Respect for Autonomy in Medical Ethics

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Mr Burke has the degenerative brain condition spino-cerebellar ataxia. By his mid forties he was dependent on a wheelchair for mobility and suffered uncoordinated movements and impaired speech. Some years from now Mr Burke will lose all mobility and eventually he will lose his ability to speak, to gesture and even to swallow. He will then be able to communicate only with the aid of a computerised device and he will need to receive food and water by means of artificial nutrition and hydration (ANH). Mr Burke's mental faculties are unaffected by the disease and will probably so remain until death is imminent. There will come a time at which, although fully conscious and rational, he will be unable to communicate even with a computerised aid. Towards the very end he will become semi-comatose before he dies.

Mr Burke is understandably fearful of the final stages of his disease. In particular, he is concerned about the periods when although conscious he will be able to communicate only by a computerised device and then unable to communicate at all. Mr Burke does not want ANH withdrawn before his death is imminent; he fears this could happen if doctors judge at an earlier point that prolonging his life is no longer worthwhile. His fear is not allayed by the guidance issued to doctors by the General Medical Council of the United Kingdom (GMC), according to which in a case such as Mr Burke's it is the responsibility of the "consultant or general practitioner in charge of a patient's care ... to make the decision about whether to withhold or withdraw a life-

prolonging treatment, taking account of the views of the patient or those close to the patient..."[1] The Guidance further instructs:

"[w]here death is not imminent, it usually will be appropriate to provide artificial nutrition or hydration. However, circumstances may arise where you judge that a patient's condition is so severe, and the prognosis so poor that providing artificial nutrition and hydration may cause suffering, or be too burdensome in relation to the possible benefits. In these circumstances, as well as consulting the health care team and those close to the patient, you must seek a second or expert opinion from a senior clinician....This will ensure that, in a decision of such sensitivity, the patient's interests have been thoroughly considered..."[2]

To be sure these guidelines say that in coming to his or her decision the doctor should *take the patient's views into account* and *assess the patient's best interests* in consultation with others, but they do not refer to the patient's *wishes* in this regard. Mr Burke will be able to make his wishes known by means of a computerised aid for some time after he loses the capacity to communicate by speech or gesture. He might also provide for the period when he will be unable to communicate at all, by making an advance statement that he does not want ANH withdrawn before his death is imminent. But the crucial question for Mr Burke is of course what status his wishes have in this regard. The answer to this question would be relatively straightforward if Mr Burke wanted ANH discontinued at some point. If he were to withdraw his consent to ANH, either while he can still communicate or at a later time by means of an advance statement made while he still has both the capacity to make rational decisions and the ability to communicate those decisions, this would have the force of a directive with which doctors would be obliged to comply. But Mr Burke does not wish to do this; on the contrary, he does not 'consent' to the withdrawal of ANH before his death is imminent. Strictly speaking, a patient can either give or withhold *consent*

[1] "Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-making" (2002), Paragraph 32. (Hereafter referred to in the text as the Guidance)
[2] Ibid, Paragraph 81

to particular treatment only if that treatment is offered or provided. Here it might seem appropriate to invoke a distinction between a patient's either *accepting* or *refusing* treatment on offer, as opposed to his *requesting* treatment. However, the characterization of Mr Burke's wish that ANH not be withdrawn before his death is imminent as (merely) a *request* for treatment on his part strikes at the heart of his concern.

In 2004 Mr. Burke sought clarification of the circumstances in which ANH could lawfully be withdrawn.[3] He asked for declarative relief: that his wish that ANH not be withdrawn before his death is imminent should be enacted.[4] The High Court decided in his favour. In a lengthy and detailed judgement that addressed a number of related matters, Mr Justice Munby ruled that on the specific issue of the continuation of ANH, Mr Burke's wishes could have the same force as a refusal of treatment. This judgement was widely regarded as a strong defence of the view that the medical law and the human rights principles relevant to Mr Burke's circumstances are grounded in the moral value of patient autonomy.[5] But if this was indeed a victory for the view that a competent patient can have a right to require the provision of particular medical treatment in specific circumstances, then it was short-lived.[6] In 2005 the GMC brought an appeal which was upheld and the decision in *Burke* [2004] reversed.[7] Nevertheless, the Court of Appeal sought to assure Mr Burke that his fears are unfounded, declaring that:

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[3] *R (on the application of Oliver Leslie Burke) v The General Medical Council Rev 1* [2004] E.W.H.C. Admin 1879 (30 July 2004)

[4]This was the core of Mr Burke's application to the High Court. He also sought to establish that relevant sections of the Guidance were incompatible with his rights under various Articles of the European Convention for the Protection of Human Rights and Fundamental Freedoms.

[5]David Gurnham, "Losing the Wood for the Trees: Burke and the Court of Appeal", *Medical Law Review*, 14, (2006): 253

[6]Munby J was not concerned with the extent to which, in general, a patient has a right to insist on particular treatment, but rather with a patient's choice of whether or not to receive life-prolonging treatment and with the right to decide "how one chooses to pass the closing days and moments of one's life and how one manages one's own death". *Burke* [2004] 63.

