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The right not to know: an autonomy based approach

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The emerging international biomedical law tends to recognise the right not to know one's genetic status. However, the basis and conditions for the exercise of this right remain unclear in domestic laws. In addition to this, such a right has been criticised at the theoretical level as being in contradiction with patient's autonomy, with doctors' duty to inform patients, and with solidarity with family members. This happens especially when non-disclosure poses a risk of serious harm to the patient's relatives who, without that vital information, could be deprived of preventive or therapeutic measures. This paper argues, firstly, that individuals may have a legitimate interest in not knowing their genetic make up to avoid serious psychological consequences; secondly, that this interest, far from being contrary to autonomy, may constitute an enhancement of autonomy; thirdly, that the right not to know cannot be presumed, but must be ''activated'' by the individual's explicit choice, and fourthly, that this is not an absolute right, in the sense that it may be restricted when disclosure to the patient is necessary in order to avoid a risk of serious harm to third persons.

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The claim for a ''right not to know'' might sound strange. Over the last decades it has been strongly stressed that the patient has the right to be informed about the risks and benefits of a treatment or intervention and, on this basis, to consent—or not—to them. Having affirmed the patient's ''right to know'' as a fundamental ethical and legal principle, we are now faced with the apparently opposite demand. This takes place particularly in the field of genetics: as the predictive power of genetic tests increases, more and more people come to know that they are at risk from a serious disease with no real chance of reducing that risk or of obtaining an effective treatment. To illustrate the problem, let us consider the following examples:

- Barbara, a 35 year old woman and mother of two children, has a family history of breast cancer. Urged by her relatives, she decided to undergo the BCRA1/2 testing. If Barbara has the mutation, she has 80% risk of developing breast cancer. Three days later, depressed by the difficult decisions she would have to make in case the mutation was found, she asked the doctor not to inform her about the test results.
- Peter, a 29 year old married man, is invited to participate in a research study about the mutations that may cause Alzheimer's disease (the most common cause of dementia) because a member of his family has been diagnosed with this disorder. DNA samples will be coded, but the unit's director will keep a confidential list of the names of each participant. Although this is a research study and not a clinical genetic test, the laboratory offers Peter the opportunity to be informed about the result of the analysis, in case it indicates the presence of a mutation. This information may be helpful in predicting his risk of developing Alzheimer's disease or of having children with this disorder. However, Peter does not want to know the results and therefore does not sign the request to be informed.

Far from being purely academic, both scenarios happen in the daily routine of genetic testing and research. In order to understand the refusal of Anne and Peter to have access to their genetic information, one has to consider that the burden of knowledge may become unbearable for them, leading to a severe psychological depression and having a negative impact on their family life and on their social relationships in general. For many people, the discovery that they have a genetic condition that places them at a high risk of suffering certain untreatable diseases could so depress them that the quality, joy, and purpose of their lives would literally evaporate.[1] Now, in such situations, ''it may not be justifiable to take away hope from a person by exposing them to knowledge they do not want''.[2] Therefore, it seems reasonable to allow these people to choose not to receive that potentially harmful information and to continue their lives in peace.

This paper argues that ''autonomy'', understood in a wide sense, provides a theoretical basis for a right not to know one's genetic status. The discussion will focus on predictive testing of adults, and not on other types of genetic testing (diagnostic testing, preimplantation genetic diagnosis, prenatal testing, and newborn screening), which raise other specific ethical issues. It is also worth mentioning here that, although the interest in not knowing may be greater in the case of single gene disorders (when a particular mutation is causally sufficient for a disease to occur) than in polygenic disorders, it is not the purpose of this paper to enter into a detailed discussion of the issues raised by each type of genetic testing. Rather, what is intended is to provide a broad philosophical and legal analysis of the debate regarding the right not to know one's genetic status.

After summarising the objections made against the right not to know (1), it will be recalled that various recent ethical and legal instruments explicitly recognise this claim (2). Then, this paper will attempt to respond to those objections (3), and will suggest some conditions that should be fulfilled for the exercise of the right not to know (4).

OBJECTIONS TO THE RIGHT NOT TO KNOW

Several criticisms have been formulated against the formal recognition of a right not to know one's genetic status. The main practical objection is that this right is not feasible because, in order to decide not to receive some information, the person should previously be informed of the possibility of having a particular health risk. Now, this is precisely what the individual wanted to avoid.[3 4]

A most fundamental objection is that, according to a long and well established philosophical tradition, knowledge is always good in itself and therefore a ''right to remain in ignorance'' appears as a contradiction; that is, as an irrational attitude, which is incompatible with the notion of ''right''.[5 6] Let us recall that, according to Aristotle ''all men by nature desire to know'' and this desire is one of the features that distinguishes humans from other animals.[7] The Enlightenment's philosophers considered also human progress in direct connection with an increasing access to knowledge. In the words of Kant, ''Sapere aude!'' (''Have courage to use your own understanding!'') was indeed the motto of the Enlightenment.[8] Adopting this latter perspective, a contemporary philosopher acidly criticises the recent international recognition of the right not to know as ''directly opposed to human rights philosophy and to ethics''.[9]

