

The Assisted Dying for the Terminally Ill Bill: an inappropriate response to the challenge of caring for the dying

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ABSTRACT The Assisted Dying for the Terminally Ill Bill concerns deliberate acts to end life, not assisting in the natural dying process. The Bill was the subject of a House of Lords Select Committee Report which will form the basis of debate in the House of Commons when the legislation is reintroduced in the current parliamentary session. Practical issues of patient assessment and implementation of physician-assisted suicide are not addressed in this legislation. There is a lack of reliable evidence as to how most dying patients feel about euthanasia and physician-assisted suicide. The interests of dying patients would be better served by increasing access to palliative care, making care of the dying a priority for our society.

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DECLARATION OF INTERESTS D Jeffrey is the Chair of the Ethics Committee Association for Palliative Medicine.

BACKGROUND

Patient choice has become a medical and political issue in recent years. Sometimes patients may insist on determining doctors' treatments, and some are ready to look to the courts for support. Nowhere is this seen more clearly than in the area of terminal care, and most starkly in the matters of physician-assisted suicide and euthanasia where the doctor, in effect, kills the patient. Doctors, and the societies in which they work, will be affected sooner or later by these developments, and accordingly the possible legalisation of physician-assisted suicide and euthanasia in the UK should be of interest and concern to doctors and the public everywhere.

The debate surrounding the legalisation of euthanasia and physician-assisted suicide has become polarised. The principal arguments 'for' euthanasia and physician-assisted suicide concern respect for autonomy and the relief of pain and suffering. Those arguing 'against', argue from the intrinsic evil of deliberately taking innocent human life. They also voice concerns about the threat to the integrity of the medical profession and the potential for abuse.¹

Lord Joffe's Assisted Dying for the Terminally Ill Bill is the subject of a House of Lords Select Committee Report.² There are practical and ethical difficulties in the Bill which make this legislation detrimental to the care of the dying.

LANGUAGE OF THE DEBATE

It is significant that the word 'euthanasia' does not appear in the proposed legislation; 'assisted dying', a fudged phrase, is used to cover both euthanasia and physician-assisted suicide. This Bill is actually about medical help to take life, since it is about both the prescription and possibly administration of lethal doses of medication. It is about deliberate acts to end life, not about assisting in the natural dying process which may be assumed by the term 'assisting dying'.

The Bill also confuses the issue further by suggesting that new legislation is needed to ensure patients with terminal illness receive analgesics. Existing law enables doctors to give pain relief, even if doing so may risk shortening the life of a terminally ill patient, and to deny patients such relief is negligent.

UNBEARABLE SUFFERING

To be eligible for physician-assisted suicide or euthanasia the patient has to be 'suffering unbearably'. Suffering is an entirely subjective concept determined not only by the experience of the patient, but also the society in which he or she lives, the healthcare professionals' view and the levels of support available. In 35% of euthanasia requests in the Netherlands, doctors refuse requests on the basis that the suffering of the patient is insufficiently severe.³

Relief of suffering is an important goal of medical care. However, there is no sort of care that could ever alleviate all suffering (especially some expressions of social, psychological and spiritual distress). The first step to addressing suffering is to ensure effective support in engaging with issues such as hopelessness, helplessness, loss of meaning and existential distress. Implementation of this Bill could increase suffering in vulnerable patients and their families by reducing trust, increasing fear and inhibiting patients from disclosing their concerns to doctors and other healthcare professionals.⁴

ETHICAL ISSUES

There is a danger of reclassifying the bringing about of a patient's death by euthanasia and physician-assisted suicide as a moral good.⁴ From experience in the Netherlands death by 'medicalised killing' can be considered to be in the best interests not only of competent patients who request it, but also in incompetent patients, where the doctor(s) may judge patients to be suffering, or in possession of a life no longer worth living.⁵

Both sides of the debate claim to have an interest in enhancing patient autonomy. Autonomy is a concept which carries a responsibility of reflecting on one's choices in the light of the harm that might result to others. Respecting autonomy in general has a high ethical priority but there are limits to individual autonomy if there is a threat to the autonomy of other members of the community.

