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The secret art of managing healthcare expenses: investigating implicit rationing and autonomy in public healthcare systems

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Rationing healthcare is a difficult task, which includes preventing patients from accessing potentially beneficial treatments. Proponents of implicit rationing argue that politicians cannot resist pressure from strong patient groups for treatments and conclude that physicians should ration without informing patients or the public. The authors subdivide this specific programme of implicit rationing, or ''hidden rationing'', into local hidden rationing, unsophisticated global hidden rationing and sophisticated global hidden rationing. They evaluate the appropriateness of these methods of rationing from the perspectives of individual and political autonomy and conclude that local hidden rationing and unsophisticated global hidden rationing clearly violate patients' individual autonomy, that is, their right to participate in medical decision-making. While sophisticated global hidden rationing avoids this charge, the authors point out that it nonetheless violates the political autonomy of patients, that is, their right to engage in public affairs as citizens. A defence of any of the forms of hidden rationing is therefore considered to be incompatible with a defence of autonomy.

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Given the limited resources of any society and the seemingly limitless opportunities to devote resources to medical treatment, healthcare rationing has become inevitable.[1] In societies with public healthcare systems, the entirety of possible treatments must be divided into two distinct sets: those that are to be available to patients within the public insurance scheme and those that are not, except perhaps at the patients' own expense. But even this restricted availability depends on the patients' being informed about treatments in both sets—that is, it demands that healthcare rationing plays an explicit role in medical consultations. On the assumption that this condition is normally met, a great deal of work in bioethics has been done to spell out the principles that healthcare rationing ought to comply with in order to be just. Among the most plausible proposals are ''fair innings''[2], lotteries[3], the rule of rescue[4], maximisation of utility[5] and fair procedure.[6 7] Again, the application of these principles depends on making the rationing problem *explicit*—that is, on the specific patient's or the general public's awareness of the varieties of treatments that may be made available to the beneficiary of public healthcare. Proper conditions for such awareness do not always seem to obtain. Indeed, as Onora O'Neill has pointed out, ''patients are typically asked to choose from a smallish menu—often a menu of one item—that others have composed and described in simplified terms''.[8] That is, actual medical practice seems to be undertaking much of the necessary rationing both out of the view of patients and out of the public eye. In order to assess this practice, our aim in this paper is to evaluate the grounds for keeping the realities of rationing implicit by gauging the compatibility of this practice with the principle of autonomy.

IMPLICIT RATIONING

''Implicit rationing'' is a somewhat ambiguous notion covering several proposals.[9–12] Notwithstanding the complexity of the literature on implicit rationing, we will focus on the claim that setting hidden limits to patients' choice is morally acceptable.

David Mechanic[9], for instance, argues that ''explicit rationing is inevitably unstable because of the ability of small groups to evoke public sympathy and support in contesting government decision making'' (p1658) and that ''neither central government nor health districts are likely to have the stomach to ration explicitly in substantial ways and thus they remain dependent on trust that physicians will use discretion in a politically acceptable and hopefully wise way'' (p1659). Hence, he argues that ''implicit rationing'' implies that rationing should at least sometimes be hidden from politicians, the public and the patients.

Our more specific aim is therefore to clarify whether implicit rationing, when conceived as hidden rationing, is compatible with autonomy. We define hidden rationing as management of expenses within healthcare that fulfils the following four conditions:

- It sets limits to the range of choices that are available to patients among potentially beneficial treatments.
- The aim of setting this limit is to reduce or contain expenses.
- The decision to set limits is hidden from patients.
- The rationale for the decision to set limits is hidden from patients.

Our argument consists of three parts. First, we analyse the concept of autonomy in order to draw

Abbreviation: GHR, global hidden rationing

a distinction between individual autonomy and political autonomy. Second, we subdivide the programme of hidden rationing into local hidden rationing, unsophisticated global hidden rationing (unsophisticated GHR) and sophisticated global hidden rationing (sophisticated GHR), discussing these positions in relation to the two notions of autonomy. Third, we conclude that local hidden rationing and unsophisticated GHR are incompatible with respecting individual *and* political autonomy, whereas sophisticated GHR is clearly incompatible only with political autonomy. This is an important point, because the defender of hidden rationing may think that a guarantee of individual autonomy, coupled with the reduction of expenses to be borne by the public purse, is sufficient to justify the practice of keeping healthcare rationing hidden. What this argument fails to take into account is that patients are also always citizens and that while rationing may not violate their autonomy as individual patients, it does continue to violate their autonomy as members of the society more generally. In short, justifying hidden rationing depends on a fixation with the *patient*, as if people are interested in healthcare only when they are sick.

