

# The cost of refusing treatment and equality of outcome

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## Abstract

*Patients have a right to refuse medical treatment. But what should happen after a patient has refused recommended treatment? In many cases, patients receive alternative forms of treatment. These forms of care may be less cost-effective. Does respect for autonomy extend to providing these alternatives? How far does justice constrain autonomy? I begin by providing three arguments that such alternatives should not be offered to those who refuse treatment. I argue that the best argument which refusers can appeal to is based on the egalitarian principle of equality of outcome. However, this principle does not ultimately support a right to less cost-effective alternatives. I focus on Jehovah's Witnesses refusing blood and requesting alternative treatments. However, the point applies to many patients who refuse cost-effective medical care.*

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Competent patients have the legal and moral right to refuse medical treatment. However, most patients do not refuse all treatment, but only some forms of care. Such a limited refusal has implications in countries with national health insurance. In England and Wales, the National Health Services Act 1977 requires the Secretary of State to ensure that a comprehensive and extensive system of health care delivery meets all reasonable requirements.<sup>1</sup> The service must be comprehensive in that: "first, ... it is available to all people and, second, ... it covers all necessary forms of health care..."<sup>2</sup>

While a person may refuse the recommended treatment, this does not absolve health care providers of a duty to provide *some* health care. But what are the entitlements of a person who has refused the recommended medical treatment?

It is important to distinguish three different situations in which a person might refuse care: (1) there is no alternative; (2) the alternative is cheaper or the same price; (3) the alternative is

more expensive. There has been little discussion of the resource implications of refusing treatment. This is partly because refusal of treatment has been most discussed in the context of end of life decisions where, it is claimed, it saves money.<sup>3</sup> But refusing treatment does not necessarily involve choosing a cheaper alternative. Consider the example of Jehovah's Witnesses.

## Jehovah's Witnesses and erythropoietin

Jehovah's Witnesses (JWs) refuse blood products because they believe that if they voluntarily receive blood, they will turn to dust when they die. But if they refuse blood and keep Jehovah's other laws, they will enjoy eternal paradise. Although they refuse blood, they "cherish health and love life".<sup>4</sup> They have identified many alternatives to blood, including use of laser surgery, gamma knife radio-surgery, an argon beam coagulator, perfluorochemicals, desmopressin, aminocaproic acid, granulocyte-colony stimulating factor and hyperbaric oxygen therapy.<sup>5</sup> The availability of these alternatives, together with Witnesses' organised pressure, has meant that their care has mostly not been compromised. However, many of these alternatives are more expensive than blood.

One example is erythropoietin (EPO), a hormone produced by the kidney which stimulates red blood cell production. It can now be produced using recombinant genetic technology. Given for two weeks prior to operation, it raises the red blood cell mass and reduces the requirement for transfusion. In one study of 208 patients undergoing hip operations, 44% of those who received placebo required a blood transfusion either during or after the hip operation. Of those who received EPO, 23% required a blood transfusion.<sup>6</sup> In another study, a total dose of EPO of around 600-1200 units/kg has been associated with a successful outcome from surgery despite a loss of around 1 litre of blood.<sup>7</sup>

Is EPO superior to the standard use of blood? The risks of blood include transfusion reaction, infection (hepatitis, HIV, other bacterial and viral infections), and other physiological and metabolic disturbances. These complications are uncom-

mon, but significant. The risks of EPO are less clearly known. They include hypertension and possible thrombosis though there are isolated reports of encephalopathy. There is insufficient evidence at present properly to compare the risk/benefit profiles of EPO and blood transfusion.

The cost of EPO is £90/10,000 units. Assuming a dose of 1000 units/kg for a 70 kg person, this would be a cost of £630. This raises the blood count by the equivalent of 1-2 units of packed cells. The cost per unit of blood is around £45.

A case from the Oxford Radcliffe Hospital illustrates the problem. One JW received a two-week course of EPO at 600U/kg/dose, given three times per week. He/she weighed over 90kg. Thus the course (324,000U) cost £2,916. Assuming that he/she would have required around six units of packed cells, this would have cost £270. Erythropoietin was 10 times as expensive as blood transfusion.

There are at least three arguments against JWs being offered EPO.

#### 1. EQUALITY OF RESOURCES

We could appeal to the principle of **equality of resources**: There should be an equal distribution of resources amongst those who have a legitimate claim on them.<sup>8</sup>

The idea is that everyone is entitled to a fair share or a "fair go".<sup>9</sup> By receiving EPO, JWs are using more than their fair share of resources. Although the National Health Service is under statutory obligation to **provide a reasonable level of health care**, this is arguably provided by blood.

