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'Assisted Dying': A View of the Legal, Social, Ethical and Clinical Perspectives

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Abstract

Discussion of legislation of physician-assisted suicide and euthanasia, often euphemistically called 'assisted dying', frequently focuses on individual cases promoted by campaigners as the reason that the law to licence doctors to supply lethal drugs to patients requesting them should change under certain conditions. But such legislation has wider consequences that simply for a handful of cases, as the relentlessly increasing numbers of such deaths have shown.

Keywords: assisted dying, physician assisted suicide, euthanasia, religion, legalisation, Parliament

1. Introduction

Current law in the United Kingdom and in most parts of the world is crystal clear. There is an absolute prohibition on killing another person, and it is illegal to help someone take their own life. But society's prohibition on assisting suicide has become eroded. Fear of dying has been publicised, with premature death being portrayed as a preferable option to a natural death with all care given. And there have been challenges to the clinical boundaries of care through court challenges about the cessation of interventions in some patients in minimally conscious states.

Against this backdrop campaigners for assisted suicide and euthanasia have mounted large media campaigns, which have gained some traction in increasingly secular and utilitarian societies. A general perception of 'better off dead' has fallen into common parlance, and yet the reality of death has become increasingly unfamiliar to people as the majority of deaths occur in hospitals out of sight of family and friends. Additionally, there has been relatively little publicity about improvements end-of-life care.

Assisted dying is a recently coined term that covers physician-assisted suicide (PAS) and physician administered euthanasia (PAE). Wherever such acts have been legalised, they all aim to achieve the same goal: they licence doctors to prescribe lethal drugs to people who request them, with certain criteria being stipulated. But it becomes important to unpick exactly what is meant by the broad blanket term 'assisted dying'. Various laws or proposed laws around the world have used the phrase in their title.

In 1998, the US State of Oregon enacted the 'Death with Dignity Act' (DWDA) [1]. California's recent 'End of Life Option Act' [2], and now Canada's 'Medical Assistance in Dying Act' imply that without the option of assisted suicide or euthanasia, death will be far worse than if life is abruptly foreshortened [3]. The Dutch in 2001, with commendable honesty in its title, passed their 'Termination of life on Request and Assisted Suicide Act' [4]—the title of the legislation describes exactly what the legislation does.

The problem with titles that are themselves euphemisms is that the public are misled, as are politicians, over what exactly legislation can and cannot do and over potential unintended consequences of it.

One difficulty is that criteria in legislation, intended to define clearly who is or is not eligible for such lethal drugs, are of themselves open to wide interpretation and some are based on flawed assumptions.

However, before the law is changed, it is necessary to ask whether there is compelling evidence that the law needs to be changed and that the benefits of such a change outweigh the adverse consequences of legal change. Such legislation alters the focus and ethics of clinical decision-making, it alters society's approach to those who for whatever reason are seeking suicide and it alters a fundamental moral code in society that one person should not deliberately bring about the death of another.

2. The law

In most countries in the world, there is a clear prohibition on assisting suicide.

Suicide is regarded as a very grave matter. Despair that drives someone to suicide requires a response of trying to support that person, as embodied in suicide prevention policies. These laws recognise the duty on all in society and also recognise the vulnerability of the profoundly depressed person with suicidal ideation to coercive pressures on them, however subtle, to think they would indeed be 'better off dead'. Linked to that is the compassionate approach to the person who attempts suicide and fails—suicide per se is not a criminal offence.

Historically, this was not the case and suicide itself was viewed as self-murder, carrying with it the opprobrium of society. However, by 1961, the UK, as well as many other countries, had recognised the inhumanity of such a law that left those who survived attempting suicide to be potentially prosecuted for the actions their despair had driven them to. And it also recognised that society was failing such people if it did not tackle the source of despair, usually severe psychiatric depression, and that suicide prevention policies needed to be strengthened.

This led to the 1961 Suicide Act [5], which decriminalised suicide but deliberately did not legalise it, because legalisation would have brought the stamp of approval on suicide itself. Parliament was very clear that suicide should remain a very grave action and one that society has a duty to do all possible to prevent such actions, and respect life itself. But Parliament also recognised, in decriminalizing suicide, that criminal sanctions were no way to treat and support those in urgent need of psychiatric help.

