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Older Adults With Advanced Bladder Cancer Want to Know What to Expect

Many people with bladder cancer are in their 70s and 80s. They seek honest, transparent news about the diagnosis.

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The median age for receiving a bladder cancer diagnosis is 73, and a significant number of those living with the disease are in their 70s and 80s.

A longstanding stereotype in cancer care is that older patients favor a more paternalistic style of care, one in which they defer to the authority of a care provider and may not ask many questions or seek more in-depth information.

However, recently published research examining the care planning priorities of older adults with advanced bladder cancer found that patients want more transparent communication with their care providers, including what to expect from treatment, how their quality of life might change, and how their families can be involved in care planning.

“What we learned is we need to work to find ways to engage patients very early on in the treatment process,” says study author Elizabeth Kessler, MD, a University of Colorado Cancer Center member and associate professor of medical oncology in the CU School of Medicine. “We need to continue to work on ways to allow for these discussions.”

Experiences of living with cancer

The research originated, in part, from Kessler’s previous studies that have been supported by an American Cancer Society clinician scientist award. In one study, she and her co-researchers analyzed data from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program, finding that the majority of older adults with advanced bladder cancer don’t receive anti-cancer treatment.

“If that’s happening, if we look at just the claims data and see that’s happening, there has to be so much more to the why,” Kessler explains. “Is it because of ageism? Because patients don’t want treatment? We wanted to learn more about what patient priorities are as we’re thinking through how that initial treatment planning is set up for patients.”

Kessler and her co-researchers interviewed ten older advance bladder cancer patients through focus groups and individually. Many of those surveyed had previously received a diagnosis of localized bladder cancer that had either recurred or progressed.

“We found that these patients continued to take themselves back to the initial cancer diagnosis,” Kessler says. “They could remember the wording, they could remember the first time they were diagnosed with cancer. Even though it was initially localized and curable, I thought it was going to be such a shift when they heard they have this more advanced state. But for many it wasn’t, it seemed to be more of a signpost along the way.”

This insight from study participants points to the profound impact of an initial cancer diagnosis, and how it can shape further experience and perspectives on living with the disease, Kessler says. “The words the health care team uses really matter. For example, describing something as ‘rare’ had some of our patients assume that it was therefore more difficult to treat—which isn’t always the case.”

Involving patients in care discussions

Among the themes that emerged from interviewing the study participants was a consistent desire for early, honest and transparent communication from caregivers. They expressed a desire for information about what to expect with changes to their physical abilities, mobility and independence.

“We learned that they really do want to be involved in discussions of their care and to have clear expectations for their treatment,” Kessler says. “They want to be engaged early in the process and not feel like they’re waiting or wishing for information.”

Also, while there was some variation among study participants about how they wanted their care partners, who often were spouses or family members, involved in discussions of their care, they expressed a desire for a clear understanding of what the care partner’s role would be.

Researchers further found that study participants didn’t feel that discussions of their prognosis and treatment had to happen only with medical doctors, but could happen with nurses, physician assistants, or other informed members of their care team.

Results from the research are informing a pilot called ABC123: A Framework for Goal Concordant Care in Advanced Bladder Cancer, a pilot project supported by a grant from the American Cancer Society that Kessler is leading. A goal for the pilot, which is nearing completion, is to pilot a framework that aligns care for advanced bladder cancer patients and takes into account their core priorities and values along with their health and physical function.

“What we’ve found is that patients really do want to talk about their prognosis and treatment right from the beginning,” Kessler says. “Instead of focusing on alignment at end-of-life, now we’re looking at ways to come up with a treatment plan that better aligns care for people right from the start.”

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