EDITORIAL

The ethics of refusing medical treatment

La Ética de Rechazar un Tratamiento Médico

In the article "Rejection to Medical Interventions," Gregorio Palacios, Benjamin Herreros, and Eloy Pacho propose a series of helpful steps to guide physicians when patients refuse indicated medical interventions. These steps are as follows: (1) provide complete information, (2) determine if the patient can decide, (3) determine if the decision is free, (4) analyze the patient’s decision, (5) attempt to persuade the patient, (6) consider conscientious objection, (7) make the decision, and (8) offer available alternatives. The authors illustrate these steps with a case study involving a 61-year-old Jehovah’s Witness (JW) male with hemophagocytic syndrome who refuses an indicated blood transfusion and opts for a more expensive alternative treatment of etoposide, corticosteroid, erythropoietin, and romiplostim.

The refusal of blood by JWs is one of the most common and well-known examples of refusing medical treatment. Refusing a transfusion occasionally results in death, but it is based on a well-understood and widely practiced religious tradition that should be honored on the basis of the freedom of conscience. The main concern is whether the refusal is made autonomously, and steps one through four above address this concern well. Also, the steps appropriately rule out the refusal of blood for patients who are too young to decide for themselves. In the case of the 61-year-old JW male, the patient has been informed of the consequences of his refusal, is competent to make the decision about his treatment, and is choosing freely.

There is some debate over whether the JW practice of disfellowshipping makes the autonomy of such refusals doubtful. Disfellowshipping is the practice of excommunicating members who disobey the Bible and do not repent, which can happen to a JW who accepts a blood transfusion. As one author argues, disfellowshipping amounts to coercion and intimidation. Nevertheless, religious excommunication is not in itself coercive, and there is little evidence – and some direct denial – that the JW practice of disfellowshipping is a pernicious, cult-like form of it.

Anyway, this should be considered in step three, and if a physician senses that the patient wants, but is afraid to, accept the transfusion or is deferring to someone else in the room, discussion should resume when the patient is alone, if possible.

In step five, Palacios et al. say that physicians ought to persuade patients to change their minds, but this raises difficult questions. How much persuasion is too much? Is persuasion always appropriate? Julian Savulescu and Richard W. Momeyer argue that the beliefs of JWs are irrational and that physicians should help their patients think more rationally. While Savulescu and Momeyer’s criticisms of JW beliefs are problematic, they correctly acknowledge that there are times when persuasion is appropriate and times when it is not: "Physicians, whose primary obligations are to the medical wellbeing of patients, will do well to resist the secondary obligation to promote rational criticism of deeply held beliefs at a time when their patients are impaired and suffering greatly. Thus the time to engage a hypothetically irrational JW in a critical enquiry about her convictions on 'eating blood' is not the time at which she might benefit from an immediate blood transfusion because her life is in jeopardy."

Perhaps the best time and occasion for persuasion would be in step one, in providing the information. In the recent literature, nudging has been suggested as the best way to resolve the tension between patient autonomy and concern with the patient’s wellbeing. Nudging is simply the altering of "choice architecture," using scientific evidence about how people choose in order to raise the likelihood of a particular outcome. Incorporating a nudge in the present case might mean providing the patient with the success rates for transfusions or telling stories about patients who did not refuse. When dealing with religious beliefs, nudging would be preferable to rational criticism because nudging avoids engaging in fruitless theological debate and may more quickly address the heart of the matter: what the patient herself actually believes, not what her religion teaches.

Finally, Palacios et al. raise the difficult question of whether the public health system should shoulder the costs...
for these expensive alternative treatments or whether patients should pay for them. The authors correctly suggest that the decision whether to offer more expensive alternatives should not rest with the physician but with the hospital or political system. The physician’s primary obligation is to her patients’ wellbeing, and as Edmund Pellegrino says, “It is not morally defensible for society to ‘unload’ its unpleasant rationing decisions on physicians”. Nor can it run the risk of physician bias or prejudice in the way resources are rationed in individual cases. Patients who are denied some needed care must recognize that it is the whole of society that has denied them and under constraints that apply to everyone.**

The best way to protect the freedom of conscience in the clinic and make tough decisions about cost containment is for hospitals to be neutral in regards to whether treatment requests or refusals are religiously motivated or not. For example, if a hospital does not honor religiously based requests for futile treatment at the end of life, say when family members are holding out hope for a miracle, then it also should not honor requests for futile treatment for non-religious reasons. In the case at hand, hospitals, or insurance companies, should decide whether they will allow expensive alternative treatments for patients who refuse an indicated blood transfusion irregardless of whether there is a religious motivation or not.

References

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