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Mental Capacity and Assisted Suicide

To what extent can mental capacity be reliably assessed in patients seeking physician-assisted suicide?

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Executive Summary

Lord Falconer's Assisted Dying Bill proposes legalisation of physician-assisted suicide for patients who are terminally ill and have mental capacity. Assessments of mental capacity are governed by the Mental Capacity Act 2005 (MCA) and the Bill proposes that capacity should be defined in accordance with its provisions. There is an inconsistency here in that the MCA requires that capacity should be assumed to exist unless its absence is established, whereas the Bill contains a requirement for the presence of capacity to be confirmed. There is perhaps an implicit recognition here that capacity assessment with a view to assisted suicide is different from capacity assessment in other contexts.

When psychiatrists and other doctors assess mental capacity, they do so with a view to protecting patients from harm. To ask them to conduct such assessments with a patient's suicide as a potential outcome is to take capacity assessment into completely new territory. Indeed, the MCA itself makes clear that it does not apply to situations of assisted suicide.

Capacity assessment is a complex undertaking. Assessments during terminal illness can be complicated by the underlying illness, by the medication being taken to relieve its symptoms and by the distress, fear or adjustment which often accompanies such diagnoses and which may affect both the patient and his or her family. In the case of terminally ill persons seeking assistance with suicide, it can be further complicated by factors such as lack of first-hand knowledge of the patient on the part of the doctor making the assessment, feelings of transference or counter-transference and distortions deriving from the doctor's personal values and from the patient's wish to 'pass the capacity test'. Evidence from Oregon, where research has revealed failure by doctors to spot clinical depression among some patients seeking legal physician-assisted suicide, is not reassuring.

Lord Falconer's Bill appears not to recognise these complexities. It requires simply that two assessing doctors should have satisfied themselves that a patient seeking assisted suicide has the capacity required to make a decision to end his or her life. It does not, however, require any specific measures to be taken, such as referral of a requesting patient for specialist psychiatric assessment, in order to be able to give the required confirmations. It postpones such issues to codes of practice to be issued after a decision has been taken to legalise assisted suicide. It is not possible therefore to judge whether the Bill, if enacted into law, would provide adequate protection for vulnerable people.

Introduction

1. A Private Member's Bill[i] has been tabled in the House of Lords proposing that 'assisted dying', by which is meant physician-assisted suicide, should be lawful in the case of persons who are terminally ill and have mental capacity to make the decision. This paper explores what the law says about mental capacity, what are the challenges involved in making capacity assessments both generally and where patients are terminally ill, and what implications these have for proposals to legalise physician-assisted suicide.

The Mental Capacity Act

2. England and Wales has a legal statute (the Mental Capacity Act of 2005) which defines both capacity and the means by which it is assessed. This is a relatively new Act, having come into force in 2007. Under the Act an assessment of capacity is functional: it assesses the decision-making process and therefore it is decision-specific. As it is not a defined state, capacity may change with time and will vary depending on the nature and importance of the decision being made. A person may, for example, have capacity to decide what to wear or what to eat, but not whether to have surgery. Someone may have the capacity to make a decision in the morning but not the same evening, and may regain and lose capacity many times.

3. Section 1 of the Act states that "*a person must be assumed to have capacity unless it is established that he lacks capacity*". Section 2 therefore defines mental capacity by defining its absence. It states that "*a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain*". It also states that "*it does not matter whether the impairment or disturbance is permanent or temporary*".

4. Section 3 gives guidance on how capacity is to be assessed. It states that "*a person is unable to make a decision for himself if he is unable—*
(a) to understand the information relevant to the decision,
(b) to retain that information,
(c) to use or weigh that information as part of the process of making the decision, or
(d) to communicate his decision (whether by talking, using sign language or any other means)".

5. Section 62 states that "*nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961*". In other words, the Act was not designed or intended to regulate capacity assessment in the context of euthanasia or assisted suicide.