By the end of the twentieth century, new sources of coercion to suicide had emerged as internet suicide sites goaded vulnerable young people to commit suicide; some such sites even had voyeuristic onlookers as the person died [6]. To meet these changing societal pressures, the Coroners and Justice Act in 2009 [7] amended the wording of the 1961 Suicide Act, to broaden the scope of the offence from that of 'aiding and abetting suicide' to the wider offence of 'encouraging or assisting suicide'.

Although this offence carries with it a maximum sentence of 14 years, it carries no minimum sentence that the courts must apply if a person is found guilty. Prosecutions for assisting suicide also require the agreement of the Director of Public Prosecutions (DPP) to proceed. The process of deciding whether or not to prosecute a person for assisting a suicide was clarified in 2010, when the then Director of Public Prosecutions was required by the House of Lords acting in its previous judicial role, which is now the Supreme Court to publish his guidance on prosecuting such acts. This clarified that there is a two-stage test that must be satisfied for a prosecution to proceed: first, there must evidence that the suspect did an act capable of and intended to encourage or assist suicide and second that such a prosecution is in the public interest. The factors which may tend towards prosecution and those tending to mitigate against prosecution were published at that time and were further clarified in 2014 [8]. Since then, the number of cases referred to the DPP has remained small with 124 cases referred to the DPP in the 7 years from 2009 to 2016 and the law continues to act as an effective deterrent to such actions. Because the two-stage test must be fulfilled, among these cases 102 did not proceed, because 24 were withdrawn by the police and in 78 cases the Crown Prosecution Service decided not to proceed. In some of these the assistance was given out of extreme compassion after trying all avenues to dissuade the person from their suicidal course of action. Among the remaining cases, six cases proceeded to prosecution for homicide or similar serious crime [9].

This prosecutorial discretion is not unique to the law on assisting suicide; it is the way the law works. Non-prosecuting does not mean the law is not working, it means the law sets clear criteria, people know what they are and when the law is breached the circumstances pertaining to the situation will be examined—in other words, the law has a stern face but an understanding heart. Take another example, a person stealing at gunpoint for personal gain can expect to be dealt with harshly, whereas a mother stealing food to feed her hungry child might well be dealt with quite differently, but no one is proposing a law to exempt certain types of theft from potential prosecution.

The law itself lays down a clear black and white line about what is acceptable and what is not; it sends social messages. It is the interpretation of the law that is then circumstance specific.

This messaging is evident in the numbers of deaths from 'assisted dying' seen in jurisdictions that have legalised such practices and where figures suggest a normalisation of the practice is

