

COMMENTARY

Ovarian Cancer Symptom Index

Possibilities for Earlier Detection

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The article by Dr. Barbara Goff and colleagues¹ in this issue of *Cancer* describing an index to identify women who are at risk of having ovarian cancer by identifying specific symptoms, along with frequency and duration, follows a logical progression in the body of knowledge about the symptoms of ovarian cancer—much of it conducted under Dr. Goff's capable leadership. The ovarian cancer survivor community has long espoused using symptoms to help identify the presence of disease while we await development and validation of an effective diagnostic panel or screening tool.

Unfortunately, recognition within the medical community that early-stage symptoms exist is a relatively new phenomenon. The survivor community has led the charge to enlighten individuals that there *are* symptoms, even in early-stage cancer. We survivors know, because we experienced these subtle yet noticeable warnings. For most women in our community, these symptoms made us seek medical care, which was the first critical step in being diagnosed. However, when the Ovarian Cancer National Alliance (the Alliance) was organized in 1997, medical school textbooks stated that there usually were no symptoms until the advanced stage, when the prognosis is poor (*Harrison's Principles of Internal Medicine* is but one example).² Consequently, the Alliance's focus continues to be to make women and healthcare practitioners aware of early-stage symptoms.

The Survivors' Challenge

In 1998, representatives of the newly formed Alliance, the umbrella organization for local, state, and national ovarian cancer groups, attended the first meeting of the Allied Support Group of the Gynecologic Cancer Foundation. During that meeting, a prominent gynecologic oncologist, when asked about early symptoms of ovarian cancer, replied that there are no symptoms. Survivors in attendance rose to their feet and challenged the physician, each discussing her symptoms and recounting the number of physicians she had seen prior to diagnosis. Dr. Goff, who was in the audience, later told a survivor that this encounter made her wonder how many previous

See referenced original article on pages XXX–XXX, this issue.

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physicians her own patients had seen before she diagnosed them and how she might integrate this aspect of the disease into her research.

The late Cindy Melancon, an ovarian cancer survivor, Alliance founder, and publisher of a survivor newsletter called *Conversations*, also attended this meeting. Dr. Goff and Mrs. Melancon jointly developed and disseminated a symptoms survey through *Conversations*. Because of this disconnect between patients' experiences and medical dogma, our community was heartened by the resulting publication of "Ovarian carcinoma diagnosis" in *Cancer* in 2000.³

In total, 1725 survivors answered the questionnaire about the type of symptoms, length of experience, and number of physicians seen prior to diagnosis. The survey confirmed that ovarian cancer does produce symptoms, with 95% of women reporting ≥ 1 symptoms and 89% reporting that they had symptoms in the disease's early stages.³ Dr. Goff, Mrs. Melancon, and other colleagues teamed up again for a study released in 2004.⁴ Their findings gave us a new piece of the puzzle by comparing the range of symptoms between women with and without cancer. Women with ovarian cancer had symptoms that were of greater frequency and severity and of more recent onset than women without cancer.⁴

A Possible New Tool

Six years after the publication of the first study and 2 years after the second, attribution of symptoms to other causes—such as menopausal status, diet, fatigue, or other medical conditions—still may be responsible for delayed diagnosis. It is hypothesized currently that an ovarian cancer symptom index can be developed as a tool to lead to early detection, similar to the clinical breast examination for breast cancer.^{5,6} Until there is a valid screening test, the symptom index may serve an important role in detecting cancers; and after a test is identified, the index may be useful as a tool in combination with other methods to contribute to early detection.

Dr. Goff's symptom index lists the symptoms that are described most universally among our community members.¹ Repeatedly, women describe a rapid increase in abdominal size, sometimes severe, persistent bloating even in the absence of a sizable meal, and other specific pelvic issues that too frequently are attributed to almost any other cause than ovarian cancer. We recognize that many women have additional symptoms linked to the nature and location of their tumors.