Assessing Mental Capacity

6. What is meant by "*an impairment of, or a disturbance in, the functioning of the mind or brain*"? The most obvious instance is the presence of a psychiatric disorder. Various studies have assessed the incidence of psychiatric illness (particularly depression) as existing in approximately 30% of people with a terminal illness[ii]. In addition to depression, other psychiatric conditions such as dementia, intellectual and developmental disabilities, and altered states of mind resulting from, for example, sedation may impair a person's decision-making capacity.

7. A common medical condition affecting the functioning of the brain in people with a terminal illness is that of delirium. Rates of delirium in a palliative care setting can reach up to 88%[iii] and are not always readily recognised due to the highly variable nature of the cognitive and behavioural changes in delirium. Various studies have estimated the rates of under-diagnosis as between 33% and 72%[iv] depending on the diagnostic instrument used. Rates of detection are increased if the physician has good knowledge of the patient prior to the onset of illness and if the physician has a high level of awareness of delirium.

8. Another factor to be considered is the impact of symptom-relieving medication, particularly potent analgesics, such as opioids, which can induce fluctuating levels of consciousness or awareness. While pain-relieving medication could be temporarily suspended, this would not address the effect of the underlying pain. Pain can be a significant contributing factor to impairment of capacity, not solely in predisposing the person to depression (up to 60% of people with chronic pain suffer from depression[v]), but also in the effect of pain and its intimate connection with the brain and mind. Pain is "*a complex condition, affecting thought, mood and behaviour*"[vi].

9. The terminal illness itself can have an impact on capacity. This is of particular importance where illnesses affecting the brain are concerned. Studies have indicated that around 30% of patients with Motor Neurone

Disease suffer from significant cognitive impairment, which may not be apparent to those around them[vii].

10. Less tangible but nonetheless important factors affecting capacity are the grief, adjustment, loss and fear that often accompany a diagnosis of a terminal illness. These are very powerful emotions with the potential for clouding the reasoning behind a decision to end one's life.

11. Assessing mental capacity in terminally ill patients is, therefore, far from straightforward. What about the doctors who would be expected to make such assessments in the case of patients requesting physician-assisted suicide? Clinical practice can sometimes involve assessing a patient's mental capacity, so most doctors will have been faced with the task at one time or another. There is, however, an important difference in the case of a request for assisted suicide. When doctors assess patients for mental capacity, they do so with a view to protecting them from harm or self-harm. To ask them to do so as part of a process for enabling a patient's suicide puts the assessment process into a completely different dimension.

12. There is no requirement for a doctor to have training in psychiatry, even in recognizing depression, a co-morbid and treatable complication of some life-threatening diseases. In a recent study UK General Practitioners recognized depression in only 39% of depressed patients visiting their practice[viii]. Another study showed that oncologists fared no better, recognizing 33% of mild-to-moderate depression and only 13% of severe depression in their cancer patients[ix].

13. A crucial feature of capacity assessment is first-hand knowledge of the patient concerned. A doctor who has treated a patient over a considerable length of time is better-placed to assess that patient's susceptibility to mood swings or depression and to understand the impact of other factors, such as the illness or the medication being taken to relieve it. A doctor who has also visited the patient in his or her home surroundings and has been able to acquire a feel for the patient's personal or family situation is better-equipped to assess whether there may be background issues which could be influencing how he or she is thinking.

14. The Mental Capacity Act Code of Practice suggests that, where the decision in question is complex or where the consequences of the decision are significant, assistance should be sought from someone with specialist

knowledge of capacity assessment (usually a psychiatrist or a psychologist). While for some decisions this may require no more than a single appointment with a specialist, for more complex or serious ones it will be necessary for a number of assessments to be carried out over a period of time and/or by a multi-disciplinary team.