PATIENTS' VIEWS

There is a lack of reliable evidence as to how most dying patients feel about euthanasia and physician-assisted suicide. Such evidence that does exist indicates that requests for euthanasia and physician-assisted suicide relate to feelings of 'dis-integration' which results from symptoms and loss of function and a 'loss of community' which describes the progressive loss of opportunities to initiate and maintain close personal relationships.⁶ These factors contribute to a feeling of a 'loss of self'. A patient's decision to have euthanasia or assisted suicide could well change with an alteration in an individual's social circumstances, quite independently of disease progression.⁶

The criteria in this legislation fail to provide a framework to address the social circumstances that contribute to the desire for euthanasia or assisted suicide. This vital part of end of life care needs to be informed by rigorous research into the patient's views and attitudes to euthanasia and physician-assisted suicide.⁷

PATIENT ASSESSMENT

Sensitive exploration of the request for euthanasia can help to identify the real needs of an individual patient.⁸ The request for euthanasia or physician-assisted suicide seems to point to a series of concerns that the patient has about dying; relating to loss of self, loss of dignity and the social context of dying. Understanding these concerns may help us to improve the care of dying patients.⁸ Communication surrounding end of life issues is a core skill in palliative care and depends upon a trusting doctor-patient relationship.

The Bill contains a requirement that a specialist in palliative care (a doctor or a nurse) must 'discuss the option of palliative care' with the patient before a declaration can be signed. The purpose of the single consultation is unclear. Is it to give the patient some basic information about palliative care, or to assess the patient to establish what precise treatment options might be available?

The assessment of the euthanasia request as envisaged in the Bill could create a barrier which subtly alters the doctor-patient relationship and paradoxically might impair the possibility of discussing the hopes and fears driving the euthanasia request. It can be even more difficult to assess a patient's needs when the goal of euthanasia dominates discussion.

Assessment in specialist palliative care depends upon continuity of care by a multiprofessional team and is an ongoing dynamic activity. It is unrealistic to imagine that a single consultation with a patient could reveal all the factors behind a request for euthanasia or physician-assisted suicide. It may take days or even weeks to establish a sufficiently trusting relationship with a patient to allow discussion of these intimate concerns. Compounding these difficulties is the lack of time, continuity and the fact that many patients have a number of attending physicians and other healthcare professionals necessarily involved in their care. The Bill makes no mention of what is to be done when the experts disagree in their assessments.⁹

PALLIATIVE CARE

Commonly in clinical practice many patients are apprehensive and may be reluctant to accept palliative care. However they often change their minds once they experience such care. Patients who have received palliative care frequently ask: 'Why did no-one tell me about this care earlier on?'

It may be that many patients would initially reject palliative care when given only basic information about it at a single interview. The medical profession in general need to be aware of the scope and availability of palliative care in order to advise patients appropriately.

DEPRESSIVE ILLNESS

There is no allowance made in this legislation for depression which falls short of incompetence. Depression may be difficult to diagnose even by those working in palliative care. The attending physician and the consulting physician do not need to have had any psychiatric training; if they miss the diagnosis and presume competence any existing safeguards of the Bill are ineffective.

IMPLEMENTATION OF EUTHANASIA OR PHYSICIAN-ASSISTED SUICIDE

The Bill does not state where the euthanasia or physician-assisted suicide will take place. What would be the effects on other patients if euthanasia or physician-assisted dying took place in the same ward or even building as the one in which they receive treatment? The Bill only makes it legitimate for a doctor to provide the patient with the means to end his life. Despite the language ('attending physician'), the doctor is not required to be present at death, and the patient is not required to administer the lethal dose immediately. What safeguards are there to ensure that the lethal medicine is kept secure and administered properly? For how long should the patient be allowed to keep the lethal dose without administering it?

