Boston hospital aims to redefine care and prevent emotional harm

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Enid Shapiro was a patient at Beth Israel Deaconess Medical Center who had an unpleasant experience at the hospital, but worked with staff to report it and ultimately change how they handle similar cases. LANE TURNER/GLOBE STAFF

One day last year, Enid Shapiro sat in her room at Beth Israel Deaconess Medical Center as the patient in the next bed underwent an unpleasant procedure, cries of distress and confusion ringing out as she was poked and prodded.

Shapiro, across the room, tried not to look. Staff flitted around Shapiro to throw away needles, oblivious to her discomfort.

“Nobody asked me,” Shapiro said. “Nobody asked me if I’d like to leave the room.”

Since she was diagnosed with breast cancer, the hospital has saved Shapiro’s life time and time again. But that sting of indifference at the hands of the hospital felt like a personal affront.

For Beth Israel Deaconess, it was a moment to learn.

Incidents similar to Shapiro’s fill the files at hospitals, so a team at Beth Israel Deaconess recently staged an intervention. It is based on one simple premise — that emotional harm is just as serious as the physical harm sometimes born in hospitals, and that hospitals have a duty to safeguard against both.

“It really gets to the core of, who do we want to be? What kind of care do we want to provide?” said Dr. Lauge Sokol-Hessner, the hospital’s associate director of inpatient quality. “The words dignity and respect cut very deeply.”

“We’re used to talking about infection and surgeries in the wrong place, and those are terrible, too,” the physician said. “But these are almost deeper values.”

Dr. Lauge Sokol-Hessner (left) and Pat Folcarelli worked on the hospital's initiative. JONATHAN WIGGS/GLOBE STAFF

The initiative at Beth Israel Deaconess grew out of a project backed by the Gordon and Betty Moore Foundation, which gave the Boston hospital $5.3 million. The foundation cobbled together a consortium of hospitals united in common purpose: eliminating preventable harm in intensive care units and working to engage families and patients in treatment plans.

The four institutions — Beth Israel Deaconess, Brigham and Women's Hospital, the University of California, San Francisco, and Johns Hopkins Hospital in Baltimore — each came up with their own solutions.

For its ICU, Beth Israel Deaconess launched a Web-based portal that helps families keep up with the patient's health care plan and teaches doctors a bit about the person they are treating.

Families can upload pictures of patients before they were ill, and enter details about the person's life. For patients who slip in and out of consciousness, a journal application on an iPad helps them keep sense of time and hold on to their memories.

It allows doctors to know who they're treating, rather than what, said Erica Dente, a patient and family adviser at the Longwood hospital.

"A lot of it is," Sokol-Hessner said, "how can we help people see and remember that when someone's critically ill and there's all these lines and tubes and they don't look like themselves, that they're still a person."

"This allows us to connect with those pieces of them."

According to Thomas Merluzzi, a psychology professor at the University of Notre Dame, it is that bond between a patient and a provider that can influence healing.

"For the average person in the hospital, the complexities of diagnostics and medical treatments are daunting," Merluzzi said. "What people do understand is the human dimension of the process — that they're fully capable of understanding, and it matters to them."

Respect for patients is a crucial part of the nursing code of ethics. Still, cases of disrespect occur at every hospital, but no systematic way exists to identify and address them.

The problem has always been a "a little too squishy," said Mark Zeidel, chairman of the Department of Medicine at Beth Israel Deaconess. Mostly, that's because things such as harm and dignity can be difficult to define, which is why the hospital set out to redefine what can be called "preventable harm."

Now, patient reports of emotional harm or a loss of dignity will get sorted into categories according to their nature and severity. Once the team identifies patterns,

the underlying causes can be addressed.

After Shapiro's incident, she was reluctant to report it to patient relations, because of her deep faith in the hospital. But staff insisted, saying they wanted to ensure that it never happened again.

"When you start to eliminate the worst harms, you start to realize a lot about your systems and what made that possible," said Patricia Folcarelli, director of patient safety at Beth Israel Deaconess. "People don't come to work in a hospital saying, "I'm gonna really make somebody unhappy today.' They come to try and do their best."

Almost always, the problems are systemic, not individual. It's the "Swiss cheese model," Zeidel said, in which multiple safeguards are precariously lined up, allowing an error to slip through.

Many times, there are communication breakdowns, or an institutional lack of training about presenting difficult diagnoses respectfully.

In one case that Beth Israel Deaconess chronicled in a paper published in July, a patient visiting the hospital was told she had incurable cancer. The doctor was reading from her file; she had never been told before.

For Sokol-Hessner, that case underscores the urgency of intervening. In many cases, emotional harms are the ones that last longest.

"You're taking away the opportunity for a patient to complete their life in the way that matters most to them," Sokol-Hessner said. "It's always important to communicate well with our patients, but especially at the end of life, we may only have one chance to get it right."

Hospital administrators said they hope that by identifying emotional harm and increasing accountability, even the most egregious cases will become easier to talk

about — and quicker to fix.

“You could worry, ‘Well maybe this will hurt our reputation, our brand,’ ” Zeidel said. “But it’s very hard to do medicine perfectly all the time and if you can’t ever admit something didn’t go the way it should have, you’re never going to improve.”

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