Should you tell patients about beneficial treatments that they cannot have?

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YES A man who is losing vision in both eyes from macular degeneration seeks the opinion of an ophthalmologist. The doctor knows there is a new treatment that might save the sight of one or both eyes. It is available and doctors are able to prescribe it. But the treatment has not been approved by the National Institute for Health and Clinical Excellence and primary care trusts are refusing to pay for it. What should the ophthalmologist do?

We are not discussing a treatment that the patient wants but that the doctor considers is inappropriate. It is a treatment that is appropriate but cannot be offered purely for financial reasons.

The patient may or may not be willing to pay for it himself; may or may not have family willing to pay; and may or may not be able to sell his car, which he is unable to drive anyway, to pay for the treatment. If the ophthalmologist does not tell him that such treatment exists, the patient will not even be able to consider his options. Depriving the patient of such knowledge is not only depriving him of choice but is a dereliction of professional duty. In this setting it is the doctor who must be the patient's advocate, and it is a betrayal of trust if the doctor does not act in the patient's best interests.

Conflict of interest

In virtually all Western societies the direct costs of medical care are paid by a third party—either the state (or one of its agencies) or an insurer. In many the doctor is independent, being reimbursed for services from the third party payer but not employed directly by it. The doctor has no consequent conflict of loyalty or obligation, although there are inevitable limits on the treatments paid for by such agencies. However, in countries such as the United Kingdom, the provision of medical care is a virtual state monopoly funded from general taxation. Many doctors are salaried employees of the state and hence have a supposed dual loyalty—to their

patients and to their employer. Hence the dilemma is genuine: do doctors owe a primary duty to the state or to the patient?

There can be no simple answer as to which treatments should be funded in an era of ever increasing healthcare costs. Any system of healthcare provision will have a limit on the funding available, and those in control of resource allocation will have to take decisions based on a complex relation between cost, efficacy, and affordability.

This, however, is not the question posed above; rather, it is does the citizen have the right to know which treatments the state or other health provider will fund and those it will not? Furthermore, can an individual make provision for health care over and above what the state will provide without so distorting the structures of society that the state can legitimately refuse to allow it?

Hypocrisy of deceit

I would argue that the answer to these questions must be yes. It is both the right of the citizen to know and the obligation of the doctor to impart this knowledge; otherwise the patient is merely the passive recipient of the largesse of the state and the doctor its passive tool. Notions of patient choice, autonomy, and empowerment are mere cant if patients are kept in deliberate ignorance about an effective treatment which they cannot have as a consequence of the system of funding or reimbursement.

It is entirely reasonable for the state or its agencies to say it will fund certain treatments but not others and that if citizens want unfunded therapies they must make private provision. But it is the grossest hypocrisy for the state to pretend to provide universal health care when it cannot, and worse if the only way of maintaining this fiction is to deprive its citizens of the knowledge of treatments that would benefit them.

It could be argued that it is harmful to tantalise patients with the prospect of a treatment that the state will not fund if they might not be able to afford it. But once patients are empowered by knowledge they can lobby government or appeal to a local or wider community for financial support. They may

also wish to spend their own money on treatment, which they must be at liberty to do. This last option may be available only to the wealthy or those who take out additional health insurance, but it cannot be right to give information only to those who can afford it and keep the poor in ignorance.

There are of course hidden motives for keeping the citizen in ignorance: sharing knowledge with patients about therapies they should but cannot receive exposes the limitations of the health system that those responsible would rather not be made public.

Doctors must be able to work in any society and with any system of healthcare funding and provision. They will inevitably have to accept limitations in what they can and cannot prescribe. What they should not do is connive with any external agency to deceive patients, who are their primary responsibility.

Competing interests: RM has acted as consultant to and has received honoraria from a number of drug companies, none of which are relevant to the case described above.