

'Distress Thermometer' a new focus of patient concern

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When the staff at Abington Memorial Hospital handed the breast cancer patient its new "Distress Thermometer" questionnaire, she instantly felt conflicted.

How could she, an early-stage patient with a good prognosis, say how she was really feeling when she saw how much worse off others in the radiation-treatment waiting room were? She left it blank.

A week later the staff asked again. Come January, [cancer](#) programs that want accreditation from the American College of Surgeons' Commission on Cancer will be required to formally ask all [cancer patients](#) about their psychosocial needs. Breast cancer patients were among the first to test the new program at Abington.

This time the woman decided to tell the truth. She was doing OK with the cancer itself, but was really upset about the way some people she had counted on were handling it. She was on the verge of tears all the time.

The staff sent her to social worker Mary Oleksiak. They talked for an hour and a half.

"It was really helpful for me," said the patient, who did not want to use her name for fear it would make her troubling relationships even worse. "Mary gave me a lot of things to think about."

Oleksiak was enlightened as well. She had thought the hospital was doing

a good job of finding patients who needed help, but here was one who would have flown under the radar without the survey. How many more would be uncovered by the questions, which the hospital began giving to all cancer patients recently.

Like others who direct psychosocial services, she is bracing for the possibility - she still thinks it's remote - that demand for help will jump when patients have more opportunities to say what's bothering them.

In her anxious moments, Oleksiak thinks, "I'm only one person and my phone is going to be constantly ringing off the hook."

Bonnie Miller, a nurse who is administrative director of the Women's Cancer Center at Fox Chase Cancer Center, also wonders. "This next year is going to be extremely telling," she said.

It should surprise no one that a cancer diagnosis starts a patient on an arduous emotional journey as well as a medical one.

So, it might be more of a surprise that only now are hospitals being required to ask their patients about their "distress," a pallid word for the massive jolt to the psyche - and sometimes the pocketbook - that an encounter with a potentially deadly disease delivers. Accredited hospitals also must help patients find the services they need, either in their own health system or elsewhere in the community.

The Commission on Cancer accredits 1,500 cancer programs that care for about 70 percent of the nation's cancer patients. Daniel McKellar, chair of the organization, said its new approach stemmed from a 2007 report from the Institute of Medicine called Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. It concluded that problems with emotions or more practical matters like transportation add to suffering and can make it harder for patients to follow doctors' orders

and get better. Experts believe distress management programs improve quality of life and communication.

"This is an important part of modern cancer care," McKellar said.

Less than two months before the new distress rules go into effect, many area cancer programs are still fine-tuning their approach.

Where there is a mandate, there is a business opportunity, and Polaris Health Directions, a Wayne, Pa., company with a long history of measuring psychological problems, is pleased by demand for its newly commercialized distress evaluation tool. The company says it has sold the product, at an annual cost of \$25,000 to \$50,000 a year, to 60 centers in the last 18 months.

Its Web-based tool can integrate with electronic medical records and generate treatment suggestions based on a patient's insurance and address.

The nonprofit Cancer Support Community has also developed a tool it sells for a "nominal" fee, said Linda House, the group's executive vice president for external affairs.

Those products are competing with the Distress Thermometer, which was created by the National Comprehensive Cancer Network and is free, and with questions developed by individual hospitals.

Certainly many hospitals have been trying for years to assess whether patients were having trouble, although McKellar pointed out they might not have done much more than say, "Hi. How are you?" They are unlikely to find out how patients are really feeling unless they ask more probing questions, he said.

In a recent Cancer Support Community survey, 35 percent of patients seen at comprehensive cancer centers and half of those at smaller centers said they were not screened for distress.

Several large centers locally offer a host of free services for patients who need counseling, help with nutrition, or stress management. Social workers address financial and transportation issues. Insurers do not pay for many of those services. Smaller centers typically have less to offer.

Hospitals are struggling with how to collect useful data while keeping things easy for patients. Officials at Cooper University Hospital, in Camden, N.J., love the way the Polaris tool can collect and analyze data and generate referrals, but Fox Chase switched to the Thermometer after patients in a pilot program complained the Polaris survey took too long.

Penn Medicine has taken a low-tech approach, asking patients since August just four questions, on paper, about anxiety and depression and following up, when needed, with face-to-face talks with social workers.

The Sidney Kimmel Cancer Center at Thomas Jefferson University is testing several surveys, including one it developed itself. That one includes a question on concerns about sexuality that many patients have checked off. "That's been eye-opening," said Greg Garber, supervising social worker.

In general, surveys flag 35 to 40 percent of patients as having high levels of distress. So far, local hospitals say the number of patients who actually want or need services has been lower.

Garber said all that many patients need is information, assurance that their feelings are normal, and time to adjust to disturbing news and decisions. "Information is a very powerful distress reducer," he said. Many patients also feel better when they have a treatment plan or see

what chemotherapy is really like.

However, 15 or 20 percent may have a "frank psychiatric disorder," he said. Many of those patients were having emotional problems before cancer added money woes, job problems, and family upheaval. It can be hard to find psychiatrists comfortable working with patients with severe medical problems, he said.

Heather Sheaffer, director of patient and family services at Penn's Abramson Cancer Center, said [patients](#) had responded well to questions about their mental health and information about the help Penn can offer them.

"Patients," she said, "are really, really thankful."

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