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Signs of Aging or the Vague Symptoms of Ovarian Cancer?

Anita Smith, PhD, RN, Rodney P. Rocconi, MD, and Michael A. Finan, MD, FACS

Diagnosing ovarian cancer at an early stage is difficult because symptoms can be associated with common, benign conditions. Women experience physical symptoms including bloating, frequent urination, and abdominal pain prior to an ovarian cancer diagnosis (Goff et al., 2007; Goff, Mandel, Melancon, & Muntz, 2004). These and other symptoms are commonly referred to as the “vague symptoms of ovarian cancer” (Goff et al., 2004; Jayde, White, & Blomfield, 2009–2010). Women with ovarian cancer shared their personal stories and mentioned the need to consider feelings and listening to one’s body and intuitions (Smith, 2008). Feelings that occur at the same time as the vague physical symptoms of ovarian cancer may be influential in a woman’s decision to seek medical care. The purpose of the current study was to explore the feelings that occurred at the same time as the vague physical symptoms of ovarian cancer.

Background and Significance

The vague and early symptoms of ovarian cancer are discussed extensively in the research literature. However, a lack of knowledge is noted regarding the signs and symptoms of ovarian cancer among women (Lockwood-Rayermann, Donovan, Rambo, & Kuo, 2009) as well as physicians (Schorge et al., 2010). Nurses’ knowledge of ovarian cancer symptoms is not noted in the literature, and discussions of women’s feelings relate primarily to the impact of an ovarian cancer diagnosis (Fitch, Gray, & Franssen, 2000) rather than feelings experienced prior to the diagnosis of cancer.

The literature clearly defines the early and vague symptoms noted by women prior to the diagnosis of ovarian cancer. Although few women (5%–10%) are asymptomatic, most experience symptoms for a period of time before a diagnosis (Jayde et al., 2009–2010). The four key symptoms experienced by women diagnosed

Purpose/Objectives: To explore the feelings that occurred at the same time as the vague physical symptoms of ovarian cancer.

Research Approach: Qualitative, descriptive methodology.

Setting: University cancer institute in southeastern United States.

Participants: 24 women (ages 39–78) diagnosed with ovarian cancer. Most were Caucasian, were diagnosed at stage II–III, had a college-level education, and had health insurance. Eighty-three percent did not know the signs and symptoms of ovarian cancer prior to diagnosis, and 91% had no family history of the cancer.

Methodologic Approach: SPSS® (version 18.0) was used to summarize the demographic characteristics and qualitative descriptive content analysis to identify and summarize themes in the narrative data.

Findings: Two themes were noted in the handwritten answers provided by the women: (a) “thought symptoms were aging” and (b) “felt or knew something was not right.”

Conclusions: Findings demonstrate and reinforce that a need exists for education regarding signs and symptoms of ovarian cancer among the general population as well as the common providers of women’s health care.

Interpretation: Education campaigns on signs and symptoms of ovarian cancer and normal aging are necessary so women are empowered with knowledge and healthcare providers can suspect and evaluate the symptoms.

with early- or late-stage ovarian cancer are bloating, pelvic or abdominal pain, frequent or urgent urination, and difficulty eating or early satiety (Devlin et al., 2010). The type and frequency of symptoms experienced are even delineated to the stage of ovarian cancer at diagnosis (Koldjeski, Kirkpatrick, Swanson, Everett, & Brown, 2003). For example, the symptom pattern noted in stage I–II relates to gastrointestinal (GI) symptoms (bloating, indigestion, painful spots, and fatigue); in stage III–IV, symptoms include other organs and systems (abdomen pain, chest pain,

back pain, lower GI tract pain, and fluid in abdomen) (Koldjeski et al., 2003).

Goff et al. (2007) developed an ovarian cancer symptom index through a survey of 23 common symptoms. The participants included women who were having an ultrasound or undergoing surgery for a pelvic mass and healthy women who were at high risk for ovarian cancer and enrolled in an ovarian cancer early-detection study. Women rated the severity, frequency, and duration of symptoms. Pelvic or abdominal pain, increased abdominal size or bloating, difficulty eating or satiety, and frequent or urgent urination were significantly associated with ovarian cancer. The frequency and onset of a symptom also were important. Patients with cancer experienced the symptoms 20–30 times per month, severity was greater, and the symptoms were recent. Patients without cancer had the same nonspecific symptoms, but they were not meaningful without being new and persistent. Use of a symptom index can provide the means to identify at-risk women.