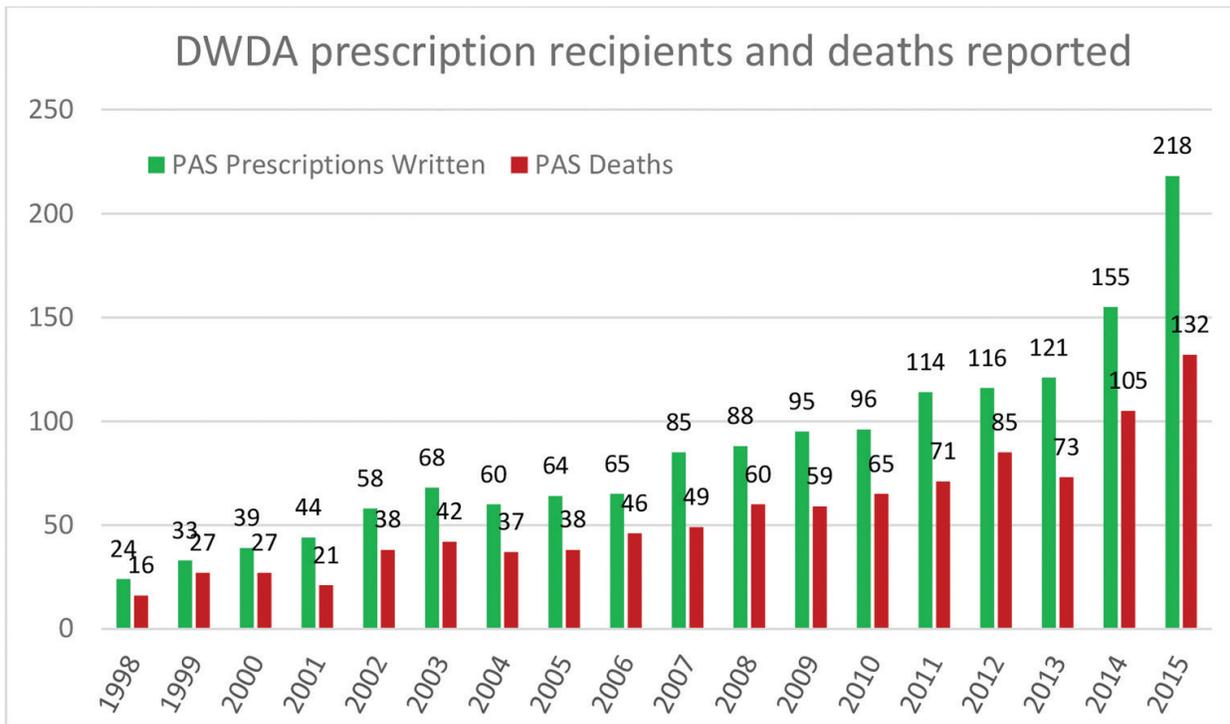


Figure 1. Oregon’s number of lethal prescriptions issued and deaths from lethal drugs recorded as being under the Death with Dignity Act [10].