Capacity Assessment in Lord Falconer's Bill

The Bill

15. The Bill now before Parliament states[x] that "*'capacity' shall be construed in accordance with the Mental Capacity Act 2005*". It requires that a patient seeking physician-assisted suicide should have been assessed by two doctors, who "*must be satisfied that the person... has the capacity to make the decision to end their own life*"[xi]. The Bill does not, however, contain any provisions governing the establishment of capacity. It envisages that these would be covered in codes of practice to be issued by the Secretary of State for Health. According to Section 8 of the Bill, these codes of practice would cover:

"*the assessment of whether a person has a clear and settled intention to end their own life, including -*
(i) assessing whether the person concerned has capacity to make such a decision;
(ii) recognising and taking account of the effects of depression and other psychological disorders that may impair a person's decision-making;
(iii) the information which is made available on treatment and end of life care options available to them and of the consequences of deciding to end their own life".

16. Schedule 1 to the Bill requires the two assessing doctors to confirm that the patient requesting assistance with suicide "*has the capacity to make the decision to end their own life*" and "*has a clear and settled intention to do so, which has been reached on an informed basis, without coercion or distress, and having been informed of the palliative, hospice and other care which is available to him/her*".

17. The absence of any provisions governing the establishment of mental capacity represents a serious structural weakness in the Bill, making it impossible for legislators to assess its adequacy from the point of view of patient protection. The Bill's superficial requirement that the assessing

doctors must "*be satisfied*" overlooks a number of issues relating to capacity assessment which need to be considered in the context of a request for physician-assisted suicide.

Selection of Doctor/Psychiatrist

18. Under Section 5 of the Bill, a doctor or psychiatrist would be able to decline on conscientious grounds to participate in processing a request for assisted suicide. While this is, of itself, a reasonable - indeed a necessary - provision, it has consequences for the assessment process. Surveys of medical opinion show that the majority of doctors do not regard assistance with suicide as an appropriate part of their practice of medicine and it is to be expected that many of them would be unwilling to participate in any law legalising such acts. While doctors could undoubtedly be found who would be prepared to carry out the required assessments, these would in many cases have little, if any, first-hand knowledge of the patient. It is beguiling to assume that patients seeking physician-assisted suicide would be assessed by a 'family doctor' figure who has treated them over time and knows them and their circumstances well. The reality can be otherwise. As evidence from Oregon shows, in many cases they would find themselves being assessed by doctors whom they had only recently met.

Referrals

19. It is apposite to mention here another aspect of Oregon's experience of physician-assisted suicide. Oregon's law requires referral for specialist assessment if it is thought by the assessing doctor that a patient seeking physician-assisted suicide might be suffering from "*a psychiatric or psychological disorder or depression causing impaired judgment*"[xii]. However, research[xiii] from Oregon published in 2008 indicated that, in one in six cases from a sample of patients who had been supplied with lethal drugs for physician-assisted suicide, the assessing doctors had failed to spot the presence of clinical depression or to refer the patients concerned for specialist evaluation. It concluded that Oregon's physician-assisted suicide law "*may not adequately protect all mentally ill patients*".

20. Lord Falconer's Bill does not require referral for psychiatric assessment, even in doubtful cases. Such an omission is difficult to understand. Expression of a suicide wish is normally regarded as grounds for psychiatric assessment and it is difficult to see why a request for assistance with suicide should be treated differently. Specialist assessment in such cases should be mandatory, not an optional extra at the discretion of the assessing doctor.

Distortion

21. Psychiatrists and other doctors assessing mental capacity are not automata: they are human beings who come to the task with views and values of their own. Such personal values may, however unintentionally, colour the assessments that are made. The risk of this is likely to be greater where the matter at issue is one where opinion is polarised. In theory, the risk of personal bias intruding into the assessment process exists in both directions. In practice, as doctors who are opposed to physician-assisted suicide are likely to remove themselves from participation in the process, the risk of bias is more likely to be an issue in the one direction than in the other.

22. There are certain other potential distortions in the assessment process that need to be considered. Doctors, even those with psychiatric training, may be unaware of feelings of transference or counter-transference, which may be intensified in such an emotive context and may exert influence on decision-making. One of the commonest counter-transference reactions is pseudoempathy, in which the doctor over-identifies with the patient and makes decisions based on what the doctor thinks he or she would wish in the same or a similar situation.