[7]*R (on the Application of Oliver Leslie Burke) v The General Medical Council* [2005] E.W.C.A. Civ. 1003 (28 July 2005)

"[w]here a competent patient indicates his or her wish to be kept alive by the provision of ANH any doctor who deliberately brings that patient's life to an end by discontinuing the supply of ANH will not merely be in breach of duty but guilty of murder. Where life depends upon the continued provision of ANH there can be no question of the supply of ANH not being clinically indicated unless a clinical decision has been taken that the life in question should come to an end. That is not a decision that can lawfully be taken in the case of a competent patient who expresses the wish to remain alive."[8]

This proffered assurance is unconvincing it seems to me, even if we set aside that it ignores Mr Burke's fears about the period in which although conscious and rational he will be legally incompetent due to his inability to communicate. Under current law in the United Kingdom a doctor will be guilty of murder if she deliberately (i.e. intentionally) brings a patient's life to an end *by whatever means*. But if the relevant sections of the GMC's Guidance are lawful (as the Court of Appeal held them to be), then a doctor who withdraws ANH before a patient's death is imminent on the basis of her judgment that the "providing artificial nutrition and hydration may cause suffering, or be too burdensome in relation to the possible benefits" does not "deliberately bring the patient's life to an end by discontinuing ANH". This is so even if the patient's life depends upon the continued provision of ANH; it is so independent of the wishes of the patient one way or the other.[9]

The withdrawal of ANH before Mr Burke's death is imminent might be objectionable for other reasons of course. For instance, if Mr Burke were to experience the painful and distressing effects of malnutrition and dehydration this would be cruel. However, presumably he could be spared these effects by heavy sedation. Mr Burke could refuse sedation while he is still competent

[8] *Burke* [2005] 53

[9] The general law of murder holds that a person intends to kill if she foresees someone's death as a morally certain outcome of her action. (Thus a person who plants a bomb in a railway carriage with the aim of killing a particular person can also be guilty of murdering other people in the carriage who die from the blast.) However, the law relating to withholding or withdrawing medical treatment invokes a stricter notion of intention, whereby in withholding or discontinuing life-prolonging treatment a doctor can foresee but does not thereby intend a patient's death.

and perhaps he could use an advance statement to refuse sedation at a later stage. But would he want to do so in these circumstances? The point is that Mr Burke does not wish simply to obliterate any pain or distress that he might suffer in the event that ANH is withdrawn before his death is imminent. He wants to remain conscious as long as possible and he does not want to die of malnutrition and dehydration.

Mr Burke's case draws attention in a particularly stark way to the question of the status of a patient's wishes in the *provision*, as opposed to the refusal of treatment. In this paper I focus on several aspects of this question in the context of thinking about some examples that involve decisions by competent patients about the provision of treatment for illness or injury. Mr Burke's is an actual case that was addressed as a matter of law. His circumstances are also unusual and extreme. The other examples that I shall introduce are based on real life and represent what I take to be reasonably common situations in which competent patients make decisions about treatment from a limited range of options. The issues that motivate the paper are primarily conceptual and ethical. They are raised by the following questions: What is it for a doctor to respect a competent patient's wishes in relation to the provision of treatment for significant illness or injury? What bearing do a competent patient's wishes have on a doctor's obligations in relation to the provision of treatment? What is the relevance of individual (patient) autonomy in this regard?

These questions are prompted by Onora O'Neill's discussion, in *Autonomy and Trust in Bioethics* of individual autonomy in relation to medical treatment for serious illness or injury.[10] O'Neill contrasts a conception of individual autonomy as an attribute of individual persons having to do with independent choice, with a Kantian conception of autonomy as "a matter of acting on

[10] Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002)

certain sorts of principles, and specifically on principles of obligation".[11] Within a conception of individual autonomy, O'Neill further contrasts a minimalist sense which individual autonomy might amount to "mere sheer choice", with a more robust Millian sense in which autonomy has to do with personal independence, self-direction and self-expression and involves individual persons "reflecting on and selecting among [their desires] in distinctive ways".[12] O'Neill argues that autonomy in medical ethics is generally seen as individual autonomy: as "a matter of *independence*, or at least as a *capacity for independent decision and action*".[13] Moreover, she maintains, it is the minimalist interpretation of individual autonomy that is mostly in play, since "the practices that are proposed for securing or respecting autonomy in medical contexts are in fact generally no more than informed consent requirements",[14] which need not represent patient autonomy in anything like a robust sense, as opposed to constituting important constraints on deception and coercion.[15] I do not wish to take issue with these claims. Nonetheless, in addressing the questions about respecting a patient's wishes and patient autonomy that I have identified above, I hope to show that a relatively robust conception of individual autonomy has a greater and a more fundamental role in medical decision-making in contexts of serious illness or injury than O'Neill suggests when she says that a "limited focus on informed consent, rather than on any more extensive conception of autonomy, serves reasonably well in medical ethics because it suits the real context of illness and injury".[16] The exercise of individual autonomy in a more-than-minimalist sense is, I think, highly significant to reasonably common cases in which patients make

