

This edition first published 2014
© 2014 John Wiley & Sons, Inc

Edition history: Prentice Hall (1e, 2001)

Wiley-Blackwell is an imprint of John Wiley & Sons, formed by the merger of Wiley's global Scientific, Technical and Medical business with Blackwell Publishing.

Registered Office

John Wiley & Sons, Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

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Library of Congress Cataloging-in-Publication Data

Medical ethics / edited by Michael Boylan. – 2nd ed.

p. ; cm.

Rev. ed. of: Medical ethics / Michael Boylan. c2000.

Includes bibliographical references.

ISBN 978-1-118-49475-2 (pbk.: alk. paper)

I. Boylan, Michael, 1952– II. Boylan, Michael, 1952– Medical ethics.

[DNLM: 1. Ethics, Medical. W 50]

R724

174'.2–dc23

2013016777

A catalogue record for this book is available from the British Library.

Cover image: Llanrwst Bridge, Conwy River, Wales © Martin Stavars, martinstavars.com
Cover design by www.simonlevy.co.uk

Set in 10.5/12.5pt Dante by SPi Publisher Services, Pondicherry, India
Printed in Singapore by Ho Printing Singapore Pte Ltd

Medical Ethics

Second Edition

Edited by Michael Boylan

WILEY Blackwell

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A. Paternalism and Autonomy

Medical Paternalism and Patient Autonomy

JOHN-STEWART GORDON

Introduction

According to Julian Savulescu and Richard W. Momeyer, it can be the case that patients suffer from irrational beliefs with regard to medical decisions they may be called upon to make. It may be that (1) their decisions are often based on ignorance, (2) patients do not devote enough attention to rational deliberation, or (3) patients may make mistakes in deliberation (Savulescu and Momeyer 2000, p. 129). With reference to such beliefs, the authors rightly argue that "it is the responsibility of physicians not only to provide relevant information (which addresses 1), but to improve the rationality of belief that grounds consent (2 and 3)" (Savulescu and Momeyer, 2000, p. 129). Admittedly, patients are not usually experts in either medicine or ethics and are therefore inexperienced in ethical reasoning and decision-making. Therefore, patients need the expertise and experience of physicians in order to make well-informed decisions. Given these circumstances it is to some extent understandable why physicians adhere to the idea of medical paternalism. However, the importance of patient autonomy needs to be stressed very strongly. It seems fair to say that, over the last 2500 years or so, physicians have adopted a disposition toward their patients based on the *Corpus Hippocraticum* (Hippocratic Corpus), which has made it almost impossible for them *not* to be paternalistic. The twentieth century has seen many atrocities conducted in the name of medicine and performed by physicians (e.g. during the Nazi era, the Tuskegee Syphilis Study, human radiation experiments). A general revulsion after the occurrence of such atrocities certainly contributed to the rise of patient autonomy and patients' rights. Nowadays, the idea of patient autonomy is highly influential and the right of a competent person to make autonomous decisions related to medical matters is acknowledged in many countries. This chapter gives an overview of some of the important issues related to medical paternalism and patient autonomy.

Preliminary Distinctions

According to Joel Feinberg, it is necessary to distinguish between two types of paternalism. The first type can be called "strong paternalism" and the second "weak paternalism" (Feinberg, 1971). Weak paternalism describes cases where a person's

decision will be overruled because that person is deemed unable to make an autonomous and competent decision in his or her own best interest. Strong paternalism describes a situation in which someone is acting on another person's behalf without his or her consent when that person is competent and autonomous. The latter case is an instance of interfering with a person's civil rights and liberties. It was John Stuart Mill who famously set out the first systematic anti-paternalistic critique of (weak) paternalism in his important book *On Liberty* (Mill, 1859), where he argued that only in cases of a possible danger to third parties should a person's right to self-determination be limited. Medical paternalism is not only confined to weak paternalism but also covers strong paternalism. In addition, (medical) paternalism is not only about interfering with a patient's freedom of action, but also concerns either the withholding of vital information or the practice of misinforming the patient about his or her health condition, that is, undermining his or her right to freedom of information.

