

The Bulletin

Creating choices infuses care, quality for ill, ailing

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By Michael Alexander and Steven Pantilat / *Bulletin* guest columnists

Among the personal stories shared in our public conversation on health system reform, a rare few have dared to touch on the delicate subject of people getting more treatment than they want — and not enough care.

Anguished families told of loved ones spending their last months and years in pain and turmoil because neither patients nor doctors knew how to talk about care options when cure is no longer possible.

The hospice model of comfort care has found wide acceptance and understanding, though many people are still referred too late. Millions more people live years with terminal conditions, in need of holistic, comprehensive hospice-type services. But because technology has extended their lives beyond the six-month hospice window, they are ineligible.

To bridge the chasm between cure and comfort, a new medical specialty was established last year for people at any stage of illness: palliative care.

Palliative care is a holistic approach that treats the whole person, including management of pain and other symptoms, while supporting caregivers and families. It's more important than ever that we learn to talk about this option: The National Palliative Care Research Center estimates 90 million Americans live with the physical and emotional pain associated with life-threatening illness — and double that is expected in 25 years.

Patients can choose palliative care in tandem with curative treatment. This distinguishes it from hospice care, which is limited to those who have a six-month prognosis. What both have in common is that palliative and hospice care bring together resources to alleviate the physical, social and emotional demands of dealing with a chronic or terminal illness, not only for the patient but for the family.

Just recognizing this new medical specialty doesn't guarantee immediate acceptance. Research shows both doctors and patients lack knowledge of, or have difficulty discussing, treatment goals and choices in general. Most people find it easier to talk about chemotherapy options than palliative or end-of-life choices and concerns.

To address these challenges, The Regence Foundation created the Sojourns Award to recognize leaders in the field of palliative and end-of-life care, to share their innovations with the broader community, and invest in their future work. We believe that palliative care offers true choices within the current health care system, creating a broader path for sick patients and their families, without taking away any options.

Heated public reaction this year to the idea of even discussing end-of-life care options shows how tender a topic this is, even in the abstract, but this is reality for many patients, families and medical professionals.

It's important to be clear: Palliative care is about expanding choices — a precious commodity in the best of times — and maximizing quality of life, regardless of its length. For many patients, this can mean both pursuing curative care while obtaining relief from disease symptoms and treatment side effects.

The \$50,000 Sojourns Award will shine a light on those organizations and individuals that have transformed this aspect of health care. We aim to extend their success by advancing the availability, quality or understanding of palliative care in their communities for all patients who can benefit from it.

Our health care system invests heavily in delivering and rewarding procedures. We should also ask that it offer us care choices, and respect the choices we make.

From the eldest to the youngest, everyone faces the possibility of needing palliative care. We hope the annual Sojourns Award opens new lines of doctor-patient communication and writes a new chapter in the stories families tell, of hope and healing, of relief and appreciation for enlightened holistic care at every stage of life.

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