Women's Health: Cancer

Becoming an Informed Health Care Consumer

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Synopsis

Important psychological issues are involved in various cancer therapies. The patient has the ability to impact her own therapy by choosing a physician through personal interview and thus considering the physical and psychological support offered. Individuals who have cancer may have further impact by agreeing to participate in controlled clinical trials to help protect future generations, although patients are often deterred by conjecture that the best care will not be available under trial conditions.

I TAKE THE LIBERTY as a "soft scientist" to bring you both facts and feelings and substance and sentiment, because, while breast cancer and all cancers are medical diseases, they are also a psychological entity. One in four Americans will get cancer in his or her lifetime. The good news is that currently 51 percent of all cancer patients are living at least 5 years, and large numbers are long-term and well survivors.

Cancer knows no economic, age, cultural, racial, or sex discrimination. However, there are certain cancers that are gender-specific, and while the mortality rate for lung cancer has surpassed that for breast cancer, breast cancer is still the most feared cancer by most women. An increasingly large number of younger women are affected by this disease, and its impact has very specific connotations based not only on the stage of the disease but also on the lifestage of the individual woman and her lifestage tasks, which are complicated, delayed, or even obliterated by either her cancer or her treatment.

The thrust of my discussion is not just to give you facts about breast cancer, but to try to help energize and mobilize you to become informed consumers of medical services. Do you ever watch a woman go into the beauty shop and walk up to the receptionist and say, "Who is good with short hair? Who does a good permanent?" It is frightening to me that most of us are more aggressive, more demanding, and more discriminating about our household products and beauty aids than we are about the doctors we select to treat our bodies and our psyches.

Too many women blindly choose their physicians. He or she lives in the neighborhood. Oh, one of my friends told me about that person, or that person has been recommended. But how many of you actually walk in and interview your physician? You pay for the service. You hire and you have the capacity to fire, if you understand the criteria by which you could make those choices. Do you ask about the individual's philosophy about treatment for breast, lung, or ovarian cancer, credentials, fee schedule? There is no reason why a woman cannot expect to get both high-level technological expertise and high-level psychological sensitivity in her health care providers. They are not mutually exclusive.

The fact that we have multimodality treatments today gives us both promise and problems: The promise of viable options to fight disease, but also the problem of being able to evaluate the data that are sometimes sensationally reported by magazines. A couple of years ago a headline appeared in one of the women's magazines: "No More Mastectomies." This statement is not an unqualified truth. It is true that more women will not require mastectomy, but mastectomy is still the treatment of choice for some women, either physician-recommended or patient-elected, for a variety of reasons. We need to become more sophisticated and take time to find those individuals to help us interpret the data as they are currently being represented.

Each woman must examine her needs, her fears, and her expectations and beliefs about the efficacy of treatment. You can request a brochure from the National Cancer Institute (NCI) that wll explain their controlled clinical trials for early breast cancer. The data are impressive and not complete, but the

answer for breast cancer treatment is not final. The only way for us to get definitive answers for our contemporaries, and certainly for our daughters, is by participating in controlled clinical trials. This is the kind of research that controls confounding variables so that we get a much clearer sense of what aspects a particular treatment, (chemotherapy, conservation surgery, or modified surgery) contributes to the outcome measured, whether it be the primary objective of longevity, or its associated effect of quality of life. The controlled clinical trial is our major vehicle for reaching that endpoint.

The Halsted radical mastectomy was once all there was to offer—a debilitating, disfiguring, and psychologically damaging operation, mostly extinct today, for which we are all very happy.

Mastectomy is still a necessary, viable, and sometimes voluntary surgical procedure, but it is not the end of the physical treatment for the disease. Mastectomy has been named the surgery that women fear most; however, breast reconstruction is the surgery that women never thought was possible.

Today, almost all women who have treatment for their breast cancer by amputation of the diseased breast are candidates for some type of reparative reconstruction. The magnitude of the original mastectomy may dictate how many procedures for reconstruction are necessary to achieve the desired result. But reconstruction is often called a reverse mastectomy, and while it does not change underlying disease, it does in many ways eliminate the body damage and altered self-image that is almost always associated with radical surgery.

