

From the “Silent Killer” to the “Whispering Disease”: Ovarian Cancer and the Uses of Metaphor

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A Pulitzer Prize winning play by Margaret Edson, entitled *W;t*, begins with an exchange between an oncologist, Dr Harvey Kelekian, and his patient, a John Donne scholar and professor of English named Vivian Bearing. He is in the process of informing her that she has stage 4 ovarian cancer:

KELEKIAN: You have cancer . . . you have advanced, metastatic ovarian cancer.

VIVIAN: Go on . . .

KELEKIAN: You present with a growth that, unfortunately, went undetected in stages one, two and three. Now it is an insidious adenocarcinoma, which has spread from the primary adnexal mass—

VIVIAN: “Insidious”?

KELEKIAN: “Insidious” means undetectable at an—

VIVIAN: “Insidious” means treacherous.

KELEKIAN: Shall I continue?

VIVIAN: By all means.

Vivian then ponders what he has just said: “Insidious. Hmm. Curious choice of word.”¹ Edson’s opening scene focuses attention on the meanings of words which are used to describe ovarian cancer. On the one hand, the physician understands himself to be using the word “insidious” as it has become part of clinical language, to refer to a gradual, undetectable and harmful physical process of the sort associated with ovarian cancer. His patient, on the other hand, recognizes that the word is being used metaphorically. As the *Oxford English Dictionary* defines it, “insidious” does mean “treacherous”, or “full of wiles or plots, lying in wait to entrap or ensnare”, and is derived from the Latin *insidiae*, meaning “ambush”, and *insidiosus*, meaning “cunning” or “deceitful”.²

The purpose of this article is to examine the history and implications of ovarian cancer’s association with metaphorical language. For most of the twentieth century, the metaphor of the “silent killer”, often linked with the word “insidious”, was a common feature of ovarian cancer discourse, and this article explores the reasons why that image became dominant and considers the role it played in both reflecting and

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¹Margaret Edson, *W;t*, New York, Faber and Faber, 1999, pp. 7–8. An HBO film of the same name stars Emma Thompson as Vivian Bearing. I thank Rob Gray for bringing this work to my attention.

²Oxford English Dictionary, <http://dictionary.oed.com/>

confirming established understandings of the disease. While the term “silent killer” has sometimes been used to describe other cancers and is also applied to such illnesses as hypertension and diabetes, its longstanding and very widespread use in defining ovarian cancer is striking and deserves analysis, as does the process whereby its use was challenged.

Some basic knowledge of the characteristics of ovarian cancer is useful when considering the language which has been used to describe the disease. While it is sometimes still described as a rare disease, ovarian cancer affects as many as one in fifty-five women in the United States.³ It is now the second most commonly occurring gynaecological cancer (after endometrial cancer) and, as a cause of cancer deaths in women, it ranks fourth after lung, breast, and colorectal cancers.⁴ There are many kinds of ovarian cancer; as one recent text explains, the ovary “produces more varieties of tumors than any other organ”.⁵ Ovarian neoplasms are categorized according to three main types: epithelial (accounting for over 90 per cent of malignant tumours); germ cell, which includes the teratomas, as discussed in Jackie Stacey’s *Teratologies: a cultural study of cancer*; and sex cord and stromal, which includes the granulosa cell tumour briefly mentioned below.⁶ The different kinds of ovarian cancer affect women at different stages of life, with germ cell tumours most often occurring in women in their twenties and thirties, while the median age for the diagnosis of epithelial carcinoma is around sixty.⁷ Current medical literature discusses several possible aetiological factors, most of them speculative, but authors tend to agree that continuous or “incessant” ovulation, uninterrupted by pregnancy or oral contraceptive use, has the strongest correlation with the disease.⁸ Like breast cancer, a portion of epithelial ovarian cancers (estimated at around 10 per cent) have a genetic link.⁹ As yet, there is no accepted general screening test for ovarian cancer, and diagnosis is often delayed due to a lack of specific symptoms or a poor understanding on the part of patients or physicians of the signs of ovarian cancer. When the disease is suspected, pelvic examination, sonography, and a blood test known as CA-125 play a role in diagnosis.¹⁰ Surgery confirms the presence of the disease and the stage to which it has progressed. Ovarian cancer is staged according to whether it is confined to the ovary (stage 1) or has extended beyond. In stage 2, the disease has spread to the uterus, fallopian tube, or to other tissues in the pelvis; in stage 3, it has metastasized to the abdominal cavity; and in stage 4, it has spread elsewhere in the

³Ivan K Strausz, *You don't need a hysterectomy: new and effective ways of avoiding major surgery*, Cambridge, MA, Perseus, 2001, p. 302.

⁴Alexander F Burnett, *Clinical obstetrics and gynecology: a problem-based approach*, Malden, MA, and Oxford, Blackwell Science, 2001, p. 374.

⁵*Ibid.*, p. 375.

⁶Kathleen M Brennan, Vicki V Baker and Oliver Dorigo, ‘Premalignant and malignant disorders of the ovaries and oviducts’, in Alan J DeCherney, Lauren Nathan, T Murphy Goodwin and Neri Laufer (eds), *Current diagnosis and treatment: obstetrics and gynecology*, New York, McGraw-Hill, 2007, pp. 872–77; Jackie Stacey,

Teratologies: a cultural study of cancer, London, Routledge, 1997.

⁷Brennan, *et al.*, *op. cit.*, note 6 above, p. 875; Tamara L Callahan, Aaron B Caughey, and Linda J Heffner, *Blueprints: obstetrics and gynecology*, Malden, MA, Blackwell, 2003, p. 258.

⁸Katherine Y Look, ‘Epidemiology, etiology, and screening of ovarian cancer’, in Stephen C Rubin and Gregory P Sutton (eds), *Ovarian cancer*, Philadelphia, Lippincott, Williams and Wilkins, 2001, pp. 168–74; Burnett, *op. cit.*, note 4 above, p. 374; Callahan, *et al.*, *op. cit.*, note 7 above, p. 258.

⁹Brennan, *et al.*, *op. cit.*, note 6 above, p. 871.

¹⁰*Ibid.*, pp. 877–8.

body.¹¹ A recent text reports that, when diagnosed at stage 1, the five-year survival rate for epithelial ovarian cancer is as high as 93 per cent, but, in over 70 per cent of patients, the cancer has spread outside the pelvis by the time of diagnosis.¹² Aggressive surgery and chemotherapy are employed to halt the disease, but at stage 3, the five-year survival rate is 23 to 41 per cent, while at stage 4 it is only 5 to 11 per cent.¹³ For much of the past century, the deadly nature of advanced ovarian cancer, combined with the apparently intractable difficulties associated with timely diagnosis, gave rise to the metaphor of “the silent killer”, which, in turn, helped to shape understandings of the disease.

The significance of metaphor in medical language is the subject of an ongoing debate which often refers back to Susan Sontag’s *Illness as metaphor*. In this work, first published in 1978, Sontag made her now famous case against the mystification of illness through the use of metaphor.¹⁴ More recent writers, including the ovarian cancer patient and sociologist Jackie Stacey, have criticized Sontag’s methodology and her basic premise that metaphorical thinking and language can be avoided in medical discourse.¹⁵ James F Childress suggests that, partly because illness very often *is* mysterious, medicine needs “the vision provided by metaphors, analogies, and symbols”, but he agrees with Sontag that metaphors are not just evocative figures of speech; they have the power to shape our understanding. Far from being “merely ornamental or affective”, he writes, metaphors “can be and often are cognitively significant”.¹⁶ In *Medicine as culture*, Deborah Lupton supports this view by pointing out that, in medical discourse, as in many kinds of communication, metaphor is “an epistemological device, serving to conceptualize the world, define notions of reality and construct subjectivity”.¹⁷

Other writers have shown that medical metaphors are deeply embedded in historical contexts. Emily Martin points out that the dominant metaphor in early scientific medicine was “the metaphor of the body as machine and the doctor as mechanic”.¹⁸ With the rise of bacteriology, metaphors of invasion and battle became commonplace, as “bacteria were identified as agents of disease that threaten the body and its defenses”.¹⁹ During the twentieth century, military metaphors came to dominate medical language, and this was especially true in relation to cancer, as governments, especially in the US, declared a “war on cancer” in the wake of the First World War.²⁰ Barron Lerner has shown that the American Society for the Control of Cancer chose to use military metaphors for very specific reasons, partly because they suited the mood of the inter-war

¹¹ Burnett, *op. cit.*, note 4 above, p. 379.

¹² Brennan, *et al.*, *op. cit.*, note 6 above, pp. 883, 880.

¹³ *Ibid.*, p. 883.

¹⁴ Susan Sontag, *Illness as metaphor*, New York, Farrar, Straus and Giroux, 1978.

¹⁵ Stacey, *op. cit.*, note 6 above, pp. 44–8; Barbara Clow, ‘Who’s afraid of Susan Sontag? Or, the myths and metaphors of cancer reconsidered’, *Soc. Hist. Med.*, 2001, 14: 293–312.

¹⁶ James F Childress, *Practical reasoning in bioethics*, Bloomington, Indiana University Press, 1997, p. 4.

¹⁷ Deborah Lupton, *Medicine as culture*, London, Sage, 2003, p. 59.

¹⁸ Emily Martin, *The woman in the body: a cultural analysis of reproduction*, Boston, Beacon Press, 2001, pp. 54–7.

¹⁹ Childress, *op. cit.*, note 16 above, p. 6.

