The Importance of Listening to the Patient's Voice in Oncology Care

BY PEGGY EASTMAN

Fully incorporating the patient's voice at all stages of the cancer journey is becoming increasingly important in the fight against the disease, said speakers at a conference in Washington, D.C. The conference, Turning the Tide Against Cancer Through Sustained Medical Innovation 2017, was co-hosted by the American Association for Cancer Research (AACR), the Personalized Medicine Coalition, Feinstein Kean Healthcare, and Cancer*Care*. It featured cancer survivors among the speakers, including luncheon keynoter Joan Lunden, a breast cancer survivor and award-winning journalist, author, and patient advocate known as the long-running anchor on Good Morning America.

The goal of this year's meeting was to identify ways to involve patients meaningfully while exploring the major issues facing cancer researchers and clinicians.

"It is an amazing time in the field of oncology," said Margaret Foti, PhD, CEO of AACR. "Scientific data are being collected, shared, and utilized in more productive ways than ever before, and cancer patients are finding it easier to search for and enroll in a clinical trial than at any time in our nation's history." Ensuring that patients have "a louder

iStock

voice and influential role" in cancer has been personal for her, said Foti; her sister is a 20-year survivor of late-stage ovarian cancer.

"It's time for patient-centered care to be the standard of care," said Patricia J. Goldsmith, CEO of Cancer*Care,* which provides free support services to patients, and former Executive Vice President and Chief Operating Officer at the National Comprehensive Cancer Network.

Patient-Centered Care

Both Lunden and Stephanie Dunn Haney, a stage IV lung cancer survivor, described how important it was to them to find the right physician to provide their patient-centered care. "We feel so vulnerable," said Lunden, who was diagnosed with triple negative breast cancer in June 2014. "My doctors helped me to believe that I would and could win the battle against cancer. I am continuing on my journey as a warrior."

"That day when I was diagnosed I hit the floor," added Haney. "My children were 2 and 4. I was 39. I thought, 'My children will never remember me.'" But, she remembered, it made all the difference when her radiation oncologist told her, "It doesn't have to be curable to be manageable."

"The theme of today is convergence," said George D. Demetri, MD, Associate Director for Clinical Sciences at Dana-Farber/Harvard Cancer Center, Professor of Medicine at Harvard Medical School, Co-Director of Harvard's Ludwig Center, and an AACR board member. "This is one area where a terrible disease can bring us together." In that collaborative endeavor, he said, stakeholders in the cancer field need patients "to help us advocate for what really matters to them."

He referred to "the urgency of now," noting it is a term used by former Vice President Joe Biden to indicate the immediate need for progress against cancer. Biden and his wife Jill recently launched the Biden Cancer Initiative to make progress in cancer prevention, detection, treatment, and cure.

Asked by *Oncology Times* if he believes the patient's voice is increasingly being incorporated into all phases of oncology, Demetri said yes. "I think there's a lot more listening to the patient's voice now," he said. He pointed out that, in a complex field with an increasing array of options and uncertainty about the right treatment choice, "it's especially important for patients and doctors to talk to each other." But, Demetri emphasized, decisions reached following these discussions "always need to be evidence-based."

Health care stakeholders are using new approaches to help move patient-centered care to the next level, said Stephen J. Ubl, President and CEO of the Pharmaceutical Research and Manufacturers of America. Ubl, who noted he spends much of his time traveling, said, "I'm really blown away with the advances being made in our member companies." He noted that U.S. biopharmaceutical companies, through the Value Collaborative, are moving to a value-driven health system that relies on data and tools to help stakeholders make well-informed decisions, quality of care measured against outcomes that matter to patients, and new payment approaches that link reimbursement to clinical outcomes.

Clinical Pathways

More work is needed to make sure the patient's voice is heard in the era of value-based care, said speakers. At the Turning the Tide conference, the AACR released a new study published in one of its journals containing recommendations for putting patients at the center as cancer care moves from a volume-based to a value-based model (*Clin Cancer Res* 2017; doi:10.1158/1078-0432.CCR-17-1609). This special report notes that, while there has been a push toward patient-centered cancer care, that push is not always compatible with the concomitant push to value-based care.

The special report is the end result of a multidisciplinary working group convened by the Turning the Tide Against Cancer initiative in the summer of 2016 to come to consensus around a set of best practices for oncology that balance innovation with patient access. The new report found that "many of the tools used to support treatment decision-making do not necessarily have the patients' needs as their primary focus and are not always sensitive to patient preference."

In terms of clinical pathways specifically, a Cancer*Care* survey found that, of 1,300 patients surveyed, 82 percent had not heard the term "clinical pathway." So, the report concludes, some of the patients surveyed unknowingly may have had their treatment determined by a clinical pathway—"a tool of which they had no knowledge."

The new report states that, while clinical pathways are supposed to help patients make informed treatment decisions with their physicians, "pathways can potentially interfere with the patient/provider decision-making process." Specifically, the authors concluded that:

Continued on page 39

PATIENT'S VOICE

continued from page 38

• There is little transparency to help patients understand how clinical pathways are developed and modified, how developers and payers choose specific regimens in their pathways, and whether and how they consider cost to designate on-pathway versus off-pathway treatments.

• Developers of clinical pathways frequently do not engage patients in pathway development and maintenance and instead see patient engagement as an "after-the-fact" responsibility of health care providers.

