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Inappropriate requests from patients

Requests from patients may be inappropriate on legal, moral, medical and other grounds – doctors have to ask serious questions to resolve conflicts.

Patients occasionally request interventions that doctors are reluctant to provide. Some of these requests are plainly inappropriate — requests for actions that are illegal, for instance, or for interventions that are clearly and uncontroversially ineffective. But other requests are more difficult. At issue are ethical questions about the proper goals and boundaries of medicine, the nature of the doctor-patient relationship, the proper use of medical resources, and the balance between respecting a patient's judgments about his or her well-being and a professional judgment about what is best for the patient's health.

In few debates have these questions arisen more forcefully, and with more confusion, than in the North American controversy over 'medical futility'. The futility debate first arose in the late 1980s as families of incompetent patients began to ask that doctors continue to provide these patients with life-sustaining treatment, even when it was clear that the patients had little or no chance to recover from their illness or injury. Some of these patients were vegetative or severely neurologically damaged. Others were children — anencephalic infants, for example, or infants with anoxic brain injury. On some occasions, incompetent elderly patients with severe health problems had previously expressed a wish to be kept alive, no matter how burdensome the treatment or how small the chances of recovery. When doctors were faced with requests for interventions they regarded as inappropriate (therapeutically misguided, financially wasteful or insulting to the dignity of the patients themselves) they began to refuse, often

with the response that doctors are not obligated to provide treatment that is 'futile'.

The debate over futility, which generated an extraordinary amount of attention in the medical literature during the 1990s, represented an odd twist on the older debates about the 'right to die'. In the right-to-die debates of the 1970s and 80s, it was *doctors* who insisted on continuing to provide mechanical ventilation, tube feedings and other life-sustaining treatments to patients, often over the objections of the patients' families. Over time, an ethical consensus began to develop in North America, the United Kingdom and elsewhere, not just that patients have a right to refuse life-sustaining treatment, but also that under some circumstances, the families of incompetent patients have a right to refuse on their behalf. This consensus was reinforced by the courts, and it was often grounded in more general claims about the autonomy of patients to determine what was to be done with their bodies, over and against the authority of doctors. So when the tables were turned and patients (or their families) wanted life-sustaining interventions that were expensive, invasive and highly unlikely to restore the patient to health or even conscious life, doctors and their ethicist-defenders turned back to familiar claims about the doctors' authority and medical expertise. Only doctors, they began to claim, have the expertise to determine when treatment is futile.

The difficulty with this claim is that the interventions that futility was invented to describe are often *not* futile. Futility describes the likelihood of an intervention

to achieve a given goal, and if the goal of life-sustaining treatment is simply to keep a patient alive, then clearly it is not futile, for it can effectively achieve that goal. Of course, whether this is a worthy goal for medicine to aim at is a matter for debate. But the debate over ‘medical futility’ merely sidelined the real issues — about the proper goals of medicine, for instance, or the just distribution of medical resources — in favour of a technical debate about the chances that a treatment will work.

The ‘medical futility’ debate is an instructive case study largely because it demonstrates how easily discussions over ‘inappropriate requests’ can go wrong. That debate went wrong because it failed to identify what was really at stake in the disagreement between doctors and patients. The more important question to be asked was: why do families want to keep these unconscious patients alive? And the answer to that question will vary from case to case. Some families may believe that a vegetative patient still has a chance of recovery. Some may believe that it is morally wrong or contrary to their religious commitments to stop life-sustaining treatment. Others may simply wish to keep a patient alive for an important event, such as a birthday or the arrival of a relative from out of town. These reasons must be judged on their own merits and weighed against the reasons clinicians might refuse to provide life-sustaining treatment. But they cannot simply be translated into judgments of ‘medical futility’. It is worth noting that in the USA, when futility cases have gone to court, the courts have generally ruled on behalf of patients, rather than doctors or hospitals.

An important first step for a clinician to take in dealing with a request that seems inappropriate is

to identify what exactly is at issue. Why is the patient making this request, and why might it be considered inappropriate? We have tried to identify a number of requests that doctors might (for different reasons) consider inappropriate. These categories overlap with one another, and they do not exhaust all possible reasons why a doctor may be unwilling to comply with a patient’s request. However, they may help clinicians begin to think about how they might respond to such requests and possible ways of negotiating a resolution.