²⁰ On inter-war cancer awareness campaigns in the US, see Kirsten E Gardner, *Early detection: women, cancer, and awareness campaigns in the twentieth-century United States*, Chapel Hill, University of North Carolina Press, 2006, pp. 17–92. On the later response in Great Britain, see Elizabeth Toon, ‘“Cancer as the general population knows it”: knowledge, fear, and lay education in 1950s Britain’, *Bull. Hist. Med.*, 2007, 81: 116–38.

years, but also because they harnessed public fears and the willingness to fight a disease which, by its very name, suggested an entity (the crab) “growing out of control and eating away at the body’s organs”.²¹ Decades later, Sontag was highly critical of the way that cancer continued to be personified as an “evil, invincible predator”, and maintained that metaphors of invasion, battle, and defeat contribute to the stigma endured by cancer patients.²² But others have emphasized that military metaphors have positive uses, not only in motivating social groups to fight disease but in supporting patients’ private struggles to recover.²³ More recently, patients’ movements have explored alternatives to the military metaphor, such as the image of cancer “as a journey”, while some practitioners have wondered, more generally, whether a greater openness to new metaphors might play a part in the re-conceptualization of medical problems.²⁴

Metaphors do not come into common usage unless, on some level, they work. Throughout much of the twentieth century, both medical professionals and laypeople applied military metaphors to cancer because they seemed both apt and useful. Cancer was, as it is now, a disease the public feared above most others. Anti-cancer campaigns focused on detecting the enemy early; patients and physicians fought diseases such as breast and uterine cancer with all the heroic methods at their disposal; and survivors celebrated their victories over the adversary. How did ovarian cancer fit into this picture? As a less common form of cancer, it posed less of a public threat than breast or uterine cancers and therefore attracted far less attention. It was also harder to detect, as it was often without symptoms in its early stages, or was characterized by non-specific gastrointestinal complaints rather than typical warning signs such as a lump or irregular bleeding. As a result, it had usually spread throughout the abdomen by the time it was diagnosed and therefore had a very poor prognosis. For all of these reasons, it was a poor target in the “war” on cancer, which depended upon an optimistic message to promote the promise of early detection and effective treatment.²⁵ Ovarian cancer was not exempt from military metaphors, but the medical profession portrayed it as an enemy which kills silently, progressing undetected until its victory is secure. Lack of success in the search for early detection strategies allowed the image of the “silent killer” to remain the dominant metaphor until the end of the twentieth century. By that point, however, an alternative metaphor was gaining ground, as ovarian cancer activists, convinced that earlier detection was possible with closer attention to early symptoms, promoted the image of a disease that “whispers” and can be “heard” if one knows what to listen for.

The “silent killer” metaphor was challenged because, in the view of some patients and practitioners, it had become inaccurate and dangerously misleading. A growing body of

²¹ Barron H Lerner, *The breast cancer wars: fear, hope, and the pursuit of a cure in twentieth-century America*, New York, Oxford University Press, 2001, pp. 44–5. On public fear of cancer, see James T Patterson, *The dread disease: cancer and modern American culture*, Cambridge, Harvard University Press, 1987.

²² Sontag, op. cit., note 14 above, p. 7.

²³ Devra Davis, *The secret history of the war on cancer*, New York, Basic Books, 2007, p. 16; Childress, op. cit., note 16 above, p. 6.

²⁴ Childress, op. cit., note 16 above, p. 6; George J Annas, ‘Reframing the debate on health care reform by replacing our metaphors’, *New Engl. J. Med.*, 1995, **332**: 744–47.

²⁵ Gardner makes only one reference to ovarian cancer in *Early detection*, op. cit., note 20 above, p. 209. She posits that “one reason that activists may have directed little attention to ovarian cancer is that early detection rhetoric had little resonance for this cancer”.

medical evidence supported the hypothesis that an awareness of “early” symptoms might hasten diagnosis and, with improvements in treatment, timely diagnosis became a major factor in long-term survival. In June 2007, the American Cancer Society publicly disassociated itself from the term “silent killer”—“a catchy phrase, but it is wrong”, announced the ACS website.²⁶ The ACS and other agencies identified a list of common symptoms which might be present even in early stage cancer, including bloating, frequent urination, pain, and eating or digestive problems. These non-specific symptoms had, in fact, been noted for decades, but new guidelines confirmed that if they were new, persistent, and worsening, women should see a gynaecologist. Further tests would then determine whether the risk involved in laparoscopic surgery was justified.

Before examining the uses of metaphor in relation to ovarian cancer in the twentieth century, this article takes a brief look at how the disease was envisioned in the nineteenth century in order to provide some historical context. It then analyses the reasons why the “silent killer” metaphor became so prominent during the inter-war years, discusses some of the means by which physicians attempted to control the disease, and notes that, by mid-century, a small number of researchers were already questioning whether earlier attention to symptoms might have an effect on ovarian cancer diagnosis. The “silent killer” metaphor persisted, however, and, during the post-war decades, researchers focused on efforts to improve treatment and, somewhat belatedly, the identification of risk factors such as family history. They also searched for a technological solution to the problem of early detection but, by the end of the century, it was clear that no viable means of mass screening had emerged. The final section of the article traces the efforts of increasingly vocal patients and those physicians and researchers who questioned the “silence” of ovarian cancer.

“Uncertain Sounds”: Interpreting Ovarian Growths in the Nineteenth Century

Ovarian cancer, while a relatively rare condition compared with breast or uterine cancers, was certainly not unknown to nineteenth-century physicians. They considered it to be an invariably fatal disease, but found it was often impossible to distinguish from non-cancerous growths unless it was very advanced. While the suspicion of breast or uterine cancer was commonly aroused by the presence of a breast lump or unexplained bleeding, the vague symptoms of ovarian cancer were usually recognized in retrospect and were only occasionally mentioned in medical literature. The British surgeon Thomas Spencer Wells, for example, looked back on the case history of one patient whose tumour had caused “incontinence of urine” for three years before her admission to the Samaritan Hospital, where she soon died.²⁷ The non-specific symptoms of the disease were also noted by the cancer expert Walter Hayle Walshe, who remarked that the patient might first report sensations that were “merely uneasy”, and that she might direct

²⁶ ‘Ovarian cancer has early symptoms’, *ACS News Center*, 14 June 2007, http://www.cancer.org/docroot/NWS/content/NWS_1_x_Ovarian_Cancer_Symptoms.The_Silence_Is_Broken.asp (accessed 14/6/2009).

²⁷ T Spencer Wells, *Diseases of the ovaries: their diagnosis and treatment*, New York, D Appleton, 1873, pp. 59–60.

attention to the ovary itself as the source of early pain.²⁸ The gynaecologist Charles Reed concurred that the “symptomatology of ovarian neoplasms is sometimes very obscure”, but acknowledged that there might be “a vague sense of discomfort in the pelvis”.²⁹

Even if symptoms had been noted more systematically in the nineteenth century, earlier diagnosis would have been very unlikely to save women’s lives. Despite the poor prognosis for ovarian cancer patients, ovarian growths of all sorts were of great interest to nineteenth-century physicians. In good part, this was because the more common, non-cancerous cysts could become debilitating and even deadly if they grew large enough, and there was good reason to seek new means of treatment.³⁰ Early in the century, ovarian growths were treated by a wide variety of techniques, including drugs, bleeding, purging, “blistering, electricity, friction, and abdominal pressure”, and by tapping, or the removal of fluid.³¹ The first successful ovariectomy (the term then used for removal of the ovaries) was performed in 1809 by the Kentucky surgeon Ephraim McDowell, who removed a 22 1/2 pound ovarian cyst. Other surgeons attempted similar operations, and the first ovariectomy in Britain was performed in 1824.³²

The dangers involved in abdominal surgery, however, brought the procedure into disrepute. Not only was there a very high death rate, estimated at close to 50 per cent at mid-century, but surgeries were performed on women who turned out not to have ovarian disease at all or had cancerous tumours adhering to other abdominal structures, which made effective surgery impossible.³³ Such a horrific procedure was not even recommended for women who were thought to have ovarian cancer and were expected to die anyway. In his *Outlines of the principal diseases of females*, Fleetwood Churchill declared in 1838 that surgery was “never advisable, for at the advanced period, at which alone so formidable an operation would be justifiable, the patient’s whole constitution is contaminated by the cancerous diathesis”.³⁴ Many also questioned whether any woman who might survive for some years without surgery should be exposed to such pain and danger. Wells would eventually make his reputation as a leading ovariectomist, but he recalled that in the early days “Surgeons stood and trembled on the brink of ovarian waters. . . . Could we know beforehand that the circumstances would admit of such treatment? The difficulty was in the diagnosis. There was a thick surgical darkness over the abdomen, and it gave out only uncertain sounds.”³⁵

Although surgery was in disfavour at mid-century, within a few years the ovariectomy would become an established, if still controversial, procedure.³⁶ The growing use of anaesthetics increased the demand for and the acceptability of surgery, and, by the

²⁸ Walter Hayle Walshe, *The nature and treatment of cancer*, London, Taylor and Walton, 1846, pp. 344–5.

²⁹ Charles A L Reed, *A text-book of gynecology*, New York, Appleton, 1901, p. 632.

³⁰ Ann Dally, *Women under the knife: a history of surgery*, New York, Routledge, 1992, pp. 13–15.

³¹ *Ibid.*, p. 135.

³² *Ibid.*, 15–19, 135. On McDowell’s pioneering surgery, also see Deborah Kuhn McGregor, *From midwives to medicine: the birth of American gynecology*, New Brunswick, NJ, Rutgers University Press, 1998, p. 160.

³³ Ornella Moscucci, *The science of woman: gynaecology and gender in England, 1800–1929*, Cambridge University Press, 1990, p. 137.

³⁴ Fleetwood Churchill, *Outlines of the principal diseases of females*, Dublin, Martin Keene and Son, 1838, p. 391.

³⁵ Wells, *op. cit.*, note 27 above, p. 117.

³⁶ Moscucci, *op. cit.*, note 33 above, pp. 156–60; Lawrence D Longo, ‘The rise and fall of Battey’s operation: a fashion in surgery’, *Bull. Hist. Med.*, 1979, **53**: 244–57.