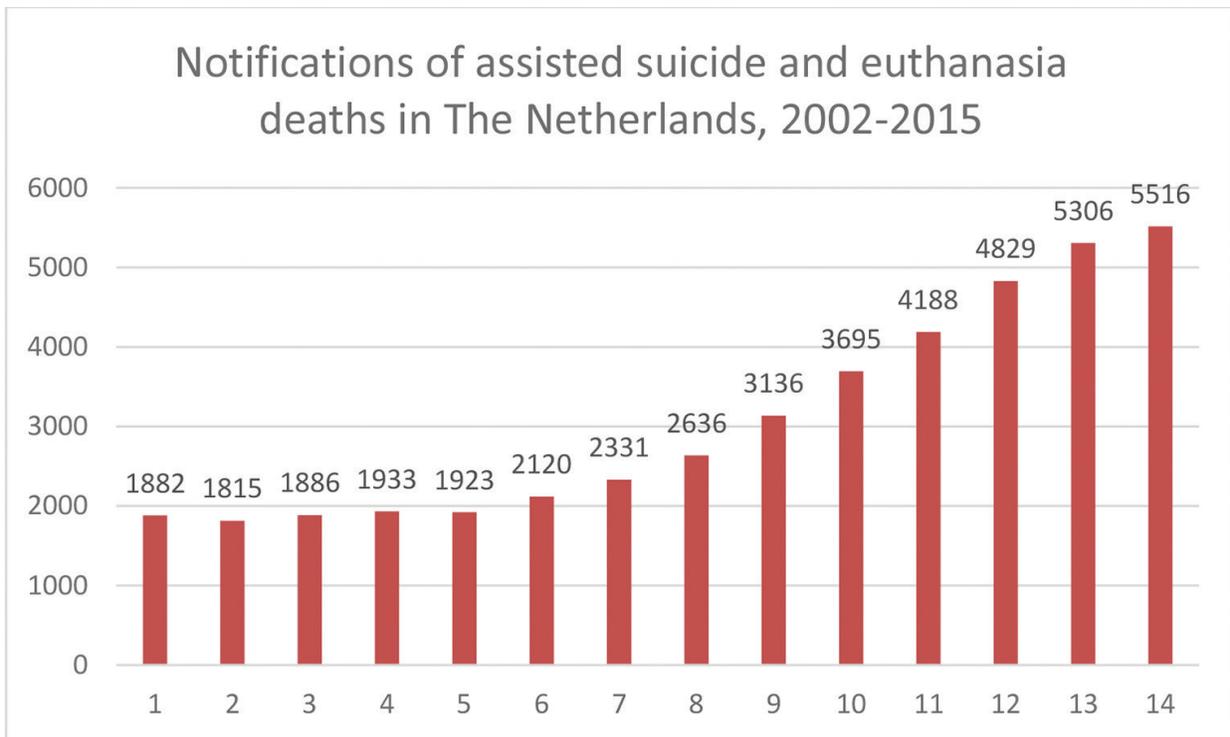


Figure 2. Deaths reported as deaths under the Termination of Life on Request and Assisted Suicide legislation in the Netherlands [11].

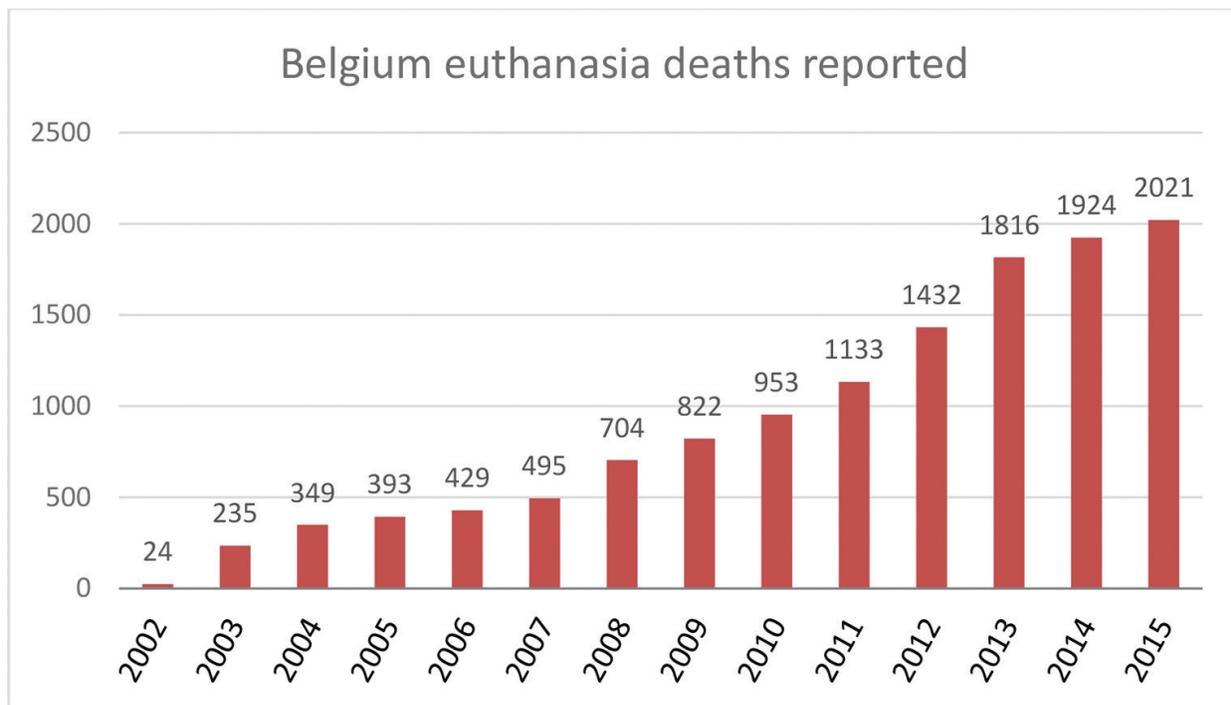


Figure 3. Deaths in Belgium reported as due to euthanasia [12, 13].

occurring. The contrast illustrates that the law is not being abused in England and Wales and is working as it should.

The numbers of such deaths vary depending on what exactly has been legalised, what the criteria are against which requests for lethal drugs are judged, and how requests are handled. But overall the numbers in each jurisdiction that has legalised some form of 'assisted dying' have been seen to increase overall year on year and have not reached a plateau anywhere (Figures 1–3).

