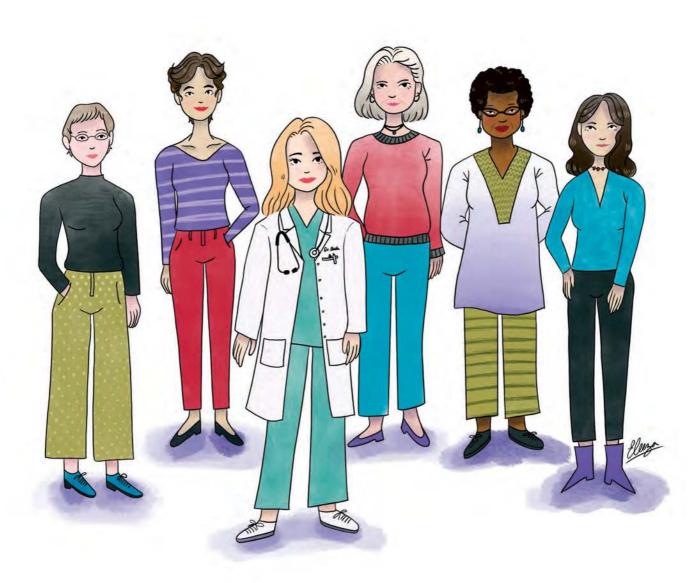
# In Reflection: A shared experience of cancer and womanhood

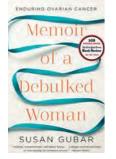


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s I prepare to embark on a journey into obstetrics and gynecology residency, I begin to reflect and realize that being a great doctor is not just about knowing facts and scoring well on tests; it is about empathy, humanity, and navigating patient narratives. This realization, coupled with my interest in ultimately pursuing a career in gynecologic oncology, is what drove me to engage with various literary works in medical humanities. Before diving into how this experience has informed my vision for my career as a physician, I would like to briefly review the works I have studied during this time.

# Memoir of a Debulked Woman



Memoir of a Debulked Woman by Susan Gubar, a feminist literary scholar, and former professor of English and women's studies at Indiana University, is a text in which Gubar reflects on her experience with ovarian cancer, from initial diagnosis to life after intensive therapies. She depicts the physical and emotional pain of a

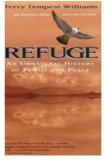
radical surgical operation (debulking), its consequences, the toxic effects of chemotherapy, how all of these events have impacted her personal and family life, and how others' testimonies about living with cancer "nurtured" her. She devotes significant time discussing how ovarian cancer is a silent killer and questioning whether such harsh treatments are worth the side effects, as she laments, "but a longer life under some circumstances may not be better than a shorter life." Ultimately, she reflects on coping with the reality of impending death and questions whether, as a patient, she "receive[d] the sort of care that takes into consideration the whole person." 1

# Wit V Mar

Wit is a play written by teacher Margaret Edson in which she exposes the internal life and witty mind of her character Dr. Vivian Bearing, an English literature professor, who, in the face of a diagnosis of stage IV ovarian cancer, publicly examines her life and how it informs her impending death.<sup>2</sup> In the play, Bearing uses lan-

guage and her career as an English professor to cope with her prognosis, and tries to understand the deeper meaning of life. There is also significant commentary on how she is treated by the medical staff, specifically the doctors, as she finds herself feeling more like an object for research than a human being.

# Refuge



Refuge: An Unnatural History of Family and Place is a memoir written by Terry Tempest Williams, a Mormon conservationist who worked as a curator of education and a "naturalist-in-residence" at the Utah Museum of Natural History.<sup>3</sup> In this memoir, she reflects on the ways in which she and her family cope with her mother's di-

agnosis and subsequent life with ovarian cancer through prayer, community, and nature.

The cornerstone of the memoir is the rise of the Great Salt Lake to record heights, and its effect on human life and wildlife. The Utah landscape becomes Williams' refuge, as she reflects, "When I see ring-billed gulls picking on the flesh of decaying carp, I am less afraid of death," and "I pray to the birds because they remind me of what I love rather than what I fear. And at the end of my prayers, they teach me how to listen." 3

Williams ultimately has to make sense of how to exist in a world without her mother.



