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Commentary

Connectors, Translators, Facilitators: Research Advocacy Today

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Patient advocacy was once the purview of professionals, particularly social workers and nurses. However, as these professionals' responsibilities grew and shifted to more documentable services, people found themselves turning to friends for help in navigating the medical system. In the 1980s, HIV and AIDS hit America, hardest in a population often ignored or marginalized—gay men. A movement to stand up for patients grew out of the despair and pain of those affected and the feelings of helplessness of partners and caregivers. This movement gained significant force, changing the care and treatment of those afflicted by this virus and its resultant diseases, including Kaposi sarcoma, which was rare until the AIDS epidemic. AIDS activists also banded together to partner with the research community as active participants in research design.

Other patients noticed this participation, particularly those with breast cancer, and the concern that the patient's voice be heard reached a tipping point. Longer-term survivors of breast cancer began to reach out to other patients and form support groups and networks. It was just a short step from support advocacy to advocate input in the development of new care alternatives—research advocacy.

By 2002, patient advocacy had divided into 5 general areas:

- Support: being present for patients and families as they deal with the diagnosis and sequelae of cancer
- Fund-raising: reaching out to the community for financial support for cancer care and research
- Political: raising government awareness of and improving government response to health issues
- Watchdog: assuring people are doing what they say they are doing around cancer issues
- Research: bringing the patient voice and perspective to the research table

Importantly, although these 5 areas are distinct, advocates and advocate organizations may engage in activities across them. However, advocate activities and collaborators differ based on the type of advocacy. Research advocates are connectors, translators, facilitators, and champions for cancer patients. This article focuses on research advocacy, and *advocate* hereafter refers to research advocates.

The Role of Research Advocates

Most advocates are themselves cancer survivors driven by an altruistic need to "give back." Their goal is to help other patients by helping researchers find the answers needed to improve treatment and move closer to cure. To succeed in this quest, advocates must have a seat at the research table. From that seat, advocates can provide 2 important elements: a changed focus and a broader set of connections and resources.

Changed Focus

Advocate presence ensures that the pursuit of good science includes consideration of patient needs. Researchers with interesting questions can have those questions actively framed by the patient's need for effective care. Just the fact that a nonscientist

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with a vested interest in the discussions' outcomes is present in the room is a constant reminder of the end game of clinical relevance, and ensures that the science focuses on bettering clinical treatment. Being present when research is designed also allows the advocate to identify issues with the trial design that could affect a patient's decision to enroll. The advocate is sensitive to the nonscientific aspects of clinical trial participation and patient decision-making around treatment preferences.

Improving Connections and Resources

Advocates can also connect research needs with new and different resources. Because advocates and researchers move in different circles, the advocate can introduce the researcher to novel relationships and opportunities. Importantly, the advocate can engage researchers with patient and advocate communities. Although researchers know that clinical care is the desired end product of their work, they are often insulated from the everyday world and experience of patients. Advocates can provide this perspective not only by being present as a cancer survivor but also by gathering and providing data from other patients.

Advocates are uniquely positioned to know and discover what is important to patients and their willingness to enroll in a trial with the proposed design. Depending on the issue being addressed, advocates can reach out to other patients, other advocates, or advocate organizations for more information. Thoughtful identification of the audience ensures useful feedback for decision-making. Advocate findings may influence trial design and also validate the importance of the question to patients. This intimate working relationship sets the stage for the advocate to work with patient and advocate communities to further champion the trial into activation and completion.

Thus, the advocate is key to connecting researchers to patient and advocate communities, key to translating research into understandable treatment options, and key to assuring research is clinically relevant to patients.

Success Stories

Successful examples within the past 10 years illustrate the value and importance of advocates in cancer research. The examples given here represent the diversity of advocate activities; they are not full accounts of events but are based on the authors' own experiences and on conversations with the other advocates whose activities are described.

An advocate has served on the NCCN Breast Cancer Panel for more than 15 years. Panel members found advocate input helpful to their discussions and expanded involvement to national breast cancer organizations, with a fourfold objective: 1) increase awareness of the NCCN Guidelines, 2) provide advocates with the science behind changes to the guidelines, 3) create a mechanism for dialogue with the breast cancer advocacy community, and 4) encourage greater use of the NCCN Guidelines in the patient community. More than a dozen advocate organizations review and comment on the NCCN Guidelines for breast cancer each year. This involvement resulted in development of 2 additional breast cancer–related guidelines: one discussing pregnancy after breast cancer and one on inflammatory breast cancer.[1]

The North Central Cancer Treatment Group (NCCTG), which has been subsumed into the Alliance for Clinical Trials in Oncology, was unique in its dedication to not only bringing trials into the community but also bringing the community into trial development. The Patient Advocate Committee (PAC) of NCCTG developed and implemented a program to, as one advocate said, "bring clinical trials to the gossip level," meaning that people should be knowledgeable about and comfortable with trials as a treatment option even before they become patients. To that end, because

of NCCTG's strong community commitment and involvement, the PAC decided to identify potential advocates in the communities NCCTG served, reach out to those advocates to educate them about clinical trials, and support them through a network infrastructure. The backbone of this effort was an annual Patient Advocate Symposium, at which active researchers taught advocates the science and methods of clinical trials. The advocates took this knowledge to their communities, volunteering at local clinics to talk with patients about clinical trials, supporting good information and dispelling myths and rumors. Through this program, advocates became a direct resource for ensuring that patients have good information about cancer clinical trials and for giving feedback to the community physician researchers on the questions and needs of patients.[2]