• Clinical pathways can interfere with the patient/provider relationship because providers may face the burden of redundant, time-consuming workflows due to managing multiple pathways. This redundancy is often exacerbated by a lack of interoperability between the pathway's IT infrastructure and the patient's electronic medical record.

• There remains "a significant lack of accountability," especially to patients, for the quality, effectiveness, and transparency of clinical pathways.

Decision-Making Aids

The authors of the new report recommend providing cancer patients with information on why use of a specific tool is being advised, and engaging patients in the development of point-of-care tools "to ensure the tool supports and enhances, rather than detracts from or interferes with the patient/provider decision-making process."

Previously, Turning the Tide recommended an independent third-party coalition of stakeholder groups should serve in an accreditation or oversight capacity for clinical pathway tools. This year, they are recommending inclusion of the cancer patient community in the development, use, and adoption of these tools.

When it comes to the use of decision-making aids in oncology, they can be a boon to help oncologists deal with an avalanche of data in a complex field, said Richard L. Schilsky, MD, Senior Vice President and Chief Medical Officer of ASCO. But, he cautioned, "We all have some responsibility to evaluate these tools. Oncology is a very dynamic field; it is not a static field."

To help patients and physicians make informed decisions, "I think we should take advantage of these new technologies," long-term cancer survivor, patient advocate, and author Wendy S. Harpham, MD, told *Oncology Times*. "They're not going away," she said of apps and web-based tools. Harpham, an internist who was forced to give up her practice by recurring illness, is an Adjunct Professor at the University of Texas at Dallas and a regular *Oncology Times* columnist who writes the award-winning column "View from the Other Side of the Stethoscope."

> "It's time for patient-centered care to be the standard of care."

The conveners of the 2017 Turning the Tide conference said they plan to use discussions from the meeting to generate solutions "around how patients can guide our collective understanding of value-based care, how patients can contribute to the reshaping of our research paradigm, and how through collaboration we can accelerate patient access to innovative care." OT

Peggy Eastman is a contributing writer.

Promising Therapeutic Leads in Nervous System Tumors, Including Glioblastoma

Virtually all cancer treatments used today also damage normal cells, causing the toxic side effects associated with cancer treatment. A cooperative research team led by researchers at Dartmouth's Norris Cotton Cancer Center (NCCC) devised a strategy to target cancer cells while sparing normal cells. This strategy capitalizes on the fact that processes allowing a cell to form a tumor, such as loss or mutation of the tumor suppressor NF1, also expose vulnerabilities in the tumor cell that are absent in normal cells. These vulnerabilities are known as the "Achilles heel" of cancer cells. Although much is known about the mutations that cause a cell to become malignant, little is known about the vulnerabilities of cells with these mutations. The team has published new findings on this Achilles heel found in cells that have been rewired by NF1 loss (*Oncotarget* 2017; doi.org/10.18632/oncotarget.19335).

Mutation of the tumor suppressor NF1 or loss of the NF1 protein is a possible cause of aggressive neurological cancers including glioblastoma (GBM) and has also been observed in lung adenocarcinoma and ovarian cancer among other sporadic cancers. Led by NCCC's Yolanda Sanchez, PhD, a multi-institutional research team has developed and conducted a novel synthetic lethality screen to discover molecules that target genetically modified yeast lacking NF1. Yeast is uniquely amenable to high throughput drug screening because the pathways are conserved. The team was therefore able to screen thousands of drug-like compounds for ones that would kill the NF1-deficient cells while sparing the wild-type cells, and sorted out the lead compounds that were successful in doing so. One of the lead candidates observed to be lethal with this particular mutation is called Y100. Y100 treatment disrupted growth of tumor cells and induced the formation of superoxides that caused the death of NF1-deficient cancer cells.

"In this paper, we describe the mechanisms by which one of our top leads, Y100, targets NF1-deficient cells," explained Sanchez. "Mutations that drive cells to become malignant, including loss of the tumor suppressor NF1, rewire cells' metabolism, which makes them uniquely sensitive to a process called oxidative stress. Our data so far suggest that Y100 can exploit this vulnerability in cells that lack the NF1 tumor suppressor." The team hypothesizes that the use of Y100 and molecules with related mechanisms of action represent a feasible therapeutic strategy for targeting NF1 deficient cells.

Based on the success to date, the team is optimistically looking ahead to trials. "Our long-term objective is to work with our board of scientific and clinical advisors to design phase 0/I trials with agents that are efficacious at shrinking the tumors in 'avatar' models," said Sanchez. "In order to test the efficacy of Y100 against GBM tumors in whole organisms we first need to examine the toxicity of Y100. To test the efficacy of Y100 we will use 'avatars,' which are mice carrying identical copies of patients' GBM tumors. When we identify the cellular target of Y100, then we can find additional inhibitors or drugs to test in the avatar models." Ongoing research will be carried out in collaboration with P. Jack Hoopes, DVM, and the neuro-oncology team at NCCC. The team is also working to find the cellular target of this small molecule in collaboration with the Scott Gerber, PhD, Laboratory at NCCC. Research utilized the Genomics and Molecular Biology and DartLab Flow Cytometry Shared Resources at Dartmouth.

Although published work is early in the drug discovery process, the multidisciplinary team expects that by following up on these discoveries they will identify new targets and therapeutic leads for the treatment of aggressive nervous system cancers driven by NF1 loss, including GBM.