

Euthanasia and physician-assisted suicide: focus on the data

We should aim at improving the care of dying patients

Modern debates about legalising euthanasia and physician-assisted suicide (PAS) in Great Britain and the United States began in the late 19th century.¹ Legislation was periodically proposed only to be defeated until, in 1942, Switzerland decriminalised assistance in suicide for cases when there were no “selfish motives”.² In 2002, euthanasia was legalised in the Netherlands and Belgium, then in Luxembourg in 2009, and most recently, in 2015 in Colombia and in 2016 in Canada.³ PAS, but not euthanasia, has been legalised in five US states. In Oregon, PAS was legalised by popular referendum in 1997. In addition, in 2009, Washington State legalised PAS by referendum and Montana by court ruling; Vermont in 2013 and California in 2015 also legalised PAS by legislation.⁴

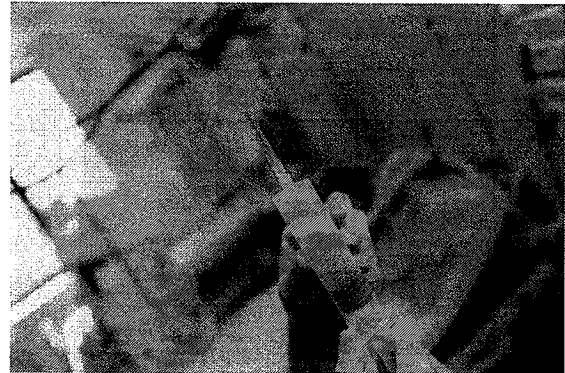
Debates about legalisation of euthanasia and PAS continue in a number of countries and states. On both sides, there are many claims and counterclaims that may not cohere with our empirical understanding. To ensure evidence-based discussions and policy formulation, it is important to consider three major points regarding the practices of euthanasia and PAS.

First, euthanasia and PAS are rarely used, even in countries where these interventions are legal and have been used for more than a decade.⁵ Since the 1980s, euthanasia and PAS were permitted and not prosecuted in the Netherlands if certain safeguards were followed, and they were finally legalised in 2002. Yet, according to the latest data from 2010, dying patients have requested euthanasia in only about 6.7% of all deaths.⁵ In a similar manner, in Belgium, only 6% of all deaths have a request for euthanasia or PAS.⁶ However, not all requests are honoured; in the Netherlands, just 45% of requests are granted, and in Belgium this rate rises to 77%.⁵⁻⁷

Moreover, few deaths are caused by euthanasia or PAS. The most recent study from 2014 suggests that in the Netherlands 3.8% of deaths are by euthanasia or PAS, most of which — about 92% of the 3.8% — are by euthanasia, and in Belgium, only 4.6% of all deaths are by these interventions.⁵ After 17 years of legalisation, in Oregon in 2014, only 0.3% of all deaths occurred by PAS,⁷ and in Washington State only 0.24% of deaths were by PAS.⁸

Not only are these interventions rarely requested, they are predominantly used by patients with cancer. Even though cancer accounts for less than 25% of deaths in high income countries, about 75% of all euthanasia and PAS cases occur in patients who have cancer.³⁻⁶ Few occur in patients with neuro-degenerative diseases, such as amyotrophic lateral sclerosis.³⁻⁶

These data mean that the claim that legalising euthanasia and PAS will help solve the problem of poor end-of-life



care is erroneous. Euthanasia and PAS do not solve the problem of inadequate symptom management or improving palliative care. These interventions are for the 1% not the 99% of dying patients. We still need to deal with the problem that confronts most dying patients: how to get optimal symptom relief, and how to avoid the hospital and stay at home in the final weeks. Legalising euthanasia and PAS is really a sideshow in end-of-life care — championed by the few for the few, extensively covered by the media, but not targeted to improve the care for most dying patients who still suffer.