The Birth of Medical Paternalism

The Hippocratic Oath and the self-conception of the physician

The *Corpus Hippocraticum* (500 BC) was the first collection of important fragments of medical practice and medical ethics in early European history that could be seen as a general ethical guide for physicians. In this text, the physician is portrayed as a virtuous godlike healer with great authority and expertise that justifies paternalistic decision-making. The dominance of the approach of the *Corpus Hippocraticum* can be easily detected by its widespread use on a global level. All physicians are nowadays obligated to swear the Hippocratic Oath and to meet the demands stated in the *Corpus Hippocraticum*. The *Corpus Hippocraticum* contains the two leading principles of medical ethics, namely, the principle of non-maleficence (*primum nil nocere*) and the principle of beneficence (*salus aegroti suprema lex*). Furthermore, it prescribes—among other things—the principle of physician-patient confidentiality, it forbids taking sexual advantage of the patient, and it allows for acting against the declared patient's will, if it is for the sake of the patient.

Over the last 2500 years, the *Corpus Hippocraticum* has deeply influenced the self-conception of physicians as godlike healers who deal with the most important human good, namely, the health of human beings. Good physicians, admittedly, have to be true experts in medicine in order to save lives and to defy death. Even with respect to less serious matters than life and death, most people tend to have a high degree of respect and honor for physicians. They are generally regarded as an outstanding group of people because it is thought that they perform such a difficult task in such a professional manner that it simply far exceeds their own capacities, knowledge, and intelligence to such a great extent that they cannot help but gaze in wonder, independently of whether this is always the case or not. Interestingly, however, many people not only see physicians as godlike healers but also think that they are (almost as) good at other tasks as well (as if they were also experts in other numerous fields), which is, of course, an absurd assumption. To put it in a nutshell, physicians have almost always been highly regarded and well respected, which, in turn,

has influenced their self-conception accordingly. This is the background of medical paternalism as a kind of “natural disposition” of physicians.

Justifying medical paternalism

What are the reasons for medical paternalism? We have already seen that the amalgam of the complex physician-patient relationship in terms of praising the praiseworthy is rather an explanation for *why* there is medical paternalism but not a justification for *why* there *should be* medical paternalism. In other words, one should seek some valid arguments to justify this position. There are, at least, three main arguments—the physician knows best, the patient may be overwhelmed by the situation, and there may be a significant risk—in favour of medical paternalism, and these will be examined below.²

The physician knows best

The idea that the physician should decide what is in the best interest of his or her patient—even if it means that some decisions are made against the will of the patient—is derived from the physician’s powerful standing as a great expert in matters of life and death related to human health, in addition to his or her great expertise in and knowledge of medicine. Against this background, the very idea to leave it up to the patient to decide which treatment plan should be followed seems almost ludicrous. The “normal” patient is usually incompetent in terms of medical knowledge and its application to specific cases (including his or her own case). If this is the case, why should the physician respect the will of the patient at all?

Doubtless, the physician is an expert and will be able to help the patient. However, it does not necessarily follow that a patient would definitely have no say with regard to the treatment plan. One might object that one must consider the particular circumstances of a given case (i.e., context-sensitivity). For example, it is certainly true that in emergency cases a patient will be unable to make a good decision—if he or she is still responsive—and hence the physician should make the decision for the sake of the patient in the patient’s best interest. In other cases, however, a different strategy is more appropriate, for example, in non-extreme cases in which the patient’s will and autonomy should be respected. All depends on the given circumstances of the particular case. Even in extreme cases such as end-of-life issues, and in particular euthanasia, it should not be entirely up to the physician to decide what the patient should do (Gordon *et al.*, 2011). Ethical reasoning and decision-making in extreme cases is strongly dependent on the personal worldview, idiosyncratic life history, cultural context, religious views, and value system of the particular patient, which have to be taken into account in order to make a good decision. Hence, it does not follow that the physician should, in general, decide what the patient must do. Physicians are morally obligated to respect the autonomy and the will of the patient, even if they disagree with the personal decision of the patient in question (see Mill’s line of argumentation against anti-paternalism in *On Liberty*).