1870s, the introduction of antiseptics (or the new emphasis on general surgical cleanliness, in the case of Listerism's opponents), reduced the risk of infection and death. Wells worked to perfect his technique by performing hundreds of ovariectomies at charity hospitals such as the Samaritan Hospital for Women during the 1860s and 1870s, and he claimed to have reduced the fatality rate in his cases from 50 per cent to 11 per cent.³⁷ Other prominent surgeons, including James Young Simpson and Robert Lawson Tait, also became advocates, and ovariectomy, says Ann Dally, became "*the operation by which a surgeon's skill and worth were assessed*".³⁸

Rising confidence in the safety of surgery, combined with a growing awareness of the changeability of ovarian growths, caused some physicians to believe that the development of life-threateningly large and even cancerous ovarian growths might be prevented if surgery was undertaken sooner rather than later—that the risk of delay might outweigh the risk of surgery. Benign tumours were increasingly recognized as being very prone to cancerous changes; Wells's extensive experience led him to observe that all ovarian cysts had the potential to degenerate into "the worst forms of epithelial cancer".³⁹ This warning grew louder by the end of the century and became the primary argument for immediate surgical intervention. In his textbook of gynaecology, Charles Reed, president of the American Medical Association, advised that all growths needed to be investigated because of the risk of "malignant degeneration".⁴⁰

But the call for immediate action should not be taken to mean that surgeons expected to save the lives of women in whom malignant ovarian growths had already developed. As one London surgeon explained, it was more a matter that one should not assume a tumour to be cancerous and therefore hopeless when surgery might prove that the diagnosis was mistaken.⁴¹ Ovarian cancer was still regarded as "absolutely fatal", for, as another advised, even when the tumour is completely removed and "no metastases can be discovered, a rapid return appears to be the invariable rule".⁴² In contrast with breast cancer, for which radical surgery was being promoted as a potential cure, the fatal nature of ovarian cancer drew frequent and despairing comment in turn-of-the-century medical texts.⁴³

The "Silent Menace" and Early-Twentieth-Century Gynaecology

Throughout the early decades of the twentieth century, the fatalism surrounding ovarian cancer stood in contrast to the rhetoric of optimism applied to some of the more common cancers in women. Cancer awareness campaigns, which emphasized the promise of early detection, portrayed both breast and uterine cancers as enemies which could be conquered through due vigilance on the part of patients and their physicians. Ovarian

³⁷ Moscucci, *op. cit.*, note 33 above, pp. 152–6.

³⁸ Dally, *op. cit.*, note 30 above, p. 139.

³⁹ Wells, *op. cit.*, note 27 above, p. 58.

⁴⁰ Reed, *op. cit.*, note 29 above, p. 633.

⁴¹ George Ernest Herman, *Diseases of women: a clinical guide to their diagnosis and treatment*, London, Cassell, 1913, p. 746.

⁴² R Olshausen, *Diseases of the ovaries*, ed.

Egbert H Grandin, New York, William Wood, 1887, p. 384.

⁴³ Charles B Penrose, *A text-book of diseases of women*, Philadelphia, W B Saunders, 1904, pp. 392–3.

cancer, on the other hand, was increasingly envisaged as a “silent killer” which would secure its deadly victory before it was even discovered.

One factor which may have enhanced the image of ovarian cancer as a particularly deceptive disease was the growing fascination with the hormone-producing granulosa cell tumour, even though it was a much less common form of the disease.⁴⁴ For researchers, especially those in the new field of endocrinology, this was an intriguing example of pathological hormonal change. These oestrogen-producing tumours, only some of which were cancerous, could cause early puberty and menstruation when they occurred in children, but much more often they affected post-menopausal women who might briefly and unwittingly welcome their “feminizing” effects.⁴⁵ “At the beginning”, wrote gynaecologists Emil Novak and J N Brawner in 1934, “there are only symptoms of hyperestrogenism and the patient appears surprisingly and pleasantly to bloom again. However, this cruel deception is not kept up for long, the disease soon destroying both this tragic illusion and the body itself.”⁴⁶ The novelist Thomas Mann was so fascinated by this expression of “the cruel demonic side of nature” that he wrote a novella, entitled *The black swan*, about a woman who dies from ovarian cancer after rejoicing in the return of her youth. He sought to create, he said, “A story of deception, of a deadly hoax played by Nature on its own good child.”⁴⁷

In the inter-war period and beyond, medical literature increasingly framed ovarian cancer of all types as a cruel trick of nature, a disease which grew stealthily until it was too late. The adjective “insidious” came into use; “Carcinoma of the ovary is the most insidious disease of the generative tract” explained one text in 1927.⁴⁸ The renowned gynaecologist Harry Sturgeon Crossen vividly evoked the “silent killer” metaphor when he reminded colleagues of the “symptomless onset and symptomless progress” of this “creeping death which defies early discovery”.⁴⁹ Despite the relatively low incidence of the disease, he and others pointed out that it was a greater threat than some might think. Crossen suggested that one could “get some idea of the magnitude and importance of this ‘silent menace’” by considering the many cases which each and every gynaecologist had encountered in recent years, and by also adding the many other patients, vaguely diagnosed with “abdominal” cancer, who might also have been victims of ovarian malignancies.⁵⁰ By mid-century, it was not unusual for medical texts to refer

⁴⁴ John G Gruhn, ‘A selective historical survey of ovarian pathology emphasizing neoplasm’, in Lawrence M Roth and Bernard Czernobilsky (eds), *Tumors and tumorlike conditions of the ovary*, New York, Churchill Livingstone, 1985, pp. 269–85, on p. 276.

⁴⁵ Fred L Adair (ed.), *Obstetrics and gynecology*, 2 vols, Philadelphia, Lea and Febiger, 1940, vol. 2, p. 324.

⁴⁶ E Novak and J N Brawner, ‘Granulosa cell tumors of ovary: clinical and pathological study of 36 cases’, *Am. J. Obstet. Gynecol.*, 1934, **28**: 637–49, p. 637, quoted in Johannes Diel, ‘Thomas Mann’s last novella “The black swan”: the tragic story of a post-menopausal woman’, *Eur. J. Obstet. Gynecol.*

Reprod. Biol., 2004, **113**: 255–7, <http://www.sciencedirect.com> (accessed 2/6/2009). Another view is that Mann was writing about a victim of uterine cancer; see Karen Nolte, ‘Carcinoma uteri and “sexual debauchery”—morality, cancer and gender in the nineteenth century’, *Soc. Hist. Med.*, 2008, **21**: 31–46. Diel’s interpretation seems most apt, however, as the protagonist not only resumed her menstrual period but “bloomed” again.

⁴⁷ Diel, *op. cit.*, note 46 above.

⁴⁸ Brooke M Anspach, *Gynecology*, Philadelphia, Lippincott, 1927, p. 395.

⁴⁹ H S Crossen, ‘The menace of “silent” ovarian cancer’, *JAMA*, 1942, **119**: 1485–9, pp. 1486–7.

⁵⁰ *Ibid.*, p. 1489.

to ovarian cancer as a “relatively common” disease, but not one which offered much hope of a cure.⁵¹

In spite of their general pessimism about treating ovarian cancer and the still very real dangers of surgery, many surgeons during the inter-war years continued to advise an aggressive approach to dealing with all ovarian masses in the hope of reducing the risk of cancerous changes developing in benign cysts. Although there was a great variation in opinion regarding the percentage of growths which would prove to be malignant, there was a growing consensus by the 1930s that all were potentially deadly and that all must be investigated as soon as they were detected.⁵² “The division into malignant and non-malignant tumors is important from the clinical aspect”, advised an *Introduction to gynecology*, “but as a matter of fact practically all ovarian tumors possess potentialities for malignant change.”⁵³ A very few gynaecologists even toyed with the hope that the lives of at least some patients with ovarian cancer could be saved through timely surgery, though reported rates of long-term survival remained extremely low.⁵⁴

Because ovarian cancer was so difficult to detect and treat, some surgeons advocated prophylactic oophorectomy as a means of reducing the risk of ovarian cancer in post-menopausal women. The removal of healthy ovaries was still a controversial procedure and, as the frequency of hysterectomy increased during the early twentieth century, the practice of performing oophorectomy at the same time caused divisions within the medical profession. Crossen advocated the removal of the ovaries when abdominal surgery was done for any reason in women past their childbearing years, which he set at forty-two. He cited several cases from his own experience of women for whom he had performed hysterectomies who later developed ovarian cancer. The lesson he had learned, he confessed, was that he should never have left the ovaries intact: “I thought then that it was advisable”, he wrote, “but I know better now.” He went on to explain that although the ovaries “have a halo about them” they are of only temporary value. By the time a woman is in her early forties, he wrote, they are “no longer an important part of the economy but vestigial structures which carry a special tendency toward cancer—and toward a particularly dangerous form of cancer, in that it develops to an incurable stage without warning symptoms”.⁵⁵ Some other practitioners opposed the procedure because the sudden hormonal change could render “the patient a physical and nervous wreck”, which they saw as an unjustifiable outcome given the odds against a malignancy ever developing.⁵⁶ Admitting that ovarian cancer was “a wholly unsolved problem”, Clyde Randall of the University of Buffalo weighed the pros and cons of the

⁵¹ Archibald Donald Campbell and Mabel A Shannon, *Gynecology for nurses*, Philadelphia, F A Davis, 1946, p. 144; Stanley Way, *Malignant disease of the female genital tract*, London, J and A Churchill, 1951, p. 182.

⁵² Estimates ranged from 15 per cent in Arthur Hale Curtis, *A textbook of gynecology*, Philadelphia, W B Saunders, 1946, p. 391; to 25 per cent in Aleck W Bourne and Leslie H Williams, *Recent advances in obstetrics and gynecology*, Philadelphia, Blakiston, 1945, p. 290; to 35 per cent in Campbell and Shannon, op. cit., note 51 above, p. 144.

⁵³ C Jeff Miller, *An introduction to gynaecology*, St Louis, C V Mosby, 1934, p. 274.

⁵⁴ Ibid, p. 17; Malcolm S Allan and Arthur T Hartig, ‘Carcinoma of the ovary’, *Am. J. Obstet. Gynecol.*, 1949, **58**: 640–53, p. 642.

⁵⁵ Crossen, op. cit., note 49 above, pp. 1486–7.

