Doc, I Don't Want Your Poison

FRANCESCA GIORGI,^a ROMEO BASCONI^b

^aUnità di Oncologia Medica, Ospedale Madonna del Soccorso, San Benedetto del Tronto, Italy; ^bUnità di Oncologia Medica, Ospedale Murri, Fermo, Italy

Key Words. Physician-patient relations • Cultural characteristics • Decision making • Health communication

Disclosures: The authors indicated no financial relationships.

Mrs. A. is a bright and intense 58-year-old woman. She is married and the mother of two sons. She is a Catholic who practices meditation, has trust in natural medicine, and believes that the mind has control over the body's physical well-being. We met her in 2003 when her mother was diagnosed with lung cancer, which eventually led to her mother's death. During this period, although Mrs. A. clearly trusted our therapeutic approach, she also prepared some homeopathic remedies for her mother, such as Bach flowers. When her mother passed away, Mrs. A. thanked us for our work. We remained in touch, and every Christmas she sends us handmade presents.

In April 2010, Mrs. A. found a lump in her left breast. After consultation with a doctor practicing complementary and alternative medicine (CAM), Mrs. A. concluded that the lump was a sign of psychological distress and did not undergo any further diagnostic procedures. However, the lump did not disappear. Six months later, Mrs. A. finally underwent a mammogram and biopsy; breast carcinoma was diagnosed. In December 2010, Mrs. A. underwent a quadrantectomy with sentinel node excision. At the follow-up examination a few days later, we discussed the biology of her tumor, which involved a risk recurrence worthy of adjuvant therapy. We proposed a standard chemotherapy regimen including trastuzumab, radiotherapy, and hormone therapy. Mrs. A. calmly but firmly refused all the suggested treatments, saying that she did not want to be poisoned and have her immune system destroyed. We did not make any negative remarks about her decision, but we asked her to consider another meeting to further discuss treatment options. She said, "Ok, I'll think about it."

Most patients with cancer accept the treatments proposed by their oncologists, even when the clinical benefit is likely to be modest [1]. Most women who undergo adjuvant chemotherapy for early-stage breast cancer consider its benefits to be worthwhile, whereas only 1%–2% of patients would not repeat chemotherapy regardless of the magnitude of potential benefit [2].

Approximately 25% of patients with breast cancer prefer to be the sole decision maker about adjuvant therapy options, with the desire for decisional control increasing after medical consultation [3].

The widespread availability of web-based medical information and internet forums in which patients share experiences and opinions may complicate the oncologist's decision-making approach [4, 5]. Moreover, CAM is a growing field in oncology, with one study reporting that 80% of patients have used these therapies at least once [6]. Patients are motivated by the perceived absence of toxicity in these approaches, even though only 37% of patients believed that they could be cured in this way. Of note, almost half of interviewed patients wanted more control over their medical care [6]. In the setting of adjuvant therapy for breast cancer, most patients use CAM as an additional therapy rather than as an alternative to the established medical practice [7]—a behavior that is usually harmless. In contrast, there are serious negative consequences in term of survival rates when the standard oncologic treatment is withheld in favor of CAM [8].

When an oncologist is faced with a mentally competent patient who makes a medically irrational choice, it is important to separate this irrational preference from the rest of the patient's values and beliefs [9]. Although physicians propose therapies based on a set of specific measurable goals (e.g., survival, morbidity), patients' decisions are ultimately based on a complex system of personal values, beliefs, experiences, and emotions [10–12]. Interestingly, a patient who refuses treatment often seems to assume that this choice terminates the patient's relationship with the oncologist [13].

Studies on how patients with cancer develop trust-based relationships with their physicians are limited. The few published studies show that professional competence, honesty, and patient-centered behavior are the main enhancers of trust

Correspondence: Francesca Giorgi, M.D., Ospedale Madonna del Soccorso, Via Manara 3-7, 63039 San Benedetto del Tronto (AP), Italy. Telephone: +390735793463; Fax: +390735793463; e-mail: romeofrancesca@gmail.com Received March 29, 2012; accepted for publication May 24, 2012; first published online in *The Oncologist Express* on June 11, 2012. ©AlphaMed Press 1083-7159/2012/\$20.00/0 <http://dx.doi.org/10.1634/theoncologist.2012-0138>

[14]. Addressing the emotional needs of patients is a fundamental task during the medical encounter. Emotional support from physicians is the most consistent long-term determinant of trust for patients with breast cancer [15].

At the next visit, Mrs. A. came alone, although she did state that her husband and sons were “by her side.” We talked about her mother’s illness and death. She said that it was a difficult time for her because she was the only family caregiver. She remembered feeling hopeful when the first postchemotherapy computed tomography scan showed complete remission—a feeling that was lost when the cancer returned and was not controlled by either medical treatment or natural remedies. Mrs. A. believed that the recurrence was triggered by a family crisis that caused serious emotional distress for her mother. Mrs. A.’s mother spent her last days at home. During one visit, we found her mother sleeping quietly, with Mrs. A. holding her hand and still hoping for recovery—even though it was obvious that this was not going to happen.

The emotional distress that Mrs. A. experienced during her mother’s illness seemed to profoundly influence her decision to refuse the proposed treatment for her own breast cancer. We then discussed her current options and agreed that her decision should not be a mere compilation of advantages and disadvantages. Instead, it should be a process that involved her whole life, her relationships with friends and family, and her ability to deal with the concept of illness.