23. The risk of distortion in the system is not limited to the assessing doctor or psychiatrist: the will of the patient necessarily plays an important role. A patient requesting assistance with suicide may view the assessment process as an unnecessary and tiresome hurdle to be overcome and may resent the requirement to see a 'shrink', especially if he or she has had no previous experience of mental health services. Capacity assessments rely on subtle cues and subjective opinion, and the patient is likely to endeavour to achieve the desired outcome. It is fair to assume that, if a patient has requested assisted suicide, that is the outcome which he or she wishes to see. In these circumstances the patient can be expected to try hard not to 'fail the test'. It is human nature not to want to fail, particularly a test which is assessing something as valuable and desired as the ability to make decisions for oneself. In her interviews with those involved in implementing Oregon's physician-assisted suicide law Dr Annabel Price found that, "*if a patient does not want to disclose information material to psychiatric assessment, the assessor may be able to ascertain little more than the 'surface' of the mental state*" and that those being assessed often have "*the ability to traverse the necessary barriers to assisted suicide as they have done in other areas of life*"[xiv].

Assessing a Patient Over Time

24. For some decisions a specialist assessment may require only a single appointment, but for others there may be a need for the assessing psychiatrist to examine the patient over a period of time. Given the gravity of a decision to seek assisted suicide and the complexities of assessment in such cases, the assessment process cannot be rushed if the patient is to be protected. In research published in 1996, only 6% of Oregon psychiatrists felt confident that they could make an accurate assessment of capacity in a single consultation[xv]. It has been argued that these decisions are so complex that they should only be made by liaison psychiatrists[xvi], but many UK hospitals do not have access to this highly specialised service.

Reflection

25. Many important decisions are protected by a 'cooling off' period. This indicates an awareness that decisions may be influenced by the circumstances under which they are made and that a period of reflection and consideration may lead to a change of mind. The more significant the decision, the longer the period needed for reflection. It is sometimes argued by advocates of legalised assisted suicide that, where a person is terminally ill, a long 'cooling off' period might frustrate a wish to end life on his or her own terms[xvii]. Lord Falconer's Bill appears to share this view: it allows for a two-week period of reflection, with a shortening of this to just six days where death is expected within one month. It is questionable whether such short 'cooling off' periods offer adequate time for proper reflection on a decision with such serious consequences.

26. Under the proposals in the Bill, a request for assisted suicide would not necessarily be acted on as soon as it had been approved and the prescribed two-week (or six days) 'cooling off' period had expired. The lethal drugs would be supplied to the patient only if and when requested for use. But this raises another difficulty. In Oregon, for all those who have died by legal physician-assisted suicide since 1997, the mean interval between first request and death by ingestion was 46 days, but this mean figure lies within a range of 15 to 1009 days[xviii] and some of those receiving lethal drugs do not take them until longer periods of time have elapsed. Given the progressive nature of terminal illness, and the high incidence of factors affecting capacity, mental capacity may be lost in the period between the request being approved and the drugs being supplied and swallowed. The relationship between time and capacity is explicitly laid out in the Mental Capacity Act Code of Practice, which states that: '*an assessment of a*

person's capacity must be based on their ability to make a specific decision ***at the time it needs to be made***[xix] (my emphasis). Thus, an assessment of capacity made at one point in time cannot be regarded as valid for a decision taken at a subsequent point, which may be weeks or even months later.

Conclusion

27. Psychiatrists and other doctors assess mental capacity, within a statutory framework, with a view to protecting patients from harm. It is a challenging enough process at the best of times. To ask them to make such assessments as part of a process which has suicide as a potential outcome is to take mental capacity assessment into completely new territory.