The patient is overwhelmed by the situation

Each diagnostic and therapeutic medical intervention can potentially present a problem for the patient’s self-determination, because it limits his or her capacity to

make good decisions—at least to some extent—because of the following factors: experiencing pain, physical and psychological distress, and ignorance/unknowingness (the list is not complete). Hence, medical paternalism is, in general, preferable since the damage to the patient’s health in cases of non-compliance with the physician’s decision may be a greater loss than the comparably smaller damage related to the limitation of patient autonomy.

If the patient is overwhelmed by the situation, for example, in emergency cases, then it seems appropriate to follow the physician’s advice. But the idea that *each* medical intervention undermines the patient’s self-determination and hence the physician should make the decisions in all cases is certainly exaggerated. Furthermore, in extreme cases where there is a living will while the patient is not responsive, the physician must consider the will of the patient and take it as seriously as possible. Otherwise, the physician should be held accountable for acting against the declared living will or current will of the patient. Patients are not little children who constantly need guidance and whose “decisions” can be easily overruled by their parents.

The significant risk

A good argument in favor of strong paternalism, according to its proponents, can be found in cases where either the non-action of the physician or the non-compliance of the patient directly leads to a significant risk of ill health with regard to the particular patient. Since the patient does not want to worsen his or her situation, he or she must accept a legitimate sense of medical paternalism.

The above-mentioned argument in support of strong paternalism presupposes that each patient is always interested in doing everything within his or her power to either remain healthy or to regain his or her strength. It can easily be the case that a particular person wants to commit suicide because of his or her ill health (or other reasons) and does not want to comply with the physician’s decision to have more painful surgery, or such like. At some point the physician must accept that sometimes treatment is either futile or that the patient feels that his or her life is no longer worth living.

The Invention of Patient Autonomy

The notion(s) of autonomy

Generally speaking, a decision is autonomous if the person can be held accountable for his or her actions. The idea of patient autonomy, with particular regard to the notion of individual informed consent, is a modern invention and it is now standard practice for the patient’s consent to be obtained with regard to a treatment plan if the patient is competent. In cases where the patient is incompetent, due to factors such as severe depression, mental disability, old age, or if they are suffering from Alzheimer’s, a surrogate decision-maker—either a family member or a legal official—must be appointed to make decisions in the best interest of the patient.

Many authors wrongly assume that the notion of informed consent has its origin in the Nuremberg Code (1947). This resulted from the famous Nuremberg trial (1946–7) of German physicians who carried out research on human beings during

the Nazi era without obtaining the consent of their guinea pigs (mostly Jews). Among the 10 universal moral principles of the Nuremberg Tribunal's judgment was one exclusively directed to the issue of research on human beings. This principle is the principle of autonomy, which contains the proposed "new" idea of informed consent. In fact, however, the idea of informed consent has a different historical origin. In particular, the idea of individual informed consent is due to the Prussian and German bureaucratic regulations of 1900/01 that appeal to the case of Dr Albert Neisser in 1896, who publicly announced his concern about the possible dangers to the experimental subjects whom he vaccinated with an experimental immunizing serum. Additionally, the investigation of the deaths of 75 German children caused by the use of experimental tuberculosis vaccines in 1931 revealed that the *mandatory* informed consent was not obtained. Robert Baker rightly states that "[t]he informed consent doctrine was thus originally a regulatory innovation created by Prussian bureaucrats. It was not an artefact of American legal or philosophical culture but of German bureaucratic culture. It was a German solution to problems created by the advances of German biomedical science" (Baker, 1998b, p. 250). Admittedly, Baker's following comment on this point is certainly true: "It is indeed ironic that the 1931 German position on *informed* consent to research on human subjects was considerably more advanced than anything in Anglo-American ethical or legal theory at the time of the Nuremberg Trial. Compounding the irony, the Nuremberg Tribunal may be the first *American* court to introduce the *German* idea of *informed* consent into American law and thus into American and international medical ethics" (Baker, 1998b, p. 269).³

The elements of (individual) informed consent are described clearly by Tom Beauchamp and James Childress in their influential book *Principles of Biomedical Ethics* (Beauchamp and Childress, 2009, pp. 99–148). The following brief and self-explanatory depiction is taken from their book (Beauchamp and Childress, 2009, pp. 120–1).