### The Cancer Journals

The Cancer Journals is a memoir by Audre Lorde, a self-proclaimed "Black lesbian feminist mother love poet," in which she recounts her struggle with breast cancer through personal journal entries, with poetry and commentary.<sup>4</sup> She walks through the complicated decision of having a mastectomy from her

multiple identities.

As a feminist, she questions the use of breast prostheses in the context of what is valued in a woman in society.

As a lesbian, she notes that there are very few public models for her in this situation.

As a poet/artist, she emphasizes the importance of sharing one's experience for others to draw strength from, as she says her "work is to inhabit the silences with which [she has] lived and fill them with [herself] until they have the sounds of the brightest day and the loudest thunder." 4

As a Black woman, she speaks about how "Black women have on one hand always been highly visible, and so, on the other hand, have been rendered invisible through the depersonalization of racism." <sup>4</sup>

As a mother, lover, and friend, she embraces the "promise of shared strength," and shares how support from loved ones helped her in all stages of her disease, giving her confidence to unapologetically share her story.<sup>4</sup>



### In the Family

In the Family is a documentary featuring, and directed by, Joanna Rudnick, a young woman who discovers that she carries a familial breast cancer (BRCA) mutation that greatly increases her risk of developing both breast and ovarian cancers.<sup>5</sup> It explores Rudnick's journey as she struggles with

how to handle this knowledge, specifically with regard to prophylactic surgery (mastectomy and/or oophorectomies), romantic relationships, and childbearing.

The documentary also follows the lives of other cancer survivors and breast cancer BRCA mutation carriers to further examine the intricacies and implications of decisions such as surgery and genetic testing. Rudnick also questions the morality of the high costs of these genetic tests.

### **Common themes**

These five resources share a number of common themes, including drawing strength from others' testimonies in the

face of crisis, both from the perspective of the patient (*Memoir of a Debulked Woman, Wit, The Cancer Journals*) and from that of family members (*In the Family, Refuge*); the importance of quality of life in illness; and how (and whether) doctors truly carry out the bioethical principle of non-maleficence.

Patients commonly feel as if no one around them truly understands what they are going through. In all of these literary works, and most notably in *Memoir of a Debulked Woman, The Cancer Journals*, and *In the Family*, this concern is repeatedly voiced. Frequently, reading memoirs of other patients who have gone through similar things provides a comfort that loved ones may not be able to provide.

In *Memoir of a Debulked Woman*, Susan Gubar admits, "Never have memoirs and novels meant more to me than during these difficult times," as they help her understand her own experience and remind her that she is never alone. ¹ She shares that "Andrea King Collier's mother woke up to a colostomy...without her permission," ¹ which parallels her own surgical experience, and notes that "one husband of a woman who died of ovarian cancer felt that her death certificate 'would have been more accurate' if it had stated 'death due to chemical poisoning." ¹ These are a few of many examples of ways in which Gubar feels empowered by others' memoirs and testimonials.

In *The Cancer Journals*, Lorde seeks poetry and testimonials from other cancer survivors. She also exemplifies this theme by emphasizing the lack of examples for her to draw from given her identity as a Black lesbian feminist.

In the documentary *In the Family*, Rudnick takes it a step further by going out and meeting survivors and fellow BRCA mutation carriers. During her sessions with these families and individuals, she seeks wisdom from those who are, or have been, where she is. Rudnick is swayed toward the option of surgery. She needs this external commentary to validate her decision and frame her thinking about the prophylactic surgeries. This desire for external validation and search for solidarity is not dissimilar to what many of the cancer patients and families feel they need.

Another important theme is the importance of quality of life in illness, terminal or otherwise. This is particularly evident in *Memoir of a Debulked Woman* and *Refuge*. During her postoperative recovery, regarding her colostomy, Gubar laments, "No longer intact, I cannot contain or control myself...according to researchers in artificial intelligence, one major marker of what constitutes life is autonomy." This is not an uncommon occurrence for patients who have a radical "debulking" surgery for ovarian cancer, as the bowel can sometimes have cancer, necessitating its removal.

