a risk factor more 161 than any other for both groups, with 90.9% of HCPs and 83.5% of women correctly 162 identifying this risk factor. HCPs were significantly more knowledgeable compared 163 to the women's group_for each risk factor with the exception of high dose estrogen. 164 165 Women's knowledge of symptoms 166 A total of 303 (40%) women were at least slightly familiar with the symptoms of 167 ovarian cancer. Women who self-reported as familiar with ovarian cancer 168 symptoms were significantly more accurate with the identification of symptoms for 169 ovarian cancer as compared to women unfamiliar with ovarian cancer symptoms 170 (Table 4). For the three non-ovarian cancer symptoms, there was no significant 171 difference between groups.

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Women's speed of reporting symptoms

In order to ascertain if familiarity with ovarian cancer symptoms translated into earlier reporting of suspicious symptoms to one's doctor, women reporting each symptom immediately were compared by familiarity level. When women were asked which symptoms they would report to their doctor immediately, there was no difference between women who described themselves as familiar and those who were not familiar with ovarian cancer for every symptom with the exception of pelvic or abdominal pain. In that case, the proportion of those who were familiar with ovarian cancer reporting the symptom immediately was significantly greater than those who were not familiar (z=2.55, p=0.0108).

In this study, 663 (81%) women reported having a regular health care provider. The reporting of several symptoms of ovarian cancer_was found to be significantly related to the presence or absence of having a HCP_by chi-squared analysis. An unexplained weight gain or loss (p_=0.006), difficulty eating or feeling full quickly (p =_0.026), unexplained changes in bowel habits (p_=0.022), continuous fever (p_= 0.004), ongoing unusual tiredness (p<0.001) were more quickly reported_for those women who had a regular HCP. There were not significant associations between speed of reporting and having a regular HCP for all other listed symptoms and tests_

Women's knowledge of risk factors

Women's knowledge of ovarian cancer risk factors separated by familiarity with ovarian cancer symptoms is presented in Table 5. Women familiar with symptoms of ovarian cancer were significantly more likely to identify risk factors correctly

except for the unknown factor of high dose estrogen. For both groups, personal or family history of cancer were identified as an ovarian cancer risk factor more often than the other listed factors, as 90% of familiar women and 80% of unfamiliar women were able to identify this risk factor.

Discussion

This study showed over half of the women sampled were unfamiliar with the symptoms of ovarian cancer. Health care providers, although more familiar, were unable to identify all symptoms of ovarian cancer or all risk factors correctly. Our study is one of the largest surveys to measure the level of awareness of ovarian cancer symptoms in a sample of women and compare it to health care providers.

We found familiarity with the symptoms of ovarian cancer to be low with only 14% of women reporting being very familiar or familiar with the symptoms. Forty percent of women reported being at least slightly familiar with the symptoms of ovarian cancer. Similar findings have been reported elsewhere [[9], [19], [20], [21]). Lockwood et al., conducted a national mail survey of women and found the level of awareness of ovarian cancer symptoms to be 15%, although 52% of the sample had previously had breast cancer [[9]]. Even among an at risk population, Anderson et al., reported a low level of awareness (24%) of ovarian cancer symptoms ([21]).

Although symptom identification was relatively poor overall among the women sampled, pelvic discomfort or pain was correctly identified by 70% of women, but

