

Dignity in dementia care: a capability approach

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In *Ending Midlife Bias: New Values for Old Age*, I argued that dignity can give practical guidance for patient care, especially dementia care.¹ Using a capability-informed analysis, I detailed threats to central human capabilities that undermine dignity for people with dementia and provide practical suggestions for managing these threats in paradigm cases.

In an article in this issue, Hojjat Soofi argues that a capability-informed account of dignity is exclusionary of people with dementia and does not translate into practical ethics guidance.² Soofi maintains that people with intellectual impairment ‘might not be able to exercise (or even have access to)’ the capabilities in question (Soofi, p4).² Focusing on Nussbaum’s capability view, Soofi cautions, it gives a narrow, blinkered assessment of what it means to live a full and flourishing human life.

In this commentary, I argue that Soofi’s critique of the capability view hastily generalises from a narrow set of premises to expansive, unwarranted conclusions.

Soofi’s first objection, that a capability view of dignity excludes people with dementia, is a sweeping and strong claim. In its support, Soofi cites dignity of the Kantian sort, which requires ‘cognitive competence to exercise rational agency,’ to argue that ‘if we want to include people with dementia in the circle of human beings with dignity, the cognitive abilities-based accounts of dignity such as the Kantian-inspired accounts do not provide the relevant grounds’ (p2).² While some Kantian scholars might dispute Soofi’s analysis,³ even if Kantian dignity excludes many people with dementia, the conclusion that capability-informed views generally are exclusionary hardly follows. Since the central target of Soofi’s analysis is Nussbaum’s rendering of capabilities, not Kant’s, it is a fair question to ask how Nussbaum’s approach fares.

I have argued that Nussbaum’s capability view fares quite well, since it includes far more than the capability for rational agency. For example, it includes the ability to be healthy and well nourished; exercise senses, imagination and thought; feel and express a range of human emotions; affiliate with others; relate to animals and nature; and play and recreate. These are the kinds of things that people with dementia, including advanced stages of dementia, can do and be. When these (and other) capabilities fall below a threshold considered minimal, the dignity of people with dementia is at risk and reasonable steps should be made to shore up threshold capabilities.

In *Ending Midlife Bias*, I show that a Nussbaum type capability account is particularly well suited to dementia, because it can distinguish between subjective and objective dignity threats (Jecker, p158–161).¹ *Subjective threats* involve a victim’s awareness of capability shortfalls. *Objective threats* occur when people lack awareness that their dignity is flouted. For example, objective threats to dignity arise ‘when someone takes advantage of and violates a small child, who lacks awareness of the wrong that is occurring [or when] adults who are unconscious, drunk, comatose, or intellectually impaired ...lack cognizance of indignities others commit’ (Jecker, p160).¹ The distinction makes sense of how people without the cognitive capacity to appreciate what is being done to them can have their dignity objectively breached. For example, molesting a person with dementia is an assault on their dignity even if the person is unaware and does not protest or feel distress.

Soofi’s second objection holds that a capability view cannot give clear, practical guidance. Hewing close to Nussbaum’s capability list, I have shown otherwise, offering a technique to guide practical care decisions for people with dementia (and other geriatric syndromes) (Jecker, p164–169).¹ The technique involves gathering evidence to identify capabilities at risk in paradigm cases and devising practical steps to support at-risk capabilities. In *Ending Midlife Bias*, I characterise a paradigm case

of dementia, to be applied to a particular case by reasoning analogically (Jecker, p165–168).¹ The paradigm case includes seven at-risk capabilities: life; health; bodily integrity; senses, imagination, and thought; practical reason; affiliation; and environment. *Life*, a capability I interpret narratively, refers to having a story of one’s life that is still unfolding. Supporting this capability might involve narrative gerontology,⁴ a technique that sets as a goal keeping people with dementia biographically active by ‘incorporating themed conversation geared toward eliciting opinions, not knowledge; inviting emotions, not facts; listening to what patients have to say; and keeping conversations going’ (Jecker, p166).¹ Other strategies involve using writing, visual art, music and other mediums, which also stimulates the *capability for senses, imagination and thought*. Supporting threats to *health* might mean managing symptoms with medication, structuring predictable routines and modifying the environment for safety, which also supports the *capability for regulating one’s immediate environment*. Managing threats to *bodily integrity* might take the form of enabling people with dementia to wander safely or go outdoors, which also supports the *capability to relate to nature*. For early stage dementia, support for *practical reasoning* might involve reorienting strategies, like displaying photos of loved ones. Safeguarding the capability for *affiliation* and *play* can occur by engaging people with dementia in humming songs together, playing cards or using different modalities of touch and voice to convey care.

Soofi’s conclusion that Nussbaum’s capability view is ‘more suited to adult, neuro-typical human beings with relatively more stable access to their basic capabilities’ (Soofi, p4)² rests on anaemic premises. It misses both the subjective/objective distinction, and the breadth of capabilities accounts like Nussbaum’s proffer. Rather than cordoning off people with dementia and excluding them, a capability view recognises all human beings as having worth and dignity.

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