It is also important to remember that some patients who request interventions that clinicians justifiably believe to be ineffective may actually be looking for something other than a clinical intervention from their doctor.

A TAXONOMY OF PROBLEMATIC REQUESTS

Requests for ineffective treatment

Doctors are not obligated to provide treatments that do not work, such as antibiotics for viral infections. But there is plenty of room for disagreement as to what counts as ineffective. For example, some interventions are marginally effective, offering only a small chance of success. In such cases, patients and doctors might disagree about whether such a small chance of success is worthwhile, especially if the treatment’s side-effects are

risky or harmful. For other interventions, the data on effectiveness are controversial or inconclusive, and the expert clinical community may disagree as to whether they are effective. When experts disagree, patients often find that different doctors offer different types of care. In the USA for example, some doctors treat chronic Lyme disease with long-term antibiotics, often at the request of patients themselves, while other doctors refuse. It is also important to remember that some patients who request interventions that clinicians justifiably believe to be ineffective may actually be looking for something other than a clinical intervention from their doctor (such as advice or a sympathetic listener).

The ‘tied hands’ problem

Sometimes patients request interventions with restrictions that clinicians believe to limit their ability to provide good care. For example, a Jehovah’s Witness may need treatment for a life-threatening illness, but for moral and religious reasons, he or she may specify that the treatment include no blood transfusions. Such requests become even more problematic when they are made on behalf of a small child. Similar issues arise with patients who want to combine their care with alternative medicine or traditional healing. These patients may aggressively pursue several different types of medical care, or they may pick and choose approaches from each tradition. Some doctors may be willing to work with patients to provide this kind of treatment even though they find it less than ideal, while others are unwilling to try it at all, because they are unwilling to provide treatment that in other circumstances would be outside the standard of care.

System limitations

Sometimes patients request treatments that are effective but very

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expensive. In some cases, a less expensive alternative is available for the condition in question, but it is not as effective or has more burdensome side-effects. Is a doctor justified in limiting the interventions available to patients on the basis of their cost? If he or she does refuse to provide the treatment in question, must he or she inform the patient of the reasons for the decision? Public health care systems have limited resources and are often forced to limit the therapies and interventions available to patients as a matter of economic survival. However, in some countries a private health care system operates alongside the public system, while in others, patients have the option of travelling to other countries and paying for care that is unavailable in their own country. While doctors cannot be expected to know about every intervention available outside their health care system, they do have an obligation to be open and honest with their patients.

Inconsistent with the goals of medicine

Some interventions are not medically necessary but may nonetheless improve a patient's well-being. Many doctors are uncomfortable with interventions that are purely cosmetic, for example, yet some of these interventions have become well-entrenched in medical practice. Family doctors routinely remove warts and sebaceous cysts; dermatologists provide adolescents with treatments for acne; in surgery, there are even professional societies for plastic surgeons who operate solely for aesthetic purposes. Yet if the primary goal of medicine is to care for patients who are sick, at some point these interventions become less a matter of medical care (strictly speaking) than of technical intervention for profit. Are diet pills a treatment for the health risks of obesity, or are they just a way to take off weight? Is

paroxetine a treatment for social anxiety disorder, or is it simply a way to help shy people overcome their inhibitions? At issue are larger questions about the expansion of illness, the use of medical interventions to deal with social problems, and the transformation of medicine from a profession aimed at curing or controlling illness into a business aimed at selling clients what they want.

Controversy over the best interests of the patient

Some requests become problematic when the doctor and the patient disagree over whether a given intervention serves the interests of the patient. For example, a patient

At issue is the balance between the doctor's duty to obey the law, his or her responsibilities to patients, and the ways in which a conscientious objector might bring about social or legal change.

might request pain medication that a doctor is reluctant to provide out of fear that the patient will become addicted. At issue here are differing judgments about the balance between the patient's legitimate need for pain relief and his or her long-term health. This kind of controversy can emerge with any intervention that requires personal judgments about the balance between risks and benefits, from potentially toxic chemotherapy to organ transplantation to the use of antipsychotic drugs. When the patient is a competent adult, negotiating a solution to these disagree-

ments must reflect a balance between the doctor's judgment about the clinical effects of the interventions and the patient's personal preferences, individual needs and knowledge about his or her own welfare. When the patient is a child or an incompetent adult, however, these disagreements become even more difficult, because they often involve fundamentally different judgments about the best interests of the patient.