⁵⁶ J M Munro Kerr, *Combined text-book of obstetrics and gynaecology for students and medical practitioners*, Edinburgh, E & S Livingstone, 1933, p. 889; Zeph J R Hollenbeck, ‘Ovarian cancer—prophylactic oophorectomy’, *Am. Surg.*, 1955, **21**: 442–6, p. 443.

procedure and concluded that perhaps “the all too apparent futility of our present treatment may have cowed us to illogical extremes”.⁵⁷

As a second front in the struggle for ovarian cancer control, some gynaecologists also advocated increased surveillance of middle-aged patients through regular pelvic examinations. The growing acceptance of this procedure as a normal part of health care was a side effect of the campaign to control uterine cancer, which encouraged apparently healthy women to seek regular checkups. Crossen was adamant that examinations for “silent” ovarian cancer should occur every six months, and there were a few gynaecologists who attempted to follow his lead. They noted, however, that the procedure, including a rectal examination, must be conducted by physicians with considerable expertise, and they acknowledged that this level of surveillance was impossible to establish and maintain in entire populations.⁵⁸

Thus, as concern over ovarian cancer grew, emphasis was placed upon preventive surgery and on signs which could be detected by the physician, rather than on sensations which might be reported by the patient. The “silent killer” image was now firmly associated with the disease, and some standard textbooks said nothing at all about its symptoms at any stage, thus leaving medical students and practitioners without a basis for recognizing possible signs of ovarian cancer experienced by their patients. Other texts mentioned only the symptoms of very advanced disease, while stressing that ovarian tumours were “silent” until they were large and incurable.⁵⁹ Because most patients presented with pronounced swelling or pain prior to diagnosis, many physicians concluded that those must, in fact, be the *first* symptoms, even though “careful questioning” might reveal that the patient had experienced more subtle discomforts for a much longer period of time.⁶⁰ These were the non-specific sensations of “unease”, along with urinary and gastro-intestinal complaints, which had been remarked upon in nineteenth-century texts. Physicians occasionally noted such complaints retrospectively; Crossen, for example, chose twelve of his case histories to illustrate the “symptomless progress” of ovarian cancer, including that of “Mrs. M.”, of whom he observed that, prior to her diagnosis, she had no symptoms at all—merely “constipation for the past year and considerable bloating”.⁶¹

Given its neglect in medical literature, it not surprising that ovarian cancer symptomatology was seldom discussed in cancer awareness campaigns aimed at the wider public. The rhetoric of early detection focused on breast and uterine cancers, which were diseases with a high incidence, specific (though not necessarily “early”) symptoms, and,

⁵⁷ Clyde L Randall, ‘Ovarian carcinoma: risk of preserving the ovary’, *Obstet. Gynecol.*, 1954, 5: 491–7, p. 496. On the continuing controversy, see Laman A Gray and Malcolm L Barnes, ‘Carcinoma of the ovary: a report of 106 cases’, *Am. Surg.*, 1964, 159: 279–90, p. 289; Daniel Winston Beacham and Woodard Davis Beacham, *Synopsis of gynecology*, Saint Louis, C V Mosby, 1972, p. 291; Seymour L Romney, *et al.*, *Gynecology and obstetrics: the health care of women*, New York, McGraw-Hill, 1975, p. 1067.

⁵⁸ Crossen, *op. cit.*, note 49 above, p. 1489; See John B Montgomery, ‘Malignant tumors of the

ovary’, *Am. J. Obstet. Gynecol.*, 1948, 55: 201–17, p. 215; Gray and Barnes, *op. cit.*, note 57 above, p. 288; Andrew A Marchetti, ‘Tumors of the ovary’, in Robert A Kimbrough (ed.), *Gynecology*, Philadelphia, Lippincott, 1965, p. 370.

⁵⁹ John Osborn Polak, *A manual of gynecology*, Philadelphia, Lea & Febiger, 1922, p. 348; Howard A Kelly, *et al.*, *Gynecology*, New York, D Appleton, 1928, pp. 769–71; Miller, *op. cit.*, note 53 above, p. 274; Curtis, *op. cit.*, note 52 above, pp. 394–9.

⁶⁰ Anspach, *op. cit.*, note 48 above, p. 395; Hollenbeck, *op. cit.*, note 56 above, p. 442.

⁶¹ Crossen, *op. cit.*, note 49 above, p. 1486.

it was claimed, a good prognosis if found soon enough.⁶² Articles in women's magazines and advice manuals intended for the middle-aged woman confined themselves to identifying breast lumps and several varieties of irregular bleeding as the danger signs which must not be ignored.⁶³ For example, in a popular work entitled *The woman asks the doctor* (1944), the leading American gynaecologist Emil Novak included an entire chapter entitled 'Cancer, The Arch-Enemy of Women' which focused exclusively on breast and uterine cancers and made no mention of ovarian cancer at all.⁶⁴

Even though the rhetoric of early detection seemed not to apply to ovarian cancer, an interest in pursuing a more nuanced understanding of its non-specific symptoms did emerge within a very small minority of medical researchers on both sides of the Atlantic. Through retrospective studies, they began, as early as the 1930s, to take note of the wider pattern of their patients' complaints and to tabulate symptoms in order of frequency for more systematic analysis.⁶⁵ Most importantly, they began to record the occurrence of mild but persistent gastro-intestinal complaints and to consider their relevance in relation to ovarian cancer detection. The British gynaecologist Beckwith Whitehouse paid a good deal of attention to "the complex subject of symptomatology", and in 1931 reported that, in a series of 200 cases of ovarian disease, digestive symptoms "occurred in 29% of my simple cases and 41% of the malignant".⁶⁶ John Montgomery of the Jefferson Medical College Hospital repeated the usual refrain about the silence of ovarian cancer, but none the less reported that 37 per cent of his patients "had abdominal symptoms, mostly referable to the gastrointestinal tract for six months to several years before a pelvic examination was made. One patient, the sister of a physician, was given 'samples' for 'indigestion' for three years before her abdomen began to swell."⁶⁷

At mid-century, another prominent British gynaecologist, Stanley Way, made a concerted effort to draw colleagues' attention to this very issue. He did not deny that of "all the aspects of ovarian cancer, the symptomatology is the least satisfactory", but he proposed that abdominal discomfort and persistent digestive problems were likely the earliest symptoms of the disease in a great many cases. Relying, as had others, on case histories of cancer patients to illustrate the problem, he recounted the death of a 52-year-old woman who succumbed shortly after exploratory surgery was performed. Two years before she died, "[S]he had been investigated in a London teaching hospital for vague abdominal pain thought to be due to pyelitis, and six months after this she had again been investigated in the medical department of a large provincial hospital for 'indigestion' thought to be due to a gastric ulcer." He insisted that because "vague

⁶²Gardner, op. cit., note 20 above, pp. 8, 30–8. In Britain, as well, the campaign was aimed at "accessible cancers", primarily breast and cervical cancer. Toon, op. cit., note 20 above, p. 119.

⁶³Miriam Lincoln, *Woman: her change of life*, London, Williams and Norgate, 1951, pp. 75–6; Lena Levine and Beka Doherty, *The menopause*, New York, Random House, 1952, pp. 168–9; Emerson Day, 'A specialist talks about cancer', *Women's Home Companion*, June, 1955, pp. 28–9; Isabel Hutton, *Woman's change of life*, London, William Heinemann Medical Books, 1958, pp. 54, 169;

M E Landau, *Women of forty*, New York, Philosophical Library, 1964, p. 29.

⁶⁴Emil Novak, *The woman asks the doctor*, Baltimore, Williams and Wilkins, 1944, pp. 113–23.

⁶⁵Carl Henry Davis (ed.), *Gynecology and obstetrics*, 3 vols, Hagerstown, MD, W F Prior, 1935, vol. 2, p. 16.

⁶⁶Beckwith Whitehouse, 'The clinical aspects of ovarian tumours', *J. Obstet. Gynaecol. Br. Emp.*, 1931, **38**: 264–79, pp. 266–7.

⁶⁷Montgomery, op. cit., note 58 above, p. 214.

digestive disturbances” were so common in ovarian cancer patients they must be considered to be “of diagnostic importance”. Lamenting that the number of ovarian cancers which “have been nurtured in a sea of bicarbonate of soda and potassium citrate by the practitioners of the world” was beyond calculation, he insisted that all women over forty who complained of such symptoms should be fully examined.⁶⁸

Old Metaphors and New Strategies

Way’s advice seems to have had little impact, and few researchers in the post-war decades challenged the image of the “silent killer”. The illness attracted growing attention, however, partly because its incidence appeared to be on the rise. In 1954, one gynaecologist reported a “startling increase of 40 per cent” in the ovarian cancer death rate in New York State over the previous twenty years, and researchers in both North America and Great Britain reported upward trends over the following decades.⁶⁹ The risk of developing the disease, reported to be 1 in 100 in 1965, had risen to 1 in 70 by the 1980s and was reported to be as high as 1 in 55 by the mid-1990s, although the reasons underlying this apparent increase were obscure.⁷⁰ Rising incidence combined with poor survival rates meant that it was a growing threat compared with other gynaecological cancers. In 1979, one American researcher pointed out that “more women die as a result of the ravages of this insidious . . . neoplasm . . . than succumb to cervical and endometrial cancer combined”, and another reported in 1983 that “one woman dies from ovarian cancer every 50 minutes in this country”.⁷¹

In the face of such discouraging facts, researchers sought new means of gaining control over the disease. Important advances in surgery and chemotherapy were made, but their long-term impact was limited by the fact that a majority of cases were not diagnosed until metastasis had occurred.⁷² By the 1980s, more concerted attention was finally given to the long-neglected epidemiology of ovarian cancer, and some progress was made in identifying women at increased risk who might benefit from increased surveillance.⁷³ Much effort was devoted, as well, to development of mass screening techniques which might make earlier diagnosis possible for all patients, but results on that front were disappointing.

⁶⁸Way, *op. cit.*, note 51 above, pp. 183–7.

⁶⁹Muriel L Newhouse, R M Pearson, J M Fullerton, E A Boesen and H S Shannon, ‘A case control study of carcinoma of the ovary,’ *Br. J. Prev. Soc. Med.*, 1977, **31**: 148–53, p. 148; M Steven Piver, Joseph J Barlow and Diane M Sawyer, ‘Familial ovarian cancer: increasing in frequency?’, *Obstet. Gynecol.*, 1982, **60**: 397–400, p. 399; Ralph C Benson, *Handbook of obstetrics and gynecology*, Los Altos, CA, Lange Medical Publications, 1983, p. 641; V Beral and M Booth, ‘Occurrence and etiology’, in Norman M Bleehen (ed.), *Ovarian cancer*, Berlin, NY, Springer Verlag, 1985, pp. 14–22, on p. 14.

⁷⁰Marchetti, *op. cit.*, note 58 above, p. 370; M Steven Piver, ‘Epidemiology of ovarian cancer’, in M Steven Piver (ed.), *Ovarian malignancies: diagnostic*

and therapeutic advances, Edinburgh, Churchill Livingstone, 1987, pp. 1–11, on p. 1; M Steven Piver with Gene Wilder, *Gilda’s disease: sharing personal experiences and a medical perspective on ovarian cancer*, Amherst, NY, Prometheus, 1996, p. 35.

⁷¹J D Woodruff, ‘The pathogenesis of ovarian neoplasia’, *Johns Hopkins Med. J.*, 1979, **144**: 117–20, p. 117; William M Rich, ‘Benign and malignant ovarian neoplasms’, in Ralph W Hale and John A Krieger (eds), *A concise textbook of gynecology*, Hyde Park, NY, Medical Examination Publishing, 1983, p. 297.