The right not to know would be also contrary to the recent evolution of the doctor-patient relationship, which tends to abandon the old paternalism that allowed the doctor not to tell the truth to the patient. Moreover, the claim not to know would be contrary to the doctor's ''duty to disclose'' risks to patients. Therefore such a claim would represent a return to a paternalistic attitude given that it puts people in a state of ignorance, depriving them of choice.[10] For the same reason, the right not to know is criticised as being opposed to patients' *autonomy*, given that the exercise of autonomy depends on the ability to understand relevant information and only on this basis to consent to treatment.[11]

Another objection refers to the value of solidarity and responsibility for others: the individual who chooses not to know his or her genetic status—thereby putting him or herself in a position of being unable to disclose that vital information to family members—could be said to be acting against solidarity. The same thing could be said about an individual who refuses to participate in a population screening programme because of a claimed right not to know.[12]

ETHICAL AND LEGAL RECOGNITION OF THE RIGHT NOT TO KNOW

In spite of the criticisms levelled against it, the right not to know has been explicitly recognised by various recent ethical and legal instruments relating to biomedical issues. The most impressive examples are probably the European *Convention on Human Rights and Biomedicine* and the UNESCO *Universal Declaration on the Human Genome and Human Rights*, both adopted in 1997. Article 10.2 of the European Convention states: ''Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed''. The Explanatory Report to the Convention justifies the right not to know by saying that ''patients may have their own reasons for not wishing to know about certain aspects of their health''.[13]

Similarly, the UNESCO Declaration on the Human Genome provides (in Article 5c) that: ''The right of every individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected''.

Other important international ethical guidelines also explicitly recognise the right not to know. According to the ''Declaration on the Rights of the Patient'' adopted by the World Medical Association in 1981 and amended in 1995, ''the patient has the right not to be informed on his/her explicit request, unless required for the protection of another person's life'' (Article 7d).[14] The WHO ''Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services'' (1997) states that ''the wish of individuals and families not to know genetic information, including test results, should be respected, except in testing of newborn babies or children for treatable conditions'' (see table 7 in these Guidelines).

It is important to note that in all the aforementioned international instruments, an explicit choice is necessary for the functioning of the right not to know: the European Convention refers to an individual's ''wishes''; the UNESCO Declaration mentions the individual's ''decision''; the WMA Declaration points out the necessity of an ''explicit request'' of the patient; the WHO Guidelines mention the ''wishes'' of individuals and their families.

At the national level, the right not to know is recognised by the French Law on Patients' Rights, adopted in March 2002: ''everyone has the right to be informed on his/her health status … . The person's will to remain ignorant of diagnostic and prognostic information should be respected, except when third parties are exposed to a risk of transmission'' (Article 1111-2, Public Health Code). Similar provisions can be found in the Dutch Medical Treatment Act of 1994 (Civil Code, Article 449), the Belgian Patient's Rights Act of 2002 (Article 6), and the Hungarian Health Act of 1997 (Section 14.1).

In the United Kingdom, the former Human Genetics Advisory Commission (HGAC) recommended in its July 1999 report that ''an individual's 'right not to know' their genetic constitution should be upheld''.[15] More recently, the current Human Genetics Commission (HGC) concluded in its report on the use of personal genetic data that ''people have an 'entitlement not to know' genetic information about themselves''.[16]

THE RIGHT NOT TO KNOW: AN EXPRESSION OF ''AUTONOMY''

The main thesis of this paper is that the claim for not knowing one's genetic status, far from being contrary to *autonomy*—understood as an individual's self determination—may be indeed considered a legitimate expression of this basic bioethical principle. In other words, the choice of not knowing the results of genetic tests does not fall into a paternalistic attitude because the challenge to medical paternalism is precisely based on the idea that people should be free to make their own choices with respect to information. If we understand autonomy in this wider sense, then the decision not to know should be, at least in principle, as fully respected as the decision to know.[17 18]

Thus, the possibility to choose not to know the results of genetic tests may constitute an *enhancement of autonomy*, because the decision to know or not to know is not taken out of the hands of the patient by the doctor. Precisely with this broad understanding of autonomy, the right not to know is widely recognised, for example, by the German legal literature as a part of the ''right to informational self determination'' (''Recht auf informationelle Selbstbestimmung'').[19 20]

In addition to this, let us not forget that there is not an absolute ''duty to disclose'' information to patients, neither on legal nor on ethical grounds. On the contrary, it is the responsibility of the healthcare professional to assess the amount of information an individual wants and is able to deal with at a particular time.[21]

If this understanding of autonomy is correct, it can be argued that the theoretical foundation of the right not to know lies on the respect for individual *autonomy*, even if the ultimate foundation of this right is the individual's *interest in not being psychologically harmed*. Both grounds are indeed situated at a different level. Autonomy is the immediate source of the right not to know, but what is in the end protected is the psychological integrity of the person. Certainly, patients do not need to prove the harmful effects of genetic information, because each of them is entitled to recognise what information may be psychologically harmful. In any case, the recognition of the potentially negative effect of genetic information allows us to better understand what the right not to know tends to protect and what, ultimately, justifies this claim. We deal here with nothing more than the oldest principle of medical ethics: ''first, do not harm'' (*Primum non nocere*), which is formulated in modern times in the so called ''principle of non-maleficence'' that certainly includes patient's psychological integrity.[22]