[11] Ibid p.84 and, more generally, chapters 2 & 4.
[12] Ibid p. 31.
[13] Ibid p. 23, emphasis original.
[14] Ibid p.37.
[15] "In contemporary medical practice patient autonomy is often no more than a right to refuse treatment. This right is important. Insofar as patients are protected by informed consent procedures that are scrupulously used, they will be protected against coercive or deceptive medical treatment. However, by themselves informed consent procedures neither assume nor ensure that patients are autonomous in any more demanding sense." Ibid, p. 49.
[16] Ibid p. 49.

decisions about treatment for serious illness or injury from a very limited range of options. Respect for individual (patient) autonomy in a more-than-minimalist sense also shapes the corresponding obligations of medical professionals in such cases, in that appropriate respect for patients and their rights can require a doctor's positive engagement with his or her patient's own values and priorities in relation to the provision of treatment. I shall couch my argument for these claims in a somewhat wider, critical examination of the notion of respect for a patient's wishes, since in medical ethics respect for individual (patient) autonomy is often expressed in these terms.

Respecting a patient's wishes

The dictum "a patient's wishes should be respected" is very familiar in medico-legal contexts. It is, however, frequently unreflectively invoked.[17] The term 'respect' admits of a number of senses and respect for a person's wishes—what he or she wants to happen—falls under the wide category of *recognition* respect, as opposed to *appraisal* respect.[18] In respecting a person's wishes I recognise them as having a certain purchase in relation to my own deliberations or conduct.[19] But what does respecting a patient's wishes about the provision of treatment require in the form of recognition, and why? In answering this question we can contrast two general ways in which a person's wishes are commonly thought to be respected.

The first I shall call "compliance respect". Compliance respect for a person's wishes is a strong type of recognition that regards the person's wishes as determinative: compliance respect for a person's wishes requires that one carry them out. Moreover, compliance respect requires that

[17]We might ask, for instance, what the judges took respecting a person's wishes to imply in *Re A (Children)* (Conjoined Twins) [2000] 4 All E.R. 961, which ruled on the surgical separation of infant conjoined twins against their parents' wishes. The Court of Appeal emphasized that the parents' wishes deserved great respect. Yet it rejected and overrode the parents' refusal of consent and permitted the hospital to do what the parents did not want.

[18]S. Darwall, "Two Kinds of Respect", *Ethics* 88 (1977): 36-49. For a discussion of this distinction and other types of respect see http://plato.stanford.edy/entries/respect/

[19]We do not recognise some wishes as having any such status of course, e.g., a busybody's wish to know your business or a thief's wish to have your wallet.

one carry out this person's wishes *qua* her wishes, irrespective of one's own evaluation of them. For this latter reason, compliance respect is also thin recognition in that it does not imply that in carrying out a person's wishes one regards her wishes as having any intrinsic merit. Rather, her wishes receive compliance respect in virtue of her role or status as, e.g., the person in authority, the property owner, or simply as a competent adult. Everyday examples of compliance respect spring readily to mind: when a customer declines the better offer that is entirely her prerogative; when she selects the better offer that too is entirely her prerogative. Compliance respect for a person's wishes does not involve one's taking his wishes into account in one's deliberations about how to act: on the contrary, it requires that one enact his wishes *qua* his wishes. Compliance respect can thus be distinguished from the second general way that a person's wishes might be respected, which I shall call "consideration respect".[20] Respect for a person's wishes is often acknowledged to consist in giving her wishes serious consideration, in taking them into account in coming to one's own decision based on a balance of reasons. Again, we can think of everyday examples: a friend asks me not to tell others about something that he finds embarrassing; a neighbour wants me to prune a tree in my garden in order to enhance the view from her property. Whether I convey the information or prune my tree is up to me, but in considering what to do in these cases I can take these people's wishes into account. Consideration respect for a person's wishes is consistent with acting in accordance with his wishes, but unlike compliance respect, it does not require this.

If one might be said to respect a person's wishes in either of these different ways, what determines which type of respect (if any) might be appropriate in a particular context? The answer to this question will depend upon the relevant evaluative norms. These cannot be identified in

[20] Several writers use the term 'consideration respect' more broadly than the sense that I contrast with compliance respect. See, e.g. William Frankena, "The Ethics of Respect for Persons", *Philosophical Topics* 14 (1986): 149-167.

