

IN EVERY ISSUE

To Be or Not To Be: Is That the Right Question?

BY HARVEY MAX CHOCHINOV, MD PHD

Like so many people who work in palliative care, I am frequently, though reluctantly, drawn into conversations about euthanasia and assisted suicide. There is an assumption somehow that knowing how to care for people near the end of life confers expertise on the rights of patients to seek out a hastened death. Because I do research and publish studies that try to understand the psychological landscape of people with life-threatening illnesses, my phone rings whenever the media features someone requesting physician-hastened death, or when there are rumblings about a challenge in the legislative status quo.

For years now, our research group has been studying the whole notion of what it means to maintain dignity in the face of a life-threatening or life-limiting illness. And no surprise, my phone rings more than ever. The term dignity, after all, has become synonymous with the right to die movement, the key platform of which is that the ability to end one's life at a chosen time affords the ultimate dignity. In their continued effort to promote social policies that include euthanasia and physician-assisted suicide, it is worth asking if they are pushing us toward or away from the most pressing questions facing palliative care today.

Take for a moment the issue of hunger and imagine being asked to focus your attention on how to suppress appetite in people who are starving, rather than engaging the question of how to feed them. In view of the problem, the solution would seem, putting it diplomatically, off the mark. As for the right to die (not so much a right, but rather a physiological obligation), I think the most intriguing questions relate to the myriad factors that influence a sick person's desire to go on living. No doubt, a thorough and honest examination of these questions informs how to provide better care for the dying, while offering important lessons for the living.

Study after study has shown an association between a loss of will to live and uncontrolled pain, inadequate social support and psychological distress. Our more recent studies have also pointed to the importance of existential considerations, such as loss of dignity, lack of control, loss of sense of meaning or purpose and a sense that one has become a burden to others.

In these particular ways then, the dying and the living may not be so dissimilar. Without a sense of purpose, meaning or being valued—all subsumed within what we have coined a “dignity-conserving model of care”—whose will to live might not be in jeopardy? Even the Hemlock Society has conceded, “If most individuals with a terminal illness were treated this way [according to the dignity-conserving model of care], the incentive to end their lives would be greatly reduced.”

For now, palliative care professionals will continue to be coaxed into weighing in on the issue of physician-assisted suicide—to be or not to be. The reason for their hesitation, however, should now be transparent. They are tactfully trying to shift the question to how to help people live the best and fullest quality of life possible. In all likelihood, in spite of the very best that palliative care can offer, there will always be a tiny minority of patients who will push for death-hastening options. Finding compassionate and moral ways to address their needs will remain a challenge for policy-makers and caregivers alike.

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