The criticism that the right not to know is contrary to the requirement of informed consent seems misplaced. The right to remain in ignorance about one's genetic make up should not be mistaken for a *waiver* of informed consent. In the exercise of a waiver, a patient voluntary relinquishes the right to an informed consent and relieves the physician from the obligation to inform. It seems to be a consensus among ethicists that the acceptance of waivers of consent is a dangerous practice.[23] But in the case of the right not to know the informed consent exists, insofar as the person is perfectly aware that he or she will be submitted to a genetic test that may indicate the risk of developing a disease. In this case, the individual just refuses to be informed of the test outcome. Thus, the ignorance does not concern the *medical practice* itself, for which a valid informed consent has been given, but only its *result*. Consequently, the individual does not receive any particular medical treatment on the basis of ignorance. A different situation may arise in the emerging area of pharmacogenetics. What if a patient arguing the right not to know refuses the test that can determine if a particular drug may have an adverse effect and in spite of that demands the medicine? In such a case the pharmacogenetic test, as far as it has been proved to be effective, should perhaps be considered as a part of the treatment itself. Therefore, it would be a breach of the physician's duty of care to prescribe a drug for a patient who intends to use it without the test having been performed. In other words, in the absence of the test, the requirement of informed consent for the treatment would not be met. This conclusion is especially valid because information about drug response could hardly be considered contrary to the patient's interests.

What about the argument that the right not to know is intrinsically not feasible because its exercise always requires a previous knowledge? Certainly, for the exercise of this right the person should have, at least, a general and abstract knowledge of the risk. We know that we are all at risk of developing genetic diseases, particularly when we have a family history of a particular genetic condition. But some risks may be so remote in our perception as to seem virtually inconceivable. In contrast, a genetic testing, which may determine individuals likely to suffer from a serious disorder or even the certainty that the disease will emerge (in the case of a single gene disorder), makes those vague concerns look much more real. This is precisely why an individual's refusal to know the results of genetic tests might make sense.

One has to recognise however that the refusal to be informed about one's genetic status may in some cases be problematic, because genetic information is not only an individual, but also a family affair. Tests results may alert family members about a serious risk, giving them the opportunity of changing their life plans, or eventually of preventing or treating a disease. The familial nature of genetic information has even led some ethicists to argue that the concept of ''genetic privacy'' is a contradiction in terms.[24] In any case, the question is: how can the right not to know be harmonised with the potential interest of a patient's relative in knowing?

As it has already been pointed out, some legal and ethical regulations try to give an answer to this difficult dilemma: the right not to know (like most rights) is *not absolute* because its exercise is conditioned by the fact that *there is no risk of serious harm to other persons*.[25–27] That means that the disclosure to family members, if ever, could be accepted as an exceptional measure, as long as two conditions are fulfilled: firstly, the disclosure is necessary for avoiding a serious harm to them; secondly, some reasonable form of cure or therapy is available. However, we should not forget that we are dealing with unsolicited genetic information. We are indeed not sure that relatives really want to receive such information. This is why we should be extremely prudent before any unsolicited approach is made.

Those ''other persons'' that the exercise of the right not to know should not harm could be society in general. Public health interests may in particular circumstances justify limitations on the right to ignore one's genetic make up as they may justify limitations to confidentiality, for instance, in the case of infectious diseases.[28] Surely, the circumstances in which the right not to know and confidentiality can be breached in the interest of public health should be well defined by law. Particularly important in this context are population genetic screening programmes, which can contribute to the prevention of genetic diseases. For example, potential parents could be alerted to the risks they may take if they marry and have children with a person who also carries the genetic trait. However, such programmes face significant challenges in terms of informed consent, privacy, and risks of stigmatisation of ethnic groups. In addition, there is the fear that public screening programmes could encourage eugenic practices, like systematic abortion of affected fetuses.[29] In summary, we have to make a substantial effort in this area to ensure an adequate balance between the respect for individuals' rights and the benefits of using genetic information for the common good of society.

THE WISH OF NOT KNOWING SHOULD BE EXPLICIT

Graeme Laurie has argued that, in addition to ''autonomy'', the right not to know might be based on a particular form of *spatial privacy*, the so called ''psychological spatial privacy'', which encompasses separateness of the individual's psyche. This aspect of spatial privacy tends to safeguard *one's own sense of the self* and to provide a larger protection of the interest in not knowing than simple *choice*, especially in those cases in which no explicit choice has been made.[30–32]

Laurie's concern is perfectly understandable: it is true that even if no wish has been expressed, the interest in not knowing can also be compromised by unsolicited revelations of genetic information. This circumstance leads the author to advocate a ''prima facie'' respect for the interest in not knowing, even in absence of an explicit choice.[33] This means, in practice, an *inversion of the burden of proof*: it is not the person interested in not knowing who should express his or her wish but, on the contrary, it is the individual who intends

to disclose the information who, before any disclosure, should be sure that some special conditions are fulfilled (for example, the availability of a cure, the severity of the condition, the nature of the testing, and the question of how the individual might react if exposed to unwarranted information).[34 35] Therefore, this position "places the onus of justifying disclosure firmly on the shoulders of those who would do so".[36]