simple terms. For instance, it would be wrong to say that compliance respect can be appropriate only in relation to a person's wish for non-interference, the relevant norms being those of non-coercion, non-deception and non-maleficence, and that a person's request for assistance on the other hand, can only ever warrant consideration respect, the relevant norm being that of benevolence. Compliance respect can sometimes be appropriate when a person requests assistance that another person has an obligation to provide on request.[21] We can think of non-medical examples in which a request for assistance carries a strong presumption of compliance respect; in requesting assistance from someone else a person might be invoking a role-related duty to provide such assistance, or calling upon a debt of gratitude, for instance. This means that in identifying the type of respect for a person's wishes that might be appropriate in a particular context we need to look beneath very general categories such as whether a person is requiring non-interference, as opposed to requesting assistance, and consider carefully and critically the relevant evaluative norms. These will include the rights and obligations of the parties concerned, both as persons and also in their role-related capacities. Such considerations can go very deep; they can influence the way in which we characterise the conduct in question. For instance, whether discontinuation of ANH before Mr Burke's death is imminent would constitute interference, as opposed to a withdrawal of assistance could depend on what we take Mr Burke's rights, and his doctor's obligations to be.[22]

[21]In making a will a person requests the assistance of others in distributing her assets after her death in accordance with her wishes. As executor of a friend's will, for example, I must ensure that her nephew receives her legacy, as she wished, even though the nephew is a wastrel and her assets would be better given to Oxfam. Wills can sometimes be overturned of course. However, in the case of wills the presumption is clearly one of compliance respect unless it can be shown that in making the will the person was coerced or deceived, or else incompetent. Wills can also be overturned on other grounds, e.g., if they are manifestly unjust. But a presumption of compliance respect for a person's wishes can, more generally, sometimes give way to other types of considerations.

[22]For more general discussions relevant to this issue see Jeff McMahan, "Killing, Letting Die and Withdrawing Aid", *Ethics* 103 (1993): 250-279, and Suzanne Uniacke, "Absolutely Clean Hands: responsibility for what's allowed in refraining from what's not allowed", *International Journal of Philosophical Studies*, 7, 2 (1999):189-209.

The prevailing view about provision of medical treatment is that compliance respect is always appropriate where a competent patient refuses treatment for illness or injury, whereas only consideration respect can be appropriate when a competent patient requests treatment. (For example, if a competent patient declines surgery on the basis of views or priorities that the doctor regards as mistaken or foolish the doctor must comply with the patient's wishes nonetheless, but if a competent patient requests a course of antibiotics the doctor may or may not take this into account in deciding what treatment, if any, to provide.) Both compliance respect and also consideration respect for a patient's wishes are frequently said to be grounded in respect for patient autonomy. The idea that respect for patient autonomy could give rise to compliance respect in one context, and be confined to consideration respect in the other, should alert us to the relevance of other evaluative norms.

In thinking critically about the basis of compliance respect for a competent patient's refusal of treatment, it is instructive to consider Onora O'Neill's claim that such a refusal can involve little or no exercise of individual autonomy in a sense that implies reflection and self-determination. If compliance respect for a patient's refusal of treatment is based on respect for patient autonomy, then as O'Neill claims, this is autonomy only in a very minimalist sense.[23] All the same, it is significant that compliance respect for a patient's refusal of treatment requires recognition of the patient's wishes as determinative *qua* the patient's wishes: it is *her* prerogative. This is so even if, as O'Neill maintains, compliance respect for a patient's refusal of treatment can be grounded in a more general commitment to a universal, impersonal principle of non-coercion.[24]

It is widely held that a patient's request for the provision of treatment could require only consideration respect. Why is compliance respect inappropriate? Why is consideration respect

[23] Onora O'Neill (2002), chapter 2.
[24] Ibid., chapter 4.

appropriate, when it is? The answer to the first of these questions concerns the domain of patient choice in relation to the provision of medical treatment for illness or injury. According to the prevailing view, patient choice can legitimately be exercised only within a range of options that are clinically indicated; this means that a doctor must make her own professional, clinical judgment about a patient's request for the provision of treatment. According to this view, the underlying norm in the provision of treatment is the doctor's obligation to provide treatment that is in her professional judgment clinically indicated. This suggests a particular model for the provision of medical treatment, one which the Court of Appeal in *Burke* [2005] explicitly set out and endorsed in reversing the decision in *Burke* [2004].[25] I shall comment on this in the next section of the paper.

On what basis might a patient's wishes in relation to provision of treatment receive consideration respect? I shall approach this question by distinguishing two ways in which a doctor might take a patient's wishes into account within a range of options that are clinically indicated.[26] The first way involves the doctor assessing the patient's wishes entirely on their own merits, so to speak; here the doctor makes an independent judgment about the reasons and the values on which the patient's wishes are based, without affording any significance to the position or role of the person whose reasons and values these are. The second way involves the doctor giving the patient's wishes weight or purchase in her own deliberations *as the patient's wishes*, in addition to her independent evaluation of the reasons and priorities on which they are based. An example will

[25] *Burke* [2005] 50.

