



Patient Advocacy and ACCC: Seeking a Common Voice

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Patient Advocacy and ACCC: Seeking a Common Voice

Over the past few years, all of us in health care have become increasingly aware of the need to stand together on common issues. Ever since its founding in 1974, ACCC has considered advocacy on behalf of its members and cancer patients as one of its most important functions. As we have learned from the AIDS community, this role can no longer be performed in isolation. Rather, it will require close communication with patients, whose collective voice is growing louder in the area of public health care policy. Since quality patient care is ACCC's ultimate focus, we must listen to that voice and seek common ground where we can work together.

Many issues currently of interest to cancer patients and cancer survivors are identical to those discussed at ACCC. The advocacy groups may have a different focus, however, since these groups represent the recipient of care rather than the provider. As we develop positions on these areas of common interest, I suspect we will find many more areas of agreement than of disagreement. Nevertheless, we must listen carefully and resist the temptation to alter the positions of the patient advocates. We may be of help to the patient advocates by clarifying issues and synthesizing similar positions, but the advocacy message will only be effective if it represents the genuine interests of our current and former patients.

A good starting place for dialogue is the recent position paper developed jointly by many of the advocacy groups in conjunction with the National Coalition for Cancer Survivorship (NCCS). This paper defines and measures quality cancer care from the patient's viewpoint. I would encourage all of you to read this document when it becomes available. The NCCS and other advocacy groups are looking for support from major provider organizations for the concepts contained in this position paper (without requiring adoption of the paper verbatim). This seems like a reasonable first step to finding a common voice on issues of mutual importance.

The future of clinical trials is an issue of common interest. At ACCC our focus has been the very survival of clinical research during the conversion to managed care. All of you are familiar with our legislative initiatives in this area. From the patient's perspective, however, the survival of clinical research is a pyrrhic victory if access to these trials is severely limited by managed care restrictions. Thus, access to trials is the major focus of the patient advocates. These positions, while somewhat different, are entirely complementary

and represent a good area for mutual activity.

A second area of mutual interest concerns both the timely referral to an oncologist for patients with cancer and the importance of having an oncologist serve as the primary physician for patients with active disease. These issues are of great concern to patients and are included in most advocacy position papers. Here ACCC's focus and that of the advocacy groups are identical. Cooperation is critical in this area because the provider (particularly the oncologist) is handicapped by the appearance of self-interest. Although we all agree on the importance of this fundamental concept of care, the patient advocates may well be the more effective voice with regard to these two concerns. ACCC can help by supplying accurate information to advocacy groups.

There are obviously many other areas in which ACCC can assist patient advocacy groups. Our active member institutions provide care for a large number of cancer patients annually, making ACCC a natural source for distribution of patient advocacy information. Our multidisciplinary membership can provide perspectives on patient care issues that differ from those the public usually sees. We may be able to share legislative contacts with patient advocates, making a joint voice stronger.

To develop this relationship, ACCC has established a committee to explore programs of mutual interest to us and to the patient advocacy groups. This committee is chaired by Dean Gesme of Cedar Rapids, Iowa, and it will be meeting at our fall conference in San Francisco. Dean is experienced in the patient advocacy area and serves on the NCCS Board of Trustees. Any ACCC member with an interest in patient advocacy or with ideas about developing this relationship should contact Dean, either at the fall meeting or through the ACCC executive office.

We all know that medical care is changing rapidly. Hard though these changes have been on providers, they have been harder still on patients. Physician-patient relationships, built up over decades, have often vanished in administrative maneuvers. Roadblocks to treatment, placed in the name of cost containment, can impact the care of cancer patients as never before. As providers of cancer care in the community, all of us in ACCC should be patient advocates first and foremost.

—John E. Feldmann, M.D.