Identification of symptoms and delays in diagnosis are studied through various research methodologies, including the use or development of conceptual models (Evans, Ziebland, & McPherson, 2007; Koldjeski et al., 2005), case studies (Hamilton, Peters, Bankhead, & Sharp, 2009; Lurie, Thompson, McDuffie, Carney, & Goodman, 2009; Webb et al., 2004), and quantitative and qualitative research designs (Koldjeski et al., 2003; Lockwood-Rayermann et al., 2009).

Evans et al. (2007) examined the delays in the diagnoses of British women using Andersen's five-stage model of total patient delay (Andersen, Cacioppo, & Roberts, 1995) as an analytical model. Data demonstrated that symptoms were experienced prediagnosis with diagnosis delays caused by referral delays, lack of follow-up, lack of attention to symptoms, and treatment as noncancer causes.

Koldjeski et al. (2005) outlined a conceptualization of diagnostic delays with ovarian cancer. Using evidence from the literature, the authors identified three phases of diagnosis: self-care, primary provider care, and specialist care. Delays were noted at the primary care provider phase, and recommendations included the need for primary providers to be aware of the early symptoms and act on this knowledge.

Bankhead et al. (2008) used quantitative and qualitative methods to identify the diagnostic factors for ovarian cancer using women from four hospitals in the United Kingdom. A key finding was the need for women to understand the meaning of symptoms, such as distinguishing the differences among persistent abdominal distension and fluctuating abdominal distension. Jayde et al. (2009–2010) summarized the literature related to ovarian cancer symptoms and the diagnostic delays by describing the diagnosis as a com-

plex route. The woman must first recognize the problem and then communicate with a provider or multiple providers. Those communications can be challenging because objectifying the vague symptoms, considered benign on most occasions, is difficult.

Case-controlled and population-based studies have assisted in the delineation of early ovarian cancer symptoms. Webb et al. (2004) used data from a previous case-controlled study (Purdie et al., 1995) to document symptoms associated with borderline, early, and advanced ovarian cancer. Symptoms related to early and advanced diagnoses were examined and clusters of symptoms were delineated in relation to timing of diagnosis. Encouraging women with abdominal issues to seek care is emphasized as well as a need for healthcare providers to be alert to the possibility of ovarian cancer even if no mass is evident. Hamilton et al. (2009) also performed a case-control study for identification of symptoms and suggested the development of evidence-based guidelines based on the delineation of symptoms. Lurie et al. (2009) used a population-based, case-controlled method to identify a set of symptoms that would allow clinicians to assist in the identification of ovarian cancer at an early stage. A four-symptom index of abdominal pain, distended and hard abdomen, abnormal vaginal bleeding, and abdominal mass was identified as the best prediction method.

Friedman, Skilling, Udaltsova, and Smith (2005) reviewed 102 medical records of women diagnosed with ovarian cancer. Records were reviewed to prevent recall bias and to identify symptoms presented two years prior to diagnosis. Abdominal and GI symptoms were frequent and experienced a year prior to diagnosis. The need to consider ovarian cancer with complaints of abdominal pain and bloating was reiterated.

Koldjeski et al. (2003) conducted a descriptive longitudinal study to examine the early symptoms and diagnosis of ovarian cancer. The sample consisted of families who were interviewed and completed written questionnaires. Clustering of symptoms was outlined and, prior to diagnosis, GI, urinary, and reproductive symptoms were noted. Vague abdominal pain, bloating, indigestion, painful spots in abdomen, fatigue, and urinary problems were considered a primary symptom cluster. Delays in diagnosis were noted, with the average diagnosis at 14 weeks. The delay was attributed to the early symptoms not being taken seriously by the family, emphasizing a need for general education on the signs and symptoms of ovarian cancer.

