Author’s response to reviews

Title: DYING TOO SOON OR LIVING TOO LONG? WITHDRAWING TREATMENT FROM PATIENTS WITH PROLONGED DISORDERS OF CONSCIOUSNESS AFTER RE Y

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Author’s response to reviews:

Dear Rob

Thank you very much for accepting the article and many thanks indeed to the two reviewers for their recommendation, their suggested revisions, and their kind words. Both suggested only discretionary revisions, all of which I have sought to take on board, as follows:

#1
Alexandra Mullock (Reviewer 1):
At the start of the article, there is a discussion about the nature of the pre Y requirement to seek court approval and since this question has now only been resolved regarding patients whose relatives are in agreement with clinicians, it would be good if there was a little more focus on the crucial question regarding the nature of the requirement post Y. Thus, on this subject and at p.7, 'Leaving such legal niceties aside..' seemed slightly inapt, as I think the points raised in the previous paragraph are very important. As the author points out, the sloppy use of 'should' etc simply continues the very problem that the case was supposed to resolve. For me, this is a really crucial point so I would not park this as a 'legal nicety'. This issue is also one that links to some of the subsequent concerns raised in the article. For example, in a 'dying too soon' case where clinicians are erroneously assuming a patient has no interests, would family opposition to withdrawal compel the clinicians to seek court approval, or might they construe Re Y to mean that it is a soft obligation without legal force? While this uncertainty is briefly identified, it deserves more attention in my view. I agree that the two opposing dangers, which seem to represent conflicting default positions, are real and important and any conflict between these concerns is generally managed well, but I wonder whether it would be good to briefly address this inherent conflict more directly. This could be done at the start and/or perhaps when it arises.
Response:
I am grateful that the reviewer believes this point warrants emphasis and should not be set aside too readily. I have excised the reference to a 'legal nicety' and have expanded the paragraph to make more explicit the point made by the referee i.e. that clinicians and families who disagree in the future might be uncertain about the next step to take. This has caused me to revise the text on page 7 lines 5-13 and I have also briefly reiterated the uncertainty on page 8 line 15.

#2
Alexandra Mullock (Reviewer 1):
The second main point in the 'living too long' section suggests that families are generally the driver for withdrawal because the professional clinical default is to treat. This obviously conflicts with the main thrust of the earlier point made about the (dying too soon) danger that clinicians might wrongly assume that people in VS, and perhaps also those in a MCS, have no interests. A critical reader might ask 'which is it then?' because while both possibilities are possible, if we are to be persuaded that we should worry about both, the conflicting arguments and evidence (that clinicians will be too keen to withdraw/that, according to the Kitzingers, clinicians don't instigate or attempt to drive withdrawal) need to be addressed.
Response:
Thank you for pointing this out; it occurred to me that I need to make more explicit the point that the courts (and therefore what I call the ‘legal logic’) seem to compel withdrawal, not necessarily that clinicians do or will. I have therefore emphasised, in the ‘dying too soon’ argument/section, that it is not necessarily clinicians who will want to withdraw treatment, but rather that the legal logic seems to suggest (or even require) this. Hopefully with this further clarified, the apparent conflict on this specific point is now addressed. The relevant revisions are on page 11 lines 14-17.

#3
Jo Samanta (Reviewer 2):
Page 3 Line 26: "Where neither exists decisions must be made in the 'best interests' of the incapacitated… Perhaps this could be clarified? For example, if an attorney has been appointed, the standard for decision making will still be that of best interests (in line with s.4 and see s.4(7)(c)).
Response:
I agree that the original wording was too broad a summary of the legal position, which did not explicitly mention the best interests constraint on welfare attorneys’ decisions. I have now amended the wording to include this, spanning page 3 line 26 to page 4 line 3.

#4
Jo Samanta (Reviewer 2):
Page 5 Line 9: VS is used presumably as an abbreviation to 'vegetative state'?
Response:
Thank you for spotting this omission. The abbreviation was listed in the abbreviations at the end but had not been introduced in the main text. This is now introduced on first use in the main text, page 5 line 12.

#5
Jo Samanta (Reviewer 2):
Page 11 Line 20: "... including an inhibiting effect on research that might benefit these patients." This is an interesting point and I wondered (subject to word count etc.) whether it could be developed (briefly?). I was left wondered whether this was for research that would benefit that particular patient, or perhaps the cohort.
Response:
Mindful that this is only a discretionary revision and that it relates to a more modest suggestion (rather than a central argument) in the article, I have briefly expanded the text to indicate the
possible benefits which might be lost, both for an individual patient and potentially the wider group of patients. The additional text is on page 12, lines 6-14.

#6
Additional edits:
I have also added thanks to the reviewers in the acknowledgements, page 25 line 2.