

Hospice workers struggle on front lines of physician-assisted death laws

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Laws that allow physician-assisted death in the Pacific Northwest have provisions to protect the rights of patients, doctors and even the state, but don't consider the professionals most often on the front lines of this divisive issue – hospice workers who provide end-of-life care.

The existing system, a new analysis concludes, has evolved into a multitude of different and contradictory perspectives among hospice organizations and workers, who historically have opposed physician-assisted death but are now the professionals taking care of most of the people who use it.

The study – titled "Dignity, Death and Dilemmas" - was just published in the *Journal of Pain and Symptom Management* by researchers from Oregon State University, and outlines a complex system in which many well-intentioned caregivers struggle to organize their thoughts, beliefs and actions when dealing with a concept they traditionally oppose. It was based on an analysis of 33 hospice programs in Washington state.

When first proposed, it was feared by some that physician-assisted death might displace the palliative and supportive care offered by hospice. Now, in practice, between 85-95 percent of the people in Oregon and Washington who choose assisted death also use hospice – but the interplay they have with their caregivers can vary widely.

"It might seem a little surprising that most people who use physician-assisted death also use hospice," said Courtney Campbell, the Hundere Professor in Religion and Culture in the OSU School of History, Philosophy and Religion. "Some hospice workers were originally concerned this concept would make them unnecessary, but in fact the level of hospice usage has actually increased."

Hospice is a national program in which trained professionals provide care to terminally ill patients,

ensuring they get proper medical care, adequate pain control, are involved in decision-making and have other needs met in a home environment. They work with both the patient and family to help make death a natural and accepted part of life.

However, hastening or actually causing death is not an accepted part of the hospice philosophy, even though hospice programs acknowledge the right of patients to make that choice where it's allowed by law. But balancing core beliefs, such as compassion and non-abandonment of a patient, with the new laws has been difficult at best for hospice professionals, Campbell said.

"About 75 percent of hospice organizations will not allow their workers to even be present when a fatal dose of medication is used," Campbell said.

The reaction in hospice to physician-assisted death varies from one national organization to another, from one agency to another, from one worker to another. There is little consistency to many complex questions about how, whether, and when hospice workers will get involved as individuals they care for make this choice. Approaches can range from outright opposition to non-participation or non-interference.

In recent years it's become even more difficult as assisted-death has become politicized, Campbell said. Even the words used in describing the serious issues involved are emotionally-charged and inherently contentious, the researchers noted in their report, making reference to legislation that embraced "ending life in a humane and dignified manner" while working its way around such topics as "suicide, assisted suicide, mercy killing and homicide."

Somewhat caught in the middle, and caring for the people who are affected by those laws, are the hospice workers with marginal guidance and conflicted reactions, researchers said.



"The conventional approach to the question of legalized physician-assisted death . . . has missed the issue of how the requirements of a new law are carried out by the primary caregiving institution, hospice care," the researchers wrote in their report.

The OSU research offered no simple solutions to this issue, but rather outlined a broad list of questions that could form the basis for more informed discussions – either among hospice providers, the organizations they work for or the general public.

These includes such topics as the <u>hospice</u> mission, patient access to information, questions about legal options, how to discuss emotional or religious factors, response to specific patient requests, documentation of conversations, responsibility to the patient's family, and many other issues.

More information: hdl.handle.net/1957/40840

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