Cancer and Quality of Life: Patient-Centered Research

To improve quality of life, drug development researchers are bringing patients into the process at the beginning

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One of the most positive changes in cancer care in the last few years has been a growing movement to incorporate patient experiences into treatment development much earlier in the process. The goal is to bring quality-of-life issues into the core of new drug development.

“As more therapeutic options become available for different types of cancer, it’s becoming equally important to have information about tolerability, toxicity and how to maintain a high quality of life for individual patients,” says Jeff Allen, PhD, president and CEO of the advocacy organization Friends of Cancer Research.

Tracking patients’ reactions to treatments is a growing area of research as U.S. medicine embraces health care that focuses less on quantity and more on quality of life. The Food and Drug Administration’s (FDA) Patient-Focused Drug Development (PFDD) program, for example, gathers input from cancer patients themselves about how side effects affect quality of life. That patient experience will then become part of the decision-making process for cancer drug approval. So far, reports have been developed for breast (see the section about side effects, above) and lung cancer. “At its core, the PFDD is about understanding the patient’s view of the drug development process, and one of the key pieces of that is what types of risks versus benefits patients—not regulatory scientists or drug developers—are willing to accept,” says Peter Pitts, a former FDA associate commissioner. “A lot of the way the FDA is going to start collecting real-world evidence is through patient organizations, which have very robust and well-designed patient databases.”

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Quality of life isn't static but fluid, shifting in importance for each person at each stage of disease and survivorship. When individuals are facing daunting odds of survival, for example, they may be willing to undergo truly heroic hardships. In a study funded by the nonprofit patient advocacy organization the Kidney Cancer Research Alliance (KCCure), patients were asked about adjuvant systemic therapy designed to prevent cancer recurrence. These therapies can have bad side effects. Nevertheless, participants' desire for disease-free survival and overall survival ranked far above treatment toxicity in terms of importance—a finding that surprised doctors. "Providers were telling us that patients wouldn't want [the therapy] because it's too toxic and it might reduce their quality of life," says KCCure founder and president Dena Battle. "But toxicity was not their major concern. One thing I remind providers is that you can't have quality of life without life. The survival numbers for metastatic kidney cancer are pretty tough."

Similarly, Melinda Bachini, the advocacy coordinator for the Cholangiocarcinoma Foundation, cites the organization's recent survey of more than 1,000 patients with either pancreatic cancer or cholangiocarcinoma that showed that patients are willing to accept significant risk and inconvenience to receive treatment. For example, a majority of respondents were willing to travel more than 200 miles to receive care from a specific surgeon, and 80 percent would undergo treatment associated with severe side effects if it would extend their life. "It showed that these patients are willing to endure side effects and pain, and a lot of them were willing to take on a certain amount of financial debt," Bachini says. Even so, quality of life matters. When asked, "What is more important to you, quality of life or quantity of life?", 83 percent choose "quality"

over “quantity.”

People facing more favorable odds may place even greater value on quality-of-life issues. In an FDA report on breast cancer that patients prepared for its PFDD program, the authors write, “While some patients identified that they were willing to live with many or severe side effects, others noted that quality of life was paramount and was the primary consideration.”

These early efforts to bring the patient perspective into drug development have yet to lead to noteworthy progress in developing effective new treatments with fewer side effects. Patient advocates such as KCCure’s Battle also argue that more dollars should be spent finding ways to reduce side effects from treatments that are already being used.

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But people with cancer don’t need to wait for new developments to improve their quality of care—or quality of life. One way to feel better is to seek out palliative care early on in treatment. Many people shy away from it, thinking it’s only for the terminally ill. But it’s for anyone who experiences serious side effects.

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