28. Lord Falconer's Bill declares that "*'capacity' shall be construed in accordance with the Mental Capacity Act 2005*". The MCA states, as one of its principles, that "*a person must be assumed to have capacity unless it is established that he lacks capacity*". The Bill, on the other hand, requires that the assessing doctor "*must be satisfied that the person... has the capacity to make the decision to end their own life*". This inconsistency - between an Act that requires absence of mental capacity to be established and a Bill that requires a doctor to be satisfied as to its presence - arises to a large extent because the MCA was not designed to deal with requests for assisted suicide. But it also perhaps reflects an implicit acceptance by the Bill's authors that, notwithstanding the reference to the MCA, assessing a request for assisted suicide is not a situation commensurate with other mental capacity assessments and that a much higher level of assurance is required.

29. Proper and effective capacity assessment is central to any proposal to legalise assisted suicide. As observed above[xx], it is a complex process, especially where the patient being assessed also has a serious physiological condition. It is therefore surprising and disquieting that the Bill makes no provision as to how capacity is to be established other than that it should be construed in accordance with the MCA (an Act which was not designed for dealing with assisted suicide) and that it would be open to the Secretary of State to issue codes of practice. These latter are important, but they need to be built around basic legislative structures approved by Parliament. The Bill's superficial requirement that those assessing a request for assisted suicide must "*be satisfied*" as to the existence of capacity provides no such structure. It leaves the nature and rigour of capacity assessment to be decided outside Parliament by the Secretary of State and such persons as he

"*thinks appropriate*"[xxi]. While such an approach may be appropriate in some other areas of legislation, its suitability in situations, such as this, where the lives of vulnerable patients are at issue is highly questionable.

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[i] Assisted Dying Bill (HL Bill 24) 2013-14

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Bowers L., Boyle D.A., *Depression in patients with advanced cance*r, Clinical Journal of Oncological Nursing, 2003, 7:281-288
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[iii] Breitbart W. & Strout D. (2000), *Delirium in the terminally ill*, Clinical Geriatric Medicine, 16, 357–372

[iv] Teodorczuk A., Reynish E. and Milisen K*., Improving recognition of dementia in clinical practice: a call for action*, BMC Geriatrics 2012, 12:55

[v] Bair MJ, et al, *Depression and Pain Comorbidity: A Literature Review*, Archives of Internal Medicine (Nov. 10, 2003): Vol. 163, No. 20, pp. 2433–45

[vi] Harvard Mental Health Newsletter, September 2004

[vii] House of Lords Report 86-I (Session 2004-05), Paragraph 125

[viii] Thompson C. et al, *Effects of a clinical-practice guideline and practice-based education on detection and outcome of depression in primary care: Hampshire Depression Project randomized controlled trial*, Lancet 2000, 355:185-191

[ix] Passik et al, *Oncologists' recognition of depression in their patients with cancer*, Journal of Clinical Oncology, 1998, 16:1594-1660

[x] Assisted Dying Bill (HL Bill 24) 2013-14, Section 12

[xi] Assisted Dying Bill (HL Bill 24) 2013-14, Section 3(3)

[xii] Oregon Death with Dignity Act, Clause 127.825, Section 3.03

[xiii] Ganzini L. et al, *Prevalence of depression and anxiety in terminally ill patients pursuing aid in dying from physicians*, BMJ 2008;337:al682

[xiv] Hotopf M., Price A., Written Evidence to the 'commission on assisted dying', Page 3

[xv] Ganzini L., Fenn DS, Lee MA, Heintz RT, Bloom JD, *Attitudes of Oregon psychiatrists toward physician-assisted suicide*, Am J Psychiatry 1996, 153**:**1469-1475

[xvi] Kissane DW, Kelly BJ, Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. Austr N Zealand J Psychiatry 2000, 34**:**325-333

[xvii] See, for example, Lord Joffe's oral evidence to the select committee on his 2004 Assisted Dying for the Terminally Ill Bill, House of Lords Report 86-II (Session 2004-05), Page 49

[xviii] Oregon Public Health Division, Official Report for Calendar Year 2012

[xix] Mental Capacity Act Code of Practice, Paragraph 4.4

[xx] See Paragraphs 18-26

[xxi] Assisted Dying Bill (HL Bill 24) 2013-14, Section 8(2)