Advocates are an integral part of the Translational Breast Cancer Research Consortium (TBCRC; http://pub.emmes.com/study/bcrc/index.html), a collaborative group founded in 2005 to conduct innovative, high-impact clinical trials for breast cancer. This consortium has a unique approach to including advocates in its program. As well as having researcher representation from each member institution, it also has advocate representation on the Patient Advocate Working Group. One advocate from each member institution synergizes the efforts of the advocates. These advocates not only represent their individual institutions but also collaborate to bring the patient voice and experience to the development of innovative trials that frequently include tissue collection. Working together, advocates review recruitment issues for TBCRC trials and study issues around tissue collection and assess the role of clinical trials in the care of patients with metastatic breast cancer. They are active, voting members of the scientific working groups. As core members of the TBCRC, the advocates work with researchers to develop and implement biologically driven translational and clinical research.[3,4]

The Metastatic Breast Cancer Network asked an advocate from the Breast Committee of ECOG (now combined with the American College of Radiology Imaging Network to become the ECOG-ACRIN Cancer Research Group) why some patients with metastatic breast cancer live longer than the average of 2 to 3 years after diagnosis. When the advocate brought the question forward, ECOG conducted a retrospective study of 12 phase III adjuvant breast trials, looking at survival after first recurrence with metastatic disease and identifying patient subsets who had survived 5 and 10 years. The researchers are currently investigating tissue from these patients to identify biologic reasons for their longer survival. Although the study may not definitively answer the question, it is a step toward understanding the issue, and shows how scientists and advocates can work together for better patient care. Information about cooperative groups can be found at http://www.cancer.gov/cancertopics/factsheet/NCI/clinical-trials-cooperative-group.

Two advocates developed and actuated the Research Advocacy Network with the goal of educating advocates on the essential and important aspects of research advocacy. Through this organization, they participated in the design of the NCI-sponsored Clinical Trial Assigning Individualized Options for Treatment (TAILORx) trial. The advocates conducted focus groups with patients and advocates and interviews with advocate thought leaders, and presented the results in a formal report to the NCI. This input changed the design of the study. The TAILORx trial had an enrollment goal of 10,000 women with early-stage breast cancer, and closed to new participants after enrolling more than 11,000 women.[5]

Through an affiliation with a cooperative group, one advocate convinced a group of myeloma researchers to test whether drug combinations that included lower doses of dexamethasone might be associated with better short-term overall survival and fewer toxicities than the higher-dose standard of care. His premise was verified

through the trial, and patients now have access to effective, less toxic treatment.[6]

In response to the perceptions that people would not volunteer to advance science, an advocate set out to prove the altruism of the average person. At a 2004 conference during which breast cancer scientists and clinicians bemoaned the lack of "normal" specimens, this advocate said, "I can't do the science, but if you need women to give you tissue, done deal." Out of this advocate's commitment and work, Mary Ellen's Tissue Bank (now The Susan G. Komen for the Cure Tissue Bank) was established. The Tissue Bank now houses more than 1500 donated samples collected in accordance with the best practices established by NCI. (Information about The Susan G. Komen for the Cure Tissue Bank can be found at http://homepages.indiana.edu/web/page/normal/10102.html.)

Advocates participating in a Department of Defense–sponsored Center of Excellence for Individualization of Therapy for Breast Cancer were asked whether biomarkers matter to patients.[7] The Center aims to improve treatment for women with metastatic breast cancer by making it possible to match a treatment regimen to the patient's genetic makeup, furthering the promise of individualized care. The advocates conducted focus groups and surveyed patients with metastatic breast cancer to answer the question and provide intelligent targets for biomarker research. Focus group participants saw biomarkers as a source of information that could reduce guesswork and increase certainty in treatment decision-making. With more than 440 respondents, the survey used conjoint analysis to understand trade-offs patients make between benefit and side effects, and determined that biomarkers would matter if the information provided changed treatment decisions. The advocates found that treatment benefit matters more than toxicity; side effect severity is important; and the presence and age of children influence a patient's decision to undergo treatment.[8]

Finally, a melanoma symposium grew from a conversation at the ASCO annual meeting a few years ago, when an advocate discussing a melanoma poster with a researcher wished that patients could have access to research and treatment discussions with clinicians in a nonclinical setting. Approximately 150 patients attend this symposium biennially. (Information about the Melanoma Patient Education Symposium can be found at http://www.sosrun.org/images/MC1205-38rev0211.pdf.)

Conclusions

These examples show that research advocates are a key element in meaningful support of research advancement and an essential presence when research needs are discussed and research is developed. In addition to connecting researchers to resources, advocates facilitate a patient-centered approach and champion a project to completion. Each advocate is one voice, but this one voice takes the message of patients to researchers and the work of researchers to patients.

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