Case One: Patient Interests and Medical Paternalism

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A 16-year-old Hodgkin lymphoma patient refuses to have his blood specimen drawn, thus canceling his scheduled oncologic treatment. As a 16-year-old, he has no legal standing as an adult. His parents are split over his decision. One supports his right to choose; the other wishes the specimen to be drawn and the chemotherapy reinstated. The physicians at the hospital are seeking legal redress to have the court order the blood specimens to be taken.

INDEX TERMS: autonomy; bioethics; informed consent; Kant; Mill; utilitarianism.

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The most fundamental question presented by this case is, "Who is in position to judge what is in the patient's best interest?" To many, the answer seems clear. Respect for the autonomy of the patient requires that he have the power to make decisions regarding his medical treatment. That is, there is a presumptive case in favor of allowing patients the right to determine for themselves the course their lives will take, and this includes the course their medical treatment or non-treatment will take. This rests on the assumption that patients are capable of exercising autonomy. But, what is required for a person to be in a position to exercise genuine autonomy?

In order to make autonomous decisions two conditions must be satisfied. First, the agent must be minimally rationally capable. In other words, a patient must be capable of recognizing and weighing differences between diverse treatment options, and then be able to reach a reasoned conclusion. In this case, the issue is complicated by the fact that the patient is a minor. Nevertheless, that we have chosen the age of 18 to be the 'age of reason' seems arbitrary, and certainly there is a case to be made that many persons under the age of 18 meet the condition of minimal rationality. The second condition for autonomous action is that the individual must have knowledge relevant to making *informed* decisions. Though one may have the rational abilities to make decisions with respect to investing money in the stock market, he might lack the knowledge to make informed choices. Hence, he should rely on others with knowledge to make decisions on his behalf. Likewise, we may wonder whether patients can make informed choices regarding their medical care.

So, does the young patient meet these two conditions? Actually, he fails on both counts. With respect to the first condition: acting according to our perceived interests is insufficient to guarantee that we have exercised autonomy, since we can, and often do, act in ways that we want but which are counter to our actual interests. In order to make an autonomous decision we must at least be able to disambiguate our true from our perceived interests (even if, in the end, we choose against them).[1] However, this requires us to take an objective and emotionally detached stance with respect to our own desires. This is difficult when we are confronted with life circumstances that hinder objectivity relative to our presently perceived interests.[2] In such circumstances, it would be in our interest to trust those who are capable of making emotionally detached judgments.

Often patients are so deeply invested in the circumstances of their lives it is a real question whether they can achieve the sort of objectivity necessary for rational choice. Patients, therefore, are unreliable authorities with regard to their best

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interests.[3] Obviously, people make mistakes adjudicating between what is or is not a genuine interest in many situations. But, certain life circumstances make it more likely (and sometimes even probable) that a person will err. Confronting a medical condition is one among these life circumstances that make it more difficult for a person to make rational, sound, and determinate judgments. Consequently, our patient is not the final authority regarding his own medical interests, *and neither are his parents*, as they also are too emotionally invested to be objective.

Moreover, patients rarely have access to the relevant knowledge requisite for making informed decisions. The complex medical data affecting even the most mundane of medical procedures is often accessible only to those who have spent their life specializing in such knowledge. Thus, even if the patient is somehow able to detach himself from his own life circumstances in order to make an objective determination of his interests, he is not necessarily in a position to make an *informed* decision since he may not have access to all of the relevant information. Some might argue that physicians and medical staff have a moral duty to inform the patient so that he can make the decision. But is that even possible, let alone desirable?[4] Given the haste with which many medical decisions must be made, and given the years of experience that guide physicians and medical staff in making decisions, it is implausible to suppose that physicians can ever adequately inform patients about *all the relevant* medical information necessary for informed choices. It takes years of intense schooling and focus to gain such knowledge, and in the context of immediate patient care it seems irresponsible to expect patients to be able to gather, synthesize, and understand everything relevant to their condition when doing so took their specialized physicians years.

Thus, it appears that neither the patient nor his parents are positioned to make informed and accurate choices. Rather, physicians are those positioned best. Certainly, physicians can make mistakes, so we need to ensure that decisions are informed by medical standards. Physicians are not infallible, but they are less fallible than their patients. Giving authority to the persons most aptly situated to make accurate judgments concerning patient medical needs is the most rational course of action. Therefore, we should adopt a policy of limited medical paternalism, whereby physicians are considered final authorities regarding patient healthcare interests.[5]

Hence, if the physicians believe it will serve the patient's medical interests to continue his chemotherapy by having his blood specimen drawn, they should be granted the authority. The patient and his medical proxy are incapable of making autonomous decisions. So, we should rely on those who are in the best position, all things considered, to make judgments regarding the medical needs of the patient: we should trust our physicians.

ENDNOTES

1. For further reading on the conditions of autonomy, see: Mill JS. On Liberty [1859]. Hackett Publishing; 1978, especially "Chapter Three"; and Dworkin G. The theory and practice of autonomy. Cambridge: Cambridge University Press; 1988.

2. For an interesting discussion concerning how certain medical conditions can hinder a person's ability to distinguish their genuine interests from presently perceived interests, see: Groarke L. Paternalism and egregious harm: Prader-Willi syndrome and the importance of care. Public Affairs Quarterly 2002;(16):3.

3. Arguments that detail the conditions necessary to be a final authority with regard to one's interests can be found in: Taylor C. What's wrong with negative liberty? In: Ryan A, editor. The idea of freedom. Oxford: Oxford University Press; 1979. Taylor makes a claim stronger than the one above, in that he argues that an individual is never a final authority with respect to his interests due to the inescapability of his emotional investment in his own life. Though, for the argument of this paper, the weaker claim that an individual can sometimes be so emotionally invested in present circumstance that he can be disqualified as a final authority with regard to his interests is all that is required.

4. For a discussion concerning possible responses to this question see: Lipkin M. On telling patients the truth. Newsweek, 1979 Jul 4.

5. For general defenses of limited paternalism see: Dworkin G. Paternalism. Monist 1972;(56):1; Raz J. The morality of freedom. Clarendon Press; 1986; and Hart HLA. Law, liberty and morality; Palo Alto: Stanford University Press; 1963.