People With Leukemia and Their Oncologists Have Vastly Different Perceptions of Prognosis

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Expert Perspective

“Regardless of when cancer is detected, the experience of being diagnosed can cause patients a tremendous amount of stress and anxiety. Effective physician-patient communication is critical so that patients can have an accurate understanding of treatment risks and likely outcomes and make better-informed decisions with their doctor,” said ASCO Expert Andrew S. Epstein, MD, moderator of today’s presscast.

ALEXANDRIA, Va. – A study of 100 people with acute myeloid leukemia (AML) receiving chemotherapy found that patient and physician perceptions of treatment risk and the likelihood of a cure varied widely. Overall, patients tended to overestimate both the risk of dying due to treatment and the likelihood of a cure. These findings will be presented at the upcoming 2017 Palliative and Supportive Care in Oncology Symposium in San Diego, California.

“Patients with AML face very challenging treatment decisions that are often placed upon them within days after being diagnosed,” said senior study author Areej El-Jawahri, MD, assistant professor of medicine at Massachusetts General Hospital in Boston, MA. “Because they face a grave decision, they need to understand what the risks of treatment are versus the possibility of a cure.”

About the Study
The researchers enrolled 50 patients who were receiving intensive care for AML (which usually meant hospitalization for 4 to 6 weeks) and 50 patients who were receiving non-intensive care (often given as outpatient treatment). The median patient age was 71 years, 92% were white, more than 50% had a college education, and most were from higher income brackets.

Within three days after starting treatment, both the patients and their physicians were given a questionnaire to assess how they perceived the likelihood of dying from the treatment. One month later, they completed a follow-up questionnaire to assess perceptions of prognosis. Within that timeframe, most patients received laboratory results that more definitively established the type and stage of cancer.

**Key Findings**

Regardless of whether they received intensive or non-intensive care, 63% of patients thought it was somewhat likely they would die due to treatment, and 28% thought it was extremely likely they would die. In contrast, 80% of the treating oncologists thought it was very unlikely that their patients would die due to treatment.

One month later, nearly all (90%) of patients thought it was somewhat or very likely they would be cured of their AML. In contrast, 74% of their oncologists thought it was unlikely or very unlikely that their patients would be cured. The gap between patient and doctor perceptions was most striking for patients receiving non-intensive therapy, with 44% of patients believing they would very likely be cured, while none of their oncologists thought this was very likely.

“There were several very important factors we were not able to capture in our study, including what was actually discussed between patients and their oncologists, and whether patients simply misunderstood or misheard the information conveyed to them,” said Dr. El-Jawahri. “Perhaps most importantly, we did not audio-record the discussions between the patients and their physicians, which could provide additional details regarding barriers to accurate prognostic understanding in these conversations.”

Prior to this study, the authors had looked at similar perceptions in people with lung, colorectal, and other cancers, as well as in people with blood cancers receiving hematopoietic
stem cell transplantation. The gaps in perception of treatment risk and cure for patients as compared to their physicians were not as large in those diseases as in AML. The researchers attribute this to higher levels of distress seen in people with AML due to the urgency of their treatment decisions.

**Next Steps**

The researchers have found that early consideration of palliative care in a treatment plan for patients with solid tumors improves patients’ understanding of the prognosis. They hope to implement a similar study in patients with leukemia.

“Clearly there are important communication gaps between oncologists and their patients,” said Dr. El-Jawahri. “We need to find ways to help physicians do a better job of communicating with their patients, especially in diseases like AML where stress levels are remarkably high.”

This study was funded by a grant from the National Cancer Institute.

View the full abstract.

**For your readers:**

- Cancer Care Decisions for Older Adults
- Guide to Acute Myeloid Cancer

**2017 Palliative and Supportive Care in Oncology Symposium News Planning Team:**

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Click here to view the disclosures for the News Planning Team.

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The American Academy of Hospice and Palliative Medicine (AAHPM) is the only national medical specialty society for hospice and palliative medicine. Since 1988, AAHPM has
supported hospice and palliative medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy advocacy. AAHPM’s membership includes 5,000 physicians and other healthcare professionals committed to improving the care of patients with serious illness. Learn more at www.aahpm.org or visit our patient website, www.PalliativeDoctors.org. Follow us on Twitter, Facebook, LinkedIn and YouTube.

About ASCO:

Founded in 1964, the American Society of Clinical Oncology, Inc. (ASCO®) is committed to making a world of difference in cancer care. As the world's leading organization of its kind, ASCO represents more than 40,000 oncology professionals who care for people living with cancer. Through research, education, and promotion of the highest-quality patient care, ASCO works to conquer cancer and create a world where cancer is prevented or cured, and every survivor is healthy. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation. Learn more at www.ASCO.org, explore patient education resources at www.Cancer.Net, and follow us on Facebook, Twitter, LinkedIn, and YouTube.

About the American Society for Radiation Oncology:
The American Society for Radiation Oncology (ASTRO) is the premier radiation oncology society in the world, with more than 10,000 members who are physicians, nurses, biologist, physicists, radiation therapists, dosimetrists and other health care professionals that specialize in treating patients with radiation therapies. As the leading organization in radiation oncology, the Society is dedicated to improving patient care through professional education and training, support for clinical practice and health policy standards, advancement of science and research, and advocacy. ASTRO publishes three medical journals, International Journal of Radiation Oncology, Biology, Physics, Practical Radiation Oncology, and Advances in Radiation Oncology, developed and maintains an extensive patient website; and created the Radiation Oncology Institute, a non-profit foundation to support research and education efforts around the world that enhance and confirm the critical role of radiation therapy in improving cancer treatment.

About the Multinational Association of Supportive Care in Cancer:
The Multinational Association of Supportive Care in Cancer (MASCC) is an international, multidisciplinary organization with members from six continents and nearly 70 countries. It operates in collaboration with the International Society of Oral Oncology (ISOO). Founded in 1990, MASCC is dedicated to research and education in all areas of supportive care for patients with cancer, regardless of the stage of the disease. MASCC promotes professional expertise in supportive care through research and the scientific exchange of ideas. A focus on supportive care leads to better treatment outcomes and greater quality of life for people with cancer.