3. What is 'assisted dying'?

'Assisted dying' is a euphemism that usually is interpreted as meaning physician-assisted suicide (PAS) or physician-administered euthanasia (PAE) of a person deemed to be terminally ill or who has unbearable suffering. The way that death is brought about is by administering a massive dose lethal drugs; it is unrelated to cessation of a futile treatment. Nor is it the doctrine of double effect, which is a serious adverse event from a therapeutic dose of drug, not a deliberate overdose.

For PAS, the person is prescribed a lethal dose of barbiturate, usually after preloading with an antiemetic to prevent the drug being vomited back. Such barbiturate doses are massive—about 50 times a dose that might be used in therapeutic practice—and such barbiturates themselves are very rarely used clinically today.

For PAE, the clinician, usually a doctor, injects a dose of an anaesthetic agent to induce coma. Then if the patient does not stop breathing and die rapidly, this is followed by a dose of

pancuronium or a similar paralysing agent so that the patient is completely paralysed and dies of asphyxia.

Although these might seem gratuitous details, they are important to understand the process and intent in PAS and PAE, in contrast to treatment withdrawal.

4. Treatment withdrawal

When a treatment fails to achieve its therapeutic goal, or the burdens of the intervention outweigh possible benefits, it becomes futile. This situation is common in oncology when cancer escapes from the effects of chemotherapy and progresses in the face of attempted treatment.

In some circumstances, the patient may decide that enough is enough and withdraw consent to ongoing treatment, preferring instead to let nature take its course, while other patients may wish an intervention to cease and are in effect withdrawing consent for the intervention. Thus, the patient on a ventilator with advancing motor neuron disease (amyotrophic lateral sclerosis) and no possibility of improvement may decide to opt for ventilation withdrawal.

In each case, the disease process is killing the patient and their death would probably already have occurred were it not for the intervention—they are dying of their disease, not because they are being given a lethal dose of drugs to deliberately foreshorten a life that may have otherwise gone on for months or years. During their dying care must not cease, so it is completely appropriate to titrate medication as required to keep the patient comfortable and with good symptom control. But massive lethal overdoses of drugs are not used and not needed.

Another misconception is that medical science is now keeping many more people alive than previously. It is nutrition, general hygiene measures and control of epidemics through vaccination and other public health measures that have contributed far more to longevity than interventions on those who are already ill. But when illness strikes, better control of disease is certainly possible now compared to 50 years ago. Control of diabetes, statins in heart disease and thrombolysis of strokes has led to far better clinical outcomes than were previously possible. Now, the greatest societal threat to health is probably the obesity epidemic and associated chronic conditions that result in multiple comorbidities [14].

As for medical intervention keeping people alive longer, the evidence is complex. People are certainly surviving under conditions that would have killed them in the past but they are also surviving better, able to resume activities of living and for some illnesses, such as breast cancer, the disease has gone from being a death sentence to being a long-term condition, often with very long periods of remission or cure.

Improvements in general health have resulted in altered expectations in the public, fuelled by political promises in a consumerist society, which have led people to be less tolerant of debility in any form and an expectation that the healthcare system can solve the problems that are almost inevitable from lifestyle-induced disorders, ranging from tobacco and alcohol consumption, the misuse of antibiotics leading to antibiotic resistance and obesity.

In general, the advances in medical science are allowing people to live much better for much longer than previously. Medical science is helping people live better and longer.

5. Criteria for assisted suicide

Different eligibility legislatures have used different criteria in their laws. It is worth examining these as there are difficulties with the verifiability of each criterion and therefore of the ability to detect if the legislation has been breached.

Importantly for patients, decisions must be based on accurate information, the patients must have the capacity to make that particular decision, and for a decision to be valid it must also be made free from coercion. Thus, the patient deciding to seek PAS/PAE must know the diagnosis is correct, the prognosis is accurate and they must be making the decision completely voluntarily.