Actions that are illegal but arguably ethical

Doctors have a *prima facie* duty to obey the law, but the law can be morally wrong. How should doctors respond to requests for actions that are illegal, but which they believe to be ethically justifiable? For example, in most jurisdictions euthanasia is illegal, but some doctors and patients believe that it is ethically justifiable in some situations and that it ought to be legalised. Another example is 'gaming the health care system'. Sometimes a patient would benefit from an intervention, but the health care system refuses to pay for it, because the patient does not meet their criteria for payment. Some doctors argue that when a health care system unjustly disqualifies a patient from necessary care, the doctor is ethically justified in falsifying data about the patient or his or her condition in order to ensure that the care is provided and paid for. At issue is the balance between the doctor's duty to obey the law, his or her responsibilities to patients, and the ways in which a conscientious objector might bring about social or legal change.

Contrary to the doctor's personal moral beliefs

Sometimes a doctor may be reluctant to comply with a patient's request because the intervention requested violates their personal moral convictions, even when the

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intervention falls within the current standard of care. Many obstetrician-gynaecologists do not perform abortions, for example.

Other doctors refuse to euthanase patients or assist in their patients' suicides, even in jurisdictions where euthanasia or doctor-assisted suicide is legal. While it is clear that doctors are not obligated to violate their own moral convictions, it is not as clear whether they have any further obligations to patients whose requests they find morally problematic. In some cases it might be argued that doctors should refer their patients to someone willing to provide the requested intervention. For example, some doctors who believe that it is morally wrong to provide what they believe to be substandard care to Jehovah's Witnesses are nonetheless willing to refer these patients to other doctors. On the other hand, a doctor who refuses to perform an abortion on moral grounds will likely disapprove of another doctor performing the abortion, and might feel almost as morally culpable for referring a patient to another doctor as she would actually performing the abortion herself.

QUESTIONS TO CONSIDER

Identifying the conflicts and issues related to inappropriate requests is central to thinking clearly about them. The following questions are meant to help doctors identify requests that are genuinely inappropriate, what issues are at stake in the disagreements over these requests, and the steps that might be taken to resolve the disagreements.

- Why does this patient want this intervention?
- What are the goals of the intervention? Will the intervention achieve these goals? Are these goals consistent with the goals of medicine?

- Does this request fall within the current standard of care?
- Does this intervention serve the best interests of the patient?
- If I morally object to the intervention requested, do I have an obligation to refer the patient to another doctor?
- If I am unable to provide the intervention requested because of financial constraints, do I have an obligation to tell the patient that the intervention is available elsewhere?

FURTHER READING

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IN A NUTSHELL

Patients occasionally request interventions that doctors are reluctant to provide.

Some requests are clearly inappropriate but others are more controversial.

A doctor faced with a problematic request should carefully determine if it is genuinely inappropriate.

Depending on the type of request, doctors have varying obligations to their patients.

Types of problematic requests include:

- requests for ineffective treatment
- the 'tied hands' problem — e.g. religious objection to blood transfusion
- inconsistent with the goals of medicine — e.g. purely cosmetic interventions
- controversy over the best interests of the patient — e.g. request for pain medication which is potentially addictive
- actions that are illegal but arguably ethical — e.g. euthanasia
- contrary to doctor's moral beliefs — e.g. abortion.

SINGLE SUTURE

Plasma cotinine concentrations in passive smokers predict risk of lung cancer

Epidemiological studies have mainly been used to assess the risk of lung cancer in the non-smoking marriage partners of smokers. There has been little quantitative assessment of the extent of exposure to the noxious constituents of tobacco smoke as indicated by markers of inhaled smoke. A study using plasma cotinine concentration as a measure of the amount of exposure to tobacco smoke was conducted recently in England. It showed that the implied increase in risk of lung cancer in non-smokers with smoking partners is consistent with the risk observed in epidemiological studies. Smoking by partners in the home is a major source of non-smoking adults' exposure to passive smoking.

It is probably true to say that this same conclusion would apply to children in the home, and be much more severe in its effects — Editor.

(Jarvis M J et al. *Tobacco Control* 2001; **10**: 368-374.)