**Oncology Issues**

ISSN: 1046-3356 (Print) 2573-1777 (Online) Journal homepage: https://www.tandfonline.com/loi/uacc20

# Patient Advocacy Issues in a Changing Health Care Environment

Cara Egan

**To cite this article:** Cara Egan (1996) Patient Advocacy Issues in a Changing Health Care Environment, Oncology Issues, 11:2, 22-24, DOI: 10.1080/10463356.1996.11904602

**To link to this article:** https://doi.org/10.1080/10463356.1996.11904602

# Patient Advocacy Issues in a Changing Health Care Environment

by Cara Egan

In the new era of competitive health care, people with cancer face challenges in obtaining access to high-quality care, interdisciplinary oncology care providers, drugs, appropriate follow-up, and clinical trials. On February 1, 1996, the Association of Community Cancer Centers hosted a one-day retreat that convened patient advocates and oncology leaders to address these challenges and to devise a united strategy for mobilizing and supporting patient advocacy at the regional, state, and local levels.

ACCC views advocacy for people with cancer, their families, and the community as a priority. ACCC President Diane Van Ostenberg, B.S., R.N., herself a cancer survivor, is strongly committed to this issue, and the Board of Trustees established a special Presidential Grant to support this commitment for her presidential year. Ortho Biotech, Inc., was this year's sponsor of the ACCC Presidential Grant.

"Only in the past decade has advocacy been recognized as a legitimate strategy for influencing the policies that shape the delivery of oncologic care in the community setting," said Van Ostenberg. "We endorse the concept of a community's responsibility to address the health care needs of all individuals dealing with cancer and to ensure access to whatever excellence is available for all cancer survivors."

*Cara Egan is ACCC Assistant Editor.*

## ADVOCACY AT THE BEDSIDE

The traditional definition of an advocate is one who pleads the case of another. Advocates, however, are most effective when they encourage patients to demand more control of their own care and treatment, according to Matthew J. Loscalzo, L.C.S.W.-C., president of the Association of Oncology Social Work (AOSW). The best way for patients to gain that control, contended Loscalzo, is through information.

"Ninety-eight percent of patients want exhaustive information," said Loscalzo, referring to a recent AOSW study on what patients want from providers. "Arming the patient with information and the ability to make decisions gives power to the patient."

Mobilizing patients and their families requires more than support and education, however. The advocate's job, Loscalzo said, is to train patients in skill-building techniques for communicating with managed care companies and legislators. Identifying specific tasks that patients can accomplish on their own behalf gives them a sense of objectivity over their situation, which leads to action.

Loscalzo called upon patient

Kimberly Calder, M.P.S., director of public policy for Cancer Care, Inc., (left) consults with Jim Kitterman, executive director of Candlelighters, a nonprofit advocacy group for children with cancer and their families.

advocacy groups to mobilize themselves in presenting a more united front in the face of rapid changes in health care. Too often, he said, patient advocacy groups revolve in their own orbits, rarely intersecting.

Meeting participants agreed that advocacy groups must work together and speak with a common voice. One important step is to clearly define quality care. Citing a recent National Coalition for Cancer Survivorship (NCCS) position paper, Ellen Stovall, NCSS executive director, enumerated criteria that managed care plans must meet in providing quality cancer care:

- The primacy of doctor/patient relationship should be preserved.
- Managed care plans should provide for appropriate and timely screening
- Upon diagnosis of cancer, the patient should be referred immediately to a cancer care specialist.
- Care should include a multidisciplinary approach.
- During the period of active treatment, the gatekeeper function should be performed by the oncologist or other specialty physician.
- Children with cancer should be treated by a physician specializing in pediatric cancer.
- Where appropriate, managed care organizations should provide for treatment of people with cancer at specialized facilities without additional financial burden.
- Managed care organizations should enroll cancer patients in peer-reviewed clinical trials.
- Cancer patients in remission should be monitored periodically by cancer specialists—not only by primary physicians—and have access to rehabilitative care when appropriate.
- Cancer patients should have access to hospice care and psychosocial services.

The role of the patient advocate, Stovall said, is to compel managed care organizations to meet these criteria and to educate patients to demand them.

## TRANSLATING VALUE INTO COST SAVINGS

To convince managed care companies that these criteria are valid and valuable, they must be translated into dollars and cents, according to Dean Gesme, Jr., M.D., medical oncologist with Oncology Associates/Iowa Cancer Care in Cedar Rapids, Iowa. Currently, for example, managed care companies are positioning primary care physicians as gatekeepers in hopes of decreasing referrals and treatments. It is up to the oncology community to show the cost efficiencies of having the cancer specialist act as gatekeeper of patient care.

"We need data to support what we already know—that having a cancer expert gatekeeper results in better outcomes and more cost-efficient care," Gesme stated. "The oncology gatekeeper must be presented as a profitable proposition for managed care companies."

The danger lies in the control that managed care companies have over the primary care physician gatekeeper, who lacks the expertise to know when managed care companies are denying quality care, according to John E. Feldmann, M.D., ACCC president-elect and medical oncologist at Mobile Infirmary Medical Center in Mobile, Ala. "For managed care companies, the cheapest form of care may be no care at all."