What does it mean to have a good quality of life? The answer is different for everyone. For Gubar, it is having autonomy, something she feels she has lost, as she no longer has control over her bowels. Removing the diseased bowel likely gave Gubar more days to live and be with her loved ones, but at what cost? Was it worth it? Gubar doesn't even know the answer to that, as she questions what the value is of more time.

Quality of life is also a recurring theme in *Refuge*. Williams' mother, sick with ovarian cancer, does not initially want chemotherapy. Ultimately, given her intense fear of dying and losing time with her family she decides to proceed with chemotherapy. However, as her disease progresses, she decides to forego further treatment in favor of resting in the comfort of her home with her family. Williams reflects, "But you can't live by your prognosis." I think she means that it is important for patients to put attention and time toward things they loved to do before they were sick. Quality is measured differently for everyone, but engagement in activities that consistently bring joy is universally important.

Skepticism about the bioethical principle of non-maleficence is another theme. "First, do no harm," is what we are taught on day one of medical school. But the ways in which this bears out in practice are far more complicated. *Memoir of a Debulked Woman, Wit,* and *Refuge* each touch on this theme. In *Refuge,* Williams attests, "Dying doesn't cause suffering. Resistance to dying does," after watching her mother go through many difficult and damaging treatments that left her far weaker than the cancer itself. Williams' mother commented, "I feel abused," after undergoing radiation therapy. Isn't it ironic that, in 2018, the only way we know how to treat malignancies is with malignancy?

Throughout the play *Wit*, Bearing questions her physicians' commitment to non-maleficence, as she feels objectified by her doctors, which is evidenced by her comment, "The young doctor...prefers research to humanity." At the end of the play, when Bearing is dying, a code team rushes into her hospital room. She had previously discussed with her nurse, the only person on her medical team whom she trusts, that she wants her code status to be DNR (Do Not Resuscitate). When the code team rushes in and starts trying to resuscitate her, the nurse exclaims, "She's DNR!" <sup>2</sup> The young oncologist replies, "She's research!" <sup>2</sup>

Is a publication in a renowned medical journal worth a life? Is it worth betraying a patient's wishes? The answers to these questions are not always as obvious as one may hope.

Gubar is also skeptical of her doctors' intentions as she reflects, "the most benevolent of doctors [are] each highly

motivated to do his or her best but each diminishing me bit by bit," <sup>1</sup> and "the hardly noticeable symptoms of cancer pale in comparison to those produced by the surgeons determined to excise it." <sup>1</sup>

On a more positive note, there are some instances in which Gubar acknowledges physicians who do follow the ethical principle. She comments, "I admired the evident integrity of a surgeon advising me against surgery that could be dangerous." <sup>1</sup>

Through my engagement with these stories of female cancer patients and their families, I have learned a great deal about myself and about the power of narrative medicine. The memoirs and reflections of these inspiring women have helped to shape my vision and orient my priorities for my career as an obstetrician/gynecologist (and ultimately a gynecologic oncologist). I have always been a perfectionist, and I have at times been obsessed with academic achievements and prestige. With this knowledge of my personal tendencies, coupled with the insights I have gained from these memoirs, I vow to myself that I will never measure my success in how many papers I publish or how low my surgical complication rate is; I will measure it in laughs, smiles, tears, and hugs. I will not just hear my patients' concerns, but I will listen to them. I will make sure I know what my patients' goals are, and what is most important to them. I will accept that these may change and it is important to re-ask during each clinic visit.

I will continually check my own intentions by asking myself questions such as, "Am I pushing chemo because it makes me feel better for my patients to live longer?" Or "Am I acting according to my patients' true wishes?"

I will seek to involve the family members of my patients, remembering that it is not one individual who gets cancer, but a whole family. And always, always, I will pay attention.

## References

- 1. Gubar S. Memoir of a Debulked Woman: Enduring Ovarian Cancer. New York: W.W. Norton & Company, 2012.
- 2. Edson, M. Wit. New York: Farrar, Straus, and Giroux; 1999.
- 3. Williams T. Refuge: An Unnatural History of Family and Place. New York: Pantheon Books, 1991.
- 4. Lorde A. The Cancer Journals: Special Edition. San Francisco: Aunt Lute Books; 1997.
- 5. In the Family. Directed by Joanna Rudnick. Kartemquin Films, 2008.

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