

Palliative Care Experts Explain Why Most Patients Still Die Away From Home

Even though many Americans would prefer to die at home rather than in a medical institution, home death is still the exception rather than the rule. Why is this? Molly Walker from *MedPage Today* undertook email interviews with a number of palliative care experts, and the answers she got were illuminating.

One reason cited for why so many patients still die in the hospital is that “surrendering” to death is not seen as a hopeful alternative – particularly by attending physicians. Michael Levy, MD, explains, “Even if there were enough palliative care available to care for all the patients that need it, many physicians still view it as something less than hopeful and valuable to offer to patients than continuing to fight their disease.” Despite the fact that palliative care is seen to have great benefits when it comes to cost reduction, it is often seen as “giving up” rather than continuing the fight against disease.

Dr. Mohana Karlekar adds to Levy's analysis, explaining that many doctors are hesitant to speak about issues of death and dying head-on. “Doctors are often not comfortable addressing end-of-life issues, and often overestimate prognosis.” How to have end-of-life conversations “was not traditionally taught in medical schools,” leaving many doctors at a loss for how to speak to these issues, or interact with patients and families in such situations. “Physicians often assume people want ‘everything done,’ so what typically happens is that patients end up in the hospital or with an advancing illness, they may not even realize they may be nearing the end of life.”

No one wants to die if they don't have to, but if death is understood to be inevitable, there are many who prefer a natural death rather than an institutionalized fight to the finish with disease. **It's clear that, if we want to see more people dying at home rather than in the hospital, more of us will have to have good information on what our prognosis actually is.** Yet, as Anna Faul, PhD, points out, this isn't always easy in our current medical culture. “At the end of life, society gravitates toward institutions to save lives. ... Although for all of us death is inevitable, we believe that going to an institution at end of life, may prolong life.” This results in a medical system where billions are spent on futile treatments in the last weeks and months of terminal illness, improving neither individual lives, nor the health care system as a whole.

At the heart of this dysfunctional system lies deep fear. “In the end, our fear of death trumps our desire to die peacefully at home,” says Faul. The United States is a deeply death-denying culture, says Patrick Coyne, MSN, which often prevents us from gaining the benefits of realistic thinking. **“One of the goals [for our health care system] should be for healthcare providers to have more open and honest discussions with patients and families about their illness and prognosis.”** We may be headed in this direction on a national level, but there's still clearly a lot of work to be done. “To be successful, we need to establish true two-way communication between patients and families and their healthcare providers.”

In addition to institutional issues, and the prevalence of a death-denying culture, those interviewed cite a lack of patient planning as a major obstacle to seeing more people die in the ways that they would most prefer. “Americans do plan for retirement and purchase life insurance but only 25% of them have prepared advance directives,” says Levy. Public awareness is a key factor that cannot be overlooked. “If palliative care had the same public passion and political strength as breast cancer care, it would be available to help all patients who want to die at home to do so.” (*MedPage Today*, 4/1, www.medpagetoday.com/PrimaryCare/GeneralPrimaryCare/50696)

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