Refusing Treatment

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The Oncologist 2013, 18:634-636.
doi: 10.1634/theoncologist.2012-0436

The Oncologist®

Reflection

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Disclosures of potential conflicts of interest may be found at the end of this article.

Key Words. Patient-doctor communication • Cancer care • Complementary medicine • Refusing treatment • Declining cancer treatment • Alternative medicine

In the late 1990s, I was working as a family physician. During that time, I was integrating complementary therapies into routine practice in family medicine, as well as being involved in academic work and teaching family physicians and residents. Even with a very open mind toward complementary therapies, when it came to patients affected by cancer, I strongly advocated that these therapies should not be used as an alternative to conventional treatment, but rather as complementary approaches with a single goal of improving patients' well-being and quality of life.

During my years of consulting cancer patients and families, I noticed an increasing number of patients who declined conventional cancer treatment, a phenomenon that piqued my curiosity but somehow was not acknowledged by my colleagues, other than to mention that they had another "difficult patient." One of these patients was Suzanna.

Suzanna, who was born in England and emigrated to Israel in her late teens, was an attractive divorcee in her mid 40s. She had been working as a complementary practitioner for many years. When she entered the room, you could not ignore her presence: she is tall with dark long hair, piercing green eyes, and a smile that warms your heart. But one day in 1997, she found a 3-cm lump in her left breast that extended to the skin. From that moment, her life turned upside down. A quick process of evaluation including mammography, ultrasonography, and biopsy confirmed the diagnosis to be infiltrating ductal carcinoma. At that time, assessments of hormone receptor status or other prognostic factors were not available.

At first, like most people, Suzanna was shocked and devastated by the diagnosis. She underwent surgical excision, which confirmed advanced disease (stage IIIB) with six of eight affected axillary glands, and she was advised to begin chemotherapy as soon as possible. She came to me distressed and ambivalent about undergoing chemotherapy. During our prolonged and charged discussion, she suddenly asked me a question I had never heard from any of my patients. She asked me to look through the medical literature and determine her chances for recovery if she received chemotherapy. With my limited knowledge of oncology at the time, I assumed that the survival rate would be around 80%.

After consulting the literature, however, I was surprised to find that, given her advanced disease stage and the chemotherapeutic agents available at that time, her chances for survival would be only 32%.

When I shared this bad news with her, she didn't seem too upset. In fact, she asked me to do her another favor: to search the medical literature again and see what her chances for survival would be without chemotherapy. With both sadness and conviction, I told her, "You will die." Still, she urged me not to jump to conclusions, but to take a second look.

So, I dove into the research once more. To my surprise, during that time, when the Internet and PubMed were relatively new, finding the answer to her question in the current medical literature was not easy.

Finally, after spending a few hours in the local medical library, I unearthed a relevant article that estimated the survival rate of women with diseases at the same stage who did not receive chemotherapy. It was 26%.

At that point, Suzanna firmly said: "Look, chemotherapy would add only 6% to my survival rate. But I would lose my hair, which is so precious to me, it would affect my social interactions, and I would suffer nausea and vomiting. In fact, the oncologist gave me a list of side effects two pages long! I've decided that I am willing to risk losing the theoretical 6% advantage chemotherapy would give me. Chemo would destroy my quality of life. I am not doing it."

I was taken aback by her cold calculations. I told her she was making a great mistake, and I tried to change her mind. Not even the persistence of her oncologist and repeated calls from various clinic staff convinced Suzanna that she should change her mind. Her oncologist, an experienced physician, was puzzled by her decision and informed her that she had 6 months to live if she did not follow his treatment recommendations, and if that was her decision, there was no reason for her to continue to see him. Nonetheless, she decided against chemotherapy and began trying a wide variety of alternative and complementary therapies that she heard about from other cancer patients.

Close to 15 years have passed, and this issue of patients refusing conventional therapy still concerns me deeply. What is the actual extent and incidence of this experience? What is the best approach to address this issue? How should we confront the issue of a patient who makes an informed decision to decline therapy that we feel might be beneficial? Should we close the door on the continued care and follow-up of these patients?

Although the refusal of cancer treatment is a serious concern and has been shown to reduce the effectiveness of treatment and decrease survival duration after diagnosis [1, 2], the phe-

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nomenon itself has been scarcely studied. The number of patients who make this decision is not very well-known, but the number appears substantial enough to warrant close attention [3]. Studies have reported rates of less than 1% for patients who refused all conventional treatment [4] and 3%–19% for patients who refused chemotherapy partially or completely [5–9].

