Title: The Cost of Compassion: Resource Allocation and Disorders of Consciousness

[OPC to Peterson, Aas, and Wasserman – What justifies allocation of health care resources to disorders of consciousness patients?]

In the nearly 50 years since Jennett and Plum (1972) first characterized the persistent vegetative state, our understanding of disorders of consciousness (DOC) has grown immensely. Technological advances have brought significant improvement in diagnosis and prognosis, and developments in treatment are creating new opportunities to improve the lives of patients with DOC. Yet these advances bring with them new challenges. Peterson and colleagues (2021) provide an insightful analysis of the complex problem that is assessing the cost-effectiveness of providing treatment to patients with prolonged disorders of consciousness. They suggest that allocating health care resources to patients with DOC could be justified by the access to opportunity it provides them. While I agree with Peterson and colleagues that assistive technologies or novel health interventions may increase the opportunities of these patients, I am less sanguine that these increases in opportunity would be sufficient to justify the allocation of health care resources required. Instead, I suggest, the most plausible justification for providing treatment is likely to be on compassionate grounds, rather than cost-effectiveness.

As Peterson and colleagues incisively describe, resource allocation in health care is often based on cost-effectiveness analysis, where the cost of care is weighed against the prospective benefit to the patient expressed using a metric like Quality Adjusted Life Years (QALYs). In the UK, for example, the National Institute for Health and Care Excellence (NICE) considers the use of health technologies that cost between £20,000 and £30,000 per QALY to be cost-effective (NICE, 2014).

Reducing the benefits of a treatment to a single, quantifiable value like QALYs allows for direct comparison of the impact of various health states on well-being. Yet it also presents several problems, owing to the fact that measuring the impact of health on well-being is notoriously difficult. As the authors note, eliciting people's preferences about different health states is often an unreliable guide to their well-being, especially when these health states are unfamiliar. In fact, some have argued that it is impossible to measure health by its impact on well-being, because the contribution of health to well-being is not separable from the contributions of other constituents of well-being (Broome, 2002).

Recognizing these problems, Peterson and colleagues present an opportunity-based framework for cost-effectiveness as a possible alternative to traditional frameworks based on patient quality of life. On this sort of view, the value of a health intervention is understood in terms of the access to opportunities it provides, rather than the increase in welfare it produces.

Why should health policy focus on promoting opportunity, rather than promoting patient welfare? A possible justification is grounded in an argument about the proper aims of social policy more generally. One might argue that the aim of social policy should be to preserve and enlarge the range of possibilities open to individuals to pursue their own conception of the good life, while remaining as neutral as possible about what the good life is (Hausman, 2015). Social policy should facilitate opportunities for citizens, not satisfy their preferences. Accordingly, health policy should be concerned with the ways in which health states impact the range of opportunities for worthwhile activities available to individuals, rather than the impact of a particular health state on individual well-being. For example, disabilities such as paraplegia, blindness, and deafness limit the range of opportunities open to individuals, but may have various effects on their well-being. Blindness denies me the opportunity to drive a car, but in an environment with accessible transit, I may not be any worse off than if I was not blind. Treatment to prevent blindness has value from a policy perspective insofar as it expands the range of opportunities available to individuals, and not as a result of its impact on their well-being.

If one views the role of the state in this way, an opportunity-based framework for cost-effectiveness is appealing. Of course, the fundamental challenge of determining cost-effectiveness seems to remain; we have simply replaced 'well-being' with 'opportunity'. The question now becomes: what interventions will generate the greatest increase in the range of opportunities available to individuals to pursue their notion of the good life, relative to costs? In some respects, this might present an easier task than cost effectiveness analyses based on well-being, insofar as changes in opportunity might be more amenable to objective measurement than changes in well-being.

For example, Peterson and colleagues argue that access to assistive technologies and novel treatments for patients with disorders of consciousness may enhance the opportunities of these patients in various ways. For example, the inability to communicate obviously limits the range of opportunities to pursue worthwhile goods open to these patients. Insofar as neuroimaging-based communication provides a way to address this limitation and increases the opportunities of these patients it has clear public value, even if this increase in opportunity doesn't result in increased well-being.