Early symptom patterns also were demonstrated by viewing electronic records and health insurance claims (Devlin et al., 2010; Wynn, Chang, & Peipins, 2007). Wynn et al. (2007) used data from health insurance claims to examine the temporal patterns of prediagnostic ovarian cancer symptoms and demonstrate

the presence of cancer-related symptoms prior to the diagnosis. The noted increase in symptoms was more pronounced 60–90 days prior to diagnosis. Devlin et al. (2010) explored the routine use of insurance claim data as a way to identify women at high risk for an ovarian cancer diagnosis. A passive screener used the database of a large insurer in the state of Washington to flag women who had two or more visits for the noted symptoms of ovarian cancer in a two-month period. Ovarian cancer symptoms were identified in the health insurance claims and were more prevalent prior to a cancer diagnosis.

Gaps in the Literature

In the cited literature, the focus is on the physical symptoms. The primary gap in the literature relates to a lack of knowledge of what women are thinking or feeling when they experience the early and vague symptoms of ovarian cancer. The symptoms that occur prior to diagnosis are known, but exploring the influence of feelings prior to diagnosis may help with understanding a woman's decision to seek or refrain from seeking medical care for the vague symptoms of ovarian cancer.

Methods

The current study consisted of a paper-and-pencil survey with 18 questions provided to women who made a clinic appointment with a gynecologic oncologist at a university cancer institute. The survey, administered once, included demographic questions, questions related to the diagnostic process, and open-ended questions designed to elicit the feelings and emotions women experienced at the same time as the physical symptoms.

The survey was developed by a member of the research team specifically for this descriptive and qualitative inquiry and has not been used in other studies. To establish validity, the questions were reviewed by two expert gynecologic oncologists. The survey questions were grounded in the ovarian cancer literature, and psychometric properties were not established as the intent of questions was to elicit descriptive information from women in their own words. The qualitative data generated by the survey were examined for identification of themes. The survey questions are listed in Figure 1.

Data Collection

Institutional review board approval was obtained prior to data collection. The procedure included providing potential participants with a research packet at the time of check-in for their clinic appointments or chemotherapy sessions. The packet included an introduction and consent letter, a questionnaire, and an

envelope with a return label and postage. The research packet was provided to potential participants by one of two clinic nurses trained to distribute the packets.

1. What is your age at this time?
2. Describe your race or ethnic background.
3. Describe your educational background, educational degrees, or certifications.
4. How old were you when you were first diagnosed with ovarian cancer?
5. If you know, what stage of cancer did you have when you were diagnosed with ovarian cancer?
6. Did you have insurance coverage when you were diagnosed with ovarian cancer?
7. Did you know what the signs and symptoms of ovarian cancer were before you were diagnosed with ovarian cancer?
8. Do you have a family history of ovarian cancer? If so, who was the family member who had or has ovarian cancer?
9. Describe your reaction to the diagnosis of ovarian cancer. For example, were you surprised, shocked, not surprised, or just relieved to have diagnosis for the symptoms you experienced?
10. How long did it take to diagnose the cancer? For example, estimate from the time you experienced physical symptoms or felt that something was wrong to the time the doctor said you had ovarian cancer.
11. How many healthcare providers did you visit before you were finally diagnosed with ovarian cancer?
12. Check all of the following healthcare providers you saw before you were referred to a gynecologic oncologist.

<input type="checkbox"/> Primary care doctor	<input type="checkbox"/> Physician's assistant
<input type="checkbox"/> Nurse practitioner	<input type="checkbox"/> Gastroenterologist
<input type="checkbox"/> Gynecologist	<input type="checkbox"/> Internist
<input type="checkbox"/> Oncologist	<input type="checkbox"/> Other _____
13. Check all of the laboratory tests and x-ray studies you had during the time between symptom onset and the time that your ovarian cancer was diagnosed.