#### 2. UTILITARIANISM

According to utilitarians, we should distribute resources in such a way as to maximize utility (measured in terms of happiness, preference satisfaction, Quality Adjusted Life Years or some other index of wellbeing). The first consequence of refusing the most cost-effective form of care is inefficiency. And health economists and utilitarians both argue that inefficiency results in injustice. It denies others beneficial treatment.<sup>10</sup>

Consider the example of hip operations. Let's assume that the cost of EPO treatment is £1,200. The cost of transfusion is £200. There are more people requiring hip operations than there are resources available to provide hip operations for everyone who needs one. Assume the cost of the hip operation is £2,800.

Assuming that the morbidity and mortality of EPO and blood transfusion are roughly comparable, a maximally efficient system would use only transfusion. For every three people opting for

EPO rather than transfusion, **one person is denied a hip operation**. That person does not receive the resources he is entitled to and does worse than others. Inefficiency, utilitarians claim, results in injustice.

#### 3. DISCRIMINATION

In practice, the option of EPO is not open to everyone. In part, the significance of this depends on whether EPO is superior or inferior to blood transfusion. Let's assume that EPO is superior. **Aristotle's principle of equality** states: "No distinction ought to be made between men who are equal in all respects relevant to the kind of treatment in question, even though in other (irrelevant) respects they may be unequal."<sup>11</sup> Or, "Equals must be treated equally, and equally unequals must be treated unequally."<sup>12</sup>

Discrimination occurs when we treat people differently on the basis of an irrelevant feature, such as race, gender, religious affiliation. If the reason that JWs were entitled to EPO was because their refusal was based on religious reasons, this practice would discriminate against those who did not hold their particular beliefs.

The reason that EPO is not offered to most patients may be that it is perceived by doctors to be an inferior or unproven option. However, apprised of the same information as Witnesses, some patients might choose to avoid the risks of blood transfusion and accept EPO. Indeed, the best option may be to reduce one's transfusion requirements by using EPO preoperatively, together with "rescue transfusion" if necessary.<sup>13</sup> This option should not be closed to non-Witnesses selectively.

Can JWs justify an entitlement to EPO?

#### i. Law

Could JWs claim that it is illegal to deny them this alternative? The answer is not straightforward. Courts have appeared to accept that decisions to limit patients' access to treatment on the basis of the scarcity of resources are necessary, but that such decisions are "not judiciable": they should be made by hospital trusts and parliament. A relevant case was that of Jaymee Bowen (Child B). She had leukaemia and received a bone marrow transplant, but her leukaemia relapsed. She was refused a second bone marrow transplant. This was expected to cost £75,000. Sir Thomas Bingham, Master of the Rolls, said: "Difficult and agonizing judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment the court can make."<sup>14</sup>

These sentiments echo remarks by Sir John Donaldson that courts could only intervene if a health authority decision was “Wednesbury unreasonable”.<sup>15</sup> That is, “so outrageous in its defiance of logic or accepted moral standards that no sensible person . . . could have arrived at it.”<sup>16</sup>

This said, the Department of Health and the courts have been reluctant to restrict treatment “purely” on economic grounds.

“The Department of Health advises that with respect to patients whose needs have not been provided for by means of NHS contracts, and who require to be referred for treatment to a hospital on an extracontractual basis, ‘[I]t is not acceptable . . . to refuse authorisation solely on the grounds of the proposed cost of treatment’.”<sup>17</sup>

The decision in *Bowen* was supposedly the result of considering “all the clinical and other relevant matters . . . and not on financial grounds.”<sup>14</sup> According to one commentator, the cost could not be justified because: the treatment was “experimental”; it had only a 1-4% chance of success, and due to its side effects, it was not in her interests.<sup>18</sup> Thus, the decision was not “purely a financial one”. (I must admit that, even knowing the side effects of marrow transplant, I would want a 1% chance of success.)

Lord Browne-Wilkinson has also warned against basing treatment limitation decisions on financial constraints. During the *Bland* case, involving the withdrawal of life-prolonging treatment from a man in a permanent vegetative state, he reflected on whether resource constraints could be relevant to a decision to withdraw treatment. The answer, he said, turned on the interests of the individual and not on financial considerations: “. . . it is not legitimate for a judge in reaching a view as to what is for the benefit of the one individual whose life is in issue to take into account the wider practical issues as to allocation of limited financial resources . . .”<sup>19</sup>

The law is under tension. On the one hand, judges recognise that difficult decisions have to be made on how to bring the greatest good to the greatest number. However, they are also attracted to the apparently incompatible claim, as Lord Keith put it, that “. . . it would not be lawful for a medical practitioner . . . to give up treatment where continuance of it would confer some benefit on the patient.”<sup>20</sup>

Perhaps the law lords believe there is a difference between discontinuing treatment and not offering treatment . . .