[26] A further question is whether it can be appropriate to take into account a competent patient's request for treatment that is *not* clinically indicated. In many cases the answer will be no (as when, e.g., a patient requests antibiotics for a virus). The answer to this question can be complicated, however, by the fact that a treatment that is not directly clinically indicated might work effectively as a placebo, because of the particular patient's (false) beliefs about its efficacy, and hence be indirectly 'clinically indicated'. In such a case, in providing the requested treatment, the doctor would not, I think, be affording the patient's *wishes* consideration respect, as opposed to taking the efficacy of the patient's false beliefs into account.

illustrate this difference. A scan reveals a small asymptomatic cerebral aneurysm in a seventy year old man, Mr A. The aneurysm can be monitored and there is presently no particular reason to suggest it will rupture. Chances are that Mr A could die of old age with the aneurysm intact. Because of the aneurysm's location, surgery to remove it would cause significant post-operative debilitation lasting twelve months or more; the surgery itself would also carry risk of brain damage. This is explained to Mr A and he requests surgery to remove the aneurysm. His doctor then considers the reasons why Mr A wants the surgery and she asks herself whether these are good and sufficient reasons to go ahead: in so doing she makes an independent judgment about whether, on the basis of these reasons, the possible benefits of the surgery are worth the side-effects and the risks. This is the first way in which the doctor might be said to take Mr A's wishes into account. The second way involves the doctor also affording significance to the reasons why Mr A wants the surgery as the *patient's* reasons, that is to say, as considerations that reflect the values and priorities of the person who would suffer the side-effects of the surgery and who wishes to assume the risks to his own wellbeing.[27]

Does the doctor give appropriate consideration to Mr A's wishes is she takes them into account only in first way? In my view the answer is no. Obviously one reason why a competent patient's request for treatment can merit consideration respect is epistemic: careful consideration of the reasons on which a particular patient's request for treatment is based can reveal relevant factors that might otherwise elude the doctor. (These might include the real extent of a patient's pain, discomfort or fear, for instance.) But this is not the only, nor perhaps even the central reason

[27] Either way of showing consideration respect for a patient's wish that *x* happen (in this case, that he receives the surgery) will involve taking into account the reasons why the patient wants *x* to happen. Whether the second way of showing consideration respect for a patient's wishes, which affords significance to these wishes *as the patient's wishes*, would also give additional weight to a patient's *express* wish (that is, to his explicit request), is not something I explore here.

why consideration respect for a patient's wishes is important. A competent patient also has a particular status in relation to decisions that affect *his own* life and health that deliberation about the provision of treatment needs to include. Some non-medical contrast examples can help illustrate the point.

Say a fellow train passenger asks me to exchange seats with him because he wants to sit by the window. In this case, affording my fellow passenger's wishes appropriate consideration respect would simply involve deciding whether, impartially-speaking, there are good and sufficient reasons for my doing what he asks. My deliberation about this can of course include my considering the seating arrangements from his perspective as well as from my own. (For instance: He wants to see the countryside. Would I particularly mind an aisle seat? Is there reason to be generous?) It is decent that I consider his request and perhaps it is right that I do so; nonetheless, simply as a fellow passenger his wishes have no particular status in relation to my giving him my seat and in deciding to do as he asks I would be doing him a favour. We can contrast this example with another, different one in which my friends' children are in my care for a few days. It is my responsibility to feed the children nutritious meals but exactly what I feed them is up to me. Their parents have asked (not instructed) me to give the children fruit with their breakfast if possible. Here my taking the parents' wishes into account in deciding what to feed the children does require affording them significance *qua* their parents' wishes. Although the children are in my care, they are my friends' children after all. Subject to familiar constraints, their parents have a particular status, based on considerations of responsibility and authority, in relation to what their children eat.

Appropriate consideration respect for a patient's wishes in the provision of treatment that is clinically indicated is like the second of these examples. Just as the children's parents' wishes are

significant *qua* their parents' wishes to what I feed the children, in similar fashion a competent patient's wishes are significant, *qua* the patient's wishes about his own life and health, to a doctor's provision of treatment. In the case of the patient, like that of the parents, appropriate consideration respect for their wishes involves recognition of that person's particular status in relation to what they want to happen.

Consideration respect for a patient's wishes is distinguishable from compliance respect in significant ways. Consideration respect requires the doctor to take the patient's wishes into account in coming to her own decision on the balance of reasons; compliance respect does not require this.[28] Compliance respect requires the doctor to carry out the patient's wishes; consideration respect is consistent with an independent decision not to do what the patient wants. However, compliance respect and appropriate consideration respect for a patient's wishes (that is, compliance respect in the second way) also share an important feature, namely that respecting a patient's wishes in both of these senses involves recognition of the significance of a patient's wishes *qua* the patient's wishes.

In the next section I focus on what bearing a competent patient's wishes might have on a doctor's obligations in relation to the provision of treatment, and on the relevance of individual patient autonomy in this regard. So far I have gone along with the prevailing view that a patient's request for treatment for illness or injury can merit consideration respect only within a range of treatments that are clinically indicated, the underlying norm being a doctor's obligation to provide treatment that is, in her professional judgment, clinically indicated. I do not intend to take issue with this view. Nonetheless, I shall try to show that appropriate consideration respect for a

[28] On the contrary, for the doctor compliance respect for a patient's wishes constitutes what Joseph Raz has identified as an exclusionary reason. (Joseph Raz, *Practical Reason and Norms*, 2nd edition (Princeton: Princeton University Press, 1990), pp. 38-43)

patient's wishes must complicate what a doctor's basic obligation in the provision of treatment can reasonably be taken to be and that this involves respect for individual (patient) autonomy in a more-than-minimalist sense.

