

A perfectionist adjunction to egalitarian concerns in the fair distribution of healthcare

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Abstract

Today, cost-effectiveness analysis (CEA) plays an increasingly important role in the distribution of healthcare. This utilitarian approach has been criticised for ignoring important priority-relevant considerations, such as prioritarian or equalitarian concerns for the worst-off. This essay will raise a further priority relevant consideration, which states that a special priority status should be granted to the needs of the worst-off at the expense of the needs of the less-badly-off *only if*, as a result of the treatment, the worst-off patients have the *potential* to reach a *minimal* state of health, which would allow them to achieve aims which are deemed central to their lives. I call this moral consideration a “mild perfectionist consideration”: “Perfectionist” because it promotes the idea that human beings should be able to pursue certain ideals, which are inherent to their human nature; and “mild” because the perfectionist ground from which I argue is of a restricted nature because it accords value to ordinary achievements which are reachable by almost all persons. This principle should be understood as an adjunction to, and not in opposition to, prioritarian or hard-line egalitarian concerns. It proposes a justification (which is nevertheless consistent with moderate egalitarian concerns) for why certain groups of particularly badly-off patients should not be given priority in the fair distribution of healthcare, even if that would result in a more unequal situation.

Cost-effectiveness analysis (CEA) is a useful tool in the distribution of health-care. It allows for the allocation of scarce resources in a way that generates the greatest total increase in health-related quality of life, usually expressed in QALYs (quality-adjusted life years), and it helps rank alternative interventions by virtue of their cost-effectiveness (cost per QALY) (Bognar& Hirose, 2014, pp.53-54.) The total increase of health-related quality of life is calculated by aggregating the total number of individual QALYs gained using a simple summation (also known as the “QALY maximisation rule”) (Dolan, Shaw, Tsuchiya & Williams, 2005, p.197). This utilitarian approach, which regards each QALY as having equal social value regardless of to whom it accrues (Bognar & Hirose, 2014, p.66), has been condemned for ignoring other priority-relevant considerations (Dolan & Olsen, 2003, p.121). For instance, Nord (2014, p.139) expresses the following criticism: “simple aggregations of QALYs do not yield reliable estimates of citizens overall valuation of different programs, because concerns for equality are not included”. And, indeed, empirical evidence suggests that people seem to be willing to sacrifice aggregate health in order to give priority to those who are worst-off (Shah, 2009, p.77).

Prioritarian and egalitarian concerns have been the subject of numerous investigations.¹ They gave rise, for example, to the cost-value analysis (CVA) formalised by Nord et al.(1999), which represents an attempt to incorporate societal concerns for both efficiency and equity into the allocation of health care resources by incorporating equity weights into the CEA, whereby QALYs are changed into EQALYs (equity-weighted QALYs) (Bognar & Hirose, 2014, p.70). Nevertheless, further priority-relevant considerations might well be relevant for the allocation of healthcare resources. In this essay, I will raise a mild perfectionist moral consideration that has largely been neglected in the literature. It states that it is sometimes permissible to give priority to the better-off patients if the worst-off patients do not have the *potential* to reach a *minimal* state of health (a certain threshold) after treatment, a threshold which would allow them to pursue their own chosen ends and to conduct a *decent* human life. I call it a “mild” consideration, because the perfectionist ground from which I

¹ See for example Shah (2009) for a literature review devoted to the prioritarian concern that the most severely ill should be given priority. See Otsuka & Voorhoeve (2015) for a discussion on egalitarianism and prioritarianism, two leading theories of distributive justice.

argue is of a restricted nature. It accords value to ordinary achievements reachable by almost all persons and not only to the highest achievements of a given elite. Hence, I don't defend the stronger perfectionistic position which stipulates that in any case the better-off patients should be given priority because they are, *ceteris paribus*, always in a better position to reach perfectionistic goods.

