Care for well-being or respect for dignity? A commentary on Soofi's 'what moral work can Nussbaum's account of human dignity do in the context of dementia care?'

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In his paper, 'What moral work can Nussbaum's account of human dignity do in the context of dementia care?', Soofi[1] seeks to modify Nussbaum's conception of dignity to deal with four key objections that arise when appeals to dignity are made in the context of dementia care. We will not discuss the first of these, the redundancy of dignity talk, since this issue has already been much discussed in the literature. Instead, we will focus on the remaining three issues raised, that of the exclusion of persons with advanced dementia from having dignity, unjustified speciesism as a ground of human dignity, and the unclear practical implications that follow from having dignity.

Being clear about what dignity is, who has it, and what follows from having it, are important topics given the widespread use of appeals to dignity in the literatures on healthcare, bioethics, and human rights.[2] I take dignity to be, roughly, a relational status that signifies that the bearer, or the bearer's achievements, are worthy of reverence or respect, and consequently certain forms of interpersonal respectful treatment are warranted.[3 4] So understood, it is not hard to see how problems of exclusion arise for dignity,[1] at least on standard Kantian accounts where our capacity (or potential) for rational self-governance is seen as the awe-inspiring feature that grounds our dignity.[3] This seems to imply that humans who lack the capacity or even the potential for rational self-governance, perhaps including people with very advanced dementia, therefore lack dignity on such accounts, although not all Kantians agree about this claim[3] (pp.120–162). However, whether Nussbaum's account of dignity can do any better in this regard is less clear, given the importance on her account of 'active striving' towards realising basic human capabilities[5] (p.31), which may be absent in people with very advanced dementia[4] (p.882).

Putting the question of who is excluded aside for a moment, what has been much less discussed is how much work dignity is supposed to do in a moral theory. If dignity is supposed to do all the work in a moral theory and someone, such as a person with advanced dementia, gets excluded from having dignity, then this might seem to place them completely outside the moral realm. But the claim that dignity is supposed to do all the moral work is often an unquestioned assumption. As Soofi rightly notes, the 'objection' that exclusion from dignity is a problem is 'based on the presumption that it is desirable (or even necessary) to attribute dignity to people with dementia'[1] (p.2). But is it necessary and desirable to do so? It is only necessary if failure to do so would be morally improper or unavoidably place those with advanced dementia completely outside the moral and legal realms. It is desirable, even if not necessary, to attribute dignity to people with advanced dementia if this is overall better than some (unstated) moral alternatives.

The question of exclusion from having dignity is always a matter of degree. More inclusion is not necessarily and uncontroversially better, as the debate around the dignity of embryos and foetuses makes clear in the boarder context of discussions around abortion rights. The most inclusive strategy commonly deployed is to claim that dignity is something that all (and usually only) humans possess. This inevitably raises a problem, since either we appeal to some dignity-conferring feature of humans, such as their capacity (or potential) for rationality, which some humans will inevitably lack (eg, those with advanced dementia), or we appeal to species membership, which raises speciesism concerns. Soofi plausibly argues that Nussbaum's account of dignity avoids the speciesism charge since it is not our species membership, but our possession of ten basic human capabilities to flourish which grounds our dignity (and, I would add, our potential for actively striving toward these capabilities). But does Nussbaum's list of basic human capabilities make sense in the context of caring for a person with advanced dementia?

Soofi[1] helpfully addresses this practical concern by drawing on Kitwood and Bredin's[6] (p.269) indicators of 'relative well-being' for dementia patients which also aims to keep the 'sufferer's personhood in being'. This intermingling of care for well-being and respect for personhood (or dignity) potentially masks an important distinction between the two. This is because there is an important shift from Nussbaum's Aristotelian focus on agent flourishing, which is about helping an agent realise the basic capabilities of their species, to well-being's focus on ensuring a person is enjoying relatively good subjective conditions. Of course, the two may be linked, since treating others in respectful ways may be important for their well-being and caring for their well-being may be essential for their self-respect.

This alternative, in the form of a shift from respect for dignity to care for well-being as the primary normative focus[3] (p.159) in cases of advanced dementia care, allows us to return to the question of whether including very advanced dementia patients in the realm of dignity is necessary or desirable. In terms of the necessity claim, there are several ways of including those who lack dignity in the moral and legal community, suggesting that dignity is not necessary. Morally, we can appeal to the fact that we care about them and that their well-being is morally significant independent of whether (or not) they have dignity. Legally, we have good reasons for providing all humans with appropriate legal protections and rights regardless of their possession (or not) of dignity (for arguments see[3] (pp.158–161)). In terms of desirability, the shift to a focus on care for well-being rather than respect for dignity is desirable for three reasons. First, because a focus on well-being could include the many helpful practical measures listed by Soofi. Further, it could arguably make better sense of this list than a dignity-focus given that this list is based on well-being (not dignity) indicators, although this is complicated by the dual focus on respect for personhood associated with this list. Second, because a focus on well-being

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could help to justify the permissibility of using lying and deception as facilitators of well-being for those with dementia (eg, by not causing distress to a person with dementia by continually reminding them that their partner is dead when they keep forgetting this fact), which would be inappropriately paternalistic if our primary focus was on respecting dignity. Third, because it shifts our attention away from dignity's focus on inherent capabilities in a person that 'should be developed'[5] (p. 31; emphasis added), towards well-being's (arguably) more appropriate focus on improving, maintaining, or at least minimising declines in the subjective well-being of advanced dementia sufferers.

Whether a normative shift from respecting dignity to caring for well-being (or some combination of the two) is desirable overall in the case of advanced dementia care obviously needs further defence, but this alternative at least deserves explicit consideration.

Acknowledgements Thanks to Hojjat Soofi for commenting on a draft of this paper.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Commissioned; internally peer reviewed.

To cite Formosa P. *J Med Ethics* Epub ahead of print: [please include Day Month Year]. doi:10.1136/jme-2022-108725

Received 26 October 2022
Accepted 26 October 2022

Linked

► http://dx.doi.org/10.1136/jme-2021-108095

J Med Ethics 2022;**0**:1–2.
doi:10.1136/jme-2022-108725

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