The appeal to privacy in order to call for an attitude of prudence in the disclosure of genetic information is fully justified, especially when there are doubts about the patient's will. Moreover, the "privacy approach" provides an insightful explanation of what is at stake in this issue. It is true that when there is no previously expressed wish in respect of the information, the potential interference is primarily with the spatial privacy interests—or let's say, with the psychological integrity—of the individuals in question, rather than with their autonomy per se.[37]

However, what is difficult to accept in Laurie's view is the assumption that those individuals who have not made any explicit choice of not knowing their genetic status (which means almost everybody) want to ignore it. In the case of competent patients, this assumption can hardly be harmonised with their "right to know", as well as with the "duty to inform" that, in principle, the healthcare professional has towards them. Both competing rights—to know and not to know—cannot be the rule. Surely, to determine which right should prevail will depend on the circumstances of each case, but law and ethics need *rules* to operate in a coherent manner; and the rule in this field is that patients have a right to know their health status. This is why it seems that the right not to know may only be accepted as an *exception*, at least with regard to competent persons. The situation is probably different in the testing of minors, in which case genetic tests for adult onset genetic disorders should perhaps be simply banned, particularly when no cure is possible.[38]

In brief, therefore, the argument of this paper is that the right not to know cannot be *presumed*, but should be "activated" by the explicit will of the person.[39] Let us recall that, for those cases in which the interest in not knowing seems clear, but no explicit choice has been made, we already have the concept of "therapeutic privilege", which allows physicians to withhold information if, based on sound medical judgement, they believe that divulging the information would be harmful to a depressed or unstable patient, especially when there is currently no effective treatment.[40 41] But this is different to recognising a "right" not to know, because the violation of a "right" (in this case, by disclosure of the unsolicited information) means that the professional could eventually incur civil liability. Now, such a serious consequence in cases in which patients had not expressed their interest in not knowing seems a step too far.

Thus, the exercise of an autonomous choice seems necessary for the functioning of the right not to know, because it is impossible to determine a priori the wish of the patient. Precisely one of the particularities of this right consists in the fact that it almost entirely depends on the subjective perceptions of the individual, who is, in fact, the best interpreter of his or her best interest. It should be noted that the problem of genetic tests is raised not so much by the information itself (which is neutral) but by the *effect* that that information may have on the person who has been tested. That effect varies greatly from individual to individual. This is why the previous informed consent should be as comprehensive as possible, in order to know in advance the patient's interests and possible fears.

One could argue that this autonomy based approach is unrealistic, because it ignores the fact that people are not always free to decide according to their real interests.[42] For instance, various forms of coercion, in a more or less subtle way, may lead individuals to choose to know their genetic make up, when in fact they would prefer to ignore it. The most obvious example is the requirement of genetic tests as a condition of employment or insurance. Nevertheless, the factual possibility of coercion in certain circumstances is not per se a sufficient reason to deny people the right to self determination regarding genetic information. It is true that coercion may happen in the field of genetic testing, but it may happen in all areas of clinical and research activities as well. If we consider that the likelihood of coercion is very high in certain circumstances, what we can do (as many ethical guidelines suggest) is simply to prohibit the requirement of genetic tests by insurance companies or employers and the requirement to disclose results of any previously undertaken genetic tests. Or at least we can put additional safeguards in place to ensure that people are free from coercion and are not exposed to unjustified discrimination. However, the risk of coercion should not lead us to deny that competent people, with appropriate genetic counselling, are in principle able to decide whether they want to know their genetic status or not.

Do third parties like patients' relatives have a right not to know? In this case one has to recognise that such a right is even difficult to conceive. Firstly, for a practical reason: how can patients' relatives exercise this right, if they probably even ignore that a family member has been tested?[43] Moreover, against *whom* would they have this right? Against the doctor who, having tried to help them, disclosed that information? Against the family member who was tested and had revealed, for example at a family gathering, that he or she is at risk of a genetic illness? Would such a general "right not to know" not be a serious obstacle to confidence within the family? In addition to this, how can doctors assume that patients' relatives do not have interest in knowing genetic information, which may be extremely important to them? Certainly, doctors should in principle avoid disclosing information about patients to individuals with whom they do not have any professional relationship. Healthcare professionals have a duty of confidentiality towards their patients. But if in a particular case a doctor considers in good faith that he or she is morally obliged to disclose that information to patients' relatives—for example, because a reasonable treatment or preventive measure is available—it would be an exaggeration to make him or her legally responsible on the basis of a supposed "right not to know" of those individuals. On the other hand, if there is no treatment or preventive measure for the disease, it is hard to imagine why healthcare professionals would be so interested in disclosing genetic information to patients' relatives. If such a thing could come to happen, the doctor would be violating without justification his or her professional duties. However, we do not need to postulate that third parties have a "right not to know" their genetic make up, which would be an excessively strong argument, in order to protect them from unjustified invasions of their privacy.

One could theoretically imagine a solution to this complex dilemma with the creation of a "public register"—similar to those that exist for organ donation—where people can express in advance their wish to know or not know their genetic status. Of course, those who do not register a refusal would not be automatically presumed to be interested in knowing their genetic make up. The only purpose of such a register would be to give people a means to specify in advance their preferences concerning genetic information and, at the same time, to facilitate the task of doctors, who could consult the register before making any unsolicited disclosures. Nevertheless, for the moment we are still very far from a general solution of this kind. Therefore, it seems that at present the right not to know can only operate within the

doctor-patient relationship and as the result of an explicit choice made in that context. In summary, ''autonomy''—that is, explicit will—is the best guarantee that we do not make a mistake in deciding for others whether they have an interest in knowing their genetic status or not.