First, I will introduce a thought experiment to illustrate the motivation of the aforementioned mild perfectionist moral consideration. On the basis of this experiment, I will then argue that the absolute level of health *after* treatment should be taken into account in the prioritising of groups of patients because the attainment of a minimal quality of life (threshold) after treatment is essential to allowing patients to pursue their own chosen ends in life. Thus, the priority-relevant mild perfectionist moral consideration partially trumps hard-line egalitarian considerations at the very bottom of the severity scale. This approach is nevertheless merely an adjunction to, and not in opposition to, egalitarian and prioritarian concerns. It proposes a justification as to why certain groups of particularly badly-off patients should not be given priority in the fair distribution of healthcare, even if that would result in a more unequal situation. This essay will conclude by addressing two potential objections: (1) that this proposal ignores the value that a severely mentally impaired person might ascribe to her life, (2) that this perfectionist adjunction is not really a *constraint* on egalitarian considerations, but merely another value alongside egalitarianism because moderate egalitarians recognise the importance of a *minimal* state of health which can potentially be attained after treatment.

Figure 1 provides a modified version of the severity scale first proposed by Nord (1993b) and adapted by Shah (2009, p.79). The scale has been modified to depict a case of intellectual development disorder (IDD) but is constructed with the same schema used in the case of mobility impairment, exemplified by Nord and Shah. The degrees of impairment *Profound-Severe-Moderate* and *Mild* are expressed in the DSM-V terminology, which provides criteria for the classification of neurodevelopmental disorders, and the descriptions relative to each state of health have been borrowed from Gluck (2014). The intervals between each level should appear to be equally significant in terms of individual utility (Shah, 2009, p.79) and each level of intellectual impairment has been assigned an equivalent in QALY, which ranges from 0 (death) to 1 (a year of

life in full health) in intervals of 0.2.

Figure 1:

	Degree of impairment	Example (in terms of intellectual development disorder)
1	None	Full Health
0.8	Mild	Slower than typical in all developmental areas, but can achieve academic success and blend in socially
0.6	Moderate	Noticeable developmental delays (i.e. speech, motor skills) Able to learn basic health and safety skills, can complete self-care activities
0.4	Severe	Considerable delays in development, little ability to communicate Able to learn daily routines and very simple self-care; needs direct supervision in social situations
0.2	Profound	Significant developmental delays in all areas, requires close supervision Requires attendant to help in self-care activities, not capable of independent living
0	Death	

Imagine you are a member of a national parliamentary committee in charge of public health.² In the context of the discussions surrounding the allocation of next years budget, you are confronted with two competing proposals:

The first proposal is to establish a special Unit **A** (the effect of which is shown on the far left column of Figure 1) for the **treatment of a severe form of IDD**, for which patients suffer considerable delays in development. They have little ability to communicate and need direct supervision in social situations (see Figure 1). According to Gluck (2014), most patients suffering from severe IDD cannot successfully live an independent life and will need to live in a group home setting. The treatment A would improve their condition and bring them from this severe state of health **to a moderate one**. In this moderate state of health, the patients would still demonstrate noticeable developmental delays but they would be able to complete self-care activities and live independently even though they would still need more support than an average non-impaired person.

The second proposal is to establish a special Unit **B** (the effect of which is also shown on the far left column of Figure 1) for the **treatment of a profound form of IDD**, from which the patients suffer significant developmental delays

² The underlying “person trade-off method” to this interpersonal trade-off finds its origin in Nord (1993b). Nord (1993a, p.41) elaborated a similar scenario in a study whose issue was the relevance of health state after treatment in prioritising between patients in Norway. The thought experiment I propose here is a slight modification of the question formulated in the second questionnaire of Nords study (see p.41).

in all areas and have an extremely limited ability to communicate. They need round-the-clock support and care for all aspects of day-to-day life (Gluck, 2014). The treatment would improve their condition from this profoundly impaired state of health **to a severe one**, already described above.

The unit costs for the implementation of both proposals and the number of patients who would potentially benefit from them are the same. Further, the total increase of health-related quality of life is identical among both groups, as patients in the former group are taken from 0.4 to 0.6 QALYs per year alive and patients in the latter group from 0.2 to 0.4 QALYs per year. Assume that each patient will live equally long after the treatment has been administered. Assume, moreover, that the post-treatment state of health is *definitive*, i.e., patients in group A would remain at 0.6 and patients in Group B at 0.4 QALYs. There is no possibility for B-patients to undergo treatment A once they have undergone treatment B, so it is impossible for them to reach a moderate level of IDD. Unfortunately, you operate under budget constraints and **only one** proposal can be funded in the coming year. To which group of patients should you give priority?