5.1. Terminal illness diagnosis and prognosis

The majority of serious and progressing illnesses can eventually lead to death, but it is difficult to predict when death will occur in an individual. Metastatic malignant disease, with expanding deposits of malignant tumour, is relatively easy to detect and where that tumour is adjacent to a vital structure such as the spinal cord, an artery or a major airway, it is reasonable to predict that progression will result in further deterioration. Even in cancer, prediction of life expectancy – the 'how long have I got?' question – is only at best an informed guess and may be inaccurate by months or even years [15]. All too often clinicians overestimate or underestimate prognosis, leading to stories of 'they gave me three months, and here I am years later'. Although prognostic indicators in disease have been repeatedly shown to be grossly unreliable [16], Oregon's legislation requires a prognosis of 6 months, whereas Canada's legislation simply requires a doctor to state that death is likely to occur in the reasonably foreseeable future.

5.2. Mental capacity

For each decision, a person makes—and none could be greater than the decision to end your life prematurely—the mental capacity to make the decision must not be impaired. This means the person should not only be free of an illness or disorder of the mind that impairs their decision making, but also have the ability to understand the information relevant to that decision, be able to retain it and weigh it up in the decision-making process and be able to communicate this decision. In England and Wales, that is laid out in the Mental Capacity Act of 2005; there is similar legislation in Scotland and some other countries [17].

Such legislation aims to protect people from coercion and ensures that clinicians are under a duty to communicate in a way that the patients can understand. Physicians are also under a duty to do all they can to maximise the person's mental capacity, by treating reversible conditions, such as infection, and minimising the adverse effects of medications that impair capacity.

Evidence from Oregon shows that clinical depression, which leads to a particularly hopeless perspective and impairs capacity for decisions about life and death, is often not detected in assessments undertaken for PAS. Depression of itself is known to be a powerful force driving a desire for death [18], and depression and hopelessness are mutually reinforcing independent predictors of those seeking to hasten death [19]. In a small, but well conducted study one in six of those who fulfilled the assessment criteria for PAS in Oregon were found to have an undiagnosed, and therefore untreated, clinical depression; these patients were in the subgroup that then proceeded to take their own lives with lethal drugs [20].

Mental illness is frequent in seriously ill patients [21]. Suicidal thoughts have been found to occur in up to 45% of cancer patients but they usually do not persist [22]. Linked to this is the repeated clinical experience that patients react differently at different times in their illness; despair and overwhelming hopelessness can give way to hope and joy in the most unexpected circumstances [23].

5.3. No coercion

Coercive pressures are particularly difficult to detect. Clinicians do not know what goes on behind closed doors in people's homes. Coercion can be external, coming from comments that range from overheard comments through to obvious complaints about the burden the person's illness is posing on the family financially, physically and/or emotionally.

Fear of being a burden has been shown in Oregon's data over 17 years to be the second most frequently cited reason that people seek to hasten death through PAS. The perception of being a burden is itself associated with a desire for hastened death; it correlates more highly with psychological problems and existential concerns than it does with physical symptoms or difficulties [24].

Even more difficult to detect is internal coercion—the person who does not want to be a burden to the family, who is fearful of what lies ahead, perhaps who witnessed a badly managed death many years previously and is haunted by such memories, who is frightened of being undignified, confused or incontinent. Some people are unable to recognise the inherent uncertainty of life and seek to control everything around them. For them, the loss of control to a disease, which has taken over their body and is destroying their very existence, is something they cannot countenance. These people are often high achievers in life, have higher education and well-paid jobs and are used to being in command [25].

6. Clinical compassion

Campaigners cite 'compassion for the dying person' as the main driver behind demands for PAS and/or PAE, which are portrayed as the way to relieve the suffering person of their suffering. The argument has traction with the public who are fearful of pain and fearful of an existence in which they are not in control.

But amongst those who have availed themselves of lethal drugs to end their lives, Oregon's Health Department's reports show that pain comes low on the list of reasons given [10]. The

main reasons given by these patients relate to existential issues, particularly being less able to engage in activities making life enjoyable (96.2%) and losing autonomy (92.4%).