CONCLUSION

The increasing access to genetic information leads law makers to recognise new rights in order to protect confidentiality and privacy of people. The ''right not to know'' is one of them. This claim is based on individuals' autonomy and on their interest in not being psychologically harmed by the results of genetic tests. Such a right, as an exception to both the patient's ''right to know'' and the doctor's ''duty to inform'', needs to be ''activated'' by the explicit will of the patient. In addition, this right has two characteristics: firstly, it can only operate in the context of the doctor-patient relationship; secondly, it is a relative right, in the sense that it may be restricted when disclosure to the individual is necessary in order to avoid serious harm to third parties, especially family members, which means that some form of prevention or treatment is available.

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COMMENTARY

A RESPONSE TO ANDORNO

Dr Andorno and I have corresponded for some time on the question of a right not to know (genetic) information. I enjoyed reading his paper and I am struck by the degree of agreement that we share. We both agree—for example, that unsolicited knowledge can be a burden which can significantly compromise an individual's psychological integrity. We both share a desire to respect individual self determination. Also we each consider it reasonable for individuals to choose not to receive potentially harmful information. I have already made these arguments, and more, elsewhere,[1] but my starting point has not been autonomy, as advocated by Andorno, but rather privacy. In essence, my argument is that individuals enjoy, and are entitled to enjoy, a measure of psychological privacy which can be invaded by unwarranted disclosures of information (Laurie,[1] pp 255–74).

The reason that I prefer privacy to autonomy is not because I have any wish to ''deny people the right to self determination''[2] but rather because I perceive deficiencies in the autonomy model. Indeed, my approach and that of Andorno are not mutually exclusive; it is simply that my approach is broader and encompasses some of the harder cases which an autonomy based approach cannot help us to resolve. Thus, most of the substance of Andorno's approach is subsumed within my model. I have—for example, no disagreement whatsoever with the view that if you have an indication that an individual would not wish to know then this wish should be respected. One might even establish novel means of discerning individuals' wishes by establishing a register to record advance refusals, as Andorno suggests. What should happen, however, if there is no indication of an individual's wishes? In such cases it is not possible to approach the individual to ask: do you want to know, because, as Fletcher and Wertz poignantly observe: ''There is no way…to exercise the choice of not knowing, because in the very process of asking 'Do you want to know whether you are at risk' the geneticist has already made the essence of the information known.''[3]

If I have understood Andorno correctly, his model leaves this dilemma unresolved. His reluctance to adopt a broader approach stems, in part, from the charge that a decision not to disclose taken by a health care professional is paternalistic. To avoid this accusation, Andorno conceptualises his

''right not to know'' as a means of *enhancement of autonomy*, whereby ''the decision to know or not to know is not taken out of the hands of the patient by the doctor''. I have three observations about this approach. First, the patient centred focus cannot answer the Fletcher/Wertz scenario. Second, paternalism is not a homogenous practice and not all forms of paternalism are bad.[4] Paternalism has become a dirty word with the rise in success of the principle of respect for autonomy. The desire to enforce this principle now dominates much ethical and medicolegal discourse, but it is disingenuous at the same time to deny the presence of paternalism and, at times, the value of certain forms of it. Most particularly, it must be recognised that the autonomy model cannot provide ethical and legal solutions to all medical dilemmas and I would argue that we are misguided in trying to make it do so. Finally, there is an irony in Dr Andorno's paper because not only does he recognise a role for paternalism at various junctures, but his argument about enhancement of autonomy, and his defence of conduct directed towards facilitating patient choices is, in itself, a form of paternalism. See—for example: ''it is the responsibility of the health care professional to assess the amount of information an individual wants and is able to deal with at a particular time''. He also states: ''…[l]et us recall that, for those cases in which the interest in not knowing seems clear, but no explicit choice has been made, we already have the concept of 'therapeutic privilege', which allows physicians to withhold information if, based on sound medical judgment, they believe that divulging the information would be harmful to a depressed or unstable patient…''.

He also asks ''…how can doctors assume that patients' relatives do not have an interest in knowing genetic information, which may be extremely important to them''. I would respond that they cannot, nor should they. By the same token, I would add: how can health care professionals assume that relatives would wish to know? Once again, I would respond that they cannot do so. This is precisely the essence of the dilemma—a health care professional does not know one way or the other what relatives would or would not wish to know.

I do not assume that people do *not* want to know, as Dr Andorno suggests. Indeed, my position is quite the opposite. I challenge any assumptions about people's wishes (Laurie,[1] pp 257–61). I have, in fact, a serious concern about the current preoccupation with autonomy and about its ascendancy to the status of supreme ethical principle in many quarters. I question this on a number of grounds, not least because it is an incomplete answer to many dilemmas and because it leads to limitations on our thinking about how to approach ethical quandaries such as those posed by an interest in not knowing. The limits are expressed by Andorno himself when he states: ''…the exercise of an autonomous choice seems necessary for the functioning of the right not to know, because it is impossible to determine a priori the wish of the patient''. The latter point may well be true, but Dr Andorno does not then go on to tell us how the harder cases should be dealt with where there is no prior indication of a patient's wishes. His idea of a register is, as he himself admits, of limited utility and should not lead to an assumption that people would want to know. If one accepts that individuals can be harmed by unsolicited disclosures and that some protection for psychological integrity is desirable, it is difficult, then, to draw a meaningful distinction between those who have exercised their autonomy and so enjoy protection and those who have not done so and so fall outside the autonomy based approach.

