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ESSENTIALS Medicine is both a scientific and a moral enterprise. It is as important to give reasons for the ethical aspects of clinical decisions as it is for the scientific aspects. The corollary of evidence-based medicine is reason-based ethics. Two concepts central to many ethical aspects of clinical practice are autonomy and best interests. Autonomy—Mill argued that society has no right to exercise its power over individuals against their will purely for their own good. In the medical context, a competent adult has the right to refuse any, even life-saving, treatment. Some conceptions of autonomy focus on competent choice; others emphasize the importance of reasons that relate to a person’s long-term interests and goals. The requirement to respect patient autonomy can be problematic when it harms the patient, or others, or when a patient lacks capacity. Best interests—when patients lack capacity to make their own choices they should generally be treated in their own best interests. But what does this mean? Philosophers have given three broad answers: maximizing positive states of mind, such as pleasure; maximizing the fulfilment of desires; and maximizing aspects of life that are objectively valuable. The legal concept of best interests is a composite of all these. Three of the most common issues for which doctors seek ethics support are consent, end of life, and confidentiality. Consent—a crucial issue if a patient is refusing beneficial treatment is whether he or she is competent to do so. The assessment of competence involves three steps. First, identify the key information relevant to the decision. Second, assess the patient’s cognitive ability: Can the patient understand, retain, and weigh the key information to come to a decision? Third, assess other factors that may interfere with decision-making, such as delusions. When a patient lacks capacity doctors must consider the patients’ best interests, whether there is a proxy decision-maker, and whether the patient has made any relevant advance directive. End-of-life decisions—different ethical approaches disagree over the significance of two distinctions: that between acts and omissions; and that between intending and foreseeing an outcome. These distinctions are important in considerations of mercy

killing; the moral difference between withholding life-extending treatment and killing; and in giving treatments that relieve distress but might shorten life. The law varies on these issues in different countries. Confidentiality—when should doctors breach confidentiality, either for the good of the patient or to prevent harm to someone else? There are differing accounts of the most important reason for medical confidentiality: respect for patient autonomy; keeping an implied promise; and bringing about the best
consequences. These different accounts can have different im- plications for when it is right to breach confidentiality in prob- lematic situations. Introduction Evidence-based medicine emphasizes the importance of critical assessment: interventions should be evaluated on the basis of evi- dence, not tradition. Critical skills are therefore crucial to modern scientific medicine. Importantly, medicine is a moral enterprise as well as a scientific one. Many clinical decisions involve a combin- ation of factual and ethical aspects. It is as important to be able to give good reasons for the ethical aspects of clinical decisions as it is for the science. Society increas- ingly expects this from doctors as part of transparent decision- making. Doctors' reasoning about ethical aspects of care will need to stand up to scrutiny—in a court if necessary—just as much as will the scientific aspects. The corollary of evidence-based medicine is reason-based ethics. Two concepts central to many ethical aspects of clinical practice are autonomy and best interests. Two concepts: Autonomy and best interests Autonomy John Stuart Mill's essay, On Liberty, is one of the great statements of liberal thinking. Mill wrote: ' . . . the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to pre- vent harm to others. His own good, either physical or moral, is not 1.5 Medical ethics Mike Parker, Mehrunisha Suleman, and Tony Hope

1.5 Medical ethics 21 a sufficient warrant. He cannot rightfully be compelled to do or for- bear . . . because, in the opinion of others, to do so would not be wise, or even right'. (Mill 1859, Chapter 1) This principle imposes strict limits on the interference of the state into individual's lives. Mill articulates at its most general level a prin- ciple that in the medical setting is known as the principle of respect for (patient) autonomy. This principle has had an enormous effect in changing attitudes to the doctor–patient relationship over the last 40 years. It has been used to criticize medical paternalism, and has informed the development of 'patient-centred' medicine. It has led to an emphasis on providing patients with information, and to the development of the concept of informed consent. It is one of the main grounds for the importance of patient confidentiality. In situations where a competent adult patient refuses treatment that is, in the doctor's considered view, good for the patient, a con- flict arises between respecting the patient's wishes, and doing what is best for him or her. This is widely seen as a conflict between the principle of respect for patient autonomy and the principle of acting in patients' best interests (often called the principle of beneficence). The concept of autonomy, however, is not straightforward, and re- specting what a patient says (e.g. his refusal of treatment) and