⁷²Rich, *op. cit.*, note 71 above.

⁷³Margaret Booth and Valerie Beral, ‘The epidemiology of ovarian cancer’, in C N Hudson (ed.), *Ovarian cancer*, Oxford University Press, 1985, pp. 22–44, on p. 22.

The first risk factor to be systematically examined was low parity, although there was much disagreement over why it might predispose women to ovarian cancer. The debate centred on the question of whether “poor reproductive performance”, optional or otherwise, was in itself a source of risk, or whether low parity was to be interpreted as a sign of poor ovarian health which might lead to malignancy.⁷⁴ The New York ovarian cancer expert Hugh Barber declared in 1978 that: “Women at high risk usually have a long history of ovarian imbalance or dysfunction, including . . . a tendency for spontaneous abortion, infertility, and nulliparity, as well as an early menopause. The ovary is like a cam running off center.”⁷⁵ At the same time, other researchers emphasized that the protection afforded by pregnancy was probably the key factor, because unmarried and childless married women both had a higher incidence of the disease.⁷⁶ More studies followed and yet the question remained open, complicated by the fact that the known causes of infertility were so diverse.⁷⁷

Attention was also turned to another hypothesis, first put forward in 1971, that uninterrupted or “incessant” ovulation might be an important factor in the aetiology of ovarian cancer.⁷⁸ This theory was compatible with studies suggesting that the contraceptive pill, which prevented ovulation, had a very significant protective effect. The U.S. Center for Disease Control, for example, estimated that “oral contraceptive use alone may have prevented up to 1700 cases of ovarian cancer” in 1982.⁷⁹ Some years later, the theory that frequent ovulation might predispose women to the disease provided an explanation for an emerging association between ovarian cancer and the use of fertility drugs. As women became more vocal about their right to know about potential risks associated with drugs and medical treatments, some cancer patients would charge that fertility clinics were negligent in not providing this information.⁸⁰

The question of a hereditary factor was also given serious consideration in 1980s. Instances of individual families with a high incidence of the disease had been mentioned in the late nineteenth century, and, from the 1930s onwards, studies of affected families grew slowly in number. One such study, published in 1950 by Amour Fiscus Liber, concerned ‘Ovarian cancer in mother and five daughters’. At the time, Liber was a lone voice calling for radical action based on his assumption of a genetic link. Although, in his words, he stopped short of advocating “eugenic limitation of breeding”, he recommended prophylactic oophorectomy for women in families thus affected, close monitoring from an early age, and the creation of agencies to keep records of all cases—even

⁷⁴ J Donald Woodruff, ‘Premalignant and malignant disorders of the ovaries and oviducts’, in Martin L Pernoll (ed.), *Current obstetric and gynecologic diagnosis and treatment*, Norwalk, CT, Appleton and Lange, 1991, p. 974; Beral and Booth, op. cit., note 69 above, p. 17; Booth and Beral, op. cit., note 73 above, pp. 27–8.

⁷⁵ Hugh R K Barber, *Ovarian carcinoma: etiology, diagnosis, and treatment*, New York, Masson, 1978, p. 98.

⁷⁶ Newhouse, *et al.*, op. cit., note 69 above, pp. 152–3.

⁷⁷ Susan Harlap, ‘The epidemiology of ovarian cancer’, in Maurie Markman and William J Hoskins

(eds), *Cancer of the ovary*, New York, Raven Press, 1993, p. 83.

⁷⁸ Booth and Beral, op. cit., note 73 above, p. 29.

⁷⁹ Lloyd H Smith and Richard H Ol, ‘Detection of malignant ovarian neoplasms: a review of the literature. I. Detection of the patient at risk; clinical, radiological and cytological detection’, *Obstet. Gynecol. Surv.*, 1984, **39**: 313–28, p. 314; Harlap, op. cit., note 77 above, p. 83.

⁸⁰ Piver with Wilder, op. cit., note 70 above, pp. 42–4. For a patient’s account of the controversy over fertility drugs in the 1990s, see Liz Tilberis, *No time to die*, Boston, Little, Brown, 1998, pp. 40–5, 246–54.

suggesting that, if possible, autopsies be performed not only on patients but on all relatives, including males, in case “there is a recognizable phenotype of male carriers”.⁸¹ During the 1950s and 1960s, the importance of a genetic link was widely dismissed, but by the 1970s the number of families on record was increasing rapidly, and there was speculation that the incidence of familial disease was actually growing.⁸² In 1981, the first Familial Ovarian Cancer Registry in the US was established at Roswell Park Memorial Institute in Buffalo. Its goal was not merely to study the “mode of inheritance” but to examine relationships with breast and other cancers, as well as inter-connections with other suspected risk factors, including asbestos exposure.⁸³ That same year, a widely cited study reported that women with a mother or sister with the disease had an alarming eighteen-fold increase in risk, and during the 1980s there was much speculation upon the nature of the familial link, whether screening procedures should be introduced for high-risk women, and whether prophylactic oophorectomy should be recommended.⁸⁴ In the early 1990s, the BRCA1 and BRCA2 genes associated with both breast and ovarian cancer were localized, removing all doubt that women in certain families faced an extremely high level of hereditary risk.⁸⁵

Because the incidence of ovarian cancer was much higher in western industrialized countries than elsewhere, researchers also investigated cultural and environmental factors. One of these was a possible association with asbestos exposure in the workplace and the use of talc (contaminated by asbestos until at least the mid-1970s) in personal hygiene. A 1960 study had suggested that women with asbestosis had a higher rate of ovarian cancer, and another published in 1971 directed attention towards the possible link with talc by reporting that, in the set of ovarian tumours which they examined, 75 per cent contained talc particles.⁸⁶ That study and others proposed that this factor might actually help to account for the rising incidence of ovarian cancer in the post-war decades.⁸⁷ Further investigations demonstrated that talc applied to the genital area could make its way very rapidly into the peritoneal cavity, and a case control study published in 1982 found that 42.8 per cent of the women with ovarian cancer had used talc regularly, compared with 28.4 per cent of the controls.⁸⁸ The association between

⁸¹ Amour Fiscus Liber, ‘Ovarian cancer in mother and five daughters’, *Arch. Pathol.*, 1950, **49**: 280–90, pp. 289–90. Liber cites cases from 1877 onwards.

⁸² Romney, *et al.*, *op. cit.*, note 57 above, p. 1065; Piver, *et al.*, *op. cit.*, note 69 above, p. 398.

⁸³ Piver, *et al.*, *op. cit.*, note 69 above, pp. 399–400; Piver with Wilder, *op. cit.*, note 70 above, p. 46.

⁸⁴ The study often referred to was G Hildreth, Jennifer L Kelsey, Virginia A Livolsi, Diana B Fischer, *et al.*, ‘An epidemiologic study of epithelial carcinoma of the ovary’, *Am. J. Epidemiol.*, 1981, **114**: 398–405. And see Smith and Ol, *op. cit.*, note 79 above, pp. 316–17; Booth and Beral, *op. cit.*, note 73 above, pp. 30–1.

⁸⁵ Barnaby D Rufford and Ian J Jacobs, ‘Identification and management of familial ovarian cancer’, in Henry C Kitchener, Jonathan A Ledermann and Andrew Miles (eds), *Effective*

management of ovarian cancer, London, Aesculapius Medical Press, 2001, pp. 128–38. On the patient experience of hereditary risk and delays in its recognition, see Nina Hallowell, ‘Varieties of suffering: living with the risk of ovarian cancer’, *Health, risk and society*, 2006, **8**: 9–26.

⁸⁶ W J Henderson, C A F Joslin, K Griffiths and A C Turnbull, ‘Talc and carcinoma of the ovary and cervix’, *J. Obstet. Gynaecol. Br. Commonw.*, 1971, **78**: 266–72.

⁸⁷ *Ibid.*, p. 271; Woodruff, *op. cit.*, note 71 above, p. 120.

⁸⁸ Howard C Jones III, Anne Colston Wentz and Lonnie S Burnett, *Novak’s textbook of gynecology*, 11th ed., Baltimore, Williams and Wilkins, 1988, p. 793; Daniel W Cramer, William R Welch, Robert E Scully and Carol A Wojciechowski, ‘Ovarian cancer and talc: a case-control study’, *Cancer*, 1982, **50**: 372–6.

asbestos exposure, talc use and ovarian cancer remained controversial, however, because researchers continued to produce conflicting results.⁸⁹

In addition to the examination of potential risk factors, a second approach to the growing incidence of ovarian cancer was the search for a means of effectively screening asymptomatic women—either entire populations, or only those deemed to be high risk. By the mid-1980s, three main screening techniques were available; these were the manual pelvic examination, the ultrasound technology which had been developed during the previous decades, and the recently devised CA-125 blood test, which measured the level of a cancer antigen associated with ovarian cancer.⁹⁰ As already mentioned, many physicians viewed regular pelvic examinations as an important means of detecting potential cancers in asymptomatic women, but others increasingly opposed this strategy, arguing that pelvic examination was limited in sensitivity and did not yield “the desired percentage of early diagnoses”. Ovarian cancer was found in only about one in 10,000 such procedures, while, at the same time, about one examination in 125 revealed some sort of mass which, they pointed out, resulted in unnecessary anxiety and potentially hazardous surgery.⁹¹ Ultrasound technology, meanwhile, held out the hope that masses not felt during examination could be detected through imaging, and also that manually locating a mass would be “safer” if it could then be assessed without surgery.⁹² Ultrasound offered a step forward but was found to be too inaccurate, and too costly, for general screening, while the CA-125 blood test was neither specific nor sensitive enough for regular use in asymptomatic women (though both came into use for monitoring women considered high risk).⁹³ Despite efforts to develop an early detection programme which paralleled mammography and the Pap smear, no viable strategy emerged for ovarian cancer.⁹⁴

Meanwhile, during the second half of the twentieth century, medical literature of various kinds re-confirmed the image of the “silent killer”. “Ovarian cancer, is unfortunately, very insidious and ‘silent’ in terms of signs and symptoms”, reiterated Novak’s authoritative text in 1988, and similar language appeared in many other works.⁹⁵ But, as the prospect of mass screening for ovarian cancer proved elusive,

⁸⁹ Mark S Shahin and Joel I Sorosky, ‘Prevention and early diagnosis of ovarian cancer’, in Alberto Manetta (ed.), *Cancer prevention and early diagnosis in women*, Philadelphia, Mosby, 2004, pp. 249–66, on pp. 254–5.