<input type="checkbox"/> Blood work	<input type="checkbox"/> Upper GI series
<input type="checkbox"/> CA-125 level	<input type="checkbox"/> Computed tomography scan
<input type="checkbox"/> Barium enema	<input type="checkbox"/> Colonoscopy
<input type="checkbox"/> Upper gastrointestinal (GI) endoscopy or EGD	<input type="checkbox"/> Other _____
14. Describe any feelings or emotions that you experienced upon hearing the results of the laboratory tests or x-ray studies.
15. What physical symptoms did you experience prior to the diagnosis of cancer? You can list or write out a description.
16. Some women described having feelings that something was wrong with them, but they did not know what. Did you get a feeling that something was wrong when you had physical symptoms? If so, can you describe the feeling or emotion and how long you experienced the feeling or emotion?
17. Many women who have been diagnosed with ovarian cancer have stated, "You should listen to your body" and "Find a doctor that listens to you." Did you share your feelings or worries with your healthcare provider? If so, what was the response to the sharing of your feelings or emotions?
18. Use the table to describe the physical symptoms and the feelings you experienced prior to your diagnosis of ovarian cancer (contact author for table presented to participants).

EGD—esophagogastroduodenoscopy

Figure 1. Study Survey Questions

The clinic nurses reviewed the daily schedule and identified the eligible participants who would be provided with a research packet. The potential participant read the information and consent letter and determined whether they would participate. If a participant chose to complete the survey at home, she could return it via the stamped, addressed envelope.

This academic research institute is located in the southeastern region of the United States and opened in fall 2008. Women were included if they were aged 20 years or older, diagnosed with ovarian cancer, and able to read and write English. Data collection took place from June 2009 to June 2010.

Data Analysis

SPSS®, version 18.0, was used to summarize the demographic characteristics. Qualitative data from the open-ended questions were entered into a Microsoft® Word® document in narrative form. Qualitative, descriptive-content analysis was used to identify themes in the participants' written answers. Common statements were counted; however, with qualitative analysis, themes or concepts can be counted for frequency, but the latent concept of the data is identified (Sandelowski, 2000). The goal of the analysis was to obtain descriptions of the emotions experienced at the same time as the vague physical symptoms of ovarian cancer and present them as themes. One member of the research team initially reviewed the narrative data and identified the themes. Then, the data and themes were reviewed by the other two members of the research team.

Findings

Twenty-four women completed and returned the survey, a 60% response rate. The ages of the participants ranged from 39–78 years (54% diagnosed from ages 53–63), with 83% identifying themselves as Caucasian, 8% as African American, and 9% preferring to remain unidentified. All stages of ovarian cancer (stages I–IV) were represented in the sample, but 58% diagnosed in stage II–III; however, 21% did not know the stage of cancer at diagnosis. Of the participants, 71% were educated at the college level, 92% had health insurance, and only 13% stated they knew the signs and symptoms of ovarian cancer. Only one participant acknowledged a family history of ovarian cancer.

The predominant reactions at the time of diagnosis were surprise (46%) and shock (25%). The length of time for diagnosis was less than a month for eight participants, within two months for five participants, seven participants were diagnosed three to seven months after symptom onset, and four participants were diagnosed a year or more after experiencing symptoms. The number of healthcare providers partici-

pants saw prior to diagnosis ranged from one provider (33%), two providers (25%), three providers (25%), four providers (13%), to five providers (4%). The most common healthcare providers that the participants saw were the primary care provider and gynecologist. The other types of healthcare providers the participants saw included a nurse practitioner, oncologist, physician assistant, gastroenterologist, internist, emergency room doctor, general surgeon, and urologist. The common laboratory and diagnostic tests included general blood work, cancer antigen-125 test, computed tomography scans, and ultrasounds. Other diagnostic testing participants underwent prior to diagnosis included barium enemas, chest x-rays, emergency surgeries, and colonoscopies.

Summary of Qualitative Data

The qualitative data participants provided were initially reviewed by question and then globally assessed for general themes. For many of the questions, the participants primarily focused on the physical symptomology, but their thoughts and emotions emerged in their handwritten narratives. Two general themes emerged from the handwritten answers: (a) “thought symptoms were from aging” and (b) “felt or knew something was not right.” The purpose of this survey was to explore the feelings that occurred at the same time as the vague physical symptoms of ovarian cancer; however, what emerged in the narratives were the thoughts related to the physical symptoms, and the feelings and knowledge of something not being right.