The doctor's obligation and the patient's choice

The Court of Appeal in *Burke* [2005] accepted the view of *Burke* [2004] that the underlying norm in the provision of medical treatment is a doctor's duty of care, more specifically a doctor's obligation to act in her patient's best interests. However, the Court of Appeal disagreed with the earlier judgment in its view about the relationship between the doctor's obligation and the patient's wishes in a case such as Mr Burke's. In *Burke* [2004] Munby J maintained that what is in Mr Burke's best interests in relation to the continuation of ANH is very closely tied to Mr Burke's own wishes on this matter, based on Mr Burke's own view about the stage at which he would find continuation of life-prolonging treatment intolerable. If this is right, then a doctor's judgment about whether continuation of ANH would be in Mr Burke's best interests is largely determined by Mr Burke's wishes in this regard. An upshot of this view is that Mr Burke's request that ANH not be withdrawn before his death is imminent could be determinative. This would not be an instance of compliance respect however, since Mr Burke's wishes would be carried out not *qua* his wishes, but rather because the doctor's obligation is to act in Mr Burke's best interests and on *this* matter Mr Burke's wishes and his best interests happen to coincide.[29]

In reversing the judgment in *Burke* [2004] the Court of Appeal adopted a somewhat different conception of the norm underlying the provision of medical treatment. It took the view (at least initially) that the doctor's obligation is to act in what is in her professional clinical judgment the

[29]If Mr. Burke's request were to merit compliance respect (exactly the same type of respect as is appropriate for a refusal of treatment) then a doctor would need to enact Mr Burke's request *irrespective* of whether or not what he requests is in his interests.

best interests of her patient. So described, this obligation *could* conflict with a patient's request for treatment in a case such as Mr Burke's (as Mr Burke fears) where in the doctor's clinical judgement continuation of requested treatment is no longer in the patient's best interests.[30] As part of its broader rulings, the Court of Appeal set out and endorsed the following procedural model for the provision of medical treatment to a competent patient:

i) The doctor, exercising his professional clinical judgment, decides what treatment options are clinically indicated (i.e. will provide overall clinical benefit) for his patient.
ii) He then offers those treatment options to the patient in the course of which he explains to him/her the risks, benefits, side effects, etc involved in each of the treatment options.
iii) The patient then decides whether he wishes to accept any of those treatment options and, if so, which one. In the vast majority of cases he will, of course, decide which treatment option he considers to be in his best interests and, in doing so, he will or may take into account other, non clinical factors. However, he can, if he wishes, decide to accept (or refuse) the treatment option on the basis of reasons which are irrational or for no reasons at all.
iv) If he chooses one of the treatment options offered to him, the doctor will then proceed to provide it.
v) If, however, he refuses all of the treatment options offered to him and instead informs the doctor that he wants a form of treatment which the doctor has not offered him, the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (i.e. he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion.[31]

This model is consistent with the prevailing view that consideration respect for a patient's request for treatment is appropriate within a range of treatments that are clinically indicated. It also represents a subtle but significant shift in the way in which the Court of Appeal regarded the relationship between the doctor's obligation and the patient's wishes. This shift is apparent in the paragraph following, in which the court went on to say:

[30] The Court of Appeal nonetheless sought to assure Mr Burke that where ANH is necessary to a competent patient's survival, there can be no such clinical judgement contrary to the patient's wish that ANH be continued. I question this reassurance above (text accompanying footnote 8).
[31] *Burke* [2005] 50.

> "…In truth the right to choose is no more than a reflection of the fact that it is the doctor's duty to provide treatment that he considers to be in the interests of the patient and that the patient is prepared to accept."

According to this statement a doctor's obligation is not to provide treatment that in her professional clinical judgement is in her patient's best interests; rather, she has a duty to provide treatment that she considers to be in the patient's interests (note, not best interests) *and* that the patient is prepared to accept. If we adopt this latter view, then the doctor's obligation includes compliance respect for patient autonomy at least in what Onora O'Neill calls the minimalist sense of individual autonomy. I want to suggest, however, that in practice a doctor's obligation of care in the *provision* of treatment will commonly also include consideration respect for individual (patient) autonomy in a fuller sense that involves genuine engagement with the patient's wishes as based on the patient's own values and priorities. O'Neill may well be right that in "contemporary medical practice patient autonomy is often no more than a right to refuse treatment"[32] and that "[t]ypically a diagnosis is followed with an indication of prognosis and suggestions for treatment to be undertaken. Patients are typically asked to choose from a smallish menu." But I do not think we should generalize from this that "[t]he minimalist interpretation of individual or personal autonomy in medical ethics in fact fits rather well with medical practice (in cases of illness or injury)."[33] O'Neill makes the important point that a patient's informed consent to treatment is necessary but not sufficient for autonomous choice. Nonetheless there are reasonably common cases in contemporary medical practice in which patient autonomy is significantly more than a right to refuse treatment. In the kinds of cases I have in mind, a restricted choice of options does not always mean a restricted interpretation of the scope of patient autonomy as merely a right to refuse treatment on offer. Here are two examples:

[32] O'Neill (2002), p.49
[33] Ibid, p. 38.

