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PAPER

Should we respect precedent autonomy in life-sustaining treatment decisions?

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ABSTRACT

The recent judgement in the case of Re:M in which the Court held that it would be unlawful to withdraw artificial nutrition and hydration from a woman in a minimally conscious state raises a number of ethical issues of wide application. Central to these is the extent to which precedent autonomous decisions should be respected in the absence of a legally binding advance decision. Well-being interests can survive the loss of many of the psychological faculties that support personhood. A decision to respect precedent autonomy can contradict the well-being interests of the individual after capacity is lost. These decisions raise difficult questions about personal identity and about the threshold of evidence that is required of an earlier decision in order for it to be respected.

It is axiomatic that decisions to withdraw life-sustaining treatment from people not imminently dying are controversial. In the overwhelming majority of circumstances, the continuance of life is regarded as a moral good, and any decision that might foreshorten it rightly requires strong justification. Where the individual in question lacks capacity to make the decision on his or her own behalf and cannot therefore protect his or her own interests, the decision is more controversial still. While the judgement in M has introduced some procedural clarity in relation to decisions taken on behalf of patients in a minimally conscious state (MCS), and has indicated the factors that the court will take into account, it invites reflection on a number of ethical issues that have wide application.¹ In this paper, I explore the way in which the judgement in M navigated some of these ethical issues, in particular the question of whether the former wishes of a once-autonomous adult should be respected after the capacity to make decisions to realise those wishes is lost. Before looking in more detail at the judgement, I introduce a number of ethical distinctions that have emerged in the bioethics literature in order to help clarify the court's finding.

BIOLOGY AND PERSONHOOD

One useful distinction can be drawn between two different versions of death and dying—'personal' death and 'biological' death—a distinction that has largely come into focus as a result of improvements in the medical technology of life support. In a recent book,² Sumner defines biological death as 'the irreversible cessation of the integrated functioning of the organism'; personal death, by contrast, is the irreversible cessation of whatever

'psychological states or capacities are constitutive of a person'. In many cases, the link between biological and personal or psychological death will be intimate, but where, for example, a patient is in a MCS, the psychological and cognitive capacities that are ordinarily constitutive of persons can be largely absent, whereas biological life can continue unimpeded for many years. The distinction is at its most stark in relation to patients in a vegetative state (VS) where the individual retains no awareness whatsoever. The separation between these two aspects of an individual's life can occur abruptly, following an accident or acute illness; in other circumstances, it can emerge gradually, attendant, for example, on the cognitive decline associated with degenerative diseases such as Alzheimer's. The strong challenge presented by the question of precedent autonomy largely arises when the expressed interests of the former person conflict with the contemporaneous interests of the biological self which has to a greater or lesser extent outlived the person previously inhabiting it.

THE IDENTITY QUESTION

One of the issues that the possible divergence of personal and biological selves can give rise to is the question of identity. It is presumably difficult to predict in advance of losing capacity how we will feel about the value of our lives—what it is that we will value and for what reasons—once that capacity is lost. It is quite plausible, for example, that, as mental capacity declines and former interests that require more complex mental functioning dwindle, new interests emerge or take priority. The autonomy interests that we express when we have capacity may therefore conflict with what we might call our welfare interests when capacity is lost. I might now be appalled by the thought of living without memory or mental faculties in a world of soft chairs and daytime television, but in the grips of Alzheimer's, I may derive demonstrable pleasure from precisely those things. Furthermore, although traumatic brain damage may lead to an abrupt shift from ordinary to significantly impaired consciousness, in diseases of degeneration the decline of capacity can be gradual. In these more familiar circumstances, our interests and our sense of what we value about our lives can migrate slowly, even imperceptibly, enabling us to acclimatise to circumstances, the sudden arrival of which we might find intolerable. As an advanced Alzheimer's sufferer, am I therefore the same person, in the sense of having recognisably the same interests, as I was when in robust health and in possession of all my



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mental faculties? It is again quite plausible to imagine a circumstance in which the apparent desires of an incapacitated adult could directly contradict earlier, autonomously formed wishes—for example, the desire for continued life. Why should my former wishes, based upon values and desires I may no longer recognise, be determinative? Certainly any treatment decision likely to have the result of shortening life in these circumstances is not only necessarily a grave decision, but one that those caring for the patient might struggle to enact.

CRITICAL AND EXPERIENTIAL INTERESTS

The challenge presented by the question of identity in these contexts has led Ronald Dworkin to introduce an influential distinction between two kinds of interests that individuals have: critical and experiential. Experiential interests refer to those things we do simply because we get pleasure from the experience of doing them—reading, hiking, eating, playing sport—and some of these kinds of interest, it is plausible to imagine, can remain with us even when the capacities that support personhood are severely diminished. While the pleasure that arises from these things is essential to a good life, the individual pursuits as good in themselves need not be. As Dworkin points out, somebody who gets pleasure from eating well rather than playing football is not thereby making a mistake. It is the experiential pleasure that matters here, not, within reason, the source of the pleasure itself. Where neurological deficit may mean that one source of experiential pleasure is not available to us, others may nevertheless come, at least in part, to substitute for it. I may no longer be able to read the books of philosophy that once meant so much to me, but the interest I take in eating, or in listening to music or sitting in the sun, may be undiminished.