| 219 | gastrointestinal and genitourinary symptoms were poorly identified. In a telephone |
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| 220 | survey of women in the United Kingdom, Low et al., found poor recognition of |
| 221 | difficulty eating or feeling full as symptoms of ovarian cancer in this population |
| 222 | [[22]]. Pap test abnormalities are frequently wrongly identified as a sign of ovarian |
| 223 | cancer, as noted by Jones et al., and Hawkins et al., ([23])In our study, the Pap test |
| 224 | was misidentified by 58% of the women. |
| 225 | |
| 226 | Although health care providers were able to identify symptoms more accurately |
| 227 | than women, knowledge deficits were still found. The inability to finish a meal and |
| 228 | early satiety were only identified by 59% and 64% respectively. Misconceptions |
| 229 | about the Pap test persisted within this group as well, with 33% incorrectly |
| 230 | identifying an abnormal pap test as a symptom of ovarian cancer. Gajjar et al., have |
| 231 | previously addressed this general lack of awareness among primary care physicians |
| 232 | showing that these physicians poorly identified gastrointestinal symptoms as alerts |
| 233 | to ovarian cancer ([2]). |
| 234 | |
| 235 | Identification of risk factors was high among HCPs with over 80% identifying family |
| 236 | history and genetic disposition as risk factors. In spite of this and the moderate |
| 237 | knowledge of the symptoms of ovarian cancer, delays in diagnosis occur frequently |
| 238 | ([5, 8, 11, 12]) |
| 239 | |
| 240 | This population did not report a significant barrier to care as 81% reported having a |
| 241 | regular primary care physician. Symptoms are frequently reported to HCPs many |

months before women are diagnosed with ovarian cancer with up to 93% of women reporting symptoms prior to diagnosis ([24]). The notion of ovarian cancer as a "silent killer" has been debunked by numerous studies. Our study showed that the presence of a primary care physician improved recognition of symptoms and also improved early reporting of some symptoms.

There are several strengths to this study. The relatively large sample size of women and providers from both urban and rural settings allows generalization of the results to a broader population. We were able to compare HCPs and women's level of awareness of the symptoms and risk factors for ovarian cancer within a geographic region, which can help to focus the development of educational interventions in the future.

Limitations of this study include the use of a convenience sample of individuals presenting to a health fair, which presents a source of response bias. Additionally, two questions were inadvertently left off some of the surveys potentially biasing the responses to those specific questions. Furthermore, although sample numbers were relatively large, the sample did not accurately represent the geographic area in terms of racial or educational level ([25]). Overall, more participants in our study had college and postgraduate degrees than the general population of Colorado or the United States_(55% vs 36%_vs_29.1%) (U.S. Census Bureau, 2013). Although it might be assumed that this sample of women is more motivated to care for their health, they still had low levels of awareness of the symptoms of ovarian cancer. The

| sample of HCPs was drawn from those participating in the health fair, which may |
|---|
| indicate a bias to providers who are especially interested in health care screening |
| and prevention. The majority of HCPs sampled were nurse practitioners and family |
| practitioners, which may not accurately represent the number of types of providers |
| caring for women in the community ([26-28]). |
| |
| This study demonstrates the lack of awareness and knowledge among women about |
| the symptoms of ovarian cancer as well as deficits in awareness among providers. |
| Ovarian cancer_is no longer the silent killer it was once thought to be and has |
| repeatedly been shown to cause symptoms prior to diagnosis even in early stages |
| [[4, 24, 29]]. Health care providers must be taught and encouraged to query women |
| at all health care encounters about symptoms of ovarian cancer. The incorporation |
| of symptoms into medical curricula has been done, although penetration to older |
| generations is lacking. An educational campaign, the <i>In the Know Campaign</i> |
| developed by the Centers for Disease Control, is currently underway for all |
| gynecologic malignancies_and is a step in the right direction_([30])However, |
| funding for further development of interventions specifically for ovarian cancer is |
| uncertain and greater efforts are needed on the local and national levels. The |
| declaration of September as Ovarian Cancer Awareness Month is encouraging, but if |
| increased awareness is to be achieved, a higher investment of funds, energy and |

effort is required.