My privacy model advocates that because we cannot assume anything about what people want in the absence of actual knowledge about their wishes then a measure of caution should be exercised in taking disclosure decisions. Various factors should be weighed in the balance before disclosure is made, including the availability of a therapy or cure, the nature of the disease and its consequences, and any advance statements made by the patient in question, if available (Laurie,[1] pp 261–4). Most specifically, however, there should be recognition of an interest in not knowing. As Dr Andorno correctly identifies, this places the onus to demonstrate that some utility would come of the disclosure, on those who would seek to disclose. The presumption is that individuals' psychological privacy should be respected unless there is good reason not to do so. Disclosures can be justified both in the interests of the individual herself and her relatives. Prior wishes should be respected but even in their absence a decision not to disclose may be reached to protect the individual's privacy. This is undeniably a paternalistic approach; but the nature of the dilemma necessarily makes it so.

As a final caveat, I would question the use of the language of rights in this context. I myself am guilty of such usage, for it can often be a helpful form of shorthand in discussion. The details and implications of rights discourse sit uneasily, however, in the present circumstances, and for these reasons I agree with Dr Andorno that there should be no legal ''right'' not to know which can be enforced against family members (Laurie,[1] p 265). A better approach, to my mind, is to talk of the *interest* that individuals might have in not knowing. On this basis, we might find that there is even less disagreement between myself and Dr Andorno.

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PostScript

LETTERS

The Roman Catholic Church and embryonic stem cells

Skene and Parker[1] raise a number of concerns about religious doctrine unduly influencing law and public policy through *amicus curiae* contributions to civil litigations or direct lobbying of politicians. Oakley[2] picks this up in the same issue with an emphasis on the Roman Catholic Church's interest in preventing the destruction of embryos for embryonic stem cell research. Skene, Parker, and Oakley seem to be concerned mostly with religious views having undue influence on public policy. My concern is the negative effect that such Church influenced public policy may have on the progress of the biomedical research that is itself foundational to the debate. Oakley seems to be particularly incensed that, as he puts it: ''Those who support a total ban on embryonic stem cell research sometimes talk as if theirs are the only views based on moral principle''.[2] What seems to be at issue here though are not the moral principles of the sanctity and dignity of human life, but the application of those moral principles to biomedical research.

The Roman Catholic Church has historically defended the sanctity and dignity of human life to varying degrees at different times. Human life for much of the past 2000 years was defined by the Church as the presence of the soul, which was thought at different times to appear at various different stages during development. Only recently, with the advent of modern biology, has the Roman Catholic Church shifted its position to claim that the fertilised egg also qualifies as the right sort of human life.[3] It should be noted that this doctrinal change was fundamentally driven by developments in our understanding of embryology and not the process of ensoulment.

The Church's current position on the embryo is thus based not solely on Church doctrine but also on a specific interpretation of our empirical observations of human development. It is the Church's interpretation of the biology of early human development that is foundational to their current stand against experimentation on early embryos. However one of the reasons we may wish to experiment on early embryos is that we know surprisingly little about them. In fact any position that claims to be based on a solid, empirical understanding of the embryo is essentially misleading, as we simply do not have the data available. The reply to this will inevitably be that we know enough about embryos to make certain claims. For example the Roman Catholic Church likes to point out that the early embryo is obviously the earliest stage of a human life, and thus attributes to it many of the rights associated with actual people.[4] Many would disagree with this on the grounds that the Church has confused being merely human with being a person. I am concerned by the claim that the early embryo is obviously the early stages of a human life.[4]

My concern is not that the claim isn't obvious to some people but that obviousness is a dangerous thing when it comes to science. It is, for example, quite obvious to me that I am currently sitting at my desk. Empirically my senses seem to confirm that I am more or less stationary. I may well believe that I am stationary. For much of human history we believed the earth to be stationary at the centre of the universe. This assumption was confirmed in the Western world by the Church itself. Church doctrine confirmed that the earth was the stationary centre of the universe with the heavens above and hell below. When Galileo challenged this view by promoting the sun centred Copernican system of cosmology the Roman Catholic Church attempted to silence him. The Church's attack on Galileo and Copernicanism was tripartite. Firstly, the Copernican system appeared to contradict some scriptures. Secondly, the Copernican system contradicted the church sanctioned science of the day represented by Aristotelian physics. Thirdly, was the appeal to obviousness or the immediate evidence of the senses. Of the three, only the scriptural objections were fundamentally doctrinal in nature. The appeals to science and obviousness were able to be settled by empirical evidence. We now know that we are not stationary at the centre of the universe although this is still far from obvious to many people.

> Any position that claims to be based on a solid, empirical understanding of the embryo is misleading: we simply do not have the data

The situation 400 years ago regarding Copernicanism thus seems to be very similar to that today regarding the status of the early embryo. The Roman Catholic Church tried to prevent Galileo from collecting empirical evidence using his telescope and disseminating his empirical evidence by banning his books. Similarly the Church today has attempted to prevent the gathering of empirical data on the early embryo by promoting a ban on all experimentation on early embryos.