In addition to these experiential interests, we have what Dworkin calls *critical* interests, interests that, in his view, 'it does make (our) life genuinely better to satisfy, interests (we) would be mistaken, and generally worse off, if (we) did not satisfy.'³ That is, in addition to the toll of pleasure and pain in our lives, we have an enduring interest in the shape and form of our life, in its internal meaning and coherence, and in our desire to ensure that our lives are more than just a disconnected sequence of days. The concept of critical interests is a complex one which sees the value of life not in some aggregation of pleasures and pains but as resting in an individual's settled views on what constitutes for them a good life, including the ending of that life. Critical interests are therefore deeply tied to the value of personal autonomy. As Dworkin puts it:

The value of autonomy...derives from the capacity it protects: the capacity to express one's own character—values, commitments, convictions...in the life one leads. Recognizing an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives to our own coherent or incoherent—but in any case, distinctive – personality...We allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values.⁴

In the more difficult cases, the cases where current experiential interests appear directly to conflict with earlier statements or decisions that are expressive of critical interests, the judgement will therefore require adjudication between them. As we go on to see, it is not merely a simple question of whether we prioritise one set of interests over another. For even if a decision is made to prioritise critical interests, there will also be important evidentiary issues—what kind of evidence is required before we can say that an earlier decision was in fact expressive of

autonomy and should therefore trump contemporaneous welfare interests?

The Mental Capacity Act

In England and Wales, the law provides practical approaches to these problems via two anticipatory decision-making mechanisms: advance decisions refusing treatment, and health and welfare powers of attorney. An advance decision enables an individual to refuse specified treatments at a future date when capacity is lost. When the decision relates to the refusal of life-sustaining treatment, the law imposes a number of safeguards: it has to be in writing, signed and witnessed and must contain a statement that it is to apply even if life is at risk. It sets therefore quite a high evidentiary threshold both in terms of specifying the decision that needs to be made and in terms of the individual's understanding of the consequences of the decision. Health and welfare powers of attorney enable competent adults to nominate an individual or individuals to make decisions on their behalf at a time when they lose capacity. In order for an attorney to make decisions about life-sustaining treatment, this authority has to be explicitly stated on the power of attorney. Although these are useful tools, advance decisions can remain open to legal challenge, particularly in relation to the evidentiary problem: does the decision specify closely enough the precise circumstances in which the refusal is to have effect? The Mental Capacity Act 2005 (MCA) also imposes an obligation on attorneys always to act in the best interests of the incapacitated adult, therefore presumably inviting the attorney to wrestle with at least some of the issues that are the subject of this paper. Useful as these anticipatory mechanisms can be, they still also leave open the question of those who become incapacitated and may have very forcefully expressed opinions when competent but who have not put either of them in place. And this brings us to M.

Best interests and substituted judgement

English law dispenses with the identity question, at least in terms of numerical identity. There is no question in law but that M is the same person. Any property she may have, for example, remains legally in her possession. What the court had to decide was not therefore whether she was numerically identical to her former self but whether earlier informal statements indicating that she would not want to be kept alive in her current state should be determinative.

In the absence of an advance decision refusing treatment, decisions made on behalf of adults lacking capacity have to be made in England and Wales on the basis of an assessment of their 'best interests'.⁵ The MCA does not define best interests, restricting itself to the provision of a list of factors that decision makers need to take into account when determining what may be in a person's best interests.⁶ A best interests decision is not an attempt to discover what the individual would have wanted—it is not a 'substituted judgement' test—instead it is as objective a test as possible of what would be in the adult's actual best interests, taking all relevant factors into consideration.

The decision to use a best interests test in the legislation is a significant one. In terms of the distinctions drawn earlier, it asks the decision-maker to take into consideration both the earlier views and wishes of the individual—in Dworkin's terms to take into consideration his or her critical interests in so far as they can be identified—as well as the current more welfare-oriented or experiential interests of the incapacitated adult. It is worth pointing out that, while the critical interests of someone in an MCS are likely to be largely lost, this is by no means the case of

all adults who may lack the capacity to make some decisions. As cognitive capacities decline though, experiential interests may come to predominate.