⁹⁰ On the development of ultrasound, see S Levi, ‘The history of ultrasound in gynecology 1950–1980’, *Ultrasound Med. Biol.*, 1997, **23**: 481–552.

⁹¹ Walter J Burdette, *Cancer: etiology, diagnosis, treatment*, New York, McGraw-Hill, 1998, p. 166; Rich, *op. cit.*, note 71 above, p. 297.

⁹² Smith and Ol, *op. cit.*, note 79 above, p. 322.

⁹³ Burdette, *op. cit.*, note 91 above, p. 166; Marilyn F Vine, Roberta B Ness, Brian Calingaert, Joellen M Schildkraut and Andrew Berchuck, ‘Types and duration of symptoms prior to diagnosis of invasive or borderline ovarian tumor’, *Gynecol. Oncol.*, 2001, **83**: 466–71, p. 466; Clare Bankhead and Joan Austoker, ‘Women’s cancer screening:

cervical, breast, and ovarian screening’, in Deborah Waller and Ann McPherson (eds), *Women’s health*, Oxford University Press, 2003, p. 484; Barbara A Goff, Lynn S Mandel, Cindy H Melancon and Howard G Muntz, ‘Frequency of symptoms of ovarian cancer in women presenting to primary care clinics’, *JAMA*, 2004, **291**: 2705–12, p. 2710. On a patient’s experience with the unreliability of ultrasound, see Barbara R Van Billiard, *A feather in my wig: ovarian cancer cured*, Portsmouth, NH, Peter E Randall, 1998, pp. 1–4.

⁹⁴ Goff, *et al.*, *op. cit.*, note 93 above, p. 2710; Shahin and Sorosky, *op. cit.*, note 89 above, p. 259.

⁹⁵ Jones III, *et al.*, *op. cit.*, note 88 above, p. 793. For other examples during the post-war decades, see Robert James Crossen and Ann Jones Campbell, *Gynecologic nursing*, St Louis, C V Mosby, 1956, pp. 136–7; Elizabeth Parker, *The seven ages of woman*, Baltimore, Johns Hopkins Press, 1960,

some voices were raised in favour of giving more attention to the non-specific symptoms which women could detect themselves, and of questioning the very use of the term “silent killer”. “Evidence that current screening techniques reduce mortality is lacking”, wrote one team. “Therefore, symptom recognition is important in the detection of ovarian cancer.”⁹⁶ Due to “problems with sensitivity and specificity”, decided another, “we have to rely on the woman and her initiative in order to achieve an early diagnosis.”⁹⁷

From the “Silent Killer” to the “Whispering Disease”

Increasing attention to ovarian cancer symptoms coincided with a much wider women’s health movement in the 1980s and 1990s. Its objectives were many, but a central goal was to transform the clinical encounter through the legitimization of patients’ own experiences of health and illness. For the nascent ovarian cancer movement, much of the focus was on reducing the risk of wrong or delayed diagnosis through educating both physicians and the public about the common symptoms of “the disease that whispers”. This campaign would eventually lead to collaboration between patient activists and members of the research community and, by the early twenty-first century, to official recognition of a pattern of what would now be termed “early” symptoms, accompanied by a widening critique of the “silent killer” metaphor.

A star was made in 1978 when Hugh Barber revived Stanley Way’s plea of nearly three decades before, declaring it was time “to change the generally accepted notion that there are no early symptoms” of ovarian cancer. Like Way, Barber observed that women’s complaints of increased girth and gastro-intestinal problems were routinely dismissed or wrongly diagnosed. “All too often”, he wrote, “the patient is considered a middle-aged crock who goes to too many cocktail parties and eats too many hors d’oeuvres.”⁹⁸ A year later, the South Dakota physician Brooks Ranney used patients’ records to tabulate the symptoms they had experienced and confirmed that most patients, including women with stage 1 and 2 disease, who therefore had a much better prognosis, had noticed symptoms over a period of two weeks to ten years.⁹⁹ In 1985, an Iowa team collected information from patients rather than from clinical records, and found that “[i]n sharp contrast to clinical perceptions and

p. 554; Marchetti, op. cit., note 58 above, p. 369; Beacham and Beacham, op. cit., note 57 above, p. 291; Romney, *et al.*, op. cit., note 57 above, p. 1067; Woodruff, op. cit., note 71 above, p. 117; Sandra L Tyler and Gail M Woodall, *Female health and gynecology across the lifespan*, Gowie, MD, Robert J Brady, 1982, p. 226; Benson, op. cit., note 69 above, pp. 640–1; Mary Daly and G Iris Ograms, ‘Epidemiology and risk assessment for ovarian cancer’, *Semin. oncol.*, 1998, 25: 255; Jo Ann Rosenfeld, ‘Ovarian cancer and ovarian masses’, in Jo Ann Rosenfeld (ed.), *Handbook of women’s health: an evidence-based approach*, Cambridge University Press, 2001, pp. 333–48, on p. 334.

⁹⁶Vine, *et al.*, op. cit., note 93 above.

⁹⁷C Wikborn, F Pettersson and P J Moberg, ‘Delay in diagnosis of epithelial ovarian cancer’, *Int. J. Gynecol. Obstet.*, 1996, 52: 263–7, p. 266.

⁹⁸Barber, op. cit., note 75 above, p. 97. Barber may well have inspired other researchers to turn their attention to this issue for, according to his obituary, he was “internationally renowned for his seminal work in ovarian cancer”. *The New York Times*, 29 Dec. 2006, <http://query.nytimes.com/gst/fullpage.html> (accessed 2/6/2009).

⁹⁹Brooks Ranney and M I Ahmad, ‘Early identification, differentiation, and treatment of ovarian neoplasia’, *Int. J. Obstet. Gynecol.*, 1979, 17: 209–19.

previous research . . . three fourths of women with locally staged tumors of the ovary” had symptoms ranging from swelling to fatigue, pain, problems with urination, indigestion, irregular bleeding, shortness of breath, and bowel changes. Nearly half of the women had dismissed these discomforts as “not serious”, especially those under forty and over fifty. They concluded that localized cancer did have symptoms, and that helping women to recognize them was an important public health priority.¹⁰⁰ Physicians, as well, needed to know what they were, and a Swedish team pointed out that, “[h]owever vague the symptoms, there are some that should alert the clinician to the possibility of ovarian cancer”.¹⁰¹

That call was repeated at intervals during the 1990s. Researchers continued to observe the long delays that separated the onset of symptoms from correct diagnosis and the challenge of finding a doctor “who is familiar with the symptoms of ovarian cancer”.¹⁰² Their efforts attracted less attention than they might have hoped, and physicians’ uneven knowledge of the disease was the subject of a pair of studies conducted in 1999. The first surveyed primary care physicians and achieved a response rate of just over one half. Within this group, the researchers reported a good deal of variation in respondents’ ability to identify risk factors correctly, while the accurate identification of symptoms ranged from 60 per cent for weight gain to 94 per cent for ascites (abdominal fluid).¹⁰³ An odd feature of this first study was that the authors’ list of six symptoms omitted any reference to the common signs of indigestion, bloating, and changes in bowel habits. The second study, however, which measured gynaecologists’ perceptions, did include abdominal bloating and altered bowel function (but excluded indigestion), and a strong majority of respondents recognized these symptoms. Only 62 per cent identified the use of fertility drugs as a potential risk factor, however, and 71 per cent identified a previous history of breast cancer.¹⁰⁴

The contrast between physicians’ sometimes limited knowledge and their seemingly unlimited authority was of major importance to women’s health activists in the 1980s and 1990s. This growing movement questioned the assumption that lay knowledge was necessarily inferior to biomedical knowledge and protested the dismissal of women’s intimate experience of their bodies. Activists sought to recover “the voice of the subject” and to recognize the role of intuition in relation to health and illness, despite the difficulties inherent in defining that concept.¹⁰⁵ These concerns would have particular resonance for the ovarian cancer movement, which—while hampered by the fact that many potential

¹⁰⁰ Elaine M Smith and Barrie Anderson, ‘The effects of symptoms and delay in seeking diagnosis on stage of disease at diagnosis among women with cancer of the ovary’, *Cancer*, 1985, **56**: 2727–32.

¹⁰¹ Folke Flam, Nina Einhorn and Kerstin Syovall, ‘Symptomatology of ovarian cancer’, *Eur. J. Obstet. Gynecol. Reprod. Biol.*, 1988, **27**: 53–7, p. 53.

¹⁰² Gamal H Eltabbakh, Pramila R Yadev and Ann Morgan, ‘Clinical picture of women with early stage ovarian cancer’, *Gynecol Onccol.*, 1999, **75**: 476–9, p. 479; Wikborn, *et al.*, *op. cit.*, note 97 above, p. 266.

¹⁰³ Ross E Gray, P Chart, J C Carroll, M I Fitch and D Cloutier-Fisher, ‘Family physicians’

perspectives on ovarian cancer’, *Cancer Prev. Control*, 1999, **3**: 61–7, pp. 62, 64.

¹⁰⁴ Margaret I Fitch, R E Gray, A Covens, Thomas G Franssen, *et al.*, ‘Gynecologists’ perspectives regarding ovarian cancer’, *Cancer Prev. Control*, 1999, **3**: 68–76, pp. 71–2.

¹⁰⁵ Laura K Potts, ‘Introduction: ‘Why ideologies of breast cancer? Why feminist perspectives?’ in Laura K Potts (ed.), *Ideologies of breast cancer: feminist perspectives*, London, Macmillan, 2000, pp. 1–11, on pp. 2–3; Jennifer Fosket, ‘Problematizing biomedicine: women’s construction of breast cancer knowledge’, in *ibid.*, pp. 15–36; Sara M Morris, ‘Lumps in the breast: negotiating risks

activists did not survive many years after treatment began—was intensely motivated by the need to improve the possibility of earlier diagnosis.

