

Case One: Patient Autonomy and the Freedom to Act against One's Self-interest

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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.

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Are people uniquely qualified to decide what is in their best interest? At what age? This case raises compelling questions concerning the role of paternalism in healthcare, and the asymmetrical nature of the physician-patient relationship. A patient often willingly surrenders some autonomy to the

physician who, as an expert, may be in a better position to recognize what is in the patient's best interest. Moreover, one of the legitimate aims of government is ensuring the well-being of its citizens. When we apply these positions to circumstances in which a patient does not have the ability to deliberate, such as small children and mental illness, the case for restricting patient choice seems straightforward.

However, one can advance an argument in favor of patient autonomy *when the patient meets the minimum standards of rationality*.¹ This argument does *not* defend patient autonomy by reference to the intrinsic value of the individual.² Rather, one can argue that it is the *quality*, not length of life that is important.³ Further, it should be up to each individual to decide what minimum quality of life is acceptable.⁴

Some argue a patient is never in a position to give *informed* consent because he or she cannot appropriately judge the advice of the physician. To achieve informed consent the patient must be competent to understand the details of his or her situation; must be provided all the relevant information; and must be free from coercion.⁵ In our case, the patient has refused to have a blood specimen collected. Furthermore, the parents have not decided what is in his best interest. Absent a decision, the 16-year-old's autonomy should be protected. To impose a minimum age requirement on when an individual is capable of rationally deliberating for him or herself is arbitrary. In the case under consideration, while the 16-year-old patient does not have legal status as an adult, presuming he is a "normal" 16-year-old, he may meet minimum standards of rationality necessary for informed consent. United States law considers a person who is at least 14 years old to be eligible for legal emancipation so it could be construed that a 16-year-old is capable of judging self-interest, regardless of legal standing as a minor.⁶

Is it ever legitimate for a government or physician to restrict the actions of citizens or patients for their own good, even when the citizen is capable of acting rationally? Many argue that the individual freedom of a rational adult should never be restricted unless it interferes with the freedom of another. This is the *harm principle*.⁷ In fact, a basic feature of individual autonomy is the ability for people to choose things that are

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not good for themselves. So, while the physician may in fact be the only one qualified to determine what is in the patient's best interest, it is still up to the patient to decide whether he will act in self-interest.

Key to assessing this issue is the recognition that it is the *quality*, not the length, of life that is important. Sometimes the pain of an illness or its treatment creates more suffering than a patient is willing to endure, even for a promise of a better life in the future. Moreover, it is up to the individual to decide what minimum quality of life is acceptable. And no one is in a better position to make this judgment than the individual. Thus, even if a physician is in a better position to know the patient's best interest, it is still the choice of the patient to refuse treatment if he views the harm as too great. Autonomy means the ability to choose things that are not in one's self-interest. Compelling people to act in ways for their own good is never legitimate.⁸ Thus, the issue is *not* who is in a better position to judge what is in the patient's best interest, for even conceding the role of expertise to the physician a patient should be allowed to choose to act against his self-interest.

One might advance further arguments that the individual, barring irrationality, is *always* in a position to judge what is in his self-interest, but this is unnecessary. What needs to be demonstrated is not what is in the best interest of the patient, but whether the patient meets the minimum standards for informed consent.

ENDNOTES

1. "Minimum standards of rationality" involves the capability to understand a concept, to reflect on a subject, and to make inferences and draw conclusions from a set of facts. See Audi R. Theoretical rationality: its sources, structure, and scope. In: Mele AR, Rawling P, editors. *The Oxford handbook of rationality*. Oxford: Oxford University Press; 2004.
2. This refers to a Kantian deontological argument, where it would violate the intrinsic worth of an individual to treat him or her as a means instead of an end. See Kant I. *Groundwork of the metaphysics of morals* [1785]. Cambridge: Cambridge University Press; 1997.
3. This is essentially a consequentialist argument, wherein life only has value insofar as it brings the person happiness. I am also alluding here to Mill's distinction between the quality and quantity of life. See Mill JS. *Utilitarianism* [1863]. Crisp R, editor. New York: Oxford University Press; 1998.
4. For a compelling argument in favor of this claim, see the case of Dax Cowart: *Confronting death: who chooses, who controls? A dialogue between Dax Cowart and Robert Burt*. *Hastings Center Report* 1998;28(1):14-7.
5. For a further explanation of the conditions for informed consent, see the Principles of the Nuremberg Code [1946-1949]. Available from <http://www.cirp.org/library/ethics/nuremberg/>. Accessed 2008 Jan 15. Though these principles are immediately concerned with the conditions of legitimate use of human subjects in medical experiments, the conditions for informed consent can be applied to consent to medical treatment.
6. See http://usmarriagelaws.com/search/united_states/emancipation_of_minors/index.shtml. Accessed 2008 January 15.
7. For a discussion and defense of the Harm Principle, see Mill JS. *On liberty* [1859]. Indianapolis: Hackett Publishing; 1978.
8. For a defense of this claim, refer to Feinberg J. *Harm and self-interest*. In: Feinberg J. *Rights, justice, and the bounds of liberty: essays in social philosophy*. Princeton: Princeton University Press; 1980.