A worry with relying on this sort of opportunity-based framework, however, is that by avoiding the problems associated with measuring well-being, it seems to lose an important aspect of patient care, namely, the experience of the patient. On the one hand, a treatment that offers only a marginal increase in opportunity across patients, but nevertheless generates a substantial increase in well-being, seems worth providing. On the other hand, if cost-effectiveness is based on an objective notion of opportunity, (i.e., on the actual opportunity created, and not the individual's assessment of the value of the opportunity), treatment for patients whose range of opportunity is severely limited by disability or chronic illness will never be cost-effective, even if it might have a substantial impact on well-being. Patients with DOC exemplify this worry. Because of the extent of their disabilities, the range of opportunities available to them to pursue their notion of the good life are highly limited. Thus, any increase in opportunity gained through treatment is likely to be marginal. Nevertheless, these patients may still be capable of an acceptably high level of well-being (Graham, 2017).

The problem here is not the inscrutability of well-being (or opportunity), but the emphasis on efficiency. Efficiency, as expressed through cost-effectiveness, is not the only value that is relevant to health policy. Values like compassion, fairness, solidarity, and equal respect also play an important role. For example, we might think that even when they stand to benefit less from treatment, those who are severely ill deserve equal (or even greater) priority with those who are less severely ill. We might also think that everyone that can benefit from treatment should have some chance of getting it, even when they are less likely to benefit or the benefit they receive will be less (Ubel, 2000). Similarly, the distribution of health benefits should avoid exacerbating existing inequalities, such as those caused by disability (Dolan et al., 2005). Accommodating these sorts of concerns requires limiting the role of cost-effectiveness on health policy.

This has direct implications for the treatment of patients with DOC. For example, an opportunity-based framework for cost-effectiveness might favour offering 100% of resources available for treating patients with DOC to those who have recovered consciousness within two weeks post-injury, because these patients tend to have a better chance of recovering significant function than those with prolonged DOC, and thus, the potential gains in opportunity through this allocation of resources are highest. While this may represent the most efficient allocation of resources, it may also strike us that failing to provide some level of treatment to the more severely injured sub-group of patients with DOC conveys a lack of compassion. Similarly, concentrating rehabilitative efforts on patients that have suffered mild or moderate brain injury, rather than those with DOC, is likely to be more cost-effective overall, because these patients are much more likely to regain access to a wide range of opportunities. Yet refusing to provide rehabilitation to patients with DOC because their disabilities diminish its cost-effectiveness only compounds their disadvantage, and might strike us as unfair discrimination.

Any health system with finite resources will inevitably fall short of satisfying the demands of compassion and fairness. Sometimes the best thing to do will be unfair, or will leave those in need untreated. Perhaps the best that we can do from the perspective of health policy is to build in conditions to a cost-effectiveness framework that allows for the provision of cost-ineffective treatment in certain cases. For example, the UK's NICE has a 'compassionate care exception' to its cost-effectiveness criterion, which allows treatment to exceed its cost-effectiveness threshold when QALYs do not fully capture gains in quality of life, where treatment is considered to have long-term value for innovation, or where there is no existing alternative treatment.

Something similar might be applied to an opportunity-based framework of the sort suggested by Peterson and colleagues. An appeals process might allow access to treatment that is cost-ineffective when measures of opportunity gained do not fully capture the value of the opportunity to the patient. In patients whose range of possible gains in opportunity are severely restricted by their disability, such as those with prolonged DOC, this might provide a justification for treatment that would be unavailable on a strict cost-effectiveness framework. Because these exceptions would be determined on a case-by-case basis, the value of the opportunity gained could incorporate the values of the individual patient (via those making decisions on their behalf). That is, rather than basing the value of an increase in opportunity on the extent to which it makes certain worthwhile activities available (as would be the case at a policy level), the value of an increase in opportunity could be based on the extent to which it increases the availability of those things that are valuable to the particular patient. Thus, treatment that would be cost-ineffective if broadly provided could be justified in individual cases by the value of the opportunity to the individual patient.

Peterson and colleagues close their paper by suggesting that the question of resource allocation is ultimately a question of what sort of society we want to live in. A society, and a health system, that values compassion as well as efficiency justifies its cost.

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