Elements of informed consent

- Threshold elements (preconditions):
 1. competence (to understand and decide);
 2. voluntariness (in deciding).
- Information elements:
 3. disclosure (of material information);
 4. recommendation (of a plan);
 5. understanding (of 3 and 4).
- Consent elements:
 6. decision (in favor of a plan);
 7. authorization (of the chosen plan).

In *Global Ethics and Principlism* (Gordon, 2011) I state that "Beauchamp and Childress propose that obtaining an individual's informed consent, which is, according to Western medical practice, an ethical and legal requirement (Agard *et al.*, 2000, p. 154)

is a specification [of] the principle of autonomy (Beauchamp and Childress, 2009, pp. 117–35). However, non-Western countries such as China, Japan and most African countries do not share the idea of individual informed consent in biomedical ethics. Instead, they generally demand that either family- or community-informed consent should be obtained in cases such as life-threatening diseases, breaking bad news at the bedside of terminally ill patients, human research experimentation, and female circumcision/mutilation." (Gordon, 2011, p. 261). The implication of this is that patient autonomy is not only limited to individual-informed consent, but also includes family- or community-informed consent. This is an important observation, since the viewpoint of the family may clash with the family member's decision in, for example, end-of-life cases (e.g., euthanasia) or in cases where the family wants to withhold information from the sick family member for the sake of the person in question (bedside rationing, truth-telling).

What is *in* the best interest of the patient? The case of truth telling

A classic case in which patient autonomy and patient rights have been (and are still) neglected on a regular basis concerns terminally ill (cancer) patients and the common idea that one should not inform the patient in question about his or her bad prognosis. This policy was often carried out in many Western countries until very recently and is still common in some non-Western countries such as Japan (Macklin, 1999). The underlying assumption in support of this paternalistic reasoning is the idea that to inform the patient about his or her severe condition, that is, to tell the truth, would not be beneficial to the patient as the knowledge would be likely to harm the patient because he or she might, in addition, develop a severe (suicidal) depression, which would worsen the condition and most likely hasten death. Hence, it follows that one should not inform terminally ill patients about their true condition because it would not be in the best interest of the particular patient.⁴ However, this line of argument not only obviously undermines the patient's autonomy (i.e., *individual* informed consent) and individual rights but also his or her dignity. Furthermore, it seems inappropriate not to give patients the opportunity to settle their affairs, for example, to say goodbye to their family (depending on who makes the decision to not inform the person), relatives, and close friends. Additionally, it also poses a problem in that patients are not given the chance to reconcile themselves with friends or relatives or some family members with whom they may have been in conflict. If one does not know that one will die (very) soon, then one cannot take appropriate steps to settle one's affairs in an appropriate manner. Of course, most patients might "feel" that they will most likely die soon but "to feel that one will die soon" is certainly not the same as "to know that one will die soon." The issue in question concerns this "small" but vital difference and there is no easy solution to the problem. To put it in a nutshell, one might cause patients some additional harm (e.g., depression), but helping them to settle their affairs certainly benefits patients. Ultimately, telling them the truth is now seen as the most ethical course and the most beneficial with regard to patients' peace of mind.⁵

The Four Models of the Physician-Patient Relationship

Ezekiel L. Emanuel and Linda L. Emanuel (1992) elaborated four different models to illustrate the dynamics of the physician-patient relationship: the informative, the interpretive, the deliberative, and the paternalistic model:

- **Informative Model**
 - a. Patient values: Defined, fixed, and known to the patient.
 - b. Physician's obligation: Providing relevant factual information and implementing patient's selected intervention.
 - c. Conception of patient's autonomy: Choice of, and control over, medical care.
 - d. Conception of physician's role: Competent technical expert.
- **Interpretive Model**
 - a. Patient values: Inchoate and conflicting, requiring elucidation.
 - b. Physician's obligation: Elucidation and interpreting relevant patient values as well as informing the patient and implementing the patient's selected intervention.
 - c. Conception of patient's autonomy: Self-understanding relevant to medical care.
 - d. Conception of physician's role: Counsellor or adviser.
- **Deliberative Model**
 - a. Patient values: Open to development and revision through moral discussion.
 - b. Physician's obligation: Articulating and persuading the patient of the most admirable values as well as informing the patient and implementing the patient's selected intervention.
 - c. Conception of patient's autonomy: Moral self-development relevant to medical care.
 - d. Conception of physician's role: Friend or teacher.
- **Paternalistic Model**
 - a. Patient values: Objective and shared by the physician and patient.
 - b. Physician's obligation: Promoting the patient's well-being independently of the patient's current preferences.
 - c. Conception of patient's autonomy: Assenting to objective values.
 - d. Conception of physician's role: Guardian.