Thought Symptoms Were From Aging

The predominant theme that emerged from among the answers was that the participants associated the symptoms with aging. Bankhead et al. (2008) explored diagnostic factors for ovarian cancer in interviews with 63 women. The study outlined how women experienced symptoms prior to diagnosis, but interpreted the symptoms as part of aging, weight gain, and other natural physiologic changes. Evans et al. (2007) also used interviews with women to gain an understanding of delays in the diagnosis of ovarian cancer. Patient-attributed delays included women thinking the symptoms were related to menopause and then self-treating the symptoms, considering them benign. The selected excerpts provide evidence of this thinking and illustrate how the early symptoms of ovarian cancer were attributed to some form of getting older.

[I] did not feel like there was a problem . . . thought frequent urination was an overactive bladder, which sometimes comes with age.

No, I have always been very, very healthy and just began to think that I was aging, silly but true.

I felt run down and tired. I just thought I was growing old, but I knew I was not right. I felt surprised that I was as sick as I was.

I knew something was going on but thought it was due to menopause. I really didn't know what to say to my doctor to help her find out what it was.

[I] thought, "I've always been thin, but I suppose it's expected to have a not flat tummy as one gets older."

Felt or Knew Something Was Not Right

Many participants acknowledged they felt or knew that something was not right. The theme also emerged when participants described their reaction to the diagnosis of ovarian cancer, described their feelings related to hearing results of the laboratory tests or x-ray studies, and when they described their feelings in relation to the specific physical symptoms. The selected quotes illustrate both feeling and knowing something was not right.

I felt something was wrong. . . . [I] guess that's why I waited so long before I went to the hospital. I was scared.

I just had a strong feeling something was wrong with my body. It just didn't feel right.

[I] felt something was wrong 3 to 4 weeks before diagnosis. [I was] very busy at work . . . so, I ignored the symptoms and hoped [they] would go away.

Yes, I knew something wasn't right because my symptoms were constant. It's one thing to feel bloated, but to have a lack of appetite with a puffy belly wasn't adding up. I just knew I needed a colonoscopy. . . . Ibuprofen would cure some of the discomfort, but [I was] frustrated that all of the symptoms would not go away.

Yes, I knew something was wrong, but never anything as serious as cancer.

Limitations

The primary limitations of this study were the small sample size and participants being recruited from one facility, a university cancer research center in its second year of operation and still building a patient population. The sample predominantly included Caucasian women with health insurance. Therefore, only a small, nondiverse sample from one geographic area is represented. In addition, participants reflected back to their experiences prior to diagnosis of ovarian cancer; therefore, data are based on recall. However, several strengths are noted. The findings reflect and concur with what is available in the published research, including descriptions of symptoms experienced prior

to cancer diagnosis, delays in cancer diagnosis, and a noted need for education on signs and symptoms of ovarian cancer.

Discussion

The purpose of this study was to explore the feelings experienced at the same time as the vague physical symptoms of ovarian cancer. The participants expressed feelings and thoughts regarding the symptoms in the written narratives. The findings note that educated women who have health insurance are not familiar with the signs and symptoms of ovarian cancer and attribute them to aging. Many of the participants voiced that they felt or knew something was wrong, but they still attributed the symptoms of bloating, fatigue, frequent urination, and weight gain in the abdomen to getting older or menopause.

The lack of knowledge regarding the signs and symptoms of ovarian cancer is reiterated in the research literature, particularly among the women experiencing ovarian cancer symptoms (Lockwood-Rayermann et al., 2009) and the healthcare providers treating women with common symptoms that may be benign or cancerous (Koldjeski et al., 2005; Schorge et al., 2010). The Education Committee of the Society of Gynecologic Oncology has provided a series of white papers on ovarian cancer (Schorge et al., 2010). That information can assist healthcare providers in the screening and care of women. Understanding the symptomology of ovarian cancer is necessary for prompt detection and diagnosis at early stages (Goff et al., 2004). Early diagnosis is vital in initiating an appropriate treatment and care plan. With no accurate screening tool for ovarian cancer applicable to all women, cancer should be considered when women voice the common signs and symptoms of ovarian cancer (Jayde et al., 2009–2010).