INDIVIDUAL AND POLITICAL AUTONOMY

It is generally agreed that patients are treated with due respect if their autonomy has been respected. Autonomy is most often conceived of as a ''capacity for independent decisions and actions'' and has more specifically been termed individual autonomy (O'Neill, 2002, p23).[8] The standard requirement for respecting autonomy is informed consent[13], and in the context of medical treatment, this requirement is often interpreted as constituting one element within a broader ideal of sharing medical decision-making between patient and physician.[14] Put simply, this ideal implies that the meeting between physician and patient should proceed as a dialogue, where the physician provides information about possible treatments, while the patient provides information about his or her values. The best among the possible treatments is the one that the patient accepts as best fitting those values. Informed consent thus involves two rights: the negative right to say no to a treatment and the positive right to participate in medical decision-making (Cohen, 2000, p392).[15]

Besides possessing specific patients' rights, however, patients are also citizens who possess general rights of equal political liberty, such as freedom of speech, political participation, suffrage and the right to stand for political office. These rights might, for example, be justified by contemporary contractualistic theory.[16 17] And since equal political liberty is ''an expression and manifestation of the value of being a free and equal member of a society whose adult members together are self-governing''[18], it enables the political autonomy of citizens in any society (Habermas, 1992, p161).[17] Patients therefore inhabit two different social roles, with which two different sets of rights are associated. As beneficiaries of healthcare services, they possess specific patients' rights that belong to the set of rights that constitutes individual autonomy—that is, the right not to be subjected to medical interventions without giving their informed consent and the right to participate in the medical decision-making process. As citizens of a society, they possess a broader set of political rights, which enable political autonomy by entitling people to participate in the political decision-making process where citizens mutually regulate their shared life conditions.

HIDDEN RATIONING AND INDIVIDUAL AUTONOMY

So our initial question about whether hidden rationing is compatible with respecting autonomy is really two questions: is it compatible with individual autonomy? and is it compatible with political autonomy? We will begin by examining the relationship between hidden rationing and individual autonomy.

Rationing often occurs at three different levels: a macro level (for example, which treatments should be included in the healthcare menu); a meso level (for example, which treatments should be available within regions or at individual hospitals); and a micro level (for example, whether the individual physician should be allowed to perform bedside rationing). In the following, however, we focus on whether there is a morally relevant difference between not informing about treatments according to whether they are or are not available within a healthcare system. Hence, we discuss rationing at only two levels. If an institution governs the distribution of goods of a system at large, we say it constitutes a global institution. For instance, in Denmark, a society with a centralised public healthcare system, the National Ministry of Health constitutes the global distributive institution of healthcare. All healthcare systems, however, also consist of local institutions, which are sometimes granted autonomy to distribute healthcare according to their own principles. Such institutions we say constitute local distributive institutions. Hospitals, nursing homes and general practitioners may constitute local distributive institutions.

A local institution that decides to distribute only a subset of therapies in order to save costs and that intentionally omits to inform patients or the public about the full set of possible treatments is carrying out local hidden rationing. Such rationing clearly does not fulfil the requirements of informed consent and shared decision-making. The health professionals at an institution that performs local hidden rationing rather than providing adequate information about all relevant therapies gives information about only a subset of the full set of treatments in order to prevent the patient from choosing certain treatments outside this subset. The result is that the consent a patient may give to a proposed therapy is not informed and, therefore, that the autonomy of the patient is violated. As Dan Brock puts it, ''Perhaps the most blatant form of manipulation is when information is deliberately withheld from patients in order to affect their choice. For example, they are not told of alternative treatments to the one the physician prefers …'' (p45).[14]

The treatment of women with breast cancer at the county hospital on the island of Bornholm in Denmark may illustrate local hidden rationing. It has been reported that at this particular hospital a breast-removal procedure for such women was suggested and performed without informing patients either that the National Board of Health recommended breast-preserving procedures or that such procedures were available at other hospitals that they could freely choose under Danish law.[19] By secretly prohibiting patients from pursuing this type of treatment, the hospital was clearly undermining the requirement of informed consent.