Their important article, "Four models of the physician-patient relationship," has come to be regarded as authoritative and has been very influential in the field of medical ethics (Emanuel and Emanuel, 1992, pp. 2221-7). The traditional paternalistic model, in which the physician is seen as an unquestioned guardian, and the (extreme libertarian) informative model, where the physician is a mere handmaid with great expertise (e.g. in cosmetic surgery), can be seen as the two extremes of the physician-patient relationship. The interpretive and the deliberative models are moderate approaches. Against this background, it seems crystal clear that one should avoid the extreme models and try to adhere to moderate approaches in order to maintain patient autonomy and to limit the influence of paternalistic reasoning and decision-making in

medical ethics. There is no good reason to simply accept the idea that there is no problem in undermining a competent person's autonomy and thereby to limit his or her self-determination (see "What is in the best interest of the patient? The case of truth telling" above). Strong and weak forms of paternalism need to be justified well and must only be applied to special cases, that is, in emergencies. They should not be regarded as the general way to proceed but should only be considered as exceptions.⁶ In the following three cases, the ethical problems of medical paternalism are examined briefly within the context of the previous discussion.

Vital Issues Concerning Medical Paternalism

Research on human subjects

Medical experiments, for example, experiments on hypothermia, high-altitude studies in decompression chambers, forced sterilizations of women with X-rays, and experiments to make sea water drinkable, which were conducted on Jews by Nazi physicians in Germany, are only one example of (medical) research involving physicians (Annas and Grodin 1995). The Tuskegee Syphilis Study, in which US physicians studied the natural spread of syphilis among African-Americans between 1932 and 1972 in Tuskegee, Alabama, is another example (NCPHS, 1979). Finally, the Human Radiation Experiments conducted on prison inmates by physicians in the United States during the Cold War period, where some inmates and their food were contaminated with radioactivity, is yet another example of medical research on human subjects (Advisory Committee on Human Radiation Experiments, 1996). What all these cases have in common is that no individual informed consent was obtained, even though it was legally necessary to do so. It is fair to claim that no research subject would have given their consent if they had had any relevant information about the details of the given research in the above-mentioned cases. In this respect, medical paternalism and patient autonomy are—at least to some extent—mutually exclusive. It is a "golden rule" that physicians and researchers are obligated to obtain the individuals' informed consent when it involves research on human subjects—a rule articulated by the Nuremberg Code (Trials of War Criminals Before the Nuremberg Military Tribunals under Control Council Law, 1947), the Declaration of Helsinki (World Medical Association, 1964), and the Universal Declaration of Human Rights (United Nations, 1948). But even in our time, some pharmaceutical companies conduct research on human beings in developing countries because the requirements are less stringent than in their home countries (Macklin, 2004). The upshot is that medical paternalism is liable to abuse in a wide range of different cases. If this is the case, however, why not take *patient autonomy* seriously in order to avoid the slippery slope? Medical paternalism is based on or presupposes a trusting relationship between patients and physicians. This trust may become treacherous and misleading in cases of abuse where the research subject is harmed. In such cases, the physician uses the trust which has been established to conduct his or her research, not for the sake of the patient but for the sake of the research. This is one of the main reasons—among others—why the abuse is so abominable.

