When a Patient's Treatment Decision Clashes With the Standard of Care

February 2020 - Dallas

The concept of patient-centered care has gained ground over the past 20 years, and recently proposed quality metrics support the idea that care should match patient goals—a trend that many people, patients and physicians alike believe is progress. But what can breast surgeons do when patient autonomy conflicts with the standard of care, possibly to the patient's detriment?

"Our current research shows that up to 20% of women with breast cancer are treated outside of conventional treatment. Are these difficult patients, or are they well-informed individuals weighing the pros and cons of treatment and making choices that reflect their values?" said Rachel A. Greenup, MD, MPH, an associate professor of surgery and population health sciences at Duke University Carver College of Medicine and Duke Cancer Institute, in Durham, N.C

A Spectrum of Diversion From Standard Treatment

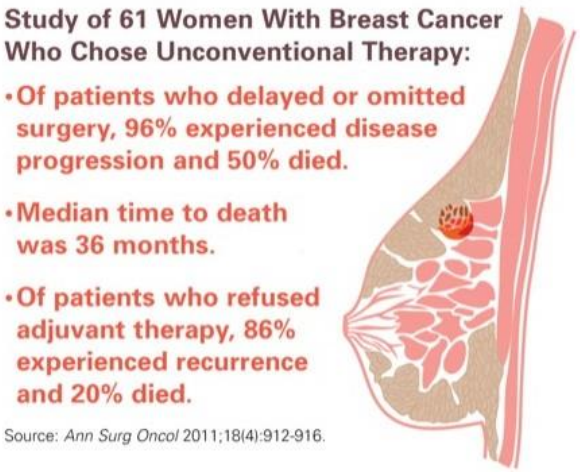
Although the 20% figure is a starting point, the differing degrees of clashes between patient autonomy and the standard of care make the definition and quantification of conflict unclear. *But the clashes do seem to be occurring more often.* Carla S. Fisher, MD, said she sees conflicts between patient autonomy and standard of care with increasing frequency, and she considers *the divide between evidence-based medicine and what patients will tolerate to be a growing gray area.*

"I think patient acceptance of 100% of what we consider standard treatment is a lot lower than we think, especially if you include requests for contralateral prophylactic mastectomy (CPM) and non-adherence with endocrine therapy," said Dr. Fisher, the medical director of breast surgical oncology and an associate professor of surgery at Indiana University School of Medicine, in Indianapolis. "There are patients who aren't going to do what you tell them, patients who feel the treatment just isn't right for them, and patients who simply can't make it to all their appointments. Figuring out how to treat our patients is really an evolving field."

The reasons that patients deviate from standard treatment are myriad. *Overwhelmingly, poor doctor–patient communication is cited as why women are unwilling to consider standard of care treatment*. There is also a fear of side effects; lack of conviction regarding the effectiveness of standard therapy; a sense of loss of control; denial of the cancer diagnosis; and challenges associated with the health care system itself, including lack of access and affordability.

Patient refusal of or delay in standard of care treatment can be deeply disturbing to physicians, who study, train and believe in the evidence-based medicine they recommend. "As physicians, we are deeply aware of the potential consequences of forgoing conventional therapy," Dr. Greenup said.

Those consequences can be dire. *One study evaluated 61 women from a community breast practice who intended to use unconventional therapy instead of standard treatment*. The patients fell into two groups: those who delayed or refused surgery, and those who delayed or rejected adjuvant chemotherapy and/or radiation.



Why would patients take such chances? *In another study, interviews with 60 women who either refused some or all standard therapy or who underwent both conventional and alternative therapy identified a few factors: negative initial experiences with their cancer team, a perception that their oncologist was uncaring, an exaggerated fear of side effects and a strong belief in the efficacy of alternative therapies* (*Oncologist* 2012;17[5]:607-612).

"These women lacked knowledge of the poor outcomes associated with refusal of standard treatment. *Notably, women in this study reported receiving their information on alternative therapies from social networks, the internet or other breast cancer patients*," Dr. Greenup said.

Many of these patients were willing to undergo surgical treatment; those who refused standard treatment tended to attribute greater risk to chemotherapy and radiation. "Surgery alone is better than no treatment. Sadly, despite their attempt to avoid aggressive therapy, many of these women required salvage chemotherapy and radiation when their disease recurred or progressed," Dr. Greenup said.

Then there are the patients who, after complying with the standard of care in terms of surgery and adjuvant therapy, can't or won't take the full duration of recommended anti-estrogenic medication. Approximately 50% of patients at five years report non-adherence to endocrine therapy. "We see patients who take their pills for only a few months when at least five years is recommended," Dr. Fisher said.

The pendulum can also swing in the direction of overtreatment, a challenge that breast surgeons face every day when lumpectomy candidates request CPM (*contralateral prophylactic mastectomy). "CPM is not associated with a survival benefit and is associated with increased risk for surgical complications and costs. It may improve cosmetic outcomes and peace of mind, but growing research suggests quality of life after breast-conserving surgery might still be better," Dr. Greenup said.

What Doctors Can Do

There are evidence-based recommendations for doctors trying to help breast cancer patients who are refusing or resisting standard treatment, according to Dr. Greenup.

"We can acknowledge their fears and communicate hope, educate them on treatment options, and allow them time to adjust to their diagnosis." If you practice in a region with a number of breast cancer surgery specialists, consider suggesting that the patient get a second opinion. "Sometimes a different messenger is really valuable for these patients," Dr. Greenup said.

Above all, avoid abandonment and fear tactics. "These do not work," Dr. Greenup said. "We need to be compassionate and nonjudgmental, to underscore patients' decision-making power, remind them that ultimately the treatment decision is theirs, and to stay open to the incorporation of alternative therapies into standard regimens."

Keeping an open mind can go a long way toward establishing a treatment plan that satisfies both patient and doctor, Dr. Fisher said. "I think the key is getting to the core of why they make certain decisions. Rather than telling them their choice doesn't make sense, ask them how they arrived at that decision."

As an example, if a patient requests CPM out of fear of more breast cancer, explore the actual risk with that patient. "For some patients, that procedure is the right choice. Others might come to another conclusion when you tell them their actual lifetime risk is only 10% or 15%.

"Most of the time," Dr. Fisher said, "we're able to agree on the *same plan that combines evidence-based medicine with what works for the individual patient*."