Now let us change the focus to cases where there is interplay between local and global distributive institutions and examine whether it is possible to find a form of hidden rationing that does not constitute a ''blatant form of manipulation''. Imagine the following scenario. First, the national ministry of health in a country with a centralised public healthcare system decides that only a subset of the full set of treatments of a given ailment should be available within the public healthcare scheme. Second, a hospital intentionally omits to inform patients about treatments outside this subset. Apparently, it could be argued that the individual autonomy of patients in such cases would not be violated. The reason for this would be that patients are not informed only about treatments that are not available to them anyway. Information about *possible* therapies would

arguably not be withheld. This type of hidden rationing can be called unsophisticated GHR.

However, initial scrutiny of unsophisticated GHR reveals that it shares with traditional paternalism the problematic epistemological premise that physicians can know what information is of relevance to patients without asking them. The argument in favour of unsophisticated GHR assumes that only information about treatments available within the patients' healthcare insurance is relevant to the patient. It is, however, likely that patients would find it relevant to be informed of treatments outside this subset so that they might pay for the treatment themselves. There might be a private-healthcare tier in their country, and there is, of course, always the possibility of going abroad. As in the case of local hidden rationing, then, the lack of information just makes it impossible for the patient to make an informed choice. Unsophisticated GHR therefore does not fulfil the requirement of informed consent and is not consistent with respect for patients' individual autonomy.

By qualifying the scope of their claim, however, proponents of unsophisticated GHR may avoid this criticism. The argument goes as follows. The full set of treatments of a given ailment consists of all potentially beneficial treatments, but often a particular public insurance scheme covers only a subset of these treatments. Treatments that are not part of a country's public insurance scheme can be further classified into two subsets: those that are realistically accessible to at least some patients (ie, they could buy them at their own expense) and those that are not realistically accessible to any patient (eg, extremely expensive cancer treatments or expensive palliative care treatments).

Proponents of what we call sophisticated GHR may now argue that a patient's individual autonomy is violated only if they are not informed about treatments that are either accessible within the public insurance scheme or realistically accessible outside this scheme. Individual autonomy, on this view, is not violated if patients are not informed about treatments outside the public insurance scheme that are not accessible to them in any case—that is, treatments they will not be able to pay for out of their own pockets.

Now, it may be objected that sophisticated GHR still shares with unsophisticated GHR the dubious premise that physicians can know what information is of relevance to patients without asking them. Strong advocates of individual autonomy may argue that physicians can never know whether certain treatments outside public insurance are too expensive to be paid for by the patient if they don't discuss these treatments with them. Thus, not informing about these treatments will violate patients' individual autonomy. Our short answer to this objection is that it is wrong. We believe that even in welfare states, there will be cases of potentially beneficial treatments that are available only abroad where it is clear that no patient can afford them out of their pocket. In the following, we set this problem on one side, therefore, and focus instead on what we believe to be a more serious problem facing sophisticated GHR.

We claim that even if sophisticated GHR constitutes a variant of hidden rationing that does not violate individual autonomy, there is still something wrong with rationing in such a fashion. A shift in perspective from individual to political autonomy will help illuminate what this problem consists in.

HIDDEN RATIONING AND POLITICAL AUTONOMY

We begin our argument for this claim by remarking that the plausibility of sophisticated GHR rests on a specific conception of the entitlements of patients as beneficiaries of healthcare. According to this conception, patients are entitled solely to (a) choose among therapies available within the public insurance scheme, (b) pursue therapies within the subset of realistically accessible treatments outside the insurance scheme or (c) reject treatment altogether.