Like many other aspects of the women's health movement, ovarian cancer activism was strongly influenced by what Laura Potts described in her study of breast cancer narratives as "a dominant culture of revelation, disclosure, and the making of testimony".¹⁰⁶ The disease story is an old genre, but during the late twentieth century it became a powerful means of giving voice to the personal experience of cancer and of furthering the goals of the women's health movement.¹⁰⁷ This sense of purpose was shared by writers of ovarian cancer narratives and, as was the case with breast cancer, the process began with the publication of testimonies written by well-known women such as the NBC correspondent Betty Rollin (who wrote about her mother's illness and death from ovarian cancer), the comedian and actress Gilda Radner, *Cosmopolitan* editor Barbara Creaturo, and Liz Tilberis, editor-in-chief of *Harper's Bazaar*.¹⁰⁸

Radner revealed that she unknowingly had most of the risk factors for ovarian cancer, including a strong family history and the use of fertility drugs. She did not recognize her own symptoms ("my stomach felt bloated and hard"), was diagnosed with stomach problems by her gynaecologist and gastroenterologist, and spent months seeking an explanation for her increasing painful condition before finally being told she had ovarian cancer, stage 4. Her physician and family friend Steven Piver recalled that, at the time of her death in the spring of 1989, he assumed that the publicity surrounding her ordeal would mean that "the days of no newspaper or magazine articles or television specials on ovarian cancer were over".¹⁰⁹ Radner's death was certainly a turning point, with both Piver and her husband, Gene Wilder, taking up the cause of early detection, but the struggle for public awareness would continue.

Many women who were not in the public eye were also motivated to publicize their experiences, whether in books, newspaper articles, or online. By the turn of the century, ovarian cancer patients by the hundreds were telling their stories on the internet where, as for many diseases, websites were being created which provided ordinary people with a forum for sharing their perspectives on the experience of cancer. On these sites, entries could be very brief and still serve some of the same purposes as other cancer narratives. As Shani Orgad writes in *Storytelling online*, the process of writing "allows the author to make sense of her experience; to organize people, events, and information that she encountered, into a coherent framework of meaning".¹¹⁰ Using such narratives as historical sources obviously has limitations; as Potts says, disease stories tend to have "an aura of authenticity" when in reality they are one person's version of events, possibly

after a cancer diagnosis', *Health, Risk and Society*, 1999, 1: 179–94, pp. 184–5.

¹⁰⁶Laura K Potts, 'Publishing the personal: autobiographical narratives of breast cancer and the self', in Potts (ed.), op. cit., note 105 above, pp. 98–127, on p. 98.

¹⁰⁷*Ibid.*, pp. 99–103.

¹⁰⁸Betty Rollin, *Last wish*, New York, Linden Press, 1985; Gilda Radner, *It's always something*, New York, Simon and Schuster, 1989; Barbara

Creaturo, *Courage: the testimony of a cancer patient*, New York, Pantheon, 1991; Tilberis, op. cit., note 80 above.

¹⁰⁹Radner, op. cit., note 108 above, pp. 53, 58, 72; Piver with Wilder, op. cit., note 70 above, pp. 27–9, 42, 67–9, 20.

¹¹⁰Shani Orgad, *Storytelling online: talking breast cancer on the internet*, New York, Peter Lang, 2005, pp. 36–7.

related in a time of crisis.¹¹¹ As a means of entry into that experience of crisis, however, they are a valuable resource.

Ovarian cancer narratives are both similar to and different from most other types of cancer stories. A shared feature is the motif of “the enterprising self”, as Orgad calls it, through which the patient is cast as the protagonist embarking on a challenging journey.¹¹² In ovarian cancer narratives, however, the theme of “the enterprising self” often emerges most powerfully during the quest for a diagnosis, when the obstacle to be overcome, through courage and persistence, is not yet the disease itself but medical professionals who do not recognize the symptoms of ovarian cancer or seem unwilling to listen to patients’ complaints. All such accounts are necessarily retrospective; they look back, after a diagnosis has been made, to the symptoms which preceded it and the false starts which were made in identifying the disease.

In writing such narratives, some patients recalled that they were not aware that ovarian cancer was called the “silent killer” until after their disease was recognized, but they later identified the term as a factor in their delayed or incorrect diagnoses. One such story was that of Ayala Miron, the editor of a book titled *Ovarian cancer journeys*. She was diagnosed in 2000 after several years of reporting symptoms to her doctors and two trips to the emergency ward, where she was diagnosed with a gallbladder attack on the first visit and diverticulitis on the second.¹¹³ “As it turned out”, wrote Miron,

my health care providers had completely misdiagnosed my symptoms. They didn’t know enough about ovarian cancer and did not suspect that my complaints were serious. After my ovarian cancer diagnosis, I realized that this disease caused the symptoms I felt. I also learned that many health care providers mistakenly consider ovarian cancer “a silent disease”. My symptoms, over a number of years, taught me differently.¹¹⁴

Miron attributed health care professionals’ apparent lack of awareness to the influence of the “silent disease” image but also suggested that she, herself, failed to identify the symptoms she was experiencing because she was uninformed.

The Johns Hopkins Pathology Ovarian Cancer Website provided a forum for women to write about their personal experiences with ovarian cancer in the early twenty-first century, and it became a particularly rich source of patient perceptions regarding the process of diagnosis. Stories of long delay were legion, and a repeated theme was that both physicians and patients must be made aware of the symptoms which may signal ovarian cancer. For example, Amy Chaiklin described “the laparoscopic discovery of ovarian cancer after 13 years of suffering”, while Becky Bennett recalled experiencing swelling and discomfort in the early 1990s, noticed a “lop-sided” abdominal enlargement by 1994, began to have problems with urination in 1999, and was diagnosed with a ten-pound tumour in 2001.¹¹⁵ A woman signing herself as “Barbara”, in a testimony reminiscent of Stanley Way’s warning fifty years earlier, wrote of “popping

¹¹¹ Potts, op. cit., note 106 above, p. 99.

¹¹² Orgad, op. cit., note 110 above, p. 62.

¹¹³ Ayala Miron, ‘Symptoms are opportunities’, in Ayala Miron (ed.), *Ovarian cancer journeys*, Lincoln, NE, iUniverse, 2004, pp. 11–17, on p. 14.

¹¹⁴ Miron, ‘Foreword’, in *ibid.*, pp. xiii–xiv, on p. xiii.

¹¹⁵ Johns Hopkins Pathology, Ovarian Cancer, Community, Personal Stories, http://ovariancancer.jhmi.edu/menu_community.cfm, Amy Chaiklin, Becky Bennett (all stories accessed 2 June 2009).

Tum's [*sic*] and over-the-counter gas medications like crazy" and being diagnosed with acid reflux, while "Chris Y." wrote of being told for three years that she had endometriosis and was then treated for a kidney infection before her diagnosis.¹¹⁶ Donna McNulty related that her swollen stomach was attributed to peri-menopausal weight gain; her bloating and nausea were treated as acid reflux; and her constant need to urinate was diagnosed as a bladder infection—all common occurrences in women, but symptoms which, seen together, comprise a pattern typical of ovarian cancer.¹¹⁷ Judy Lidgate experienced the usual symptoms and was told she was suffering from depression, while Karen Leonard's intense pain was attributed to gallstones or a parasite.¹¹⁸ An especially common misdiagnosis was irritable bowel syndrome, or IBS, and women sometimes blamed themselves for not questioning their diagnosis. Augusta Gluck admitted, "I regret that I accepted the diagnosis of irritable bowel syndrome and did not investigate further . . . But I had seen my internist, my gynecologist, and a gastroenterologist. No one even mentioned that my symptoms might have been ovarian cancer and my life threatened by it."¹¹⁹

Often employing the term "whispering disease" brought into use by the ovarian cancer movement, such testimonies addressed the relationship between the two principal metaphors considered in this paper. They argued that ovarian cancer is not "silent" but that women must "listen" to their bodies in order to recognize the signs of "the disease that whispers". They urged others to put aside their fears of disapproval, trust their own perceptions and intuitions, and—shifting their use of the word "listen" to its more literal sense—demand their doctors' attention: "Don't just listen to your body (we all know or have heard that ovarian cancer whispers), make sure the doctor is listening, too."¹²⁰ The notion of "the disease that whispers" itself came under criticism, however, for it lacked resonance for women whose symptoms had become intense well before they were diagnosed. As one woman declared in a newspaper interview, "It's such a whimpy, cop-out term. I hate it. It's not a whispering disease. It's a shouting disease."¹²¹ Another woman, a long-term survivor of stage 4 cancer, told of how by the time a diagnosis was reached "the 'disease that whispers' was screaming out to her".¹²² The majority, none the less, focused on the need to heed the earlier, subtler symptoms of ovarian cancer, and various permutations of "the whispering disease" metaphor gained wide currency in the ovarian cancer movement.¹²³

In spite of the efforts of the ovarian cancer movement, many women's health manuals and menopause guidebooks, written by women's health advocates and physicians, were slow to reflect need for more information about symptoms of the disease. In part, this reticence may have reflected other priorities of the women's health movement. The

¹¹⁶ *Ibid.*, Barbara, Chris Y.

¹¹⁷ *Ibid.*, Donna McNulty.

¹¹⁸ *Ibid.*, Judy Lidgate, Karen Leonard.

¹¹⁹ *Ibid.*, Augusta Gluck. And see Amy Chaiklin, Vanessa Marshall, Jan Witsoe, Kate "jemakri" beckman (*sic*).

¹²⁰ *Ibid.*, Beverley; and see Diane Paul, Diane McNulty.

¹²¹ Freda Ariella Muscovitch, quoted in Gabor Mate, 'Ending the deadly silence', *Globe and Mail*, 2 Oct. 2001, p. R5.

¹²² Marlene Eisner, 'The disease that whispers', <http://thesuburban.com> (accessed 1/6/2009).