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370 Table 1. Women and Provider Participant Demographics

| Demographics | Percentage (n) |
|---------------------------------|--------------------------------------|
| | $\frac{1}{\text{(total n = 857)}^a}$ |
| Women | |
| Age | |
| Under 40 years | 18 (145) |
| 40-59 years | 50 (417) |
| 60 and over years | 32 (261) |
| Race | |
| White | 80 (649) |
| Latina/Hispanic | 15 (121) |
| African American | 2 (18) |
| _Other | 3 (26) |
| <u>Education</u> | |
| College/Post-graduate | 55 (439) |
| Some College | 29 (234) |
| High School or less | 16 (128) |
| Familiarity with Ovarian Cancer | |
| Knew someone | 37 (309) |
| Didn't know someone | 63 (518) |
| Health Care Providers | (total n=188) ^a |
| <u>Specialty</u> | |
| Family Practitioner | 22 (40) |
| Nurse/Nurse Practitioner | 48 (86) |
| Obstetrician/Gynecologist | <u>3 (6)</u> |
| <u>Other</u> | <u>27(46)</u> |
| Age | |
| Under 40 years | 33 (60) |
| _40-49 years | 24 (44) |
| _50-59 years | 26 (48) |
| 60 and over years | 17 (31) |

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^aDifferences in total number due to missing response data

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373 Table 2. Identification of symptoms of ovarian cancer

| Crimintoni | Dancont | Dangant | Domaont | 95% | 2-sided |
|---------------------|-----------------------------------|-------------------------|-----------------------|--------------------|-------------------|
| <u>Symptom</u> | Percent | <u>Percent</u> | Percent Difference | Confidence | |
| | HCPs (n) | <u>Women</u> | | Interval of | <u>p-value-</u> |
| | <u>Total N =</u> 188 ^b | <u>(n)</u> Total N = | Between HCPs and | Difference | |
| | 1000 | 857 ^b | Women | Difference | |
| Frequent or | 60.9 (112) | 23.3 (194) | 37.6 | 29.8, 44.9 | <0.001 |
| urgent need to | 00.9 (112) | 23.3 (194) | 37.0 | <u> </u> | <0.001 |
| urinate | | | | | |
| Bloating; pelvic | 90.4 (170) | 72.2 (613) | 18.2 | 12.5, 22.9 | <0.001 |
| or abdominal | 70.4 (170) | 72.2 (013) | 10.2 | 12.3, 22.7 | <0.001 |
| swelling | | | | | |
| Unexplained | 89.2 (166) | 55.5 (467) | 33.7 | 27.6, 38.8 | < 0.001 |
| weight gain or | 07.2 (100) | 33.3 (407) | 33.7 | 27.0, 30.0 | <u> <0.001</u> |
| loss | | | | | |
| Difficulty eating | 64.1 (116) | 33.0 (275) | 31.1 | 23.2, 38.4 | <0.001 |
| or feeling full | 01.1 (110) | 33.0 (273) | 31.1 | 23.2, 30.1 | 30.001 |
| quickly | | | | | |
| Vague or | 80.1 (149) | 52.1 (442) | 28.0 | 20.8, 34.1 | < 0.001 |
| persistent | | | | | |
| stomach | | | | | |
| discomfort such | | | | | |
| as gas, nausea or | | | | | |
| indigestion | | | | | |
| Unexplained | 73.0 (135) | 41.6 (350) | 31.4 | 23.8, 38.1 | < 0.001 |
| changes in bowel | | | | | |
| <u>habits</u> | | | | | |
| Ongoing unusual | 81.1 (150) | 48.4 (403) | 32.7 | <u>25.6, 38.7</u> | < 0.001 |
| <u>tiredness</u> | | | | | |
| Pelvic or | 93.6 (117) | 70.9 (429) | <u>22.7</u> | <u>17.3, 32.2</u> | < 0.001 |
| abdominal pain | | (n=601)a | | | |
| Inability to finish | <u>59.5 (75)</u> | <u>25.1 (151)</u> | 34.4 | <u>25.0, 43.2</u> | < 0.001 |
| a meal you would | | (n=601)a | | | |
| ordinarily be able | | | | | |
| <u>to finish</u> | | | | | |
| <u>Frequent</u> | <u>13.7 (25)</u> | <u>14.8 (124)</u> | <u>-1.1</u> | <u>-5.1, 6.1</u> | 0.704 |
| headaches (Not a | | | | | |
| symptom of OC) | 00.0.57.13 | 00.0.5100 | 7 0 | 0.0.11: | 0.041 |
| Continuous fever | 29.0 (54) | 22.0 (182) | 7.0 | 0.0, 14.4 | 0.041 |
| (Not a symptom | | | | | |
| <u>of OC)</u> | 00 (((1) | (10.00 | 0.7.1 | 200 170 | 0.004 |
| Abnormal Pap | 32.6 (61) | 57.7 (490) | <u>-25.1</u> | <u>-32.2, 17.3</u> | < 0.001 |
| test (Not a | | | | | |
| symptom of OC) | | | | | |

