'Mrs A': a controversial or extreme case?

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It is sometimes said by legal scholars that 'hard cases make bad law', by which they mean an extreme case provides a poor lens through which to view general laws. It can be said in retort that 'bad laws make hard cases'; implying that the case may be a controversial one only because the general laws that govern it are poorly formulated. The same tension may be found in medical ethics. Perhaps extreme cases provide a poor lens through which to view general ethical standards, or perhaps the case is controversial by virtue of the prevailing ethical standards being poorly formulated. It becomes important to consider whether a case is controversial or extreme.

At first blush, the case of 'Mrs A'—outlined in this edition by Miller *et al*¹—is both. The article by Miller *et al* raises a series of ethical questions concerning Advanced Euthanasia Directives (AEDs) and highlights weaknesses in the Dutch regulatory procedures. Also included in this edition are responses to the Miller *et al* article, by Menzel² and Jongsma *et al*.³ These responses challenge some of implications that Miller *et al* seek to draw from the case. Miller *et al* have also replied to Jongsma *et al* in this edition.⁴

While the Miller *et al* article provides a detailed account of the formulation and application of Mrs A's AED,¹ I wish to draw your attention to the text of the directive. As Miller *et al* explain, soon after being diagnosed with Alzheimer's, Mrs A formulated a directive, which stated:

I want to make use of the legal right to undergo voluntary euthanasia when I am still at all mentally competent and am no longer able to live at home with my husband. I absolutely do not want to be placed in an institution for elderly dementia patients. I want to take a dignified farewell from my precious loved ones... Trusting that at the time when the quality of my life has ended up in the above-described situation, I would like to undergo voluntary euthanasia.

Over 3 years later, Mrs A revised the directive, substituting in two sentences:

I want to make use of the legal right to undergo euthanasia whenever I think

the time is right for this... Trusting that at the time when the quality of my life has become so poor, I would like for my request for euthanasia to be honored.

After Mrs A was placed in a nursing home, two physicians eventually agreed that Mrs A was 'suffering hopelessly and intolerably'. On the basis of this finding and her revised directive, Mrs A was euthanised, without informing her, and while being held-down by her family.

The case, in its full detail, raises a number of important points of disagreement between Miller *et al*, Menzel and Jongsma *et al*. There is disagreement as to the inferences that can be drawn about a patient, such as Mrs A, and his or her decision-making capacity to write and revise the directive. There is also disagreement as to whether 'suffering' or 'unhappiness' are the appropriate reference points for understanding anticipatory treatment decisions, especially with regard to patients with dementia.

The centre of gravity for the debate nonetheless rests around Miller *et al*'s claim that the revised directive does not provide a 'sufficient basis for generally overriding a conscious dementia patient's desires and feelings'.¹ In their response, Jongsma *et al* explain that '[c]hanges in behaviour or a change of preference by dementia patients may be caused by the disease itself, rather than by a conscious adjustment to the disease'.³ It follows for Jongsma *et al* that we should be careful not to overlook the patient's prior preferences, in favour of the patients current desires and feelings, since the patient's 'changed behavior is most likely caused by the loss of the ability to hold on to prior preferences, not by a (sub) conscious choice to change or adapt'.³ In response to Miller *et al*, Menzel seems to imply that although the case of Mrs A cannot be defended through respect 'reflective critical interests', the controversy of the case does not 'decimate' the argument for AED for patients with dementia.²

The difficulty with the case of Mrs A is that the revised directive may not be an Advanced Directive at all. As Menzel explains, '[a]ny advance directive... needs to be clear about not only what is and is not to happen, but when'.² In

the revision, Mrs A affirms her right to undergo euthanasia when she thinks 'the right time is for this'. Menzel asks: "[i]f the right time is the time that she thinks is the right time for euthanasia, then what work is the advance directive doing?"² The problem is that, even if the revised directive embodies a 'prior preference' or 'critical interest' that ought to be respected (at the expense of 'experiential interests' or the patient's 'current desires or feelings'), the revised directive does not identify the conditions for when that critical interest ought to be respected. On the language used in the revised document, Mrs A is attempting to preserve her legal ability to—when the time if right in the future—have her then-formulated critical interests respected. On the language used, she is not asserting her legal ability to have her past-formulated critical interests respected in the future.

If the revised directive is not an advanced directive, then Miller *et al* may be right that the revised directive is an insufficient 'basis for generally overriding a conscious dementia patient's desires and feelings'. At the same time, if the revised directive is not an advanced directive, then Menzel may also be right to imply that the case does not indicate that there is 'something inherently objectionable in implementing AEDs for dementia'.² The implication from Miller *et al* is the case of Mrs A is a controversial case, and the prevailing standards are poorly formulated. In comparison, the implication from Menzel is that Mrs A is an extreme case that provides a poor lens through which to view the applicable standards. It becomes important for us to consider, when reading these engaging articles, whether the case of Mrs A is a controversial or extreme case.

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