



## Legitimising values

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While apparently helpful concepts such as “best interests” appear to have the virtue of simplicity, they are really place holders for the communication, time and listening that’s required to understand what truly matters to patients and others involved in healthcare. When we know what matters to a patient, we can have confidence that we have a “legitimate” view of what’s important to them. Two papers in this issue of the *Journal of Medical Ethics* explore different ways in which values can be legitimised and applied consistently in healthcare.

When a patient can no longer say what it is that matters to them and a significant decision needs to be made, the values that will inform what should happen next need to be legitimised in some way. Common ways of doing that include proxy decision makers or advanced directives. In this issue Jacob Appel calls for the ways in which “substituted judgments” are used for patients who have previously expressed a wish to die, to be used consistently for mental and physical illnesses.<sup>1</sup> In American jurisdictions substituted judgments, whereby a proxy decision maker gives evidence for what the patient would have chosen if they were still able to express their will, are commonly used as a way to “best vindicate the right to autonomy of incapacitated patients.” The problem Appel analyses is the way in which those with an “extremely poor medical prognosis and/or low quality of life” and a mental illness that impairs their capacity, are typically not able to reply on a substituted judgement if they wish to be allowed to die. Clearly this raises a delicate set of issues, particularly if we were to imagine a young patient, but he suggests a very unwell...

...depressed patient may voice a desire for death under circumstances in which they would prefer death even if not depressed. Such a wish could reflect a longstanding attitude toward a proposed medical intervention, a desire to control one’s means and time of dying...

He claims that treating mental and physical illnesses consistently in this respect

“...would empower patients and families, while affording psychiatry an opportunity to conform its practice to the ethical norms of general medicine.”

The importance of patient values for clinical practice is a central pillar of medical ethics, and it’s also important for prioritisation and the health care system more generally. Health economic tools such as QALYs are invaluable for making comparisons between the cost utility of health care services, and they are used extensively in countries such as the United Kingdom, Canada, Australia and New Zealand. (2) They’re used less extensively in the United States, where it seems the implication that they measure the quality of a person’s life and attach a financial value to it, led to their use not being permitted by some federal legislation.<sup>2</sup> Indispensable as such tools are in many countries, they are generally accepted as one element of sound prioritisation and that they need to be supplemented by other considerations such as rarity of the condition, how many therapeutic options there are for that condition and fairness more generally.

The British National Institute for Clinical Excellence (NICE) was one of the first institutions to augment cost utility analysis with methods to incorporate other values.<sup>3</sup> Their original social values framework and use of a Citizen’s Jury to inform prioritisation was criticised at the time in the *JME*<sup>4 5</sup> primarily on the grounds of whether it lived up to its aim to follow Daniels and Sabin’s “accountability for reasonableness” framework.<sup>6</sup>

Jonathan Michaels expresses the concern that current attempts to introduce social values into prioritisation run the risk of a “distorted assessment of value.”<sup>7</sup> A commitment to the Daniels and Sabin requirement for “transparency” in prioritisation decision-making would have helped resolve a number of the distortions he identifies. He explains how since the NICE social values document, other agencies have adopted “...additional value elements such as innovation, rarity, burden of disease and end-of-life

treatments...” As he observes, while such values seem relevant, how can they be legitimised for public policy and how should they be weighted? Michaels offers a taxonomy of the values that have been proposed for evaluating health outcomes and raises challenges that each one presents. For him, legitimising these values requires a commitment to demonstrating their “relevance”, another procedural requirement from the accountability for reasonableness framework. Central among these is the requirement that values are applied consistently across different decisions and the opportunity costs of decisions are part of their application. One of the central challenges for medical ethics is legitimising value and although that is often contentious, it is vital for the task of reaching well justified ethical decisions.

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