A fifty-eight year old man, Mr C, is diagnosed with prostate cancer. The cancer is localised and with appropriate treatment the prognosis is very good. Surgical prostatectomy is an option in early-stage prostate cancer. However, this is not recommended in Mr C's case because of the particular location of the cancer and the high risk of damaging adjacent tissue. The alternative treatment is radiotherapy. Acceptance of the radiotherapy option is relatively straightforward as far as Mr C is concerned. However, the specialist also recommends a course of hormone treatment over a number of months prior to and during the radiotherapy. This will decrease the cancer by starving it of testosterone, thereby increasing the likelihood that the radiotherapy will eliminate all of the remaining cancerous cells. The loss of testosterone causes side effects in almost all men but the degree and extent of the side effects of hormone therapy in a patient with prostate cancer are impossible to predict. Mr C is informed of the possible side effects, which include hot flushes, decreased sexual desire, erectile dysfunction, fatigue, weight gain, osteoporosis, decreased muscle mass, and memory loss. He can have targeted radiotherapy without the prior hormone treatment but this is not what his doctor recommends. It is important not to delay his treatment. In the next year Mr C has important personal and professional commitments which he cannot postpone; they would be seriously impeded by some of the possible side effects of the hormone therapy.

Ms D, a woman in her mid thirties, suffers from endometriosis which seriously affects the quality of her personal and professional life. The symptoms of the endometriosis might be partly relieved by drug treatment; conservative surgery to remove endometriosis deposits is also a possibility. However, her doctor believes that at this stage a hysterectomy offers the best chance of relief and that in postponing this Ms D would only continue to suffer in order to 'put off the inevitable'. A hysterectomy is something that Ms D is reluctant to accept at this stage. Endometriosis can adversely affect fertility but it does not do so in 60-70% of patients with the

condition. Although Ms D has unsuccessfully tried to conceive during the past four years she hopes that she can still become pregnant.[34] Her doctor believes on the basis of Ms D's medical history and the severity of her endometriosis that the chances of this are negligible.

What conception of individual (patient) autonomy is applicable to these two examples? Given these patients' medical conditions and the limited range of options available to each of them, arguably it is not the fully robust sense of individual autonomy that Onora O'Neill reminds us concerns "individuality or character, [and is] about self-mastery, or reflective endorsement, or self-control, or rational reflection, or second-order desires, or about any of the other specific ways in which autonomous choices supposedly are to be distinguished from other, mere choices."[35] But neither is it individual autonomy only in a minimalist sense that amounts to the (possibly unreflective) acceptance or refusal of treatment on offer. In deciding whether or not to undertake the hormone therapy, Mr C must engage in rational reflection and he must make very important, possibly life-shaping decisions based upon his considered values and priorities.[36] Ms D must consider whether the significant physical, emotional and professional costs of postponing the recommended hysterectomy are 'worth it' in order to preserve what is at best a very slim chance of pregnancy that may well come to nothing. Ms D's decision, too, will reflect her values and priorities and possibly the shape of the rest of her life.

If Mr C decides against the hormone treatment, and Ms D decides against the hysterectomy, in the professional, clinical judgments of their respective doctors both Mr C and Ms D are not acting in their own best interests. (Their doctors might also believe that these patients are not

[34]Hormone treatment aimed to reduce the endometriosis would need to be stopped should Ms D intend to conceive, however.
[35] O'Neill (2002), p. 37.
[36] Within the U.K. healthcare system Mr C will be strongly encouraged to consider carefully how his disease is managed. http://www.nhs.uk/prostatecancer

acting in their own best interests more broadly construed, since if things don't work out as they hope, both Mr C and Ms D might later regret their decisions.) Their doctors must treat Mr C's and Ms D's refusals of particular treatments with compliance respect, irrespective of their own evaluations of their patient's reasons. However, we should not lose sight of the fact that Mr C and Ms D have not simply *refused* particular treatment; both of them have also made a positive decision *for* alternative treatment.