But this conception is inadequate. Most patients are also citizens of the society in which they are treated for their disease. As citizens, they are entitled to participate in the political process concerning how to allocate resources. This entitlement stems from the earlier-mentioned set of rights of equal political liberty. It constitutes a set of rights that enables political autonomy in a society—that is, one that makes it possible for citizens to govern themselves. In order to determine whether sophisticated GHR in general is compatible with autonomy, we have to determine whether it accords with political autonomy, namely, the right of citizens to govern themselves.

One approach might be to limit the scope of political autonomy. Weber and Schumpeter argued that ordinary citizens are not capable of judging or understanding public affairs, and this idea might plausibly be applied to health policy. The purpose of democracy, on this view, is restricted to generating and legitimating leadership, and "the role of the voter is confined to accepting or refusing one "boss' or another" (Held, 1987, p175).[20] This minimalist position is what David Held has called competitive elitist democracy.

In fact, some such minimalist position seems to underlie hidden rationing in general. The claim that citizens and patients are incapable of making prudent political choices concerning rationing of healthcare seems to be an essential premise of Mechanic's argument for hidden rationing. By invoking such a minimalist position, proponents of sophisticated GHR can claim that this method of rationing is compatible with political autonomy. The argument would simply be that citizens who have had the chance to govern themselves by means of voting have had their political rights respected.

But this argument is of course only as convincing as the minimalist account of political participation. It is certainly questionable whether it conforms to the ideal of equal political liberty, that is, "an expression and manifestation of the value of being a free and equal member of a society whose adult members together are self-governing" (Gutmann, 2003, p173).[18] After all, if sophisticated GHR is accepted, patients and citizens in general will be able to govern themselves within the sphere of health policy only by electing politicians and not by choosing policies of rationing. Policies are to be secretly chosen by professionals. Patients and citizens will not know which policies are operative, nor will they be able to find out. They will not be able to monitor whether operative policies match their preferences, and they will not be able to hold their decision-makers accountable for policy. Hence, patients and citizens will not be able to know whether they in fact exercise political autonomy, that is, govern themselves. It seems absurd to claim both that a group of citizens are autonomous and that they are deprived of the possibility of knowing that they are autonomous.

Moreover, political autonomy is incompatible with the general programme of hidden rationing, and not only with sophisticated GHR. All versions of this programme operate by means of hiding possible treatments from patients and the general public. Respect for political autonomy demands that, on the contrary, citizens in general should be able to involve themselves in public deliberation concerning public affairs. In the case of allocating healthcare resources and setting limits to the patients' range of choices, this implies that patients, as citizens, should not be limited to functioning as beneficiaries of healthcare but should rather also be entitled to function as distributors of healthcare.[21]

IS THERE AN ALTERNATIVE WAY OF RATIONING THAT RESPECTS POLITICAL AUTONOMY?

If individual and political autonomy are perceived as values central to healthcare, then informed consent and public deliberation

constitute benchmarks for policies of rationing, and the minimalist conception of democracy must be abandoned. However, is there a feasible alternative that respects political autonomy?

The pioneering work of Norman Daniels and James Sabin on fair procedure may offer an answer to this question. Contrary to implicit rationing, which wants to shield decisions of rationing from public scrutiny, fair procedure insists that both decisions about rationing and the arguments for them should be publicly available.[6 22] Such a view obviously exhibits *prima facie* respect for political autonomy. But it remains for future bioethical work to determine whether merely publicising decisions about rationing and their rationales is sufficient or whether actual participation by patients and citizens in the decision-making process is also called for. In the meantime, it is worth noting that this emphasis on the procedure of decision-making is not of mere academic interest but is in fact echoed within various reports on how to ration in the Scandinavian welfare systems.[23]

CONCLUSION

Implicit rationing conceived as hidden rationing does not appear to be compatible with a respect for autonomy. Whether local or global, unsophisticated or sophisticated, it fails to respect at least political autonomy and in most cases also individual autonomy, on pain of restricting our conception of democracy to the minimalist and elitist view that citizens should be able to choose only their leaders, not their policies. But while the concepts of individual autonomy and informed consent are well worked out within the bioethical literature, the ideas of political autonomy and public deliberation have received considerably less attention, and this may well be why an argument for some form of hidden rationing sometimes seems plausible.

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