There is an argument put forward that the difference between the terminally ill seeking suicide and others seeking suicide is that the terminally ill do not want to die but they recognise their impending death as inevitable and they wish to avoid suffering when dying. This would seem at first sight logical, but the difficulty is the inability to define who is truly facing death, and who, despite serious illness, can resume living well with the appropriate support. The acceptance of the inevitability of death and that disease will take its course to that death, is fundamentally different from deciding that because death seems an imminent possibility, the remainder of life, however long it is, should be dispensed with.

Some campaigners say that PAS/PAE is only intended to be available for those in the last days of life but they have not fashioned a legislative proposal that restricts requests to the period that appears to be the last days or weeks, such as the anticipated last 4 weeks of life, when prognostication stands a chance of being slightly less inaccurate. [15].

7. Autonomy

The concept of personal autonomy is also a cornerstone of arguments for legalisation of PAS/PAE. The argument is made that it is for a person and for them alone to decide the time and manner of their death. And so it may be, but that does not explain why another person (a clinician in most cases) should be involved in bringing about that death. Nor does it recognise that 'no man is an island'; we affect those around us and the very nature of society is that we are interdependent for our existence and indeed for our survival. As Onora O'Neill has pointed out, autonomy is relational [26].

It is important to recognise that the way a person dies can have profound and devastating effects on those left behind. Take the child whose mother opted for assisted suicide and who was then left feeling that his love for her was inadequate, that he had failed her by not being 'good enough' to give her a reason to live; such a sense of guilt is inconsolable and irreconcilable.

8. Dignity

Concerns about loss of dignity are also frequently given as the reason for PAS/PAE being better for a person than continued living. As Cicely Saunders said 'Dignity is having a sense of personal worth' [27] and Chochinov's work has shown that the way a person is treated by others either enhances that sense of personhood and worth, or undermines it [28].

Laws termed 'Death with Dignity Act' have an inherently misleading title as they imply that PAS of itself confers dignity on the dying person. Such an assumption is misleading. Care of the dying is not rated as highly in these countries as it is in the UK [29], where no such PAS/PAE legislation is in place and where palliative care developments have led the

rest of the world in care of the dying [30]. Such perceptions that dignity in dying is synonymous with PAS/PAE mislead those other legislatures and societies considering such legislation, as well as subtly coercing patients who are wrestling with making decisions about their own lives.

9. Dying in society

As dying at home has become increasingly unusual, people have lost familiarity with dying and with death. The media, by its very nature, needs to capture viewers and listeners' attention with dramatic stories, hence the portrayal of unusual and dramatic deaths. By contrast, the thousands upon thousands of peaceful well-managed deaths that occur year in year out do not make headlines. The apparently well-managed death of David Bowie was an exception, because he was such a well-known figure, so his death was spoken about widely and opened conversations on death and dying.

The numbers of people who have not made any preparations for their own death, such as making a will, may be a reflection of fear of the unknown and a sense of denial about the reality of their own mortality. In the UK a charity, Dying Matters, has been promoting open conversations across society; the majority of those engaging in the conversation are people who are recently bereaved or had an exceptional experience of care—either good or bad—and want to talk. This lack of familiarity with dying has led to increased searching for quick solutions to complex problems, rather than a recognition that we all live with uncertainty all the time and that there are often unexpected moments of great value and tenderness as life draws to a close, if dying is planned for, accepted, and managed well.

10. Pain

Societal attitudes to death and how it should be managed have shifted over recent years, with the development of the hospice movement emanating from the UK and now adopted to greater or lesser extent around the globe. Despite advances in the science of end of life care, long-perpetuated myths about opioids have meant that these essential pain-relieving drugs remain unavailable to about 80% of the world's population. Even in those countries with legislation that enables good analgesic prescribing, misconceptions about how to prescribe such analgesics safely have led to many patients receiving inadequate analgesia to fulfil their needs. This is then witnessed by relatives, who are traumatised at seeing the person they love in ongoing pain.

The solution to the problem is to rapidly improve analgesic use and educate professionals about what pain management. As Robert Twycross has said 'you do not need to kill the patient to kill the pain' [31]. But in a search for a solution those who are unaware of what can and should be done have resorted to feeling that pain in dying patients is an unsurmountable problem to which the solution is to end the life of the sufferer.

