A terrible beauty

A physician's story of ovarian cancer

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When the fourth member of my 9-person book club was diagnosed with breast cancer, I felt grateful for my own good health and good fortune. We were all baby boomers in our 50s, Western, white, educated, socioeconomically advantaged women. One in 9 Canadian women will confront breast cancer in her lifetime. We had entered the "at risk" population, but these seemed terrible odds. Then it was me.

I was diagnosed with one of the relatives of ovarian cancer—a highly aggressive peritoneal tumour with ascites and widespread abdominal metastases. Stage 3. A woman can get this kind of cancer even if she has had a hysterectomy and oophorectomy.

It has become important for me to find a way to make my experience useful to my successors in this illness. Few family doctors see many patients with ovarian cancer in their practices. In my practice as a family doctor, only 2 women with my diagnosis came to me, both very late in the course of their disease.

Risk factors and genetic testing

I was unaware until I was researching my own bloodline that 3 of the 6 women in my paternal grandmother's family had died of either breast or ovarian cancer. I had only 1 other risk factor, never having had children.

Few studies of risk factors have focused specifically on ovarian cancer, but we have learned from the overlap of many studies that have targeted breast cancer; age, familial predisposition, and less childbearing are shared risks with breast cancer. Other risk factors for ovarian cancer include polycystic ovarian syndrome and more frequent menstrual cycling, including early onset of menses and late menopause. Use of oral contraceptives substantially reduces the risk.[1]

Having 1 first-degree relative or 2 or more clustered second-degree relatives with breast or ovarian cancer, especially before menopause, increase a woman's risk for breast and ovarian cancer. Descendants of Ashkenazic Jews are at greater risk of having the BRCA1 and BRCA2 genes, which are associated with a lifetime occurrence of breast or ovarian cancer of up to 40%. Approximately 2% of the general population carry BRCA1 or BRCA2 gene. In general, known familial factors account for only about 10% of ovarian cancers.[2]

Screening and prevention

Genetic testing is not something we do for ourselves. We do it to determine choices for our offspring and our sisters and their daughters. Testing is for them.

Regular examinations and Papanicolaou smears do not help detect ovarian cancer in its early stages. Serendipitous testing, usually to investigate another problem, sometimes uncovers an unexpected early cancer. For those with risk factors, primarily family history or having the BRCA1 or BRCA2 genes, studies are under way to determine whether biomarkers, such as the cancer antigen 125 test (CA125) and pelvic ultrasound, can alert physicians to the need for further investigations in time.[3]

For women at high risk, most physicians recommend annual assessment of CA125 levels, bimanual pelvic examination, and transvaginal ultrasound for screening, until better measures are developed.[4]

The need for better screening methods is clear. The critical question is, Will such screening affect outcomes? Even when family history is compelling, the drastic step of surgical removal of breasts, ovaries, and uterus is a very difficult step to take based only on probability. The US Preventive Services Task Force recommends considering prophylaxis with drugs shown to reduce breast cancer incidence, such as tamoxifen and raloxifene.[2]

Symptoms

My own symptoms hit quickly. There was new pain—pain when my bladder filled, especially at night. There was discomfort with intercourse and with pressure on my left lower abdomen.

Ovarian cancer usually metastasizes into the abdomen before it causes symptoms. While most public education urges early attention to warning symptoms, only about 10% of ovarian cancers are diagnosed at a curable stage.[5] By the time symptoms begin—urinary urgency, abdominal bloating, bowel irritability, fatigue, painful intercourse—the cancer is virtually always widespread. Weight loss, breathlessness, anemia, early satiety, and abdominal pain are symptoms that come later.[6]

Diagnosis

Most of the women I have come to know experienced the frustration of not having their symptoms recognized

as serious. As a result, several weeks or months passed before appropriate investigations were undertaken.

One study indicates that most women have symptoms for at least 6 months before diagnosis.[4] Doctors often initiate investigation with gastrointestinal or bowel studies in light of the symptoms, but these studies are generally not helpful. Despite its vague presentation, it is the *persistence or escalation* of symptoms in ovarian cancer that is serious.[6]

Investigation of suspicious symptoms should include a pelvic examination, assessment of CA125 levels, and transvaginal ultrasound. On pelvic examination, an adnexal mass is usually evident, but the ovary is not always enlarged. Computed tomography scanning is often necessary. Pelvic fluid should not be dismissed as "normal," particularly in postmenopausal women.[4]

The CA125 test is the best single tool we have to identify and follow a tumour. Levels, however, are not numerically correlated to extent of disease, except within a given individual. Although more than 80% of women with ovarian tumours have elevated CA125 levels when diagnosed, levels are often not elevated until the cancer has spread. False-positive and false-negative results (early in the disease) can occur.[7]

Treatment

It is not uncommon to think that, faced with this illness, a person might decide not to accept treatment; however, this rarely happens. Meeting women who have been through surgery and chemotherapy, who are finding meaningful life not only during the glorious remission, but also during the treatment process itself, will kindle the weakest hope and strengthen the remotest resolve. Most of the interventions do not add to the quantity of time we live, but rather to the quality.