Increasingly, oncology nurses are being replaced by "assistive personnel," stated Kathi Mooney, R.N., Ph.D., A.O.C.N., F.A.A.N., president-elect of the Oncology Nursing Society. "We must remember that access to cancer specialists includes oncology nurses and the entire cancer care team," said Mooney.

Stovall agreed, stating that too often supportive care is the first to be eliminated as a result of cost-cutting measures. "We need data to show that patients receiving supportive care are saving health plans money," she said.

Mike Heron (far left), national vice president for public affairs at the American Cancer Society, joins ACCC President-Elect John E. Feldmann, M.D., Kathi Mooney, R.N., Ph.D., A.O.C.N., F.A.A.N., president-elect, Oncology Nursing Society, and Lee E. Mortenson, D.P.A., ACCC executive director, for informal discussion.

## IMPEDING ACCESS TO TRIALS

"Managed care is about finding out what is most effective. It naturally follows that managed care companies *should* be interested in funding clinical trials," said Kimberly Calder, M.P.S., director of public policy of Cancer Care, Inc., a nonprofit organization whose mission is to help patients and families cope with cancer.

Unfortunately, access to clinical trials is threatened in the managed care environment. A 1995 ACCC survey of 856 oncologists in 20 states showed that 3,361 patients were unable to enter clinical trials because of insurer denials.

Calder reported that through state legislative action, some managed care companies are being forced to take more responsibility for covering clinical trials. In New York, for example, the state legislature is expected this year to mandate payment for clinical trials. Calder encouraged her fellow advocates

*continued on page 24*

## Patient Advocacy Issues in a Changing Health Care Environment

*(continued from page 23)*

to become more involved in the state legislative process and to mobilize their constituencies to lobby state legislators.

The avalanche of paperwork required by managed care companies is also impeding physician efforts to place their patients on clinical trials. But that is only part of the problem, contended Susan Stewart, editor of the *BMT Newsletter.* She is concerned about physician hesitation to inform a patient about a clinical trial for which reimbursement will very likely be denied. "Patients should have the right to know about treatments that they may in fact be able to receive or at least try to receive," Stewart argued.

### A REPORT CARD ON SERVICE

To make educated decisions when choosing a managed care plan, employers and health care consumers require more information. To that end, meeting participants proposed creating a report card that would rate the priorities and level of care of managed care organizations. Patients would report on their experiences with, for example, ease of access, reimbursement delays, or even the number of phone calls required to have questions answered. The report card would serve as a measure of patient satisfaction with managed care plans.

Amy Langer, M.B.A., executive director of the National Alliance of Breast Cancer Organizations and facilitator for the discussion, defined the changing health care environment as one in which care is constrained, physicians are controlled, the needs of cancer patients are not paramount, and quality of life interventions are viewed as dispensable.

"Patient advocates must fight to raise awareness of quality of life issues through information and education, regulatory change, and legislative lobbying," said Langer. "But perhaps most importantly they must enlist patients to become advocates for their own care."

---

# Treatment of HIV-Positive Patients

by John S. Hoff

There is an interesting new case concerning the obligation of health care providers to treat HIV-positive patients. The Americans with Disabilities Act (ADA) prohibits a place of public accommodation from preventing a person from enjoying the full and equal enjoyment of services because of disability, unless the patient would pose a direct threat to the health and safety of others. A person is disabled and falls under the protection of the ADA if he or she has a physical or mental impairment that substantially limits one or more of his or her major life activities.

A recent case dealt with an HIV-positive but asymptomatic woman who visited a dentist to have a cavity filled. During her visit she revealed her condition. The dentist stated that, pursuant to his infectious disease policy, he would not fill the cavity at his office but would do so at a hospital, which would require an extra charge for the use of hospital facilities. The woman sued the dentist for violation of the ADA. The court concluded that the dentist had violated the ADA.

Providers everywhere need to understand the reasoning behind which the court based its decision. The court found that asymptomatic HIV constitutes a physical impairment under the ADA. However, physical impairment itself is not enough to invoke the ADA. The impairment must substantially limit a major activity of life. The court determined that this test was met because the patient said that her asymptomatic HIV status limited her reproductive activities. The risk that pregnancy would present to her own immune system, the risk of transmitting HIV to a child, and the fear that she would die and thus leave a child without a mother deterred her from bearing children. The court found that conceiving and raising one's own children are basic civil liberties and major life activities under the ADA. Thus, even though the HIV did not render the patient sterile, it limited a major activity of her life. She was therefore protected by the ADA.

The next question was whether treating the patient would harm others. The dentist argued that performing "invasive" dental procedures in his office presented a significant health risk to himself and his staff. A witness from the Centers for Disease Control and Prevention testified that if the CDC guidelines were followed, treatment in the dentist's office would not present a direct threat to the health of others.

Courts in a number of cases have found that treatment by HIV-positive health care *providers* presented a threat to the health of patients. The court distinguished those cases, stating that, in such instances, the infected providers presented a risk to patients, which the patients could not control. In contrast, the dentist treating a patient with HIV could guard against personal risk by taking the protective measures suggested by the CDC. Consequently, the court found that the patient's HIV status did not present a direct threat to the health of others. The dentist was found to have violated the ADA.

---

*John S. Hoff is ACCC legal counsel with Swidler & Berlin, Washington, D.C.*