

# Paternalism, reasonableness, and neutrality: a response to commentators

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I thank the commentators for their consideration of my views and for their insightful suggestions.

Robert Truog thinks that doctors can first emphasise patients' preferences but end by advocating what they think are objective goods because when patients' views are not knowledgeable, doctors see a conflict between respect for autonomy and beneficence.

Some concerns about Truog's views are: (1) He describes autonomy as a 'sociological trend' characteristic of our culture, but there may be a normative justification for emphasising individual autonomy. Often it is normatively justified for persons to decide on matters about which they know little and others much (eg, checking out of a hospital against doctors' advice). (2) What sometimes alters matters may be what Truog calls doctors' 'moral agency,' when *they* would have do what they conclude is objectively wrong. In his example, parents want their dying child who will soon be removed from a ventilator to also be taken off sedation so they can have meaningful time together. Doctors know that because the child will panic at his inability to breathe, the parents will not get what they want and will get something they do not want (ie, the child's panic). I think this case is like one involving 'soft paternalism': there is no disagreement between parents and doctors about whether an end is valuable but only about whether stopping sedation is a means to achieving it. It is like Mill's case of someone who wants to get to the other side of a river but does not know that the bridge is broken. We may interfere with his using the bridge because it would not achieve what he wants and achieves what he does not want. By contrast, the cases I discussed involved different opinions about ends rather than means. For example, I argued that the view that peacefulness and non-invasive support constitute a good death is not the only reasonable view. When there are multiple reasonable views, a doctor should not be

as concerned that his involvement would be wrong. (3) I agree that doctors should make vivid the possible costs and benefits of options. This is why I worried that some end of life decision guides do not require that patients be fully informed but only get the information they prefer.

Dominic Wilkinson focuses on the possibility, desirability and reasonableness of professional neutrality. His comments on the first two overlap with Schenker and Arnold's, which I shall deal with later. The third concerns his view that despite reasonable disagreement about what way of dying is best, we should agree that some ways of dying are bad. He gives the example of death by torture undertaken for its own sake and claims that "deaths that occur in the setting of high technology medicine appear dangerously close to 'death by torture'." He says that doctors should not be neutral towards treatments at the end of life that (A) 'lack benefit' and (B) 'risk substantial suffering.'

Some concerns about these remarks are: (1) Treatments that are known to lack benefit should not be used at any point in life, not merely at its end, but a treatment that risks substantial suffering is not the same as one that has substantial risk of (substantial) suffering. Presumably we would not want to exclude a treatment at the end of life that has a high probability of big benefit and only a small risk of substantial suffering. And if one possible benefit is extension of life worth having, then it is not necessarily true that it would be a treatment 'at the end of life.' Then the question is what probability of success is worth risking a 'bad end.' Should one element in this calculation be that it is the very end, per se, that may involve suffering rather than any time before? Suppose a treatment aimed at extending life would cause the same suffering if it failed but 6 months before death was always expected to occur and that death would be peaceful. Could this treatment be reasonable but the one that causes suffering at the very end is not? Furthermore, if a bad end results from a reasonable but failed effort to extend or improve life, the end is different from torture undertaken for its own sake.

(2) An example Wilkinson gives of what doctors should oppose despite a patient's preferences involve a man who had spinal surgery when he was terminally ill, then dying in the intensive care unit. Assuming the surgery would not extend life, perhaps he chose it because it might improve the quality of his remaining life. We cannot know this is unreasonable without knowing the chances of such improvement and how important that was to him by contrast to a better end. Note also that if assisted suicide or euthanasia were legally permitted, more terminal patients could reasonably risk such procedures because they could exit the 'torture' of unsuccessful outcomes.

Schenker/Arnold argue that the sort of more precise and balanced questioning I suggested for end of life questionnaires 'risks biasing preference elicitation.' Specifically, their first concern is that '... Kamm's model assumes that people have pre-formed preferences for end-of-life treatments.' But I recognised that this was not true when I pointed to Coalition to Transform Advanced Care's (C-TAC) view that new preferences may arise from reflection. I related this to Richard Moran's view that when people want to know what they think about something they are *not* aiming to uncover something they already believe but rather to form an opinion.