As indicated above, the legislators could have opted for a substituted judgement test rather than a best interests approach. Substituted judgement involves the decision maker trying to determine what choice the incapacitated adult would make had she or he retained the relevant capacity. This can involve a thought experiment whereby the incapacitated adult is imagined as having a brief lucid interval and is then asked to make a decision about what treatment should be provided when she or he relapses. Substituted judgement is more respectful of critical interests and it is difficult to imagine the judge in *M* reaching the same decision under such a regime. The MCA's best interests regime does incorporate elements of substituted judgement, but they are not necessarily determinative. It states in the Code of Practice that the 'wishes and feelings, beliefs and values' of an incapacitated adult should be taken 'fully into account', but, 'they will not necessarily be the deciding factor.' It concludes:

Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests.⁷

There is a problem here though, for if best interests are in part determined by prior wishes and feelings, appeal to best interests in assessing the validity of those wishes and feelings seems illegitimate. It seems more accurate to say that the concept of best interests refers to a loose amalgam of factors, between which, as in the case of *M*, there is the ever-present possibility of conflict. In the case in question, the conflict is largely between experiential and critical interests, and the concept of best interests gives the decision maker little to go on when trying to assess the strength of their relative claims. So how did the court approach it?

Balancing critical and experiential interests—the sanctity of life

In accordance with case law,⁸ when assessing *M*'s interests, the court took a 'balance sheet' approach, comparing the 'advantages of withdrawing ANH (artificial nutrition and hydration) against the advantages of continuing the treatment.'⁹ As part of that balance sheet approach, the court accepted as true family accounts of the statements that *M* made when she had capacity that she would not want to live in the circumstances of Anthony Bland, the young man left in a VS after suffering severe brain damage at the Hillsborough football stadium tragedy. One factor in favour of withdrawing treatment was therefore that the decision would accord 'with a number of comments she made prior to her illness.'¹⁰ This was qualified by the observation that she had not 'made any advance decision, nor addressed the specific question whether she would want ANH withdrawn if she were in MCS.'¹⁰ The balance sheet also listed on the negative the continued suffering associated with her condition, and, on the positive, the modest pleasures it enabled her, including the possibility that these could be enhanced. In the end though, taking all these things together, the court held that 'the importance of preserving life is the decisive factor in this case.'¹¹ The fundamental principle here, drawn from the case of Tony Bland, is the sanctity of life.

That the principle of the sanctity of life should be drawn from a case that permitted the withdrawal of ANH from a patient in a persistent VS clearly indicates that the principle cannot be an absolute one. Lord Goff, in the leading speech in

the Bland case,¹² made it clear that the principle could give way to a decision by a competent adult—give way, that is, to the principle of self-determination. Nor did the principle require prolongation of life in all circumstances, irrespective of its burdens. There were occasions when the best interests of the individual would require a cessation of life-sustaining treatment. To return to Sumner's distinction, the persistence of the biological functioning of the organism, even where, as in the case of Bland, irreversible brain damage means that any enduring interests he may be said to have must lie outside the calculus of experiential benefits and harms, is not sufficient for the principle of the sanctity of life to be engaged.

For the court, the principle of the sanctity of life is engaged where there is demonstrable evidence of some consciousness. As the judgement states, 'unlike Tony Bland, and other patients in the VS, *M* is conscious, albeit minimally so. She is sensate, clinically stable, aware of herself and her environment'.¹³ Although the judgement restricted itself as far as possible to the facts of the case, the strong reiteration of the sanctity principle is likely to be influential in future cases. In the absence of an advance decision refusing ANH in an MCS, or of burdensome suffering that is not offset by any enjoyment in life, it is likely that, in future, patients in an MCS will be kept alive.

THE EVIDENTIARY QUESTION

From its inception, the MCA was widely seen as autonomy-promoting legislation; yet decisions made within its framework to keep people alive in an MCS have been criticised as putting excessive emphasis on very limited contemporary experiential interests, thereby frustrating the autonomy it was designed to promote. The MCA does enable people to make advance decisions that would be applicable in these circumstances, therefore protecting the anticipatory decision-making rights of those who both desire, and are able, to make proper use of them. Any challenge to the decision in *M* must, however, directly address the evidentiary question: what quality of evidence, other than that provided by an advance decision, would constitute sufficient proof that the individual clearly wanted the decision to be respected? If the issue is respecting autonomy, then the principle ordinarily requires that consent given contemporaneously is informed—that is, it is based on an appropriate understanding of the nature of the decision and its likely consequences. Consent given in advance, particularly long in advance, may struggle to meet these evidentiary—and therefore autonomy-respecting—standards. When a competent adult makes a contemporaneous refusal of life-sustaining treatment, particularly strenuous efforts are often made to ensure that the individual fully understands both the nature and the consequences of the decision. Again, respect for the patient's autonomy requires it. In the absence of an advance decision, why should any less rigorous standard be applied when capacity to make the decision is lost?

Reference to the sanctity of life can be confusing. It is more helpful to recognise that the courts acknowledge, and will ordinarily seek to protect, the experiential interests of adults who cannot promote those interests themselves. Some of the criticism of the judgement in *M* might arise from a visceral sense that people would not like to be in an MCS. A movement from fully autonomous life to minimal consciousness is a considerable deprivation, and few would countenance it. But minimally conscious people do have interests, and the justification for a decision that may foreshorten their lives has to be a strong one. The law has provided a mechanism for people to make that decision for themselves in advance. But in the absence of

such a mechanism, the courts have shown themselves reluctant to make such a grave decision on their behalf.

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