A symptom index, however, is only 1 of a number of promising research tracks the ovarian cancer advocacy community actively supports. Another—the real

key to early detection—is development of a screening test, like one that uses proteomics to detect the unique protein patterns within the blood of a woman with ovarian cancer. A test like that for the general population is years away. However, its use as part of every woman's annual medical examination, and not just high-risk women, is highly speculative unless the benefits ultimately outweigh the costs. We wish we could point to current means of detecting ovarian cancer that have more potential. Several studies have indicated that our current tools—the CA-125 blood test and transvaginal ultrasound—are not effective in diagnosing women early and, consequently, do not improve overall mortality.^{7,8}

We also are extremely encouraged that ovarian cancer will be 1 of the 3 cancers studied in the Cancer Genome Atlas pilot project, which has the potential to speed up scientists' understanding of the molecular basis of cancer. We must keep moving research forward quickly, which includes continued support for Dr. Goff's promising research path. Dr. Goff proposes to next study the symptom index for use in the general population by having clinicians ask patients 3 simple questions: Are you experiencing any of these symptoms (as referenced in the study by Goff et al.¹)? How long have you been experiencing them? How often each month do you experience them?

This multiyear study would confirm whether a symptom index ultimately has any effect on the number of women who are diagnosed early. Without a prospective study, we will never really know whether the symptom index can be used in the general population. If continued research indicates that a symptom index has merit, then we will need to ensure that primary care physicians and gynecologists understand and use this simple tool. If a symptom index is validated, then the entire ovarian cancer community—physicians, researchers, and advocates—will need to do everything possible to make the index part of standard practice.

Our Work Continues

The Alliance, In My Sister's Care (an organization focused on medically underserved women), and other interested organizations will continue our work to raise public awareness. Women need to be their own best advocates with their physicians. They need to know the symptoms so that, if cancer develops, it is diagnosed early.

Educating both women and healthcare practitioners continues to be an uphill climb. A recent National Ovarian Cancer Coalition study showed that only 15% of women are familiar with ovarian cancer's symptoms and that 82% have never discussed symp-

toms and risk factors with their physicians.⁹ In focus groups that were conducted in 2000 to help develop the Alliance's *Until There's a Test, Awareness Is Best* campaign, the most frequently mentioned misconception about ovarian cancer was that a Papanicolaou smear can detect it. This belief still is widely held.

The news media can be a significant source of information and, sometimes, misinformation. Imagine the impact on the thousands upon thousands of *New York Times* readers who learned erroneously that, often, ovarian cancer has no symptoms until it is advanced, a statement that appeared in an article about the recurrence of ovarian cancer in Patricia Dunn, the former chairwoman of Hewlett-Packard.¹⁰

The Alliance and our sister organizations have taken and continue to take proactive steps to address all facets of the symptoms issue, such as conducting programs for medical students, creating awareness campaigns for women, and testifying before Congress for increased funding for federal research and first-time funding for a national awareness campaign. The Alliance offers an innovative educational program, *Survivors Teaching Students: Saving Women's Lives*. In the program, future healthcare professionals—physicians, nurse practitioners, and physician assistants—learn from survivors about ovarian cancer symptoms and risk factors so that they can diagnose the disease in its early stages, when outcomes are optimal. *Survivors Teaching Students* is now in 41 medical schools throughout the United States.

Let us never forget that ovarian cancer is the deadliest of the gynecologic cancers. In the United States, approximately 20,000 women are diagnosed and 15,000 die each year from the disease a woman has a one in 69 lifetime chance of getting ovarian cancer.¹¹ The ultimate victory for survivors will be the identification of specific biomarkers for ovarian cancer that will enable development of a screening test. The symptom index has the potential to be a valuable tool—further research will determine to what extent. In the meantime, the ovarian cancer survivor community remains steadfast in helping other women and healthcare practitioners learn about the disease. Together, as a voice for the approximately 172,000 ovarian cancer survivors in the United States, we seek new and innovative ways

to use breaking research, such as the symptom index, to support our work and to save women's lives.¹¹

The voice of the ovarian cancer survivor community was strengthened by women like Cindy Melancon, whose foresight gave credibility to the existence of symptoms. Currently, awareness of these symptoms is our best hope for early detection.

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