The authors' second concern is that emotions are not revealed by precise, neutral questions; 'inductive, interpretative conversational style' is required to 'illuminate patients' emotional statements...[and] values.' But my article only considered questions used to prepare for and guide conversations, and these are separate from the conversations. One such question was 'What are you afraid of?'; I suggested that one could uncover fears without assuming there are any by asking the more neutral 'Are you afraid of anything?' Schenker/Arnold's third concern is that 'more precise questions impose a pre-existing medical framework.' For example, asking someone how much she is willing to do to get more time assumes she cares about time per se rather than certain accomplishments (eg, going to her daughter's wedding) and so will fail to 'elicit her true values.' But this complaint is really about the question already in the questionnaire I was examining: 'How much are you willing to do to get more time?' My concern was that persons could reasonably respond, 'Well that depends on how much time I will get.' Only when the question becomes more precise (perhaps in conversation)

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can they give a useful answer (eg, 'for five months I would do x, for a year I would do more'). Schenker/Arnold are suggesting that another reasonable response to the question is, 'Why do you assume I care about time per se rather than going to my daughter's wedding?' But putting the question in terms of time could capture her concern if she said she would do a lot to get a time period that, in fact, sufficed for attending the wedding. Questions that ask what project a person wants to achieve risk the mistaken implication that the person does not care about living except to achieve the project (a problem in the Conversation Project's opening paragraph to which I pointed).

The authors note that the questions I criticise as imprecise were developed based on clinical experience. But is it the imprecision that makes them useful? Could they be improved, for example, by eliminating the suggestion that not wanting to satisfy relatives' wishes for one's end of life implies not wanting them to be involved in one's end of life, or the suggestion that caring *only* about quantity and not quality is properly contrasted with caring *more* about quality than quantity? Since my aim was to examine a limited number of documents whose authors were interrelated, I did not consider Schenker/Arnold's own approach which is to ask open-ended questions: 'Who are you as a person? What do you hold dear? What gives your life meaning? What do you most want to avoid?' Their aim is 'not an accounting of preferences but...understanding of patients' values and goals' to guide decisions by patients and doctors together. Notice that the first most general question is made more precise by the follow-up questions, without which it is not clear how one should answer. Their approach differs from that taken by the Conversation Project and Serious Illness Conversation Guide (SICG), which ask specific questions in order to help people discover their position on more general ones. I agreed that because values and goals most often ground preferences for specific courses of action, it is good to clarify and record them. But I also pointed to the case of the weak-willed Christian Scientist, competent at the time of decision making, to show that if we looked at values, goals and even preferences rather than to his actual choices (eg, to have a

blood transfusion), we would make a moral mistake.

Fourth, Schenker/Arnold's object to my suggestion that questions be phrased neutrally so as not to 'nudge' in one way. They claim that such neutrality (A) is not possible either in forms of language or in human beings and (along with Wilkinson) (B) is not desirable because it does not counteract pre-existing biases. My responses are: (1) Arguing that neutral questions should be used does not 'presume that it is possible for clinicians to be completely neutral' since clinicians can present a balanced view of the option they favour and the one they oppose (so that one cannot tell which option they prefer by the way they present each).

(2) Even if, as they say, 'every choice of words involves framing (...nudging) of some kind,' this would not imply that some words are not closer to neutral than others. 'Do you want to end your pregnancy?' is more neutral than 'When do you want to end your pregnancy?' (though it assumes pregnancy and the possibility of its ending). Further, if framing and nudging involve choices intended to have a specific effect on people, they are not involved in 'every choice of words' that have unintended effects. And some changes in preferences and values could be due to words that constitute a rational argument (ie, so the patient decides to do something for the sake of the reasons that actually justify the decision) which (contrary to Sunstein and Thaler) is not a nudge.

(3) Schenker/Arnold and Wilkinson share the view that when we 'know the direction of many biases...nudging may be helpful in counteracting such bias... and allowing people to express their true wishes' and 'to redress the balance' (Wilkinson). Notice that this view itself assumes that one can tell when we are closer to neutrality (redress of bias) and that achieving it might be possible, contrary to the earlier claim (A). And if the authors truly aim to achieve neutrality in this way, they should favour a nudge towards medical treatment if society came to favour hospice.

But is a skewed question (a) necessary to achieve neutrality, (b) does it even do so, and (c) might it be morally problematic for other reasons? Regarding (a), a more neutral question such as 'Are there

treatments you do not want?' (rather than 'What medical treatments do you not want?') undermines a pre-existing bias by implicitly denying the assumption that all treatments are wanted. Perhaps that suffices to level the playing field without assuming that some treatments are not wanted. (Analogously, compare countering a lie with its denial rather than with an opposing lie.) With respect to (b), rather than being left in neutral territory when a new nudge is introduced to neutralise a pre-existing one, a patient may act in the light of the most recent nudge. (This is subject to empirical test.)

With regard to (c), imagine a conversation in which a professional asks a Conversation Project question 'When would it be okay to shift from a focus on curative care to focus on comfort care alone?' and the patient responds 'Why do you assume I want to do that?' To be transparent (as Truog wants), the professional should say (something like) 'I don't assume it. I just said it to counteract a preexisting bias toward treatment,' thus confessing to dishonesty and manipulation (even if for a good end). Is this the basis for meaningful conversations or 'rational dialogue concerning the patient's best interests' (as Wilkinson wants) in which doctors present their actual, non-skewed reasons supporting their favoured position and can openly discuss existing social biases? Asking the more neutral question prevents this moral problem.

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