



CAREGIVER'S PERSPECTIVE

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Palliative Care Through the Eyes of the Family Caregiver

Palliative care is one of the most misunderstood terms in health care. It is often associated with death and dying. It is a concept that needs a makeover.

One definition of palliative care is “specialized medical care for people with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses, social workers, and other specialists who work together with a patient’s doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment” (<https://getpalliativecare.org/whatis/>).

I saw palliative care through fresh eyes earlier this year when my elderly mother was in excruciating pain due to multiple compression fractures of the spine. Our “palliative care lady,” as we referred to her, was a nurse who visited the long-term care facility where my mom resided to make sure that her pain level was under control. She tweaked medications and made sure that my mom was comfortable, often making recommendations to her doctor. This gave me peace of mind and another set of eyes to monitor the poor care my mom received in the long-term care system.

I wish I had researched palliative care much sooner when it came to my mom. It would have been helpful to have this crucial support in place following her last cancer surgery or after one of her many serious falls. Keeping people comfortable and free of pain should be a national priority across the care continuum — not just at the end of life.

The “a-ha” moment for us came during one of my mom’s many hospital stays when we were asked if we would like a palliative care consult. Desperate for additional help of any kind ahead of a looming care transition, we nodded our heads affirmatively, not knowing what benefits (if any) this would bring.

This particular hospital had an on-site palliative care specialist. He was skilled at eliciting our goals and putting a strategy in place to ensure my mom was pain-free. This included coordinating the community-based palliative care nurse who came into the nursing home to monitor mom after she was discharged from the hospital.

Pain is a tricky issue, especially for seniors. My mom was acutely aware that narcotics made her very confused. Over the years, she had several episodes of paranoia and hallucinations caused by high doses of pain meds. Some drugs

were worse than others. Clinicians who didn’t know my mom often missed the signs. Our assertions of “that’s not my mom, that’s the drugs” fell on deaf ears or resulted in unnecessary arguments. In reality, the family caregiver often recognizes these issues before clinicians do, simply because we are intimately familiar with the medical challenges of our loved ones and their normal vs. abnormal dispositions.

Our palliative care nurse communicated regularly with me so she knew what “normal” was for my mom and could spot behavior that indicated a reaction to the pain medication. Communication among all care team members is key to the success of palliative care; this is especially true when the patient has dementia.

Red Flag

Dementia should be a red flag for palliative care. Unresolved pain can impact quality of life for the patient and make a caregiver’s job exhausting. I have heard many anecdotes from families whose loved one complained of pain but could not identify the source of the discomfort, hampered by their failing memory. It took a skilled and patient clinician willing to take the time to solve the mystery. In a country where dementia is an epidemic, we have a distinct gap in clinician training when it comes to dementia care.

Ideally, a palliative care consult should be part of the process following every surgery and before every emergency department discharge, particularly for elderly patients. It is no longer acceptable to send patients and family caregivers home with a bottle of narcotics to manage their own pain. For seniors, this often leads to overuse of prescription pain medications (often prescribed by different doctors), reactions with other medications, and increased risk of falling.

Results from a study published in *The Gerontologist* in 2013 showed that palliative care led to a significant reduction in emergency department visits and depression among elderly participants, according to researchers at Hebrew SeniorLife’s Hebrew Rehabilitation Center and Institute for Aging Research, an affiliate of Harvard Medical School. Their 2-year study included 250 elderly long-term care patients, half of whom received palliative care. Recipients had about half as many ED visits and were much less likely to suffer depression, compared with those who didn’t receive palliative care.

Palliative Care Awareness

Studies aside, I learned important lessons from my experience.

First, we are not using this important discipline to its full potential, thus missing opportunities to help patients manage pain and reduce the possibility they will misuse pain medication. This is partly due to the impossible word we have chosen to describe it: palliative. Language matters. This word is a mystery to most people, even those who are highly educated, and needs a plain language alternative. We have a wealth of phrases to choose from: pain and comfort care, comfort management, or quality-of-life care.

Second, education. The concept of palliative care needs to be as intrinsic to medical care as the stethoscope and part of medical education across all disciplines. Patients and families need to be educated as well, so this term becomes as synonymous with pain-and-other-symptom management in their health care vocabulary as antibiotics are for treatment of bacterial infections.

Third, stigma. The palliative care discipline has been inextricably linked to hospice and death, resulting in unnecessarily stressful conversations for families. Some refuse to discuss it because of this negative connotation. It’s time to correct this misconception.

Lastly, we need to revise archaic processes in our medical facilities, linked to episodic events, that don’t prioritize palliative care evaluations. We need to focus our attention on longitudinal health, where palliative services fall naturally into the care continuum. 

Ms. Sterling is a speaker and educator on family caregiver issues and dementia, and has been featured in *Kiplinger*, *The New York Times*, *USA Today*, and *The Wall Street Journal*. She is chief executive officer of Sterling Health IT Consulting. Follow her on Twitter at @SterlingHIT.

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