What's the Appropriate Target of Allocative Justification?[1]

AJOB Neuroscience Journal

Open Peer Commentary

Zara Anwarzai and Ricky Mouser

[1] We would like to thank Matthew Adams and Gary Ebbs for their helpful comments.

Peterson, Aas, and Wasserman (2021) advance a prospective benefit framework that aims to account for a more holistic picture of patient well-being than previous proposals. To achieve this, they include both subjective and objective features of the lives of patients with disorders of consciousness (DoC). Although the authors' use of prospective benefit analysis is innovative and valuable, we argue that their subjective/objective distinction may lead us to venture beyond the medically relevant scope of the well-being of patients. For this reason, we follow Shelly Kagan (1994) in drawing a metaphysical distinction between quality of life and personal well-being. In our discussion of personal well-being, we introduce a further epistemic distinction between first-personally and third-personally accessible data, leveraging the force behind Peterson et al.'s original subjective/objective distinction.

Peterson et al. acknowledge the deep limitations of contemporary technical tools used for allocative justification, such as quality-adjusted life years (QALYs). A typical QALY survey asks us to compare *x* years of life in 'perfect health' against *y* years of life with a DoC. In other words, the QALY framework evaluates prospective benefit by assessing *lives* quite broadly, at the level of years of lived experience. Even so, tools like QALY can provide some subjective data, which is why Peterson et al. call for the development of novel technical tools in this vein (Peterson, Aas, and Wasserman 2021, 16-17). Our concern is that instead of contributing to a more complete picture of well-being, these sorts of tools capture medically irrelevant data.

To see this, consider Kagan's example of a businessman who is pleased with his life, believing that it is going well (Kagan 1994, 311). But unbeknownst to him, his wife is cheating on him, his children detest him, and his business is on the brink of failure. Kagan concludes quite reasonably that "something is amiss in the deceived man's *life*" (Kagan 1994, 321). Despite his relatively poor *quality of life* from the 'outside,' he seems to be experiencing a high level of *personal*

well-being from the 'inside.' This is because, despite the deep strains on his relations to the world and others (perhaps through no fault of his own) his own perspective is not yet impacted.

If this is right, then only some aspects of quality of life relate to personal well-being. This is why there is no medical need to treat the businessman just because his wife is secretly cheating on him. (Although if he finds out, he might need the medical attention of a therapist or cardiologist for his heart.) Certain considerations of how things are going for persons are not appropriate in medical contexts. As a minimal constraint, we must focus on the person herself and her first-personal perspective, rendering *patients* the appropriate targets of allocative justification. To avoid diluting concerns central to treating patients, we should aim to treat *them* equally, not their lives, and certainly not their quality-adjusted life years (Persad, Wertheimer, and Emanuel 2009, 428).

How, then, should we measure personal well-being? A good first step is revisiting the intuition underlying Peterson et al.'s distinction between subjective and objective data. Their distinction seems designed to encourage us to collect data about both the patient's perspective from the 'inside' and the doctor and family's perspective from the 'outside.' (Peterson, Aas, and Wasserman 2021, 15) But a more direct way to capture this intuitive cut is to distinguish between first-personally and third-personally epistemically accessible data. Our access to first-personal data is limited but might include interviews with recovered DoC patients about their experiences. Third-personal data might include neuroimaging studies on the effects of possible courses of treatment in order to improve our grasp on the status and prognosis for patients with DoC.

Our proposed distinction has immediate implications for our current data collection practices. For example, it challenges the relatively privileged status of QALYs. Because we have such limited first-personal data from patients with DoC, we may have felt dependent on third-personal QALY data, which at least provide subjective data from survey participants. But this asks too much

of a poor substitute, and as Peterson et al. note, is liable to magnify paternalistic or even ableist biases (Peterson, Aas, and Wasserman 2021, 14). Allowing QALYs to masquerade as epistemically privileged subjective information overinflates the status of merely third-personal data.

So how can our adjustments help to allocate medical resources when they are limited, scarce, or costly? Working out the technical details may be tricky, but we should remain keenly aware of our own epistemic limitations by noting just how little first-personal data we have in hand. Following the authors, we can still apply a prospective benefit analysis, albeit one based on patients' personal well-being instead of their quality of life. From there, resource allocation may be determined based on the distribution of prospective benefit when considering the personal well-being of *all* patients. Allocative justification should be respectful of *persons*, and thereby rely only on medically relevant sources of data about patients' conditions.

Bibliography

Kagan, Shelly. "Me and My Life." *Proceedings of the Aristotelian Society,* 94 (1994): 309-324.

Persad, Govind, Wertheimer, Alan., Emanuel, Ezekiel J. "Principles for allocation of scarce medical interventions." *The Lancet,* 373, no. 9661 (2009): 423-431.

Peterson, Andrew, Aas, Sean. and Wasserman, David. "What Justifies the Allocation of Health Care Resources to Patients with Disorders of Consciousness?" *American Journal of Bioethics Neuroscience* (2021).