What view would courts take of National Health Service (NHS) trusts denying Jehovah’s Witnesses EPO? It is difficult to say. It might make a difference whether treatment had already

commenced. It would depend on the benefits of EPO. However, in one sense, trusts would not be denying all relevant care: they would only be denying the more expensive alternative. Courts might be reluctant to become involved in decisions about the fairness of resource allocation but any decision to withhold EPO could not be made on the basis of “cost alone”. This might be a minimal constraint. Other considerations besides cost which have weighed in judicial minds have included urgency (*Collier*<sup>21</sup>), effectiveness (*Bowen*) and existing quality of life (*Bland*). If benefit is the other factor to be considered, it might be legitimate not to offer it if it is less effective than blood. However, there has not been a case in which an effective treatment has not been provided because there is a cheaper, effective alternative which has been refused.

## ii. Medical ethics

Jehovah’s Witnesses could give at least four arguments to support access to more expensive alternatives.

### 1. RESPECT FOR AUTONOMY

Witnesses might say: “If society is serious about respecting autonomy, then our choices should be respected.” I do not believe that formulating the problem as a conflict between respect for autonomy and justice draws us closer to resolution.

Firstly, justice is prior to autonomy. It is only when the range of alternatives which society should offer us has been set that we can choose the option which we think is best for ourselves. We are only as free as the constraints of cooperative social existence allow.

Secondly, the case is not only a conflict between respect for autonomy and justice, but a conflict of autonomy and autonomy: conflict between the autonomy of the Witness and the autonomy of others who will be denied treatment because there are not enough resources left. The upshot of inefficiency is that other people are denied the treatment they want. Justice is about how to resolve these first order conflicts.

### 2. LIFE-TIME HEALTH CARE COST AND RESPONSIBILITY FOR ILLNESS

Witnesses could argue that they care greatly for their health, for example, not smoking or drinking. Over their whole life, their health care costs will be lower.

If the premise is true, this argument seems plausible. However, it is difficult to see how individual life-time health care costs could be prospectively calculated.

This argument also raises the issue of responsibility for illness. It is difficult to attribute responsibility for illness. Moreover, JW's are responsible for their refusal of the cheaper alternative, blood.

### 3. THE RIGHT OF CONSCIENTIOUS OBJECTION

Considerable importance is given to the right to conscientious objection. We have allowed people to avoid conscription when going to war offended their deeply held values. Not going to fight may have had bad effects on others in society, but that is an apparently acceptable price for respecting people's moral commitments.

There are difficulties with appeal to the right to conscientious objection. The right to conscientious objection only requires that JW's not be forced to accept blood, and not that they be provided with an alternative. Jehovah's Witnesses could reply that to allow people to live in society as conscientious objectors requires that such alternatives be provided.

Another difficulty lies in constructing a robust notion of conscientious objection. How do we differentiate between values and desires? Why should your moral objection to war carry more weight than my concern for my life? What is special about the requests of JW's? In the next section, I will suggest one way in which their refusals may be special.

### 4. EQUALITY OF OUTCOME

Jehovah's Witnesses could argue: "Utilitarians are right. The ultimate goal of medicine is that resources are distributed to make everyone as well off as they could possibly be. But this cannot be achieved. So we need to temper our principle of distribution to respect the equality of all persons. *The goal of medicine is that resources are distributed to make everyone enjoy at least a reasonable level of wellbeing, and that that level be as good as possible.*"

Call this version of egalitarianism, **equality of outcome**. Whereas utilitarianism is concerned to maximize utility, this version of egalitarianism aims to ensure that everyone enjoys a decent minimum. This may require denying great benefits to one (such as curing the infertility of one person) to bring two people up to the reasonable level of health (by repairing their large herniae).

Let's assume that EPO is as effective as or less effective than blood transfusion. Effectiveness here could be "medical effectiveness", that is, effectiveness in preventing death, in preventing hypoxic organ damage, in promoting recovery from surgery, etc. The idea here is that medicine is about getting everyone to a reasonable state of health. If health is narrowly construed in this way,

equality of outcome would not justify any special claim by JW's on EPO since blood transfusion will secure this level of health.

However, the value of a treatment is not merely constituted by its medical effectiveness. Health is not the only component of wellbeing. Jehovah's Witnesses could claim that although blood may save their lives, it has detrimental effects on other aspects of their lives. They may become depressed and alienated from their community. In virtue of these effects, EPO better promotes their wellbeing overall.

Such an argument could justify the special treatment JW's receive. Because others fail to hold their particular beliefs, blood transfusion does not affect their quality of life in the same way. If it did, others would be entitled to these alternatives. There is thus no discrimination in favour of JW's.