re- specting his autonomy may, on some views of autonomy, be different. Some aspects of autonomy The term autonomy has no clear single meaning. As Dworkin wrote (Dworkin, 1988, p. 6): 'It is sometimes used as an equivalent of liberty . . . , sometimes as equivalent to self-rule or sovereignty, some- times as identical with freedom of the will. . . . It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests. . . . It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts and to principles.' In the ideal of autonomy decisions should be rational, consistent with the person's life plans and based on critical reflection. If a desire, or choice, is not based on a rational evaluation then, on some views, it is not autonomous. This is one reason why respecting a person’s autonomy is not necessarily the same as respecting her choice. Respecting patient autonomy can be problematic for doctors in at least three situations: 1. when to do so harms the patient herself; 2. when to do so harms others; and 3. when the patient lacks the capacity to make choices for herself. With regard to the first situation patients sometimes refuse treat- ment that doctors believe is strongly in their best interests. This be- came a legal matter in England when an adult patient with motor neurone disease and who had capacity wanted to have her life sup- port removed. Her doctors refused because they thought this was tantamount to killing her. The court, consistently with Mill’s prin- ciple and English common law, said that her wishes must be com- plied with: ‘The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their judgement in answering the primary question whether the patient has mental capacity to make the decision’ (Re B, 2002). The conflict between respecting autonomy and harm to the patient or to others can also arise in the context of confidentiality (see next). In the third situation, when a patient lacks capacity to make de- cisions for himself, is it possible to respect the patient’s autonomy. Consider the following case (Hope et al., 2007). Case example: Alzheimer’s disease Mr D always valued academic and artistic pursuits. ‘If I develop Alzheimer’s disease allow me to die if given the chance,’ he says. Mr D subsequently develops Alzheimer’s disease. He no longer recognizes his family, but he remains physically fit. He is looked after in a nursing home and appears to enjoy a simple life: flowers, food, TV. Mr D gets a chest infection. This could be treated with antibiotics. Without cur- ative treatment he could be kept comfortable and would probably soon die. On a straightforward view it would seem that we respect Mr D’s au- tonomy by withholding antibiotic treatment and allowing him to die. This is consistent with the wishes that he expressed when he had the capacity to do so. But there are at least three concerns that we might have even if our only ethical value were to respect autonomy. First, do we know that when he expressed his view about being al- lowed to die he had taken into account all the relevant facts of his current situation? For example, at what stage in Alzheimer’s disease did he want to be allowed to die; was he meaning to refuse even a simple treatment like giving antibiotics; and did he take into account the possibility that he would generally be enjoying life? Second, he might have changed his mind after he had made the statement about being allowed to die and before he lost capacity, but no one knows of this change of mind. Third, is it possible for a person when healthy to imagine sufficiently the state of having Alzheimer’s? When we allow a person with capacity to refuse beneficial treatment we can take care to ensure that this is what the person really wants, and that he understands all the relevant issues. Even if it is possible in this case to respect the patient’s autonomy, in many (probably most) situations where a patient lacks capacity there will not be sufficient information about his previous views and values to make a decision about what to do based only, or even mainly, on this principle. The more useful principle in such situ- ations is the principle of beneficence that is treating people in their best interests. Best interests In many situations judging a patient’s best interests is straightfor- ward but this is by no means always the case. Consider again Mr D. What is in his best interests? The answer may differ depending on your conception of best interests. The philosophical discussion relevant to best interests has been conducted mainly in terms of the concept of well-being. There are three main theoretical approaches to well-being. Mental state theories According to these theories, well-being is defined in terms of mental states. At its simplest (hedonism) it is the view that happiness or pleasure is the only intrinsic good, and unhappiness or pain the only intrinsic bad. If Mr D with Alzheimer’s disease is generally enjoying the ‘simple’ pleasures then, on this view, it will be in his best interests to continue to live by treating the infection. The fact that he might previously have despised enjoying the TV soaps he now enjoys is irrelevant. Desire-fulfilment theories According to desire-fulfilment theories, well-being consists in having one’s desires fulfilled. If desire-fulfilment theories are to provide a plausible account of well-being it is necessary to restrict the relevant set of desires. In one view, only those desires pertaining to life as a whole count as relevant in the analysis of well-being. These are desires that relate to a person’s life plans. According to this view Mr D’s prior intellectual values would be relevant. Withholding antibiotic treatment would be fulfilling