The incompetent patient and surrogate decision-making

There are quite a few cases where a person may suddenly lose his or her autonomy and hence become incompetent, by virtue of a severe accident, for example (other cases may include persons with a mental disability⁷). The patient, therefore, needs a surrogate decision-maker. If the accident was very bad and the patient is in coma and the prognosis means that recuperation is impossible, then the question of what to do remains. Sometimes people have made a living will that depicts the kind of circumstances under which they would, for example, wish to be unplugged from a respirator, and so on, and be left to die in peace and dignity, according to their personal beliefs, because they may have decided that such a life would simply not be worth living (e.g., the Terri Schiavo case; see Caplan *et al.*, 2006). If this coincides with the viewpoint of the surrogate decision-maker—who is either a family member or a legal official—then the patient in question might be unplugged from the respirator given that there is no probability of recuperation. This last step, however, could bring some great problems. Physicians, including members of the administration, working at a hospital are usually not very keen to comply with such demands and often opt out by claiming that such a procedure is against their professional ethos (i.e. the Hippocratic Oath), their conscience, personal and cultural values, or religious views. In such cases, the patient will have no opportunity get have his or her wish fulfilled, unless there is another physician who is willing to unplug the patient from the respirator. Even if a court decrees that unplugging the person from the respirator can be done, it still needs a person to unplug the patient. This means that since one cannot force a physician—and maybe rightly so—to act against his or her conscience, this kind of situation regularly poses problems for relatives. This is a case where medical paternalism may be in conflict with patient autonomy, since the very idea of the *living will* is to represent a person's autonomy in cases of incompetence. The physicians' negative attitude is a case of strong paternalism. There is, indeed, no easy way out in such cases.

The cost-efficacy ratio and futile treatment

The most straightforward case with regard to a clash between medical paternalism (physicians, hospital administration) and patient autonomy concerns cases in which a particular medical treatment is seen as futile, with a high cost-efficacy ratio (particularly important in times of great strain on the healthcare systems) and very limited benefit to the patient.⁸ The treatment is, medically speaking, futile and the physician and the hospital administration deny that further action should be taken. The patient and his or her family want the medical treatment because they believe that it would be (very) beneficial to the patient. If the patient's decision is based on ignorance or on a failure in rational deliberation (Savulescu and Momeyer, 2000), then the physician should try everything in his or her power to clarify the facts (e.g., consult other physicians, discuss the issue with a clinical ethics consultant⁹). If it is not possible to come to a solution and the physician still denies further medical treatment, then the patient should have the opportunity to ask another physician and/or hospital. The physician, however, should not be forced to treat a person against his or her professional judgement (that it would be a futile treatment) concerning the case in question. Medical

knowledge should be decisive in such cases, but one should, of course, acknowledge that such cases are not only about medical facts but also raise concerns about underlying values, and cultural and religious views, as well as substantive views of how one should live and die in dignity. The different views of the particular parties (i.e., physicians, patients) may make a simple solution very difficult and sometimes (almost) impossible. Hence, it follows that in some (rare) cases one should not fulfill all wishes and comply with all the ideas a patient has only because one is obligated to respect his or her patient autonomy and rights. Patient autonomy is no charter for everything that a patient wants in medical matters. Patient autonomy should be respected as long as it is reasonable. But what is reasonable? A medical decision about the reasonableness of a given treatment—whether it is futile or not—certainly involves medical facts, rational deliberation/practical wisdom, and the ability to put oneself in the position of the patient. If all the issues have been carefully considered and the particular case has been competently examined in great detail and effort, then one should accept and trust the physician's advice to forgo the medical treatment.

Conclusions

Medical paternalism—as a *general* strategy of ethical reasoning and decision-making in medicine—should be in retreat. Taking patient autonomy and patient rights seriously is not only a matter of taking competent adults seriously but also respecting them as rational human beings of equal moral standing. Physicians *must* obtain the informed consent of the patient so that there is an agreement with regard to the treatment plan. Otherwise, they act immorally. With regard to the disclosure of vital information concerning the health of the patient in question, it seems that the physician is obligated to reveal the truth under normal circumstances. In extreme cases, however, it seems reasonable to withhold the relevant information if and only if it is beneficial to the patient.