A prioritarian would prioritise the funding of B, as she is more concerned with the severity of the *pre-treatment* health state (the “start point”) (B=0.2; A=0.4). All other things being equal, treatment B would be regarded as more valuable by a prioritarian because, in her view, helping the worst-off is *intrinsically* socially valuable (Shah, 2009, p.79).

A hard-line egalitarian would also prioritise the funding of B, but on another ground. Egalitarians are concerned with how the level of each person compares with the level of others (Parfit, 1995, p.23) and would therefore favour B. Indeed, choosing B would help reduce inequalities between A and B: both groups of patients would remain severely impaired if B were to be carried out, but both would at least be equally impaired (A=B=0.4). From an egalitarian perspective, more equality brings more social value *per se*.

In contrast, I contend that in this case it would be permissible to give priority to the better-offs (A), even if that would result in a more unequal situation. I regard the *post-treatment potential state of health* (“the potential end point”) as an important criterion in the prioritising between different patients when

operating with scarce healthcare resources. The post-treatment potential state of health is so important because it plays a decisive role in the conduct of a patients life after treatment. Reaching a minimal state of health is a necessary condition for the pursuit of certain activities. While it is true that certain activities are more basic than others, such as breathing, crying and excreting, some others, such as gaining knowledge, working towards personal achievements or conducting deep personal relationships, are deemed to be essential for the conduct of an intrinsically desirable life (Hurka, 1993, p.3). The faculties that are necessary to pursue those kinds of activities are constitutive of human nature “they make humans human” (Hurka, 1993, p.3). If one is not (anymore) in a position of being able to develop those human faculties, then ones life seems less intrinsically desirable. That is why, in my opinion, to justify a *special* legitimate claim over healthcare resources, thus to be granted a special priority status in the sense of the prioritarian or egalitarian view (priority to the worst-off), B-like patients must, as a result of the healthcare resource allocation, have the *potential* to reach a *minimal* state of health (a certain threshold), which would allow them to pursue their own chosen ends and to conduct a *decent* human life. In respect to the thought experiment above, I suggest that this threshold lies somewhere between 0.5 and 0.6 QALYs per annum alive if this state of health is to remain definitively at this level for the rest of the patients life. Below this threshold, many would agree that the depicted life is of limited value, because we would not be in a position to develop the faculties which make us human. Since the B-patients in our example do not reach this threshold after treatment (they would still not be able to successfully conduct an independent life and they will continue to rely on others to a great extent, *even after treatment*), they should not be granted a special priority status. On the other hand, if group A were to receive the treatment, A-patients would land in a more favourable position relative to their starting point, which would allow them to pursue realistic ends in life and to live a decent life. Indeed, they would be able to complete self-care activities and even live independently if the adequate environment is provided. Therefore A-patients should be granted the funding for the treatment.

I propose that the following principle explains and justifies this judgement: a special priority status should be granted to the needs of the worst-off at the expense of the needs of the less-badly-off *only if* the previously defined

threshold is attainable; a threshold which would allow patients to pursue their aims in life as a result of the treatment. In other words, not only should the pre-treatment health state (the “start point”) matter in the prioritising between different patients, but what also matters is the *post-treatment potential state of health* (the “potential end point”). This principle should be understood as an adjunction to prioritarian or hard-line egalitarian concerns since it does not trump prioritarian or hard-line egalitarian concerns *overall*, but only at the very bottom of the severity scale. This is so because when we are operating with scarce healthcare resources, we would do best to allocate them to patients whose capabilities would thereby be enhanced in a way that would allow them to achieve aims which are deemed central to their (human) lives.