We tend to think that refusing therapy leads to a poorer quality of life as the disease progresses without treatment. Interestingly, that might not be the case.

A study that evaluated the quality of life of 140 cancer patients who had refused, discontinued, or completed chemotherapy revealed that the quality of life of patients who refused or discontinued chemotherapy was no different than that of patients who completed treatment [10].

In my interactions with patients who seek advice about complementary therapy options, I occasionally meet patients who have actually decided to decline treatment. Some have shared their decision process to refuse treatment, partially or completely, but most have not shared this decision with their treating physician. More commonly, during their search for second or third opinions, patients do not return to any of their original physicians for treatment and are lost to follow-up. Patients are looking for a physician to share their decision with a trusted professional who is willing to listen to their account of their painful journey. When they share their rationale for refusing conventional treatment, they mention multiple reasons, such as fear of adverse side effects of cancer treatment (particularly chemotherapy), uncertainty about treatment effectiveness, hopelessness, helplessness, loss of control, denial (about their illness), psychiatric disorders, dysfunction in the health care system, and, above all, issues surrounding communication and the patient–physician relationship [4, 11–18].

Patients are often aware of the serious side effects and complications that are likely to accompany conventional therapies, and some have witnessed the ultimate futility of such interventions. They weigh the evidence and often make choices that reflect their underlying values and beliefs rather than rely on medical evidence or advice as the determining factor. Nonetheless, these patients keep their medical appointments and seek reassurance that they will not be abandoned, that when needed, palliative care services would be available to them, and that they would not die in pain, but with dignity and have some control over the end of their life. In the meantime, they focused on living in the present, keeping to their usual schedules and routines, working, presiding over family gatherings, and seeking support and affirmation from close family and friends [16].

The unique patients who refuse conventional treatment are at times self-directed, confident, and active, and have thought deeply about the meaning of life and cancer and about their cancer treatment options.

It may not always be easy for clinicians to deal with these type of patients as they deviate from the norm and challenge current evidence [3]. Physician response is not always supportive of these decisions that patients make. Although physicians understand that patients have the right to decide about their treatment and recognize the possibility of an in-between phase when treatment effects and outcomes are far less predictable, physicians nevertheless tend to categorize their patients dichotomously: those who can be cured and those for whom a cure is no longer possible [18]. Patients who fall into the former category and refuse conventional treatment are considered "difficult patients" or "noncompliant."

Current evidence suggests that health care professionals often feel uncomfortable, troubled, and even distressed when dealing with patients who make decisions that go against medical advice. In such situations, communication between patients and the health care team can become strained, impacting on future contact and quality of therapeutic interaction [16]. In a recent qualitative study on women who refuse conventional treatment, and reflect back to their experience, they mention that a better first experience with their physicians might have made a difference in the treatment path they ultimately chose. They said that they would have been more likely to accept conventional treatment earlier had they felt that they had caring physicians who acknowledged their fears, communicated hope, educated them about treatment possibilities, and allowed them time to adjust to their diagnosis and assimilate information before starting treatment [17].

This experience with Suzanna made me aware that the communication between the patient and the physician must integrate the medical balancing of pros and cons of treatment effectiveness with the patient's personal perspective. It seems with the current trend of "patient-centered care" that there is a need to get a better insight into the role that the patients' view of life, their values, and personal judgments play in the decision-making process. In addition, an approach that uses effective communication with these patients and integrates their values with current medical evidence is needed.

Communication is crucial in establishing trust with patients, gathering information, addressing patient emotions, and assisting patients in decisions about care [19–21]. The quality of communication in cancer care has been shown to affect patient satisfaction, decision making, patient distress and well-being, compliance, and even malpractice litigation [22, 23]. Treatment decision making is an ongoing process; thus, patients who initially refuse treatment may later choose to undergo conventional cancer treatment if given the adequate support, information, and time necessary to make the decision. Even if patients have declined oncologic care, they may continue to see their primary care providers and family physicians. Patients need to feel that they have not been permanently excluded from the health care system even if they make choices that are contrary to the recommendations of their medical team [24].

As to Suzanna, to my initial astonishment, she thrived. In 2007, she published a book with an inspiring title: *Six Months to Live, Ten Years Later* [25]. She became a daily reminder for me that there are exceptional patients, and refusing treatment is only the tip of the iceberg and presents a major challenge that needs to be addressed.