This argument still leaves JW's open to an objection. Jehovah's Witnesses have responsibility for the beliefs they hold and so, indirectly, for the impact blood has on their global wellbeing. At this point, JW's can appeal to freedom of conscience or religion. Society allows people to believe what they wish, provided that they do not directly harm others, and in particular to commit themselves to any religious belief. The impact on health care of holding these beliefs is just one of the prices we pay for this freedom. However, it is because of the effect of the alternative treatment on wellbeing and not because they request the alternative that their claim for the alternative is legitimate. Medicine, I believe, is not fundamentally about giving people what they want, but what is good for them.

On this argument, equality of outcome justifies a claim to EPO. However, this argument, though appealing, is flawed. Available resources will not raise *everyone* to a reasonable level of health. If this is the case, we should introduce a principle of maximization.

The goal of health care is that resources are distributed to make *as many people* as possible enjoy at least a reasonable level of wellbeing.

This can be called maximizing equality of outcome. There are clearly going to be arguments about where a reasonable level of wellbeing should be set, and consequently what constitutes a necessary good and what constitutes a luxury good. What constitutes a reasonable level will be resource-sensitive. But let's say that we are able to define the reasonable level of wellbeing as X. On any plausible public policy, we should distribute resources so as to get as many people as possible to X. Insofar as distributing EPO to a JW results in the consumption of resources which could raise more others to X, we should not offer EPO. The others, too, can appeal to equality of outcome.

(Let me signal that egalitarianism need not be fully maximizing in the sense that we must get as many people to X as possible<sup>22</sup>; it may be that it is good enough to get a threshold number to X.<sup>23</sup> But this probably does not affect the present argument as it may be that devoting expensive resources to those who refuse cost-effective treatment prevents us getting *enough* people to X.)

**Thus, the consequence of inefficiency is ultimately greater inequality of outcome. Importantly, the best argument Witnesses can marshal - appeal to equality of outcome - does not justify a right to refusal and alternative treatment. In order to provide equality of outcome for the most people possible (and indeed to respect the autonomy of as many people as possible), we should reject the right to refuse the most cost-effective treatment and expect a less cost-effective alternative. On either utilitarian, economic grounds or on plausible egalitarian grounds, JW's should not have access to EPO.**

### Refusal of treatment: beyond Jehovah's Witnesses

Jehovah's Witnesses, however, are not the only patients who refuse standard treatment and receive more expensive alternatives. Consider the following four examples:

- The person who refuses amputation of a gangrenous limb. She still receives hospital care, and antibiotic therapy, and such care may go on for months. The costs of such care may far exceed the costs of amputation and aftercare.

- The chronic alcoholic who refuses to participate in a programme of detoxification and rehabilitation. He is still entitled to other medical care. He may develop liver failure, which may require repeated admissions to hospital.

- The person who could be treated for an infection with a short course of intravenous antibiotics in hospital. He refuses. Is he then entitled to an expensive new oral antibiotic that is restricted?

- The smoker with chronic respiratory failure who requires repeated hospital admissions because he refuses to give up smoking.

Refusal of recommended treatment often involves access to care which may be expensive. This problem can only become greater as we identify the most cost-effective forms of care. Refusal of the most cost-effective care will often involve a *de facto* request for a less cost-effective alternative. As consumers of health care become better educated, they may increasingly request a more expensive alternative.

### Refusal of treatment, equality of outcome or efficiency?

The right to refuse medical treatment has important implications for resource allocation. In the context of a health care system aiming at comprehensive and reasonable health care, what began as a right to avoid bodily intrusion becomes a stubborn block to efficiency, maximization of wellbeing and ultimately equality of outcome.

There are several solutions. If equality of outcome requires efficiency, and we believe that equality of outcome for all is the most important principle governing a national health service, then a right to refuse the most cost-effective treatment in favour of a less cost-effective option should be rejected.

Or we could give up concern for both equality of outcome in favour of equality of resources alone. We could adopt a rule stating that more expensive alternatives cannot be provided than the most cost-effective option. If a person refuses the recommended treatment, he would only be entitled to care of equivalent cost from the public purse. While promoting choice, this, however, would not justify access to EPO if the cost of EPO were outside the personal health resource limit.

At present we have three mutually incompatible concerns. We cannot have:

- a right to refuse the most cost-effective medical treatment in favour of a less cost-effective option
- equality of outcome
- efficiency

One of the three has to go.

More broadly, justice at times requires paternalism: requiring that people be offered only a more effective and cheaper option. But it may also require that people be offered a less effective but cheaper option, if as many people as possible are to enjoy a reasonable standard of wellbeing. Justice imposes important constraints on both autonomy and beneficence.

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