The Copernican revolution itself has become a paradigm for the process of theory change in science. Science is not simply a collection of results from experiments (or facts) but perhaps more importantly science is the interpretation of those results and the planning of further experiments. For all its claims of objectivity science is, so the philosophers of science tell us, essentially a theoretical construct. The practical and theoretical sides of science are of course intimately connected. In fact it is well known that a researcher's actions and observations are most likely guided to some degree by their own hopes and expectations. These same researchers develop the theories that they use to interpret their data. These theories fit the results (or facts) that have been previously observed and predict new experiments to be done. The role of theory at this stage of the process is often underestimated. Theories do not fall out of results. In fact in biology especially theories are often essential to making sense of what is signal (result) and what is noise (artefact). Theory then is not just a bridge to the next fact or experiment but arguably the very heart and soul of science. Theories that do not fit the facts are of no use and should be discarded. But in biology especially, theories can define what counts as a fact and what does not. Sooner or later a startling new observation is made that cannot be accommodated within the existing theoretical framework. New theories are developed and past observations are re-categorised. What was written off as noise is heralded as fact. Thomas Kuhn called this a paradigm shift and his paradigmatic case was the Copernican revolution.[5] One overarching theoretical construct is replaced with another—our understanding of the world is literally changed forever.

A problem arises when an organisation such as the Roman Catholic Church erects its doctrinal structure on the shaky foundations of a specific theoretical construct. Biology and developmental biology in particular are comparatively young sciences that are progressing rapidly and are thus quite theoretically diverse. By lending its support to a certain theory or position within biology the Church may well be able to distort the natural balance that exists in science whereby theories are valued for their explanatory power or instrumental use, not their doctrinal compatibility. External interest groups with political lobbying power may thus hijack the delicate process of progress in science with dire consequences for future advancement in science and medicine. The Roman Catholic Church's influence on science is indirect and usually through the medium of public opinion and public policy. As we have seen in the American debate over the status of the embryo with regards to the derivation of embryonic stem cells this influence may be decisive in the formation of public policy. Indeed President Bush's decision to effectively ban public funding of embryonic stem cell research in America is widely believed to have set back progress in the field worldwide by many years.[6]

The Roman Catholic Church's input into the embryonic stem cell debate has not been simply moral or ethical as one might assume but has openly defended a particular claim about the biology of the early embryo. Given the basic lack of empirical evidence regarding the embryo and such developments as the unexpected properties of stem cells the Roman Catholic Church's choice of position on the biology of the embryo seems to be chosen solely as a prop for its doctrinal position. This prop has then been introduced into the secular debate on the status of the embryo as a somehow obvious empirical claim.

I believe the Church's religious fervour for its preferred doctrinal and scientific position of the day is fundamentally at odds with the process and progress of science. Science is an exploration of the physical world that is characterised by continual advancement and, historically at least, major shifts in understanding. Over the last 400 years the Roman Catholic Church has been slow to accept that science progresses at all and has preferred to maintain its doctrinal position as a matter of faith even when it has been shown to be empirically unsound. My concern here is I think similar to that of Skene

and Parker. The Roman Catholic Church's contributions to public policy are based not only on their moral or ethical principles, but on an effectively arbitrary and dogmatic application of those principles that is backed by the full force of what is effectively a very powerful lobby group in many countries.

Like Skene and Parker, I have no answer to the problems I have raised. Historically one thing is certain, in the future the Roman Catholic Church's current position on the embryo will be judged to have been right or wrong with the wisdom of hindsight. Just as we judge the Church's persecution of Galileo almost 400 years ago now.

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Non-compliance: a side effect of drug information leaflets

The problem of non-compliance with treatment and its repercussions on the clinical evolution of different conditions has been widely investigated.[1–4] Non-compliance has also been shown to have significant economic implications, not only as a result of product loss but also indirectly through the complication of disease management and its subsequent healthcare and social costs.[5–7]

Non-compliance as a health problem

The term ''non-compliance'' might be taken to refer both to the failure to follow a drug regimen and to the failure to adopt other measures that contribute to improvement in health—for example, changes in lifestyle or diet. This letter focuses on the former.

Non-compliance with a drug regimen can be the result of a number of different factors[9–11] and a variety of techniques have been developed in an attempt to control it.[12 13] Of these, the few techniques that have been shown to be effective have only managed to solve the problem in specific situations over short periods of time. The use of such techniques to control non-compliance, particularly where these are effective, raises interesting ethical questions about the extent to which their application constitutes an infringement of the patient's right to decide on how to manage their own health.[8] Here we suggest that in some cases one factor that leads to non-compliance is the tendency to provide extensive and exhaustive information on side effects in patient information leaflets. Consider the following case.