Notes

- 1 In the introduction to *A Companion to Bioethics* Helga Kuhse and Peter Singer cite M.B. Etzioni (1973) in the following way: "A monument in the sanctuary of Asclepius, for example, tells doctors to be 'like God: saviour equally to slaves, of paupers, of rich men, of princes, and to all a brother, such help he would give'" (Etzioni, 1973, in Kuhse and Singer, 2009, p. 4).
- 2 Bernard Gert, Charles M. Culver, and K. Danner Clouser thoroughly examine the notion of paternalism and its justification in the chapter 10 ("Paternalism and its justification") of their book *Bioethics. A Systematic Approach* (Gert *et al.*, 2006, pp. 237–82). The general view is that "Although paternalism is often unjustified, it is not always morally unacceptable. On the contrary,

not only is paternalism often justified, it is sometimes even morally required so that in some situations not acting paternalistically can be immoral" (p. 237).

- 3 The answer of the main question, then, as to why the Germans did not practice "informed consent" on their subjects of experimentation, namely the Jews, is obvious. They did not regard the Jews as *human beings*. They were, rather, *Untermenschen* and, hence, according to the doctrines of Nazi Germany, were not protected by the legal regulations of informed consent of 1931 (see also Baker, 1998a, p. 211). Animals were better protected than those people who were guinea pigs of German research experimentation. These people were treated as non-humans and were

also regarded as standing below the animals—a detestable point of view.

- 4 A (still) valuable contribution is Donald Oken's influential study, first published in *JAMA* (Oken, 1976), of medical paternalism with regard to legally competent patients in "What to tell cancer patients: a study of medical attitudes", subsequently reprinted in *Moral Problems in Medicine* (eds. Samuel Gorovitz et al., 1976, pp. 109–16). Even though one has to acknowledge that there has been a great deal of change since that study, it is still fair to say that many physicians around the world do not inform their patients in cases of terminal cancer.
- 5 An interesting discussion with further compelling arguments in support of truth telling with regard to terminally ill cancer patients can be found in Allen Buchanan's article "Medical paternalism" (Buchanan, 1978).
- 6 Tom Beauchamp argues in his article "The concept of paternalism in biomedical ethics" (Beauchamp, 2009) that strong paternalism can be justified in some cases, despite the contemporary trend in biomedical ethics to question the strong paternalistic approach. His final conclusion is "It is clear that many paternalistic

interventions are justified. It does not follow that they all are. I have argued that it is an open question whether reasonably minor offenses to autonomy such as withholding certain forms of information are justified in light of critical medical goals such as the administration of life-saving therapies and the prevention of suicide" (p. 92).

- 7 For this particular problem see, for example, Stephen Wear's article "Patient autonomy, paternalism, and the conscientious physician" (Wear, 1983).
- 8 Nancy S. Jecker, on the contrary, argues in her article "Is refusal of futile treatment unjustified paternalism?" (Jecker, 2000) that it is not the case that to refuse futile treatment is (always) an instance of unjustified paternalism, but instead may be consistent with patient autonomy and other positive values in medicine. It seems fair to say that, indeed, not all cases in which futile treatments are refused are due to medical paternalism, but that some cases can be plausibly conceived of in this way.
- 9 On the issue of clinical ethics consultation see the book *Clinical Ethics Consultation. Theories and Methods, Implementation, Evaluation* (Schildmann et al., 2010).

