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From the USA: understanding requests for physician-assisted death

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In this issue of *Palliative Care*, the Ethics Committee of the EAPC publishes its revised position paper on euthanasia. Its original paper, published in 1994, took a firm and explicit stance against legalization of euthanasia. The updated version, which is less shrill, more nuanced and flexible, and imbued with a substantial degree of humility, focuses on the need for better communication, respect for diversity of opinion, and greater understanding of the complex and manifold reasons patients make these requests. Is there evidence to support adoption of a new stance?

As clinicians in Oregon and neighboring Washington, and researchers on physician-assisted suicide and the Oregon Death with Dignity Act, which legalized assisted suicide in 1997, we have been humbled, as our original theories about why patients request assisted suicide have been altered. Oregon's law allows a competent, terminally ill patient to request a lethal prescription for self-administration.[1] Now five years into this social experiment, our understanding of these patients is supported by both qualitative and quantitative studies of physicians who have received the requests,[1,2] hospice nurses and social workers who have cared for these patients,[3] amyotrophic lateral sclerosis (ALS) patients interested in this option,[4,5] and clinical experience with requesting patients and family members.

These studies challenge several assumptions about legalized assisted suicide. First, patients do not primarily make these requests because of physical symptoms, such as pain or fatigue, though fear of worsening physical symptoms may impact the request.[1–5] Nor does it appear that patients who die by assisted suicide lack adequate palliative care – 78% are enrolled in a hospice program.[3] Physicians initially respond to requests for assisted suicide with palliative interventions rather than lethal prescriptions.[1] Secondly, the Oregon data do not support the assertion that patients who die by assisted suicide are depressed.[1–5] This somewhat counterintuitive finding may reflect that depressed patients have difficulty marshalling the energy, focus, and determination needed to persevere through the requirements of the law. Thirdly, these patients do not appear disproportionately socially vulnerable. Patients who die by assisted suicide have a higher socioeconomic status than other Oregonians, and are not motivated by poor social support and financial concerns.[1,3] Although many patients are concerned about burdening their families, hospice nurses reported that only 11% of families of patients dying by assisted suicide were more burdened by care, and only 3% were more financially burdened by care, compared with other hospice families.[3] Finally, either despite or even because of the Oregon law, there have been measurable improvements in end-of-life care since initial passage of the Act. Currently, 36% of Oregonians die in hospice care and physicians report improvements in their ability to care for dying patients.[6]

Who, then, are these individuals? Patients appear to request assisted suicide for psychological and existential reasons: they value control, dread dependence on others, are ready to die, and assess their quality of life as poor.[1–3] The value they place on control and independence appears lifelong. Many tell of childhood experiences with unempathetic and overcontrolling adult figures where they learned that receiving care from others is humiliating. Despite this lesson, these individuals have lives filled with work, love, and play, but with limitations: in their relationships they must hold an equal or dominant position. When exposed to the exigencies of the dying process, they face dreaded dependency and loss of control not easily addressed by advance directives and symptom management. Responding with more palliative care is a double-edged sword: although data from Oregon support that palliative interventions can lead some patients to change their mind about assisted suicide, for other patients more care fuels fears of more dependence on others. A longitudinal qualitative study of patients in Washington and Oregon indicates that many communication issues cloud discussions about physician-assisted suicide, and that physicians face a complex situation in trying to respond compassionately, maintain reasonable boundaries, and individualize palliative care.[7] Clearly cultural issues and legal restrictions impact these choices,

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and the situation in Oregon may differ from elsewhere in the USA or other countries.

Palliative care practitioners must understand these patients in order to develop interventions that address existential concerns, fear of dependence, and lack of control, so that these patients may choose alternatives to euthanasia. The EAPC position paper's admirable openness and tolerance sets the stage for empirical studies to address these concerns.

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