This principle is of a *perfectionist nature*³ because it promotes the idea that human beings should be able to pursue certain ideals, which are inherent to their human nature, such as gaining knowledge, working towards achievements, conducting deep personal relationships and so on. But this is only a *mild form of perfectionism* because it does not claim that patients should be capable of pursuing unrealistic achievements of excellence. The definition of perfectionism does not have to be restricted to a Nietzschean account of the good, which would hold that “only the highest achievements of the highest specimens of humanity have any value” (Arneson, 2000, p.40) and which would open the door to all kinds of extreme and morally repugnant conclusions. The form of perfectionism I endorse is closer to the measured form of perfectionism that Arneson (2000, p.63) defends: “an account of human good that accords significant value to ordinary achievements reachable by almost all persons”, and which would remain a viable option within the theory of justice”. That is why the threshold should be fixed at a modest level, at say, as I suggested above, 0.5 or 0.6 on our severity scale of intellectual disability.

One might object that this proposal ignores the value that a severely mentally impaired person might ascribe to her life. Perhaps someone who is not able to complete self-care activities and live independently could still value her own life very highly. I would contend that, on average, patients who attain the threshold in the wake of the treatment are more likely to make the most out of their lives and to value it more highly than patients who are not able to attain

³ See Hurka (1993) for a formulation of a condonable version of perfectionism.

this threshold. This objection also ignores the effects on others (externalities) that such a patient might bring about. A type-A patient will, for instance, rely much less on other peoples help after the treatment than a type-B patient, which makes them less of a social burden.

I argued before that the priority-relevant mild perfectionist moral consideration raised in this essay partially trumps hard-line egalitarian considerations at the very bottom of the severity scale. But is this perfectionist adjunction really a constraint on egalitarian considerations or is it rather merely another value alongside egalitarianism? I have been alerted to the fact that constrained egalitarian would nevertheless recognise the importance of the *minimal* state of health which can potentially be attained after treatment.⁴

In his discussion about the basis of equality, Rawls (1971, pp.504 ff.) defines the minimal requirements in virtue of which human beings are to be treated in accordance with the principles of justice. In his framework, only *moral persons* are entitled to equal justice (Rawls, 1971, p.505). This excludes prima facie animals from the principle of justice, but not only animals. In order to be regarded as having the status of a moral person, one must fulfil two conditions: (1) being capable of having a conception of the good (which is further articulated as being able to conceptualise a rational plan of life) and (2) being capable of having a sense of justice (Rawls, 1971, p.505). Those two capacities should be fulfilled at least to a certain minimum degree for people to be regarded as moral persons. Rawls does not define exactly what this “minimum degree” amounts to, but the requirements are not supposed to be too demanding since he assumes that the overwhelming majority of mankind possess those faculties: “Only scattered individuals are without this capacity, or its realization to the minimum degree, and the failure to realise it is the consequence of unjust and impoverished social circumstances, or fortuitous contingencies” (Rawls, 1971, p.506). Following this definition of *moral person* a moderate equalitarian could argue that in the case of group B patients, who suffer from a profound form of IDD and could only be raised to a severely impaired state of health after treatment, Rawls’s two conditions are not fulfilled and therefore the grounds for egalitarian concern may fall away, giving priority to group A after all. Constrained egalitarians seem not to

⁴ I am indebted to Alex Voorhoeve for having brought to my attention the objection which follows.

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be committed to the value of equality between those patients who are permanently incapable of achieving Rawls's minimal requirements and those who are so capable. To illustrate their point they might say that they are not concerned with inequality between themselves and a cat (or a grizzly bear⁵), for example, since the latter is simply not a (moral) person. A severely mentally disabled person would analogously be deprived of moral agency.

The perfectionistic adjunction outlined in this essay would in this case indeed not contradict egalitarianism so understood. I contend nevertheless that Rawls's two criteria to qualify as a moral person are of a perfectionistic nature.⁶ Thus, this objection does not limit the force of my argument. The priority-relevant mild perfectionist moral consideration can still be viewed as an interesting adjunction to egalitarian concerns - as a valid justification as to why certain groups of especially badly-off patients should not be given priority, even if that would result in a more unequal situation.

⁵ See for example Otsuka, 1994, p.92 for a similar line of argument in respect to why it might be justifiable to kill a psychotic human being in self-defense.

⁶ (maybe Rawls was a constrained perfectionist after all!)

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