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The Opinion Pages | OP-ED CONTRIBUTOR

Failing Patients With Heart Failure

By HAIDER JAVED WARRAICH AUG. 10, 2015

HEART disease is the world's No. 1 killer, despite advances in medical technology, as well as public health initiatives that have eased the burden of heart disease drastically. While one marvels at the progress, we often ignore how heart-disease patients die.

Patients with heart disease are more likely to suffer excessively at the end of life than those with other conditions. While surveys show that people overwhelmingly want to die at home, patients with cardiovascular disorders are much less likely to do so than patients with other diseases, such as cancer.

All heart disease, as it progresses, results in heart failure, or a gradual weakening of the heart. Patients commonly experience difficult breathing, extreme fatigue and swelling of their legs and abdomen. Heart failure is the leading cause of hospital admissions among those older than 65 years of age annually.

And yet these patients rarely get high-quality end-of-life care, in part because it is so hard to predict how individual cases will play out. The heart weakens slowly, over years, followed by sudden death from abnormal cardiac rhythms or from progressive failure of its pumping function. There is great variation in survival from patient to patient; death can occur days to decades after the initial diagnosis.

I remember a patient a few years ago who had heart failure, but seemed able to get around rather well on her own. Minutes after leaving the clinic, she collapsed in the parking lot. She was admitted to the hospital and passed away a few days later.

The most important reason for the lack of good care is a lack of research and training. Research I presented at the American College of Cardiology showed that physicians were not very good at estimating how long patients with heart failure had to live, compared with patients with cancer. And I found that doctors were actually more comfortable discussing palliative care with cancer patients than with those who had terminal heart disease.

While heart failure is common, studies show that patients generally don't have a great comprehension of it. I remember talking to a patient who struggled with heart problems for decades, and had even received a pacemaker. But he couldn't recall ever hearing the term "heart failure."

Physicians do a bad job of explaining heart disease to patients, but frequently, patients don't respond to a diagnosis of heart failure the way they do to, say, one of cancer, even though advanced heart failure carries a prognosis similar to, if not worse than, many malignant cancers.

Well-designed studies show that patients with heart failure and their doctors grossly overestimate survival, leading them down a path of dangerous optimism. Sometimes I wonder if everyone would take heart failure more seriously if we simply changed its name to heart cancer.

Even when patients, their families and medical teams recognize that the end is imminent, they face further hurdles. While we've made great progress in the management of symptoms like chronic pain in patients with terminal disease, the alleviation of difficult breathing has not been prioritized. Hospice teams, while generally well equipped to handle pain, nausea and anxiety, have limited options and training when it comes to making a patient's breathing more comfortable.

None of this is to demean medicine's advances in fighting heart disease. We can open a clogged artery without putting someone under the knife. But we must do more to help patients when all these innovations are futile and death is inevitable.

The first step is identifying patients at highest risk and not only providing them with the best possible therapies, but also timely palliative care. One important intervention, currently being investigated in a trial at Duke called PAL-HF, would be to get a well-trained palliative care team to collaborate in the care of all patients with end-stage heart failure, instead of coming in after the doctors are through.

Just last year, I was taking care of a wonderful old lady who had heart failure and whose only wish was to be able to go home. When I called the hospice team, they refused to believe that she had less than six months to live, a criterion for acceptance to hospice. They were wrong — she passed away in less than a week, alone in the inert expanse of her hospital room. Had they been on the case from the beginning, they would have known better.

While I failed to help her achieve her goal, we need to do more as a health system as a whole to help patients with heart disease to the very end.

Haider Javed Warraich, a fellow in cardiovascular medicine at Duke University Medical Center, is writing a book about modern death.

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