his previous desires and these are the desires that fit with his long-term values. Desire-fulfilment theories of well-being have much in common with respecting autonomy, but they are not the same. In the case of Mr D, desire-fulfilment theories highlight the question of whether Mr D, at the time of deciding whether to give antibiotics, has relevant desires. From the perspective of autonomy, the issue is whether he has capacity. Objective list theories According to objective list theories of well-being certain things can be good or bad for a person and can contribute to her well-being, whether or not they are desired, and whether or not they lead to pleasurable mental states. Examples of the kind of thing that have been given as intrinsically good in this way are engaging in deep personal relationships, rational activity, and the development of one’s abilities. Examples of things that are bad might include being betrayed or deceived, or gaining pleasure from cruelty. An objective list theory does not give an unequivocal answer to what is in Mr D’s best interests. On most lists—although not all— the pursuit of worthwhile life goals would normally take precedence over very simple pleasures. But that is not the choice that faces the carers of Mr D. The question is whether it is in Mr D’s best interests to be dead, given that he can only enjoy these simple pleasures. Composite theories Each of the three theories of well-being outlined earlier identifies something of importance, but none seems adequate. Because of this, we might opt for a composite theory in which well-being is seen as requiring aspects of all the theories. A composite theory has some practical implications for medical practice. The main implication is that when considering what is in a patient’s best interests, particularly when these are not clear, it may be relevant to consider the aspects of well-being that are highlighted by each of the three theories. This does not tell us how to balance these considerations but it does suggest that in coming to a decision about Mr D’s best interests it is relevant to take into account all of the following factors: his previous values and wishes, his current experiences (of enjoyment, for example), and any current desires. Three issues in medical ethics Doctors who seek help with ethical issues in their clinical practice often do so with regard to three types of issue: consent, end of life, and confidentiality—each of which presents questions relating to autonomy and best interests. We will discuss each in turn. Consent The philosophical basis of informed consent rests on the principle of patient autonomy. Valid consent is widely regarded as requiring three main criteria: that the patient be informed and competent (or having capacity); and that the consent is voluntary. In the legal and ethical analysis of treating people against their will, a great deal depends on whether the patient is competent (or has capacity) to make the relevant decision. The approach to competence endorsed by both law and most ethical analyses is what is known as the functional approach. This focuses on the process by which the person comes to the particular decision. One implication of this approach is that competence is specific to a particular decision. A person may, at one time, be competent to make one decision (e.g. whether to take a particular medication) but not a different decision (e.g. whether she is capable of living alone). When patients are making decisions (e.g. refusing treatment) that appear to be (significantly) contrary to their best interests, then doctors must carefully assess the capacity of that patient to make that decision. In broad terms, if patients have the capacity, then their decision must be re- spected, although the doctor must make sure that the implications of the decision have been fully understood. The law in the United Kingdom and North America gives competent adult patients the right to refuse any, even life-saving, treatment. If, on the other hand, patients lack capacity to consent to (or refuse) treatment then they should be treated, generally, in their best interests (but see next). Assessing competence There are three main steps in assessing competence. Step 1: Identify the information relevant to the decision The critically relevant information includes the likely consequences of different decisions (e.g. different possible treatments, or treatment versus nontreatment) and including both wanted and unwanted ef- fects; and understanding in broad terms what would be involved in carrying out a decision. Step 2: Assess cognitive ability The Mental Capacity Act (2005) which is the key legislation in England and Wales states that a person is unable to make a deci- sion (i.e. lacks capacity) if he is unable to understand the information relevant to the decision; to retain that information; to use or weigh that information as part of the process of making the decision; or to communicate his decision (whether by talking, using sign language or any other means). Step 3: Assess other factors that may interfere with competence Cognitive impairment is only one factor that may interfere with the elements of information processing just outlined. It may also be im- portant to assess whether there is such interference due to a mental illness. A delusion, for example, may interfere with believing the in- formation. An affective illness (depression or mania) may interfere with the weighing-up of information and coming to a decision. Making decisions for people who lack competence There are four theoretically possible approaches to making deci- sions about the healthcare of incompetent patients (Buchanan and Brock, 1989).

