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The Legislative Arena: Physician Advocacy for Patients' Rights

by Kristen A. Zarfos, M.D., F.A.C.S.

Until the latter part of the 20th century, medical practice was driven and guided by patient needs. Those involved in medical research and technology responded to these needs, producing cures in previously incurable cancers, providing remarkable medical management in previously unmanageable diseases, and offering new surgical and anesthetic technologies, all of which resulted in greater longevity and quality of life for Americans. However, these advances brought about an upward spiral of health care costs.

Enter the managed health care system, whose primary goal has been to curtail this explosion in cost. With it has come, in some cases, intrusion into the patient-doctor relationship. Insidiously, medical and surgical management decisions are dictated to the physician, many times in contradiction to the basic standards of care.

Thus sets the scene in the State of Connecticut in 1996. HMOs had increasingly been nibbling away at the length of hospitalization for surgical procedures. Hernia repairs and laparoscopic cholecystectomies were considered outpatient procedures unless significant comorbid conditions existed. That same year modified radical mastectomies were added to the list of outpatient requirements.

Connecticut Hospital Association statistics for 1996 showed that the average length of hospitalization

for a woman undergoing a mastectomy in the previous five years had been a two- to four-day admission. Despite this information, in July 1996 two Connecticut HMOs adopted a set of practice guidelines written by Milliman and Robertson.¹ These guidelines clearly state that both lymph node dissections (following lumpectomy) and modified radical mastectomy are ambulatory surgeries.

Like many physicians in Connecticut, I found these guidelines unacceptable and decided to take action. I surveyed 225 of my patients, most of whom had had mastectomies, to find out their thoughts and concerns about outpatient mastectomies. One hundred percent of women surveyed responded in anger and outrage at their levels of pain and their concerns about handling the drains at home, which they believed had been ignored by their HMOs. These women believed that their emotional and psychological needs had also been disregarded by the HMOs they had paid to provide basic health care.

During that same time, I battled with an HMO over the course of seven hours and nine phone calls to have a patient granted a twenty-four-hour admission—two days short of the medical standard of care. Fortunately, the patient was admitted. During her first twenty-four hours after surgery, she was overwhelmed with nausea, in pain, and had passed out on the way to the bathroom—conditions that even her supportive husband could not have managed at home.

While some women have the resources and the desire to choose outpatient breast cancer surgery, the majority of women who have undergone this surgery find it untenable. Some women who have

chosen outpatient breast cancer surgery have done well; others have regretted it. And yes, there are well-respected institutions in this country where outpatient mastectomies are the norm. But in 1997, very few community hospitals have the resources or clout of these institutions to adequately provide this service in an outpatient setting.

As physicians, we have a choice when an HMO denies any hospitalizations. However, the choice is dictated by the HMO, not medically proven standards. I can appeal a denial of hospitalization, yet still be denied without recourse. If I do not follow the HMO guidelines and admit a patient undergoing breast cancer surgery, I can be penalized and potentially deselected. Then, either the patient pays out of pocket for care she has already paid for once, or the hospital swallows the cost. If I follow the HMO guidelines, I abandon the patient's needs—the patient whose care should be my primary responsibility and concern.

A PHYSICIAN-PATIENT-LEGISLATOR PARTNERSHIP

By autumn 1996, the voice of the constituents had brought the issue of outpatient breast cancer surgery to the federal and state legislative arenas. I sought help from U.S. Rep. Rosa L. DeLauro (D-Conn.), a survivor of ovarian cancer. After conducting extensive research with the help of my patients and many others throughout the state, Rep. DeLauro drafted the Breast Cancer Patient Protection Act of 1997, which would require insurers to cover a minimum of forty-eight hours of hospitalization for mastectomies and twenty-four hours for lymph node excision. Connecticut State Senator Edith Prague also introduced legislation to guarantee

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forty-eight-hour hospitalization for mastectomy patients and for lymph node dissection patients, if the patients so choose.

How did we get to this point? As a physician, I worked with my patients to organize their experiences and present them as part of a collective voice. This process involved writing letters to patients, informing them of upcoming legislation, and encouraging them to contact their representatives in the state and federal legislatures. In taking action, I have done what all of us do day in and day out—inform our patients, listen to our patients, and advocate for our patients.