¹²³ Jane Brody, 'The deadly whispers of ovarian cancer', *New York Times*, 2 Oct. 2001, online. <http://www.nytimes.com/2001/10/02/health/personal-health-the-deadly-whisper-of-ovarian-cancer.html> (accessed 1/6/09).

prophylactic removal of healthy ovaries when hysterectomies were performed was still common, and one way to counter that practice was to downplay the danger of ovarian cancer. Lonnie Barbach's *The pause*, for example, assured readers that ovarian cancer is a sufficiently rare disease that the ovaries "should not be removed preventatively".¹²⁴ Even in the early twenty-first century, most health manuals aimed at middle-aged women said little or nothing about ovarian cancer symptoms. In her *Menopause and hormone book*, Dr Susan Love passed lightly over the complexities of ovarian cancer diagnosis with the simple comment that there is "no good way to detect it early", while Ivan K Strausz's *You don't need a hysterectomy* described the early symptoms of the disease as "entirely inconspicuous" and remained highly pessimistic about the prospect of timely diagnosis.¹²⁵ And yet, this neglect was far from uniform, for the Boston Women's Health Book Collective had already begun, as early as the 1984 edition of *Our bodies ourselves*, to detail the "warning signs" of ovarian cancer which, they cautioned, "are frequently dismissed merely as 'stress' or nerves". These symptoms included "indigestion, gas, constipation or diarrhea, loss of appetite or weight, a feeling of fullness, lower abdominal discomfort or pain, frequent urination, fatigue, backache, nausea, vomiting, nonmenstrual vaginal bleeding, enlargement or bloating of the abdomen or an unusual growth or lump". Persistence of such symptoms, they advised, called for "a thorough physical evaluation for ovarian cancer" by means of a symptom review, family history, pelvic and rectal examination, CA-125 blood test, and ultrasound.¹²⁶ This disparity within the popular women's health literature shows that information about symptoms and diagnostic procedures was available to the public, even if many authors chose not to include it in their works.

"Official" Recognition of Ovarian Cancer Symptoms

By the late 1990s, a growing body of research was providing more and more evidence that there was, indeed, a pattern of early warning signs of ovarian cancer which should be more widely publicized and acted upon. The growing ovarian cancer movement, meanwhile, lobbied for further research initiatives, and, on occasion, worked with members of the research community to document ovarian cancer symptom patterns. One leading activist was Cindy Melancon, a registered nurse living in Amarillo, Texas, who was diagnosed in 1992 and started a newsletter, *Conversations*, as a forum for women with ovarian cancer and as a vehicle for disseminating information.¹²⁷ A seminal moment in the relationship between lay activists and professional researchers came in 1998, when Barbara Goff, a gynaecologic oncologist from Seattle,

¹²⁴ Lonnie Barbach, *The pause: positive approaches to menopause*, New York, Penguin, 1995, p. 99.

¹²⁵ Dr. Susan Love's *menopause and hormone book*, New York, Three Rivers Press, 2003, p. 164; Strausz, op. cit., note 3 above, p. 303.

¹²⁶ Boston Women's Health Book Collective, *Our bodies, ourselves*, New York, Touchstone, 1984, p. 627.

¹²⁷ Johns Hopkins Pathology website, op. cit., note 115 above, Cindy Melancon.

Washington, met Melancon at a conference for the lay public. As Goff described the meeting:

Cindy and other survivors challenged the notion that ovarian cancer is a silent disease. After listening to these survivors' exceptional stories, I decided to team up with Cindy so that we could evaluate symptoms and early diagnosis in a scientific manner. During medical school, residency, and even gynecologic oncology fellowship I had been taught that ovarian cancer was a silent disease and so initially I was not optimistic that our studies would yield new information.¹²⁸

Although a number of researchers were already challenging the language long used to describe ovarian cancer, the findings of Goff and her colleagues would eventually prove to be a turning point. Their first study was published in the American Cancer Society's journal *Cancer* in 2000. It was a retrospective study based on information collected from ovarian cancer patients through a survey sent to subscribers of Melancon's newsletter, and the authors concluded that the great majority of women diagnosed at an early stage experienced symptoms. They analysed the reasons for delays in detecting the disease, ranging from women's own ignorance of symptoms to dismissive attitudes on the part of some physicians and the failure to perform pelvic examinations or order tests. While acknowledging the possibility of both selection bias (the women were Melancon's subscribers) and recall bias (they were recalling symptoms after receiving their diagnoses), Goff's team concluded that "women with ovarian carcinoma do have symptoms in contrast to what is stated in most textbooks and taught in most medical schools".¹²⁹ A second study responded to the problem of bias and also addressed a concern voiced by primary care physicians, which was that the non-specific symptoms of ovarian cancer are experienced by a great many women and can hardly be considered a guide to early diagnosis. By tabulating symptoms experienced during the past year by women about to undergo surgery for a pelvic mass compared with two control groups attending primary care clinics, the team found that, while women commonly reported at least one of the symptoms associated with ovarian cancer, those eventually diagnosed with the disease had much more severe, frequent and varied symptoms, even compared with women suffering from IBS. They concluded that their study "adds further evidence that ovarian cancer is not a silent disease".¹³⁰

Other researchers pursued the same question, and their combined work eventually led to a public statement released in June 2007 by the American Cancer Society, the Gynecologic Cancer Foundation, and the Society of Gynecologic Oncologists announcing that, for the first time, a "national consensus" had been reached in the US regarding early signs of ovarian cancer.¹³¹ The signs were listed as "bloating, pelvic or abdominal pain, trouble eating or feeling full quickly" and "urinary symptoms, such as urgent or frequent feelings of needing

¹²⁸ Barbara Goff, 'Introduction', in Miron (ed.), *op. cit.*, note 113 above, pp. xv–xvii, on p. xv.

¹²⁹ Barbara A Goff, L Mandel, H G Muntz and C H Melancon, 'Ovarian carcinoma diagnosis: results of a national survey', *Cancer*, 2000, **89**: 2068–75.

¹³⁰ Goff, *et al.*, *op. cit.*, note 93 above, pp. 2705–12.

¹³¹ 'Ovarian cancer has early symptoms', *op. cit.*, note 26 above. Other studies included S H Olson,

L Mignone, C Nakraseive, T A Caputo, *et al.*, 'Symptoms of ovarian cancer', *Obstet. Gynecol.*, 2001, **98**: 212–17; Barbara P Yawn, Brigitte A Barrette and Peter C Wollan, 'Ovarian cancer: the neglected diagnosis', *Mayo Clin. Proc.*, 2004, **79**: 1277–82; Lloyd H Smith, C R Morris, S Yasmeen, A Parikh-Patel, *et al.*, 'Ovarian cancer: can we make the clinical diagnosis earlier?', *Cancer*, 2005, **104**: 1398–1407.

to go”.¹³² The news media quickly spread the word, and Goff was one of the main spokespeople called upon to interpret these findings to the public. “There’s been this myth about ovarian cancer being silent and people saying there’s nothing you can do about it”, Fox News reported her as saying, “well, that’s simply not true anymore.”¹³³ In an interview with Jim Lehrer on PBS, the American public television network, Goff addressed the old problem of the non-specificity of symptoms by explaining that “it’s not simply just having the symptom that is important”, but that the symptom is new, persistent, and increases in severity.¹³⁴ “The majority of time”, she advised, such symptoms will not signify ovarian cancer, “but it’s just something that should be considered.”¹³⁵ She recommended that persistent symptoms, when reported by patients, should lead to a pelvic examination, including “a recto-vaginal exam so that the ovaries can be appropriately felt”, followed by ultrasound and a CA-125 blood test, if warranted. If the ultrasound detected a mass and the blood test revealed an elevation of a tumour marker that is common with ovarian cancer, the patient should be referred to a specialist in gynaecologic cancers.¹³⁶ Debbie Saslow, director of breast and gynaecologic cancer at the American Cancer Society, was also widely quoted, and spoke to the still relevant concern over causing more women to undergo unnecessary and hazardous surgery. She revealed that the ACS still had reservations about the recommendations, due to the fact that “[w]e don’t have any consensus about what doctors should do once the women come to them”.¹³⁷ None the less, leading members of the cancer research community stood firmly behind the public statement. Columbia University’s director of gynaecologic oncology, Thomas J Herzog, commented, that “By no means do we want this to result in unnecessary surgery. But I would not expect that to occur in the vast majority of cases.” He also saw a need for physicians to reverse their old approach and discuss the existence of early symptoms with their patients so that women might become “more proactive” in recognizing them. The gynaecologic oncologist Carol Brown, at Manhattan’s Memorial Sloan Kettering Cancer Center, agreed that “[t]his is something that women themselves can do”.¹³⁸ While the June 2007 announcement did not suddenly produce a consensus within the medical community regarding the significance of early symptoms, researchers would continue to investigate the role they might play in improving ovarian cancer diagnosis.¹³⁹

Conclusion

This article has examined ovarian cancer’s long association with the metaphor of the “the silent killer” and has traced the process by which that metaphor, and the understanding of ovarian cancer symptoms which it signified, were eventually challenged in the

¹³² ‘Ovarian cancer has early symptoms’, op. cit., note 26 above.

¹³³ Associated Press, ‘Doctors identify early symptoms of ovarian cancer’, FoxNews.com, 14 June 2007, <http://www.foxnews.com/story/0,2933,281653,00.html> (accessed 1/6/2009).

¹³⁴ ‘Doctors identify possible early signs of ovarian cancer’, 13 June 2007, http://www.pbs.org/newshour/bb/health/jan-june07/cancer_06-13.html (accessed 2/6/2009).

¹³⁵ Denise Grady, ‘Symptoms found for early check on ovarian cancer’, *New York Times*, 13 June 2007, <http://nytimes.com/2007/06/13cancer.html> (accessed 2/6/2009).

¹³⁶ Ibid.

¹³⁷ Ibid.

¹³⁸ Ibid.

¹³⁹ B A Goff, L S Mandel, C W Drescher, N Urban, *et al.*, ‘Development of an ovarian cancer symptom index’, *Cancer*, 2007, **109**: 221–7.

pages of medical journals and through the voices of ovarian cancer activists. It has attempted to show that, while the use of metaphorical language in medical discourse is inevitable, metaphors arise within particular contexts and may outlive their utility in expressing medical realities. In the early twentieth century, within the context of the “war” on cancer, the adoption of the “silent killer” metaphor in medical texts reflected the fact that the disease almost always progressed to an advanced stage before it was diagnosed and was almost always fatal. These factors also supported its exclusion from public information campaigns and popular medical literature aimed at women readers. From mid-century onwards, a small number of physicians openly questioned the accuracy of this metaphor and the medical assumptions which it signified, but only during recent years were the existence of early symptoms and their possible role in diagnosis widely and publicly addressed in both the lay and medical press. The association of the “silent killer” metaphor with ovarian cancer was exceptionally tenacious, and it arguably played a role in diverting attention away from systematic attention to symptoms which were later deemed relevant by a growing number of researchers. This history provides support for the conclusion that medical metaphors do have a role in defining “notions of reality” and therefore deserve close scrutiny.¹⁴⁰

¹⁴⁰Lupton, *op. cit.*, note 17 above, p. 59.