1.5 Medical ethics 23 Best interests One approach for a doctor faced with an incompetent patient is to ask which plan of management serves the patient's best interests. We have already outlined some different approaches to the ques- tion of what is in a person's best interests (see the case example on Alzheimer's disease earlier). Proxy An alternative approach is for a proxy to make decisions on behalf of an incompetent patient. Such an approach raises the question of why the proxy has such a right. The most obvious answer is that the patient had nominated the proxy at a time when she was compe- tent to do so. The proxy of course is left with the question of the basis on which the decision should be made. English law, under the Mental Capacity Act [2005] allows a competent person to nominate someone else ('Lasting Power of Attorney') as proxy in the case of loss of capacity. The proxy (rather like a parent of a young child) must act in the person's best interests. If doctors believe a proxy is refusing highly beneficial treatment, then they may need to seek a court ruling. Substituted judgement The criterion of substituted judgement asks the hypothetical ques- tion: suppose the patient were (magically) able to become compe- tent, what treatment would he choose? In order to try and answer this question, the doctor could use a range of evidence: reports of what the patient has said about this kind of situation in the past; the kind of general values the patient held; and experience with other patients. This criterion is problematic, not only in practice, but also theoretically since it is unclear precisely what are the person's abilities and beliefs in this magical state. Advance directives Advance directives (or advance decisions as they are called in the English Mental Capacity Act [2005]) are statements made by people at a time when they are competent, about how they want to be treated in the future were they to become ill and at the same time incompetent to give consent for treatment. The central justification for advance directives is that they extend patient autonomy to include situations in which a person is no longer competent. One problem with advance dir- ectives is that they need to be interpreted when applied to the specific situation and this can be difficult. More fundamentally is the concern that when completing the advance directive, the person may not have been able to sufficiently imagine the situation at the time a decision needs to be made (see the earlier discussion of Mr D). End of life Killing someone is of course morally wrong. Doctors often care for patients who are near the end of life and perhaps who are suffering. Modern medicine can in many circumstances prolong life. Paradoxically it is the very fact that doctors care for patients that can make the general moral ban on killing ethically problematic. It is problematic in at least two ways. First killing can, to some at least, appear merciful. Second, there is some ambiguity around what counts as killing. Mercy killing Lillian Boyes was an English patient with very severe rheumatoid arthritis, so severe that she was expected to die within a few weeks. She was in so much distress that she wanted to be killed, but she retained full decision-making capacity. Painkillers did not overcome her distress. Her caring relatives also wanted her to be killed. If the doctor caring for Mrs Boyes were to apply the principle of autonomy and respect her competent wishes, should he not kill her? If every day of continued life was for her a burden, and there was no prospect of significant change until she died naturally, was it not in her best interests to be killed? The principles of autonomy and of beneficence point to the same action: to kill Lillian Boyes. In the United Kingdom, and North America, however, a doctor who killed such a patient would commit murder. In some counties, the Netherlands, for example, such a mercy killing (active voluntary euthanasia) can be legally carried out under carefully controlled conditions. The principle of the sanctity of life One reason why mercy killing might be wrong is because of an additional relevant principle: the principle of the sanctity of life. There are differing versions of this principle. The most extreme form is called vitalism: human life is of absolute value. Whenever possible, human life should be maintained; and it is always wrong to take human life. A less extreme form is one that sees life as a basic but not an absolute good. Preserving life on this view does not necessarily outweigh all other goods but the value of life cannot be completely accounted for in terms of a person’s experiences and beliefs. In English law, and in that of many other countries, there are two components to the act of killing. First, the death results from a positive action on behalf of the killer, and second that the killer intends to cause the death. In a clinical setting this means that omitting to do something, such as withholding