Second, pain is not the primary reason why people seek euthanasia or PAS. It is commonly thought that patients in excruciating and unremitting pain would want these interventions. Many healthy people believe that pain would be the reason why they may want them; however, evidence suggests otherwise. Patients who request and receive euthanasia or PAS infrequently experience pain; similarly, few patients in pain actually want euthanasia or PAS. Two decades ago, research with patients who had cancer or HIV showed that those who were interested in euthanasia or PAS were not those experiencing pain.⁹ This has been confirmed multiple times; for instance, the data from the state of Oregon in the US, which has followed patients who have requested and used PAS for 17 years now, show that fewer than 33% of patients are experiencing — or fearing — inadequate pain control.⁵ Even in Australia, when for a brief moment seven patients were given euthanasia in the Northern Territory, none had uncontrolled pain.¹⁰

If not pain, then what motivates patients to request euthanasia and PAS? Depression, hopelessness, being tired of life, loss of control and loss of dignity. These reasons are psychological — they are clearly not physical pain — and are not relieved by increasing the dose of morphine, but by antidepressants and therapy. In the states of Oregon and Washington, the reasons for wanting PAS were: 90% of patients reported loss of autonomy, 90% were less able to engage in activities that make life enjoyable and 70% declared loss of

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dignity^{5,6} — depression and hopelessness are not listed and are not included in the reporting list. Likewise, in the Netherlands, the main legal requirement is “extreme physical or mental suffering,” and patients’ reasons are classified in this manner, making it hard to know whether the reasons are physical symptoms of depression. However, when researchers from the Netherlands — who were convinced that the main rationale was pain — interviewed patients who requested euthanasia, they found that few of the ones using euthanasia were experiencing pain, but most were depressed.¹¹

The importance of psychological suffering as patients’ rationale for requesting euthanasia and PAS indicates that these interventions are less like palliative care and more like traditional suicide condoned and assisted by the medical community. The main drivers of traditional suicide are psychological problems. Despite the importance of psychological suffering as the main motivator, few physicians in the jurisdictions where euthanasia and PAS are legal receive psychiatric consultation. Indeed, in the states of Oregon and Washington, less than 4% of patients who had PAS had a psychiatric consultation.⁵⁻⁷ In Belgium, where an independent physician needs to be consulted for non-terminal cases, in 42–78% of cases that physician is a psychiatrist. Since psychological reasons dominate, one would think that requiring psychiatric evaluation would be a reasonable safeguard before providing euthanasia or PAS. Therefore, we need to think very differently about what drives people to want euthanasia. The picture most people have of patients who are writhing in uncontrolled pain despite morphine is simply wrong.

Third, many people believe euthanasia and PAS are flawless, quick and painless. This belief is common but mistaken. No medical procedure — even simple ones like blood draws — is flawless; every medical procedure has

problems and complications. Euthanasia and PAS are no exceptions. According to a study in the Netherlands from 2000, 5.5% of all cases of euthanasia and PAS had a technical problem and 3.7% had a complication. An additional 6.9% of cases had problems with completing euthanasia or PAS. Technical problems, including difficulty finding a vein and administering oral medications, occurred in 4.5% of euthanasia cases and in 9.8% of PAS cases. Moreover, 3.7% of euthanasia cases and 8.8% of PAS cases had complications, such as nausea, vomiting and muscle spasms. Overall, an additional 1.1% of patients who had euthanasia or PAS did not die but awoke from coma.¹² The data suggest that the common view of euthanasia and PAS as quick, flawless, and painless ways to die is unrealistic.

When considering this evidence, the case for legalising euthanasia and PAS looks less compelling. They will not improve the care of many dying patients, they are not helping people in pain and enduring inadequately treated physical symptoms, and are far from quick and flawless. What is then the great impetus to legalise interventions to end lives for a small minority of patients who are depressed, worried about losing autonomy and being tired of life?

We should end the focus on the media frenzy about euthanasia and PAS as if it were the panacea to improving end-of-life care. Instead, we need to focus on improving the care of most of the patients who are dying and need optimal symptom management at home.

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