CASE STUDY RESPONSE

A violation of ethics on all counts

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While assessing the questions brought up by the case, I will use the moral principles theory and its adaptation by the Indian Council of Medical Research (ICMR) for its ethical guidelines. I will briefly refer to the principles of informed consent and voluntary action, professional competence, risk minimisation, and maximisation of public interest (1). Though the guidelines are principally for medical research, the principles they are based upon -- autonomy or respect for persons, beneficence and non-maleficence, and justice (2) -- are widely accepted as fundamental to the practice of modern medicine. I will also briefly refer to the Code of Ethics of the Medical Council of India (3), which subscribes to these principles through its regard for the respect for patients, welfare of patients, the professional competence of physicians to ensure that patients are not harmed, and the welfare of society.

What are the ethical implications of rationing ART?

From the description provided it appears that the key elements of the policy of rationing are: (a) provision of ART to registered PLHAs based on blood tests to assess eligibility, and on a "first-come first-served" basis; (b) drugs provided only for short periods of time requiring the PLHA to report to the centre to receive supplies for the next period.

For a policy or law to be morally justified, Gillon suggests that we need to assess both the process through which it evolved, as well as its contents. Morally justified policies are those made through democratic processes representing conflicting views, and made on the basis of common moral values reflecting the four moral principles (4). Thus for ART rationing policy as a whole to be morally justified, it ought to have been made taking into account the knowledge, experience, and expectations of all involved parties including PLHAs. Though the case does not provide us with this information, I will assume for the sake of argument that the process was indeed morally justified. This brings me to the elements of the policy that I have identified. I will consider them in turn.

In the first case, the policy of providing ART to registered and eligible PLHAs on a "first-come first-served" basis can be justified on the basis of the moral principle of justice, particularly distributive justice, which demands fair distribution of scarce resources. ART is relatively expensive and government resources to ensure free access to ART in the face of competing health-related claims can be classified as "scarce". Assuming that all PLHAs seeking ART are eligible, registration on a "first-come first-served" basis can be seen as contributing to fairness. Registration itself depends on public awareness of the availability of ART and access to the centres, but I will not discuss these issues at this time. The assessment of eligibility based on blood tests can be justified under the moral principal of beneficence, which requires that patients benefit from the intervention. It would appear that the blood tests are designed to ensure that this is the case.

With regard to the second element of the policy, competing principles appear to be at work. While the reasons for providing ART for short periods of time are not given in the description of the case, I will assume for the sake of argument that they have to do with ensuring that the drugs are not misused, either through sale or through sharing with another individual, and that the patients need to be regularly evaluated in order to determine appropriate dosage.

Viewed from the perspective of the ART centre, these can be justified on the basis of the obligations of both distributive justice (against sharing with unregistered persons) and legal justice (against unlawful sale). Equally, it is necessary to prescribe ART based on an evaluation of the patient's condition to comply with the principle of beneficence. The conflict arises when we view the policy from the perspective of the individual, as in the case of Mr K. His inability to continue ART during his time away from the centre led to a situation that could adversely affect his health. This violates both the principle of beneficence and of rights-based justice (the right to life).

One way to resolve this conflict would be to ensure the availability of ART to K at a centre that he can access more easily while he is away. This would satisfy the moral requirements of both the institution and the individual. This however does not appear to be the case, leading me to conclude that the system of ART rationing is not ethical.

Was it ethically correct of the doctor and counsellor to offer ART to K?

The doctor and the counsellor are first of all obliged to follow the policy of the medical centre if it is morally justified. Again, for the sake of argument, I will assume that the policy is morally justified both in terms of the process by which it was made, and in terms of its content. Viewing the doctor and counsellor as staff of the medical centre, I would conclude that they were ethically correct in offering ART to K if he satisfied the criteria for treatment eligibility.

Viewed on the basis of the principle of professional competence stressed both by the Medical Council and by ICMR, however,

one needs to understand more about the nature and content of the counselling received by K. The case description only tells us that K underwent adherence counselling as part of policy for selected patients. The National AIDS Control Organisation describes counselling as "a confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS" (5). The emphasis is on helping clients make decisions that are appropriate in the context of their life circumstances. As a professional it was essential that the counsellor understood K's situation and its implications for treatment, and ensured that K did the same. In addition he needed to have alerted the doctor -- a situation that might have provided an opportunity for the three of them to discuss the issue further so that both the doctor and K could have arrived at a more informed decision about starting ART. This discussion does not appear to have taken place.

This brings up the issue of informed consent, which K would presumably have had to give before embarking on the treatment. Among other things, a principal requirement of consent is substantial understanding of the information material. This means that K: a) needed to have had the information about ART adherence, conditions of availability, consequences of non-adherence, and unavailability of free second-line therapies; b) needed to have understood what this would mean for him in the context of his life; and c) needed an opportunity to discuss with the counsellor potential problems and solutions so as to have made an informed and voluntary decision about the treatment. There is nothing to suggest in the case description that these requirements were met. Here the counsellor has failed to respect the right of the patient to self-determination. As the head of the centre the doctor too is implicated in the counsellor's failures.

When K had to go away for a few months, what should the doctors and counsellors have done?

Having once accepted K on treatment, the doctor and the counsellor should have acted on the basis of the principle of rights-based justice on the one hand and beneficence and non- maleficence on the other. This means ensuring that K continued to receive the treatment that was owed to him, as well as seeing that he was not harmed by its discontinuation. This could have been done through facilitating K to receive ART at an appropriate centre in Bihar.

Is K justified in making claims about human rights and criticising government policy?

The answer to this question is a recapitulation of the points made earlier. We currently do not know how the policy was made and therefore are unable to judge its moral validity. We are also unable to assess the extent to which K made an informed and voluntary decision with regard to treatment. Clearly the policy has failed to respect the principles of beneficence and non-maleficence and of rights-based justice. In addition, starting K on treatment and losing him a few months later does not contribute to fair sharing of scarce resources.

References

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