The use of the term 'attending physician' demonstrates a lack of understanding of the complexity of a team approach to care which has largely replaced any single doctor providing continuity of care. There is no mention in the Bill as to the methods involved in either assisted suicide or in euthanasia. It is worth noting that complications such as failure of completion, myoclonus and vomiting may occur in both assisted suicide and euthanasia in 3–16% of patients resulting in suffering for patients.¹⁰

MONITORING EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE

A monitoring commission is useful only to the extent that cases are reported to it. The Dutch experience demonstrates that almost 50% of cases are not reported to the authorities.¹¹ Indeed it could be the most borderline cases which do not fulfill the criteria for euthanasia which are concealed. In the Bill before the House of Lords the monitoring commission reviews cases retrospectively. Surely it would be a better safeguard for patients and doctors to monitor applications to ensure the qualifying conditions had been met for euthanasia or assisted suicide before not after the death.

RESOURCE IMPLICATIONS

Palliative care resources are limited and in reality largely confined to a proportion of those people with cancer. Further resources would be needed, both to enable

assessments to take place, and then to ensure that adequate palliative care is available to meet identified needs.

In the provision of the Bill, patients wishing to remain in a hospice or specialist unit could avoid discharge simply by making a euthanasia request, thus distorting priorities for access to care. The Bill also states that the patient making a request for euthanasia or physician-assisted suicide must be informed of the alternative of 'care in a hospice'. It seems unjust that patients who are considering euthanasia become automatically and legally entitled to care in a hospice regardless of their actual care needs. There may well be other patients whose need is greater but who have no right in law to ensure they will get a hospice bed.

INTEGRITY OF THE PROFESSION AND IMPACT ON MEDICAL PRACTICE

The risk of losing trust and damaging the doctor-patient relationship is high. This is an area of practice where research is needed to establish the consequences of legislation. Would euthanasia and physician-assisted dying become legitimate treatment outcomes that doctors would be obliged to raise with all dying patients?

How will the new law be enacted if a majority of doctors conscientiously object to performing euthanasia and physician-assisted suicide? Administering euthanasia and physician-assisted suicide is contrary to the ethos and practice of palliative medicine. There is a strong possibility that some palliative care specialists could also refuse to carry out the required assessment consultation, fearing that they might become implicated in euthanasia. Specialists in palliative care should not act as gatekeepers to euthanasia.

SOCIAL IMPLICATIONS

What will be the effects on society of permitting direct acts of killing, and so weakening the prohibition against killing which currently protects us all? There are strong cultural, moral and legal prohibitions on killing. Will this new Bill change the way in which society views the sick and dying and come to see them as an inconvenience to be disposed of?

Will patients feel more of a burden to their families and society and feel they ought to ask for euthanasia, and feel guilty if they don't? There is much that to learn about the impact of a patient's social circumstances in generating a request for euthanasia or physician-assisted suicide.

CONCLUSIONS

Palliative care is concerned with enabling patients with advanced life-threatening conditions to live with the best possible quality of life until they die. Clinical experience and research suggests that the majority of requests for

euthanasia or physician-assisted suicide arise as a result of poor symptom control, depression, poor social and family support and a loss of autonomy. Palliative care concentrates on improving these aspects of a patient's life and the provision of this care should be the starting point for any debate on assisted dying. There is a need for training in palliative care at all levels of medical and nursing education so that it is seen as an integral part of all good care.

The Assisted Dying Bill is ethically unsound, practically flawed and damaging to the integrity of the medical and nursing professions. It displays a lack of understanding of the nature and scope of palliative care which is provided in both specialist and generalist settings. It threatens to undermine the progress in care of the

dying that has occurred in this country over the past three decades.

The interests of dying patients would be better served by increasing access to palliative care, improving standards of care in all settings and making care of the dying a priority for our society.

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