ACKNOWLEDGMENTS

I thank Suzanna Marcus for sharing her unusual story so that physicians and patients can benefit from her experience.

DISCLOSURES

The author indicated no financial relationships.

REFERENCES

1. Han E, Johnson N, Delamelena T et al. Alternative therapy used as primary treatment for breast cancer negatively impacts outcomes. Ann Surg Oncol 2011;18:912–916.

2. Li BD, Brown WA, Ampil FL et al. Patient compliance is critical for equivalent clinical outcomes for breast cancer treated by breast-conservation therapy. Ann Surg 2000;231:883–889.

3. Verhoef MJ, Rose MS, White M et al. Declining conventional cancer treatment and using complementary and alternative medicine: A problem or a challenge? Curr Oncol 2008;15(suppl 2):s101–s106.

4. Huchcroft SA, Snodgrass T. Cancer patients who refuse treatment. Cancer Causes Control 1993;4:179–185.

5. Puts MT, Monette J, Girre V et al. Characteristics of older newly diagnosed cancer patients refusing cancer treatments. Support Care Cancer 2010;18:969–974.

6. Levin M, Mermelstein H, Rigberg C. Factors associated with acceptance or rejection of recommendation for chemotherapy in a community cancer center. Cancer Nurs 1999;22:246–250.

7. Cassileth BR, Lusk EJ, Strouse TB et al. Contemporary unorthodox treatments in cancer medicine. Ann Intern Med 1984;101:105–112.

8. Simmons K, Lindsay S. Psychological influences on acceptance of postsurgical treatment in cancer patients. J Psychosom Res 2001;51:355–360.

9. Velanovich V, Gabel M, Walker EM et al. Causes for the under treatment of elderly breast cancer patients: Tailoring treatments to individual patients. J Am Coll Surg 2002;194:8–13.

10. Gilbar O. The quality of life of cancer patients who refuse chemotherapy. Soc Sci Med 1991;32:1337–1340.

11. Levin M, Mermelstein H, Rigberg C. Factors associated with acceptance or rejection of recommendation for chemotherapy in a community cancer center. Cancer Nurs 1999;22:246–250.

12. Richardson JL, Sanchez K. Compliance with cancer treatment. In: Holland JC, ed. Psychooncology. New York, NY: Oxford University Press. 1998:67–77.

13. Kunkel EJ, Woods CM, Rodgers C et al. Consultations for "maladaptive denial of illness" in patients with cancer: Psychiatric disorders that result in noncompliance. Psychooncology 1997;6:139–149.

14. Goldberg RJ. Systematic understanding of cancer patients who refuse treatment. Psychother Psychosom 1983;39:180–189.

15. Appelbaum PS, Roth LH. Patients who refuse treatment in medical hospitals. JAMA 1983;250:1296–1301.

16. Kacen L, Madjar I, Denham J et al. Patients deciding to forgo or stop active treatment for cancer. Eur J Palliat Care 2005;12:113–116.

17. Citrin DL, Bloom DL, Grutsch JF et al. Beliefs and perceptions of women with newly diagnosed breast cancer who refused conventional treatment in favor of alternative therapies. ***The Oncologist*** 2012;17:607–612.

18. Madjar I, Kacen L, Ariad S et al. Telling their stories, telling our stories: Physicians' experiences with patients who decide to forgo or stop treatment for cancer. Qual Health Res 2007;17:428–441.

19. Epstein RM, Street RL Jr. Patient-centered communication in cancer care: Promoting healing and reducing suffering. NIH Publication No. 07–6225, Bethesda, MD: National Cancer Institute, 2007.

20. Institute of Medicine. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press, 2007.

21. Pincus HA, Patel SR. Barriers to the delivery of psychosocial care for cancer patients: Bridging mind and body. J Clin Oncol 2009;27:661–662.

22. Frenkel M, Ben-Arye E, Cohen L. Communication in cancer care: Discussing complementary and alternative medicine. Integr Cancer Ther 2010;9:177–185.

23. Frenkel M. Components of a successful integrative medicine clinical consultation. J Soc Integr Oncol 2008;6:129–133.

24. Shumay DM, Maskarinec G, Kakai H et al. Cancer Research Center of Hawaii. Why some cancer patients choose complementary and alternative medicine instead of conventional treatment. J Fam Pract 2001;50:1067.

25. Marcus S. Six Months to Live, Ten Years Later. Israel: Open Doorway Press, 2007.