Differentiating between aging and symptoms of ovarian cancer is an education need particularly in the general public. More importantly, an emphasis on what normal aging entails for women 40 years and older is necessary. Iggoe (1997) stressed the need for public education, and research continues to emphasize the need for educating the public and medical communities regarding the signs and symptoms of ovarian cancer.

Conclusion

The authors' study highlights what women think and feel when experiencing the vague symptoms of ovarian cancer prior to an official cancer diagnosis. The women considered the symptoms part of aging; however, at same time, they felt something was not right. An extensive public education campaign is necessary to reach all women and their family and friends. Education also

needs to include all healthcare providers who care for women so they are aware of the symptoms of ovarian cancer, particularly when middle-aged patients voice concerns about common ailments such as constipation, bloating, frequent urination, and back pain. Public education needs to focus on contrasting the signs and symptoms of ovarian cancer with what is considered normal aging. With no definitive screening tool for ovarian cancer available, knowledge of the signs and symptoms of ovarian cancer and deciding to seek care for the vague symptoms is vital for earlier detection.

Implications for Nursing

Nurses can take the lead in disseminating information on this life-threatening cancer by developing education campaigns in public venues, continuing education for practicing nurses, and serving as advocates for women with healthcare providers. Through a therapeutic relationship, a nurse can assess whether the signs of aging, verbalized by a woman, suggest a need for patient education or for empowering the woman to express all her symptoms and ask for further diagnostic testing.

General education must emphasize the importance of feelings and thoughts related to the symptoms. Healthcare providers should focus on taking a thorough history when the common symptoms of ovarian cancer are voiced by women and acknowledge their health concerns. Consideration of women's thoughts and feelings in regard to the severity and onset of symptoms provides subjective data in the patients' history. Finally, education also should include empowerment strategies that promote confidence in women's knowledge of their bodies. A woman needs to have the confidence to be an advocate for herself. The nurse at the bedside or in the clinic can be the advocate for this woman by empowering her to verbalize her thoughts and feelings and by reminding the healthcare provider that common, benign symptoms can be the vague symptoms of ovarian cancer.

Providers need to listen to the woman who voices her concern and investigate further if necessary. Healthcare providers need to tell women that getting older does

not necessarily mean constant bloating, incontinence, and fatigue and investigate the symptoms further if they are a new onset or prolonged.

Future research should include evaluation of education campaigns tailored for the public and healthcare providers. Evaluation is necessary for diverse populations. As evidenced by breast cancer awareness in the United States, public education campaigns can be effective if continuously marketed to the public. Therefore, the early signs and symptoms need to be broadcast to the general public.

Exploration of healthcare providers' knowledge of ovarian cancer, particularly those working in a primary care settings, is another research trajectory to consider. Understanding how primary care providers recognize the common symptoms and how they interpret and act on a woman's verbalization of symptoms is essential. Koldjeski et al. (2005) noted that one phase of delay in cancer diagnosis is at the primary care level; therefore, assessing primary care providers' knowledge of ovarian cancer symptomology is vital as it can provide insight on refining education for this group.

Another consideration when interpreting the findings from the qualitative data is the need to develop screening tools that include the feelings and thoughts of women experiencing the common physical symptoms. Integrating those within a symptom index or screening tool facilitates the collection of objective and subjective data from the woman, which may assist healthcare providers and lead to an earlier detection and diagnosis of ovarian cancer.

Anita Smith, PhD, RN, is a professor and chair in the College of Nursing, Rodney P. Rocconi, MD, is the Abraham A. Mitchell Cancer Research Scholar and an associate professor in gynecologic oncology in the Mitchell Cancer Institute, and Michael A. Finan, MD, FACS, is the chief of the Gynecologic Oncology Department in the Mitchell Cancer Institute and professor of obstetrics and gynecology, all at the University of South Alabama in Mobile. No financial relationships to disclose. Smith can be reached at anitasmith@usouthal.edu, with copy to editor at ONFEditor@ons.org. (Submitted August 2011. Accepted for publication October 26, 2011.)

Digital Object Identifier: 10.1188/12.ONFE150-E156

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