Reconstruction is an integral part of the controlled clinical trial at NCI, but we must acknowledge that some women elect not to have a reconstruction. Those of us who know that it has potential psychological value must always hear what a woman's issues are when she is evaluating the risks and benefits of a breast-repairing procedure. We must be careful not to become overly zealous in recommending this as an answer. It is an option, and when one looks at the possible outcome, you can imagine some of the salutary effects that it has on a women and her feelings about herself and her body image.

A major alternative to mastectomy is lumpectomy, in which the cancerous tumor is removed, and the breast is preserved. This may be followed by radiation or chemotherapy. Today, this breast-sparing operation is an acceptable alternative for many women and is intended to preserve the cosmetic appearance of the breast without compromising the woman's survivorship. There are many reasons women elect breast-sparing surgery and many reasons they elect not to have it. This includes concerns about the treatment, belief about its efficacy, or anxiety from preoccupation with possible residual cancer cells left in the breast.

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A study in The Netherlands showed that women who were treated with breast conservation surgery were less obsessed rather than more concerned about recurrence, and it may be because they were less preoccupied with breast concerns; specifically, breast anxiety intruded into their everyday activities less frequently because there was a minor or minimal alteration to their body image.

Today, irrespective of age, race, socioeconomic status, and to a large extent, degree of pathology, any woman facing a diagnosis of breast cancer could be a candidate either to preserve her treated breast or to replace the breast that has been surgically removed. There are no age limits to the choices, and women need to be encouraged not to be embarrassed or to be thought that they are narcissistic or vain because they want to preserve their body integrity. That is a natural, acceptable, and desirable aspect of a healthy personality. And seeking to keep one's breast and/or to restore it may be evidence of healthy adaptation rather than what was once believed a neurotic inability to accept her defect. Wanting to reverse that which is indeed reversible, or keep that which is so important to physical and psychological integrity, is a health, coping strategy.

We have analyzed some data on the psychological aspects of a controlled clinical trial here at NCI. It is too early to report the final outcome in terms of longevity and medical issues or to report what the long-term psychological outcome will be, but the trends are very evident. Based on self-reports by the patients, radiation resulted in more physical problems, such as soreness and pain in the affected area and limited arm motion. Women with mastectomies reported more emotional stress such as sadness, frustration, loss of libido, lack of control, and feeling that life is not worthwhile. When the mastectomy-

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and radiation-treated patients underwent chemotherapy, their reactions were similar, except that the mastectomy patients reported more nausea and vomiting. Both groups of women felt satisfied with the effectiveness of their therapy, which is a desirable attitude.

Some of the psychological and political issues that need to be looked at are the influence of legal mandates on physician-patient interaction and patient decision-making, research on the long-term psychosocial and pyschosexual effects of chemotherapy, and the impact of familial breast cancer on a daughter's health care behavior, health care vigilance, and psychological adjustment.

Seven or eight States have mandated informed decision or communication about options. We have not systematically evaluated how this kind of standardized information package is affecting women's decision-making abilities. How many women, and are there subsets, are not mobilized by the way this information is presented but are frightened and paralyzed by it? We need to investigate that with the same kind of scientific rigor that we do some of the medical and biologic concerns.

Effects of chemotherapy may be long-term psychosexual sequelae, osteoporosis, vasomotor changes, senile vaginitis, frequent and distressing cystitis, and for a large number of women, a premature menopause and an imposed infertility. We need to think about how these affect women. This statement summarizes the situation for many women.

"I didn't know I would be sick, nauseated, frightened, unable to sleep, irritable, undergo strange mood changes, get terrible hot flashes, lose my hair on my head and other places, feel exhausted like having the flu, and have my vagina get tight and dry. Losing my breast was just one tiny piece of the whole tiny saga."

We need research to examine the psychosexual and fertility concerns. Chemotherapy and many cancer treatments affect both recreational sex and procreational sex, and we do not have enough information about this aspect.

For the daughters, we need to help them develop healthy vigilance and routine health care maintenance without morbid preoccupation, and we need to understand that delicate balance more effectively.

Susan Sontag said: "Illness is the nightside of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged at least for a spell to identify ourselves as citizens of that other place."