11. Society normalisation

In those legislatures that have PAS and/or PAE, marked changes can be seen in attitudes to death and dying, with an inexorable increase in the numbers of premature deaths through the ingestion or administration of prescribed lethal drugs. In effect, this method of death has become normalised rather than being an exceptional event. The numbers have increased year on year, as can be seen with an 80% increase over the last 2 years in Oregon, with an eightfold increase in numbers since the 'Death with Dignity Act' came into force (see **Figure 1**). Although the absolute numbers seem small, 132 PAS deaths reported in 2015, Oregon has a very small population of only 3.8 million, which is less than half that of London.

But other changes have emerged associated with this legal change. The economic pressures of healthcare around the globe have impinged, as almost inevitably they will, on the way such decisions are viewed and reports have emerged of subtle coercive effects, whereby the costs of treatments are not funded but the far lower cost of PAS is covered by health insurance [32].

The effect on the clinical relationship between doctor and patients needs recognising too. In Oregon, there is evidence of doctor shopping, with one physician writing 27 prescriptions for lethal drugs last year even though the majority of doctors wrote none. This change reflects the process whereby patients whose doctors do not think they should have PAS are then being steered towards and assessed by physicians who do not know them as patients beyond their case notes and who have shown themselves to be more willing to prescribe lethal drugs than others.

In the Netherlands, numbers of PAE/PAS deaths are far higher than in Oregon and most are by PAE, where last year a death rate from PAE/PAS of 1 in 26 of all deaths (all causes) was reported. This may reflect several factors. Firstly, the law does not restrict the criteria to those deemed to be terminally ill, but includes those deemed to be those with intractable suffering, whatever the cause. Thus, the assessment is the patients' description of their suffering and its management, rather than also requiring consideration of the nature of the underlying pathological process. It may also reflect that the passive nature of holding out an arm for the doctor to inject lethal drugs is emotionally easier than the active gesture of raising a glass of lethal drugs and drinking the solution down, or it may reflect a different societal approach.

In Belgium, where PAE alone is legalised, the death rate appears even higher, but the statistics are harder to verify. Cases widely reported from Belgium include those who could never be classified as terminally ill, including the victim of a botched sex change operation, a prisoner with depression, twins with progressive visual deterioration towards blindness and several patients with long-term psychiatric conditions [33].

For all these cases, the term 'assisted dying' is deeply misleading as they were not dying prior to the lethal drugs being given. As such, the morality of the term itself warrants exploring. In these circumstances, terms such as 'ending life' or 'killing' would be more accurate descriptors.

12. Conclusion

Parliaments everywhere are faced with some key questions when changing the law on anything: first, does the law need changing? And second, would whatever legislation replaced it be safer overall for the whole population? better overall?

To answer the first question, it is necessary to ask what the problem is that the law is trying to solve. Some have argued that palliative care is not a universal panacea and indeed it never would be because no treatment or condition management in clinical practice ever has 100% success rate; there will always be some people for whom such approaches to their care are inadequate. But then the question of unintended consequences for the majority also needs to be explored.

At the population level, when Parliaments change the law they need clear facts on which to base their planned legislation, rather than be driven by pressure and emotive spin from campaign groups. To answer the second question, legislators need to look at the effect on the whole tenor of care in society for its vulnerable, the tensions between the costs of health and social care, and the duty to provide such care.

Legislators need to consider possible unintended consequences of legislation around PAS/PA and should look particularly at the trends from those places that have brought this into clinical practice.

Similarly, at the individual level, when patients make decisions over the options facing them, they need clear facts including information about the uncertainty around diagnosis, prognosis and other options.

For healthcare professionals themselves, there is also a need to honestly review their own roles, the financial and time pressures on them and to question their fundamental duty to patients.

In this complex debate, there is an increasing need to look at whether the law does need to be changed and how such change will alter the moral landscape. To inform that process, the evidence of the effect of legal change cannot be ignored. There is also a need to question whether the terms used are honest or misleading and to explore whether there are far safer options for patients than to licence doctors to provide lethal drugs when asked to do so.

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