References

- Advisory Committee on Human Radiation Experiments (1996) *The Human Radiation Experiments*. New York: Oxford University Press.
- Agard, E., Finkelstein, D., and Wallach, E. (2000) Cultural diversity and informed consent. In: M. Boylan (ed.), *Medical Ethics. Basic Ethics in Action*. New Jersey: Prentice Hall; pp. 150–55.
- Annas, G.J. and Grodin, M. (eds) (1995) *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation*. New York: Oxford University Press.
- Baker, R. (1998a) A theory of international bioethics: The negotiable and the non-negotiable. *Kennedy Institute of Ethics Journal* 8(3): 201–31.
- Baker, R. (1998b) A theory of international bioethics: The negotiable and the non-negotiable. *Kennedy Institute of Ethics Journal* 8(3): 233–73.
- Beauchamp, T.L. (2009) The concept of paternalism in biomedical ethics. *Jahrbuch für Wissenschaft und Ethik* 14: 77–92.
- Beauchamp, T.L. and Childress, J.F. (2009) *Principles of Biomedical Ethics*. New York: Oxford University Press.
- Buchanan, A. (1978) Medical paternalism. *Philosophy and Public Affairs* 7(4): 372–87.
- Caplan, A.L., McCartney, J.J., and Sisti, D.A. (eds) (2006) *The Case of Terri Schiavo: Ethics at the End of Life*. New York: Prometheus Books.
- Emanuel, E. and Emanuel, L. (1992) Four models of the physician-patient relationship. *Journal of the American Medical Association* 267(16): 2221–6.
- Feinberg, J. (1971) Legal paternalism. *Canadian Journal of Philosophy* 1(1): 105–24.
- Gert, B., Culver, M., and Danner Clouser, K. (2006) *Bioethics. A Systematic Approach*, 2nd edn. New York: Oxford University Press.
- Gordon, J.-S. (2011) Global ethics and principlism. *Kennedy Institute of Ethics Journal* 21(3): 251–76.
- Gordon, J.-S., Rauprich, O., and Vollmann, J. (2011) Applying the four-principle approach. *Bioethics* 25(6): 293–300.
- Jecker, N. (2000) Is refusal of futile treatment unjustified paternalism? In: M. Boylan (ed.), *Medical Ethics. Basic Ethics in Action*. New Jersey: Prentice Hall; pp. 80–86.
- Kuhse, H. and Singer, P. (2009) *A Companion to Bioethics*. Oxford: Blackwell.
- Macklin, R. (1999) *Against Relativism. Cultural Diversity and the Search for Ethical Universal in Medicine*. New York and Oxford: Oxford University Press.

- Macklin, R. (2004) *Double Standards in Medical Research in Developing Countries*. Cambridge: Cambridge University Press.
- Mill, J.S. (1859) On liberty. In: J. Gray (ed.), *On Liberty and Other Essays*. Oxford World Classics (2009). Oxford: Oxford University Press.
- NCPHS (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research) (1979) *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Washington, DC: U.S. Government Printing Office.
- Oken, D. (1961) What to tell cancer patients: A study of medical attitudes. *Journal of the American Medical Association* 175(13): 1120–8. Reprinted in: S. Gorovitz et al. (eds) (1976), *Moral Problems in Medicine*. Englewood Cliffs, NJ: Prentice Hall; pp. 109–16.
- Savulescu, J. and Momeyer, R. (2000) Should informed consent be based on rational belief? In: M. Boylan (ed.),

- Medical Ethics. Basic Ethics in Action*. New Jersey: Prentice Hall; pp. 128–40.
- Schildmann, J., Gordon, J.-S., and Vollmann, J. (2010) *Clinical Ethics Consultation: Theories and Methods, Implementation, Evaluation*. Farnham: Ashgate.
- Trials of War Criminals Before the Nuremberg Military Tribunals under Control Council Law (1947) *The Nuremberg Code*. <http://ohsr.od.nih.gov/guidelines/nuremberg.html> [accessed February 21, 2013].
- United Nations (1948) *The Universal Declaration of Human Rights*. www.un.org/en/documents/udhr/ [accessed February 21, 2013].
- Wear, S. (1983) Patient autonomy, paternalism, and the conscientious physician. *Theoretical Medicine and Bioethics* 4(3): 253–74.
- World Medical Association (1964) *The Declaration of Helsinki*. <http://www.wma.net/en/30publications/10policies/b3/index.html> [accessed February 21, 2013].

Rational Non-Interventional Paternalism Why Doctors Ought to Make Judgments of What Is Best for Their Patients

JULIAN SAVULESCU

It is almost universally accepted that doctors ought to make judgments of what is medically best for their patients. However, the view that doctors ought to make judgments of what is, all things considered, best for their patients has fallen into serious disrepute. It is now widely believed that it is up to patients, not their doctors, to judge what they ought to do, all things considered. I will argue that doctors ought to make value judgments about what is best for their patients, not just in a medical sense, but in an overall sense.

In the bad old days of paternalism, doctors did make judgments about what patients ought to do, all things considered. They also compelled patients to adopt what they

"Rational Non-Interventional Paternalism: Why Doctors Ought to Make Judgments of What Is Best for Their Patients," by Julian Savulescu, originally published in the *Journal of Medical Ethics* 1995; 21: 327–31. Reprinted with permission of the BMJ Publishing Group.