The procedural model endorsed by the Court of Appeal in *Burke* [2005] is a streamlined specification that omits significant discussions and deliberations that are appropriate at and between the various steps in the procedure. For instance, the move from step (ii) to step (iii) can require, as part of the doctor's duty of care, her engagement with the patient's deliberations, and this might include discussion of non-clinical factors that are relevant to the patient's decision. What can occur at step (iv) is also very compressed in the procedural model. The treatments that Mr C and Ms D request are, to be sure, within a range of treatments that are said to be 'clinically indicated' for their conditions. But a treatment is clinically indicated provided it will provide 'overall clinical benefit', and this is a broad and relative notion.[37] A treatment that is clinically indicated for a patient's condition might provide minimal overall benefit compared with an alternative treatment, for instance. In fulfilling her obligation of care, it can be a matter of judgment on the doctor's part in what way to provide treatment that is clinically indicated, and for how long.

Appropriate consideration respect for a patient's wishes requires the doctor to take the patient's wishes into account as the *patient's* wishes*,* in her own deliberations about the provision

[37]The so-called 'Bolam' test refers to a form of treatment that is recognized as clinically appropriate for a particular condition by a large body of responsible and competent relevant professional opinion.

of treatment. The risk Mr C decides to take by opting for radiotherapy without the hormone treatment may not work out as Mr C hopes; but it is a risk that Mr C wants to take on the basis of reasons that his doctor might well need to take into account in her deliberations as the *patient's* reasons. Her doing so might significantly influence how Mr C's treatment is delivered. (Is Mr C's doctor obliged to schedule the radiotherapy to commence as soon as possible, or is it permissible for her (is she obliged to?) delay it a little in the hope that Mr C will reconsider having the hormone treatment?) Similarly, Ms D's request for treatment that aims to relieve some of the symptoms of endometriosis might well be a mistake, but her doctor can recognise that it is based on the patient's reasons and that it can be appropriate to take this into account in deciding, e.g., for how long to persevere with drug treatment or at what point to call a halt to conservative surgery. Appropriate consideration respect for a patient's wishes in relation to the provision of treatment can significantly influence both the way in which, and also the extent to which, a doctor discharges her duty of care.

O'Neill's claim that "[w]hat is rather grandly called 'patient autonomy' often amounts simply to a right to choose or refuse treatment on offer, and the corresponding obligations of practitioners not to proceed without patients' consent" is probably true of most *acute* cases in which a competent patient can either accept or refuse medical treatment. But in cases like those of Mr. C and Ms D this generalization draws attention away from the way in which patient choice can often engage more-than-minimal individual autonomy even in circumstances where there are quite limited treatment options. O'Neill notes that "[o]f course, some patients may use this liberty [the right to choose or refuse treatment on offer] to accept or refuse treatment with a high degree of reflection and individuality, hence (on some accounts) with a high degree of personal autonomy.

But this need not generally be the case." Indeed it need not generally be the case. But examples in which it is the case are not unusual.[38]

In light of the preceding discussion, we might now consider Mr. Burke's request that ANH not be withdrawn before his death is imminent. The withdrawal of ANH contrary to Mr Burke's wishes would not constitute coercion. Might lack of consideration respect for Mr Burke's wishes be said to show disrespect for individual (patient) autonomy in a more robust sense? Arguably it is simply inappropriate to invoke the notion of respect for individual autonomy in relation to Mr Burke's circumstances. By the time ANH might be withdrawn against Mr Burke's wishes, Mr Burke will be completely dependent on others for his survival; he will be incapable of any action other than mental action, and eventually he will lose the ability to communicate any 'decisions' he might make. What Mr Burke sought from the High Court was, as Munby J said, *protection* from lack of treatment which would result in him dying in avoidably distressing circumstances.[39] And perhaps respect for Mr Burke's wishes can best be defended in these terms.

On the other hand, in seeking legal protection, Mr Burke also sought to exert his own independent decision about something very important to him, namely "how he passes the closing days and moments of his life". Within the very strict limitations for choice that his illness will inevitably impose on him, he seeks to manage his own death. And it is crucial for Mr Burke that he reflects very carefully on his request that ANH not be withdrawn before his death is imminent,

[38]For instance, prostate cancer is the most common cancer in men in England, causing about one in four of all new male cancers. Endometriosis is said to affect 15% of pre-menopausal women in the UK.

[39]The relevant part of Munby J's ruling is as follows: "Personal autonomy – the right of self-determination – and dignity are fundamental rights, recognised by the common law and protected by Articles 3 and 8 of the Convention. (8) The personal autonomy which is protected by Article 8 embraces such matters as how one chooses to pass the closing days and moments of one's life and how one manages one's death. (9) The dignity interests protected by the Convention include, under Article 8, the preservation of mental stability and, under Article 3, the right to die with dignity and the right to be protected from treatment, or from a lack of treatment, which will result in one dying in avoidably distressing circumstances. (10) An enhanced degree of protection is called for under Articles 3 and 8 in the case of the vulnerable." *Burke* [2004]: 116

in the knowledge that if he were to change his mind he will be unable to revise his request once he can no longer communicate.[40]

[40] Thanks are due to participants in the British Academy conference, "Ethics and Politics Beyond Borders: the work of Onora O'Neill" (24-26 September, 2009), to philosophers at the University of Glasgow, and to Antony Hatzistavrou and David Archard for helpful comments on earlier versions of this paper.