As a political novice, I had to learn the ropes of contacting legislators one-on-one by letter, telephone, and personal meetings, as well as testifying at legislative hearings. But the voices heard best were those of my patients doing the same. When patients told their own stories of their struggle with breast cancer surgery and joined me in meetings with legislators and Connecticut Governor John Rowland, real progress occurred.

Uniting the voices of breast cancer patients opened the flood gates and brought attention to the denial of basic rights of breast cancer patients. The media researched and reported on our endeavors extensively. Breast cancer advocacy groups were outraged and supported our efforts. Soon breast cancer patients all over the state were writing letters, making telephone calls, and testifying at committee hearings.

At the time of this writing, Sen. Prague's bill has passed both the Connecticut Senate and House of Representatives unanimously. U.S. Rep. DeLauro's Breast Cancer Patient Protection Act, along with U.S. Senator Alphonse D'Amato's (D-N.Y.) similarly proposed bill, is currently undergoing the legislative process in Washington, D.C. The states of Illinois, Florida, Massachusetts, and Rhode Island have developed legislation similar to Sen. Prague's in Connecticut. New York and New Jersey have since passed legislation guaranteeing a woman undergoing mastectomy a forty-eight-hour admission if she chooses.

These legislative initiatives are hopeful signs that the rights of breast cancer patients will not be

ignored. But our work is not finished. Until legislatures can pass laws to protect the rights of all patients with any diseases to basic health care for which they have paid, we are left with a crisis for women with breast cancer—a crisis created neither by legislators nor physicians but placed in their hands by managed care companies. Some detractors might argue that these legislators are practicing medicine. Neither the legislators, patients, nor physicians want disease-by-disease legislation. However, legislators, along with physicians, are responsible for defending the health care rights of their constituents—our patients.

THE PHYSICIAN AS ADVOCATE

Advocating for patients at the legislative level does take away physician time from practicing medicine. The process requires organizing the collective energies of your patients; sending letters to patients, the media, and legislators; and speaking to community groups and anyone else who will listen. These efforts do require sacrifices on the part of physicians. However, if we do not spend the relatively small amount of time in this endeavor, in the long run we will lose the ability to care for patients in the individualized way they need.

Anyone involved in the care of cancer patients can be an advocate. Here are some tips that will help you get started.

- Keep up to date on the issues affecting your patients and the stands your legislators take.
- Contact the legislators both for and opposed to your stance. In addition, know the names of the legislative leadership and contact them.
- Find out which committees will hear your issue and target the chairman.
- Contact legislators via telephone, letters, and personal meetings, with or without patients.
- Inform your patients who their legislators are, and provide their telephone numbers and addresses. Clearly and simply specify the issues and how patients can help.

I once called a leading Connecticut HMO to schedule an inpatient lymph node dissection for breast cancer in a 64-year-old woman with insulin-dependent diabetes,

hypertension, and heart disease significant enough to warrant several medications. I was told by the HMO's screening staff, "Our guidelines say this is ambulatory surgery, and the patient does not qualify for inpatient care." Although the medical director reversed this upon my appeal, what if I had not appealed?

In November 1996 the American Association of Health Plans announced that its 1,000 HMO members would allow the physician to determine the length of hospitalization after breast cancer surgery. Physicians must actively respond to denials to ensure that this statement provides more than just empty words to our patients.

In closing, this excerpt from the Patient-Physician Covenant² written in 1995 by Cranshaw and colleagues so aptly explains what we as physicians need to do:

"Our first obligation must be to serve the good of those persons who need our help and trust us to provide it. Physicians, as physicians, are not, and never must be, commercial entrepreneurs, gate closers, or agents of fiscal policy that runs counter to our trust. Any defection from primacy may compromise quality of or access to medical care. As advocates for the promotion of health and support of the sick, we are called upon to discuss, defend, and promulgate medical care by every ethical means available. Only by caring and advocating for the patient can the integrity of our profession be affirmed."

If physicians do not advocate for patients and stand up for their rights to basic health care, who is left to do so?

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- ¹ Milliman and Robertson. Healthcare Management Guidelines. September 1995, Second printing.
- ² Cranshaw R, Rogers D, Pellegrino E, Bulger R, Lundberg G, Bristow L, Cassel C, Baroness J. Patient-physician covenant. *JAMA* 273(19), May 17, 1995. ■