During the past 10 to 15 years, most women with ovarian cancer have had initial surgery to reduce tumour bulk, ideally to microscopic size. Almost 80% of women are candidates for surgery either before or after initial chemotherapy. They might require an ostomy from bowel or bladder structures to achieve the best possible results.[8] Surgery is followed by chemotherapy, which usually entails 6 to 8 cycles of platinum and taxane drugs, each lasting 3 to 4 weeks. Women with "platinum-sensitive" tumours generally go into a remission lasting at least 6 months.[9,10]

Recently, intraperitoneal chemotherapy as a treatment option has been reexamined. A major US study found that a combination of intravenous and intraperitoneal chemotherapy after primary surgery increased time to recurrence by a median of 12 months and survival by 16 months.[11] Although this study demonstrates the first major improvement in survival in many years, it is associated with more severe side effects in the short-term and can be performed only with optimal surgical results and in patients free of other illness.

Many women I know have sought the advice of therapists in the "wellness" or naturopathic movement to try to maximize nutritional and immunologic strengths.

Other commonly accessed resources include therapeutic touch, relaxation, massage, neurolinguistics, healing workshops, and spiritual guidance. There is little study data available to evaluate these therapies with regard to objective benefits in cancer care, but they are regarded as very helpful by women struggling to cope with the disease.

Prognosis

Living under the spectre of a short life expectancy is shocking, confusing, depressing, unnerving, and—sometimes—has a terrible beauty. Every moment becomes precious. I have had my remission. Now I have my own "appointment in Samarra."[12]

More than 80% of those diagnosed with epithelial ovarian cancer are already in advanced metastatic stages. Fewer than 10% of these women will live 5 years. They will be "long-term survivors" and will typically have had several rounds of chemotherapy with shorter and shorter remissions. More than half of those who respond to platinum chemotherapy relapse by 12 to 18 months. Median survival ranges from 28 to 40 months. While there are other less lethal types of ovarian cancer, they constitute less than 20% of cases.[5]

Relapsed ovarian cancer is currently incurable. While ovarian cancer in Canada affects only one tenth of the number of women affected by breast cancer, it will claim more life years. The profile of survival has barely changed in more than 30 years.

Reactions to diagnosis

At some point in our cancer stories, most of us ask "Why me?" I am saddened to hear a great deal of misinformation when I listen to answers to that question.

Resources

Information about clinical trials

- US National Institutes of Health: **www.clinicaltrials.gov**
- National Cancer Institute: **www.cancer.gov**
- National Ovarian Cancer Association (Canadian): **http://ovariancanada.org** or **www.ovairecanada.org** (en français)

Information for patients and families

- Ovarian Cancer Canada: **www.ovariancancercanada.ca**
- National Ovarian Cancer Association (Canadian): **http://ovariancanada.org** or **www.ovairecanada.org** (en français)
- Canadian Cancer Society: **www.cancer.ca**

Having cancer is often the subject of shame, blame, or remorse. In addition to their grief, anger, and angst, women often feel a sense of failure. There is very little evidence that women who develop ovarian cancer are different from other women except for their genetic predispositions and reproductive histories.

There is no evidence that "bad feelings" cause cancer or that "good feelings" cure cancer. Feelings are just feelings. Professionals need to help patients to identify and express their feelings before rushing to explain, suppress, or deny them. Hope should never be discouraged. People do unexpectedly defy the odds.[13]

Support

The stress of living with cancer is enormous. The expectation that we can all emerge hopeful, positive, and courageous is an additional burden. Added to this, many of the afflicted women I know have no partners and no children.

When asked what is most helpful in coping with the distress of this disease, almost all women with ovarian cancer name family, professional caregivers, and other women who have walked the same path before them. Understandable information is another key element in coping with cancer. The wealth of information on ovarian cancer available on the Internet can be overwhelming at times.

Clinical trials

Many of us, knowing that our lives will be limited, would be willing to risk the potential consequences of being involved in clinical studies. We offer a good testing model because outcomes become evident within a fairly short interval, and our lives are already compromised.

We are long overdue for a national cancer strategy* to help inform the public and coordinate services so that patients know what resources are available and can participate in studies that are trying to answer key questions.

Vaccines, monoclonal antibodies, angiostatins (inhibitors of neovascularization) and stem-cell transplants are among the promising treatments of the future.[5,14,15] Most cancers, including ovarian cancer, occur partly because growth factors are "turned on" without normal control mechanisms. Much current research is focusing on ways to block this overactive process.[16]

Studies are looking at drugs that target human epithelial receptor factors because approximately 30% of women with ovarian cancer have positive test results for this factor.[14,17,18] Other epithelial growth factor receptors are also common in women with ovarian cancer. Some tumours trigger a native immune response, and studies are looking at how to enhance this defence.[16,19]

At the cutting edge of future technologies is nanotechnology, where tiny particles with attachments pass through leaky blood vessels into the tumour and deliver drugs lethal only to the tumour or deliver metallic particles that can then be exposed to infrared light to attack the cancer.[20]

Dr Linda Spano *died on September 10, 2006, of ovarian cancer.* **Dr Michael Brennan** *and* **Dr Linda Spano,** *together with their families and many friends, have established The Brennan/Spano Family Foundation, which has a major interest in supporting research dedicated to the early detection and treatment of ovarian cancer. For more information, contact The Brennan/Spano Family Foundation within the Victoria Foundation, 109-645 Fort St, Victoria, BC V8W 1G2, or visit* **www.victoriafoundation.bc.ca**.

*__Editor's note:__ The Canadian Partnership Against Cancer was announced in November 2006 by the Government of Canada. See **www.partnershipagainstcancer.ca** for more details.

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