Mrs. A. stated that she had not changed her mind, but she seemed less convinced. When asked again about the reasons for this choice, Mrs. A. said that “conventional medicine destroys the immune system... doesn’t have a holistic approach, [and] does not take into account the psychological dimension,” which she believed was the key to her illness. We reiterated the difference between “getting better” and “feeling better” [16]. Although chemotherapy, trastuzumab, and hormone therapy could be transiently detrimental to her quality of life, the long-term benefit is well established. We discussed the evidence for the proposed adjuvant therapy and re-emphasized that CAM therapies have not been shown to have any clinical benefits [17]. We also discussed the key point of contention—treatment toxicity. At the end of our meeting, we asked if all the issues were sufficiently clear and stated that we were available to discuss her concerns again.

Mrs. A. decided to begin chemotherapy—against the advice of her family and friends. She completed all scheduled treatments, even when she needed granulocyte colony-stimulating factor support for febrile neutropenia after the second cycle of chemotherapy. Upon completion of radiotherapy, trastuzumab and hormone therapy were started after some delay because Mrs. A. still was not convinced about this therapy; the term “antibody” frightened her. Trastuzumab was eventually interrupted when a heart ultrasound revealed a 15% drop in the left ejection fraction.

At the next visit, Mrs. A. stated that she was “depressed” and that “hormone therapy had made her another person.” She refused any psychological support and ultimately decided to discontinue the treatment. Although a follow-up ultrasound revealed an improved ejection fraction, Mrs. A. confirmed her decision to stop any oncologic therapy at that time. However, she did state her intention to continue to be followed at our clinic and expressed her appreciation for our medical care. Despite the difficulties and complexities of this particular patient-doctor relationship, which were mostly related to profound differences in cultural backgrounds and views, Mrs. A.’s trust was not lost due to the emotional support she received during her mother’s illness and after her own diagnosis of breast cancer. She did not feel judged for her choices and appreciated our open-minded attitude, which were probably the key elements to maintaining the relationship.

From this experience, we learned that it is important to maintain a trusting relationship with our patients, even when the decisions we suggest are dismissed for reasons with which we do not agree. A compassionate approach is critical to help patients face their disease, now and in the future.

ACKNOWLEDGMENTS

We thank Guido Silvestri, M.D. (Emory University, Atlanta, GA) and Catia C. Confortini, Ph.D. (Wellesley College, Wellesley, MA) for assistance with revision of the manuscript.

AUTHOR CONTRIBUTIONS

Conception/Design: Francesca Giorgi, Romeo Bascioni

Manuscript writing: Francesca Giorgi, Romeo Bascioni

Final approval of manuscript: Francesca Giorgi, Romeo Bascioni

REFERENCES

1. Slevin ML, Stubbs L, Plant HJ et al. Attitudes to chemotherapy: Comparing views of patients with cancer with those of doctors, nurses and general public. *BMJ* 1990;300:1458.
2. Duric V, Stockler M. Patients’ preferences for adjuvant chemotherapy in early breast cancer: A review of what makes it worthwhile. *Lancet Oncol* 2001;2:691–697.
3. Brown R, Butow P, Wilson-Genderson M et al. Meeting the decision preferences of patients with breast cancer in oncology consultations: Impact on decision-related outcomes. *J Clin Oncol* 2012;30:857–862.
4. Helft PR, Hlubocky F, Daugherty CK. American oncologists’ view of internet use by cancer patients: A mail survey of American Society of Clinical Oncology members. *J Clin Oncol* 2003;21:942–947.
5. Truog RD. Patients and doctors: The evolution of a relationship. *N Engl J Med* 2012;366:581–585.
6. Richardson MA, Sanders T, Palmer JL et al. Complementary/alternative medicine use in a comprehensive cancer center and the implications for oncology. *J Clin Oncol* 2000;18:2505–2514.
7. Burstein HJ, Gelber S, Guadagnoli E et al. Use of alternative medicine by women with early stage breast cancer. *N Engl J Med* 1999;340:1733–1739.
8. Chang EY, Glissmeyer M, Tonnes S et al. Outcomes of breast cancer in patients who use alternative therapies as primary treatment. *Am J Surg* 2006;192:471–473.
9. Brock DW, Wartman SA. When competent patients make irrational choices. *N Engl J Med* 1990;322:1595–1599.
10. Van Kleffens T, Van Leeuwen E. Physicians’ evaluations of patients’ decisions to refuse oncological treatment. *J Med Ethics* 2005;31:131–136.
11. Epstein RM, Peters E. Beyond information, exploring patients’ preferences. *JAMA* 2009;302:195–197.
12. Politi MC, Studts JL, Hayslip JW. Shared decision making in oncology practice: What do oncologists need to know? *Oncologist* 2012;17:91–100.
13. Huijter M, Van Leeuwen E. Personal values and cancer treatment refusal. *J Med Ethics* 2000;26:358–362.
14. Hillen MA, de Haes HC, Smets EM. Cancer patients’ trust in their physician: A review. *Psychooncology* 2011;20:227–241.
15. Arora NK, Gustafson DH. Perceived helpfulness of physicians’ communication behaviour and breast cancer patients’ level of trust over time. *J Gen Intern Med* 2008;24:252–255.
16. Buckman R, Baile WF. A practical guide to communication skills in cancer care: Disk 1. Toronto: Medical Audio Visual Communication; 2001.
17. Gerber B, Scholz C, Reimer T et al. Complementary and alternative therapeutic approaches in patients with early breast cancer: A systematic review. *Breast Cancer Res Treat* 2006;95:199–209.