374 a This question was inadvertently left off 256 surveys

375 <u>b Totals varied slightly due to missing values.</u>

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Table 3. Identification of risk factors for ovarian cancer

| Risk Factor | Percent HCP (n) Total N = 188 ^b | Percent Women Total N – 857b | Percent Difference | 95% Confidence Interval for the Difference | 2-sided asymptotic p-value |
|---|---|--|---------------------------|--|----------------------------------|
| Personal or family history of ovarian, breast | 90.9 (170) | 83.5 (707) | 7.4 | 1.9, 11.7 | 0.011 |
| or colon cancer Genetic predisposition | 84.8 (156) | 74.8 (628) | 10.0 | 3.5, 15.4 | 0.004 |
| Increasing age Use of high dose estrogen | 71.4 (132) 50.0 (92) | <u>44.1 (368)</u> <u>45.3 (380)</u> | <u>27.3</u> <u>4.7</u> | <u>19.5, 34.1</u> -3.2, 12.6 | <u><0.001</u> <u>0.250</u> |
| without progesterone a Obesity | 61.3 (114) | 34.6 (291) | 26.7 | 18.8, 34.0 | <0.001 |
| <u>Undesired</u> <u>infertility</u> | 41.9 (78) | 25.7 (216) | 16.2 | 8.7, 24.0 | <0.001 |

378 a Unknown effect on risk of ovarian cancer

379 <u>b Totals varied slightly due to missing values</u>

380

381

Table 5. Women's knowledge of ovarian cancer risk factors by self reported

382 <u>familiarity with symptoms</u>

| Risk factors | <u>Total</u> | Familiar with | <u>Unfamiliar</u> | <u>p-value</u> |
|------------------------|--------------|---------------|-------------------|----------------|
| | <u>N=759</u> | OC symptoms | with OC | |
| | | N=303a | symptoms | |
| | | | N=456a | |
| | <u>% (n)</u> | <u>% (n)</u> | <u>% (n)</u> | |
| Personal or family | 83.9 (630) | 90.4 (273) | 79.5 (357) | < 0.001 |
| history of ovarian, | | | | |
| breast or colon cancer | | | | |

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| Genetic | 75.3 (561) | 84.8 (251) | 69.0 (310) | < 0.001 |
|------------------------------|-------------------|------------|-------------------|---------|
| <u>predisposition</u> | | | | |
| Increasing age | 43.9 (325) | 48.6 (144) | 40.8 (181) | 0.034 |
| Use of high dose | 45.1 (335) | 48.8 (144) | 42.6 (191) | 0.097 |
| estrogen without | | | | |
| progesterone | | | | |
| (Unknown if risk | | | | |
| <u>factor</u>) | | | | |
| <u>Obesity</u> | 34.4 (256) | 42.8 (127) | <u>28.8 (129)</u> | <0.001 |
| <u>Undesired infertility</u> | <u>25.1 (187)</u> | 30.9 (92) | 21.3 (95) | 0.003 |

a Totals varied slightly due to missing values

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