life-extending treatment (IV fluids, mechanical ventilation, for example) on the grounds that it is kinder to the patient to ‘let nature take its course’ is not considered to be a positive action, and is not killing. Such withholding of treatment is not only perfectly legal but might be seen as good clinical practice, and morally required. Furthermore, in English law, withdrawing treatment (taking down the IV line; switching off the ventilator) is seen as equivalent to withholding treatment. The intention too is crucial, at least legally. Sometimes a treatment for unpleasant symptoms can shorten life. This might be the case when large doses of morphine are given to very ill patients in order to control pain, because morphine can reduce respiratory drive. Giving morphine in such a situation is not killing and would normally be perfectly legal because the shortening of life is not intended, but is only foreseen. If killing is wrong but these two examples are not killing and not generally wrong, a lot of ethical weight rests on two distinctions: that between acts and omissions and that between intending and foreseeing. Those who believe that what is of primary importance in judging the morality of an act is the foreseeable consequences will not find any significant moral difference in either of these distinctions. If we foresee, for example, that giving morphine will shorten life, then this has the same moral weight as if we intend the shortening of life. We cannot close our eyes, on this view, to the foreseen consequences of our actions by claiming that although we foresaw them, we did not intend them. An alternative framework sees the nature of the choices and not only the foreseeable consequences as of moral significance. One idea within such a framework is known as the Doctrine of Double Effect. At the core of this doctrine is the claim that there is a moral distinction between foreseeing a result and intending a result. Thus, it may be forbidden on moral grounds to bring about a bad result if that re- sult is intended (even if as a means to a better overall outcome), but not forbidden to bring about the same result if the result is foreseen but not intended. Confidentiality Much of the information that a doctor gains about a patient in her professional duties is confidential. By this it is meant that there is an expectation that the doctor will not divulge that information to an- other person without the agreement (possibly implied) of the patient. What is the basis for medical confidentiality? There are at least three different grounds. On all three approaches doctors should nor- mally keep information about patients confidential. The ethically problematic situations are generally those in which breaching con- fidentiality will reduce a risk of harm either to the patient himself, or to someone else. The professional guidelines for UK doctors em- phasize the importance of confidentiality but state that: ‘Disclosure of personal information about a patient without consent may be jus- tified in the public interest if failure to disclose may expose others to a risk of death or serious harm’ (General Medical Council, 2009). Such guidelines need interpretation in applying to particular cir- cumstances, and the interpretation will sometimes be affected by one’s views about what underpins the importance of confidentiality. Three different answers to this question are: respect for patient au- tonomy; keeping an implied promise; and bringing about the best consequences. Respect for patient autonomy This principle implies that a person has the right, by and large, to decide who should have access to personal information about him- self. If respect for patient autonomy is considered an important ethical principle, then any breach of confidentiality is potentially serious and only the prevention of serious harm would justify it. Furthermore, on this approach, it might be argued that, contra to the General Medical Council (GMC) guidelines, if a competent patient refuses to give consent for a doctor to inform a third party, where failure to inform risks serious harm to that patient only, breaching confidentiality is wrong. After all, we allow a competent patient to refuse even life-saving treatment. Can there be a serious breach of confidentiality if the patient never knows about the breach? On the view of confidentiality which con- siders that respect for patient autonomy is of key importance, the answer is yes. Keeping an implied promise Some views of the doctor–patient relationship see it as having elem- ents of an implied contract. Such a contract may include an implied promise that doctors keep information about their patients confi- dential. Patients generally expect doctors to treat information con- fidentially, and professional guidelines emphasize the importance of high standards of confidentiality. This view of confidentiality is different from that of patient au- tonomy. It does not ultimately depend on what the patient would want or believes. It