

Physicians debate whether patients need to know they're dying

April 28 2013, by Melissa Healy

In the days when American physicians dispensed oracular commands and their judgments were rarely questioned, a doctor could take it upon himself with few ethical qualms to keep from a patient the bad news of a terminal diagnosis.

For better or worse, those days may be well behind us. But physicians have not ceased debating one of the stickiest and most universal ethical quandaries of [medical practice](#): How, when and why does one inform a patient that he or she is dying? The latest evidence of that ongoing discussion was published Wednesday in the *British Medical Journal*.

The latest question in the journal's "Head to Head" feature, "Do [patients](#) need to know they are terminally ill?," essentially pits one side's reasonable arguments that "we're all dying" and "you never really know when and of what a patient will die" against another side's equally compelling assertions that "knowledge allows better decisions" and "a patient can still have hope - to live to see a daughter married or achieve a cherished goal or to die a peaceful death at home."

Either way, the two sides in *BMJ's* debate appear to converge on one key rule: Patients whose lives will probably be limited or ended by a disease deserve a forthright explanation of what treatment is available and what it probably would, and would not, accomplish if undertaken. Given that this is a matter of [consensus](#), the difference seems to come down to how forcefully a doctor should press the point when a patient seems unwilling to face the realities of his or her diagnosis.

The debate is a sign of the times. The authors on both sides of the BMJ debate - yes, a patient needs to know he is terminally ill, and, no, she does not - are palliative care specialists: Often flanked by [social workers](#) and nurses and pastoral caregivers, these physicians work to maximize the "quality of life" of seriously ill patients. As this new medical specialty gains a foothold in hospitals throughout the United States, it has brought a new focus on the value of caring for, not curing, patients with life-limiting chronic illnesses (including diagnoses such as cancer, emphysema, heart failure and complicated diabetes).

Because many in palliative care come from the hospice movement or are affiliated with hospice as well, these specialists tend to be on good terms with the reality that all patients eventually die. But they also know that many patients may have a good deal of life left to live. Hence, the debate over telling patients they are terminally ill.

Many palliative care doctors are firmly convinced that when patients know that cure is no longer possible, they will generally choose to forgo costly and invasive tests and procedures, make the best of the time they have left and eventually die in the peace and comfort of their homes, which is what most Americans at least say they want. By this logic, ensuring the patient knows she has a terminal illness is the first step in seeing that her wishes will be honored and the quality of her life remaining will be maximized.

"Knowledge is power," write Drs. Emily Collis and Katherine E. Sleeman, both palliative care specialists in Britain's National Health System.

But other palliative care physicians focus on the surprising finding that "terminal" patients actually live longer, on average, when they get palliative care, possibly because they get off the risky and intensive "curative treatment" treadmill and focus on comfort and [quality of life](#).

By this logic, it may be more important to tend to a patient's comfort than to jam down her throat false certainties about the time or cause of her eventual death.

"Does telling someone that they are terminally ill mean telling them how long they have to live? (hard to know for any individual)," writes Dr. Leslie J. Blackhall, a [palliative care](#) specialist at the University of Virginia School of Medicine. "Does it mean telling them that they will eventually die (true for all of us)? Does it mean telling them there is 'nothing we can do' (never true)?" Blackhall writes. And at exactly what point in a protracted illness for which there is little prospect of a cure does a physician declare a patient "terminal," she wonders.

It may surprise readers to know that in Britain's health care system, the physicians' regulatory body tells doctors that "information should be withheld from terminally ill patients only if it is thought that giving information will cause serious harm, specified as 'more than becoming upset.'"

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