depends on a concept of the doctor–patient rela- tionship that is independent of what a specific patient believes. There are, however, two problems with this view: first, there has been no explicit promise, so the issue of an implied promise is to some extent a fiction; second, it raises the whole issue of why it is important to keep promises. The reason for the importance of keeping promises is likely to be grounded either in autonomy or consequences. Bringing about the best consequences From the perspective of a consequentialist ethical perspective it is the (foreseeable) consequences of the breach of confidentiality that determine the seriousness of the breach, and indeed that underlie whether breaching confidentiality is wrong in the first place. There are several different types of consequence that could be relevant, and the analysis of the situation depends in part on how these are viewed. If respect for autonomy is the principal basis for confidentiality, then when maintaining confidentiality puts others at risk of harm there is a clash of two incommensurable values: respecting the patient’s autonomy and preventing harm to others. From the consequentialist perspective, the judgement is conceptually simpler. There is only one question: Which action (breaching or maintaining confidentiality) has the better overall consequences? At first sight it might seem that on this consequentialist view risk of even modest harm to others justifies a breach since we have to balance the harm to others against only the patient’s emotional response to the breach. But this is too simplistic. Unless doctors are trusted to maintain high levels of confidentiality patients in general may lose trust and not seek healthcare. The issue is not just about ill health: there are other consequences of untreated illness. For example, if people with uncontrolled epilepsy drive they may kill other road users. There is a public interest in ensuring that such people receive good healthcare in order to maximize control of the epilepsy. Even where the harm to others is potentially great, as in the example of epilepsy, it could be the case that more lives will be lost if doctors do breach confidentiality because fewer people with fits will seek medical help. So although the consequentialist approach can deal with difficult cases in a conceptually clear way, in practice the lack of evidence and complexity can make such judgements difficult. From a consequentialist perspective, as opposed to the perspective of respect for patient autonomy, if a patient never finds out that a doctor has breached confidentiality and no harm comes to the patient as a result, that breach is trivial, even if it concerned something that the patient would strongly wish to keep confidential.

Conclusion

Ethics, like science, is at root a rational enterprise. For those of us who are concerned to do the right thing, and this includes most medical students and doctors, the questions arise: How can we examine our own moral standards and behaviour in specific situations; how can we develop these standards; and how can we ensure that our views stand up to scrutiny? We believe that rational enquiry is central to an answer to these questions. Such enquiry involves arguing with others, facing counterarguments, and seeing how good our own arguments are. If the counterarguments are stronger, we need to change our views. If there is a contradiction between what we thought our principles were and what we think is right in a specific situation, then we need to resolve that contradiction. There may be no final grounding of morality in nature but from that it does not follow that our personal moral system and our decisions in specific situations should be irrational or arbitrary.

FURTHER READING

Ashcroft R, Draper H, Dawson A, McMillan J (eds) (2007). Principles of health care ethics, 2nd edition. John Wiley & Sons, Chichester. Beauchamp TL, Childress JF (2008). Principles of biomedical ethics, 6th edition. Oxford University Press, New York. Buchanan AE, Brock DW (1989). Deciding for others: the ethics of surrogate decision making. Cambridge University Press, Cambridge. Dworkin G (1988). The theory and practice of autonomy. Cambridge University Press, Cambridge. General Medical Council (2009). Confidentiality: protecting and providing information. GMC, London. https://www.gmc-uk.org Hope T (2004). Medical ethics: a very short introduction. Oxford University Press, Oxford. Hope T, Savulescu J, Hendrick J (2007). Medical ethics: the core curriculum, 2nd edition. Churchill Livingstone (Elsevier), Edinburgh. Mill JS (1859). On liberty. Many modern editions, including: Harmon dsworth: Penguin Books, 1982. Parker M (2012). Ethical problems and genetics practice. Cambridge University Press, Cambridge. Re B (2002). Adult: refusal of medical treatment. All England Reports 449 at 445. Shakespeare T (2006). Disability rights and wrongs. Routledge, London.

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