A true story

One morning Dr Smith woke up with a slight cold—muscular aches, headache, chills, and nasal congestion. He decided to take some medicine to counteract its effects. His initial thought was to find something to combat his runny nose, so he chose a product specially indicated for nasal congestion: ''StopSnot''. After reading the product information leaflet, however, Dr Smith felt another kind of chill run down his spine. He was struck cold by the contraindications, warnings, interactions, precautions, and adverse reactions listed in the leaflet. If he used this drug, it said, he would run the risk of suffering nausea, anxiety, agitation, insomnia, hallucinations, convulsions, amazement, weariness, arrhythmia, dizziness … . Rather than risk all of this, he thought, why not suffer a few bothersome snuffles? For his muscular aches, Dr Smith chose another drug, ''Abatache'', but the risks described in the accompanying information leaflet seemed even worse. These included baldness, skin blistering, aseptic meningitis, pneumonitis, fatal hepatitis, gastrointestinal perforation, blood in the urine, jaundice, kidney disease, peptic ulceration, mouth ulceration, visual abnormality … . So in the end, armed with his clinical and pharmacological knowledge, Dr Smith simply opted to continue blowing his nose and suffer a few muscular aches. He had no desire to play Russian roulette with his health.

The principle of autonomy and the right to information

The principle of autonomy in medical ethics places the patient at the centre of medical decision making about his or her care. It places particular emphasis on the importance of informed consent, and suggests that, except in rare situations,[14] no patient should undergo medical treatment or surgical intervention without his or her fully informed authorisation. This is the basis of patient-centred medicine.

To obtain valid informed consent, it is argued that the patient must receive sufficient understandable information to make a fully informed choice. In practice this means that someone undergoing a specific treatment receives information from at least two sources. First they will be given direct information from their doctor or another health professional about the drug to be taken, recommended lifestyle changes, and perhaps a warning of the hazards related to non-compliance. At this time, they will also be provided with information on some of the side effects attributed to the drug being prescribed. Individual patients will tend to understand this information in a range of different ways, and it is well recognised that they will respond with a variety of known behaviour patterns.[8]

Secondly, the patient will also receive additional information on side effects from the information leaflet provided with the drug itself. These leaflets tend to cite each and every one of the undesirable effects related—note ''related''—to the principle active ingredient used in the drug. The information can in some cases be so complete or detailed that even any extremely unusual syndrome described in relation to the use of the drug will inevitably be listed in the leaflet as a possible ''side effect''.

This information can sometimes have a significant effect on the likelihood that a patient will take the drug in question and may lead to significant ''non-compliance''. When patients with minor ailments read about all the problems that may occur from using the prescribed medication, they may start worrying, to say the least. Some people read the leaflet again and again. They may then consult another source of medical information such as a website and perhaps decide to take only half the dose for half the amount of time prescribed, or simply decide not to take the medicine at all.

In addition to the problem of non-compliance, the so called nocebo effect[15] needs to be considered, whereby the patient's mindset is often a key element in the appearance of either physical or imaginary side effects, as has been shown in various studies.[16 17] Such an effect may be caused by information leaflets.

Complete information versus sufficient information

Practically any city dweller would refuse to use transport services, work tools, or recreational facilities if they were supplied with complete, absolute, and extensive information on the hazards using these might entail. Precautions and warnings are usually good things, but they should be kept within reasonable limits to avoid creating outright alarm. Too much information can sometimes undermine autonomy and also lead to significant harms through non-compliance.

It was shown some years ago[18] that information supplied by doctors can generate side effects that cannot subsequently be corroborated by physical examination. As it happens all too often, the information was not as exhaustive or complete as it might be.

In view of this, we believe that the kind of information given in drug descriptions should be reassessed. The information should be true, accurate, and easy to understand in as complete a way as possible, but it should not generate alarm that can lead to deleterious consequences in the healthcare sector or in the economic sphere.

So what did the patient decide?

The patient, shocked and dismayed at the drug's side effects, finally decides not to follow the doctor's recommendation. He (or she) will try to relax, perhaps by smoking a cigarette laced with nicotine, tar, and a number of other substances. True enough, doctors recommend giving up smoking. But who will listen to what a doctor says about smoking when they appear to be prescribing drugs truly hazardous to health? After all, a pack of cigarettes only says that cigarette smoking seriously damages your health. There is certainly no leaflet listing each and every one of its possible side effects. Tobacco kills, but it sometimes looks as if medication is worse.

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Symposium on consent and confidentiality. *J Med Ethics* 2003;29:2–40

We read with interest the papers on informed consent published in a recent issue of the *Journal of Medical Ethics*.[1] Whatever their differences, and however much they questioned some aspects of the duty to respect autonomy through attempting to obtain informed consent for therapeutic interventions, there was general agreement that competent adult patients are entitled to a core of basic information about their treatment options. There was also consensus that training in the process of obtaining consent is important. In our experience, two dimensions of such training are of particular interest. On the one hand, students require good theoretical understanding of the ethical and legal background to the professional emphasis now placed on informed consent. On the other hand, they need practical training in the relevant communication skills and how to apply them to obtain consent for specific clinical procedures. To do so, doctors must obviously also have a good understanding of these procedures. We recently encountered serious problems as regards such understanding in a study among junior doctors in England (Schildmann J, Cushing A, Doyal L, Vollmann J. The ethics and law of informed consent: knowledge, views and practice of pre registration house officers, submitted for publication). No matter how good their philosophical and legal knowledge, preregistration house officers (PRHOs) will not be able to deliver the minimal standards of informed consent outlined by O'Neill unless, suffice it to say, they know what—practically speaking—they are talking about.[2]

In contrast to Bravo *et al*'s results (in the same issue of the journal), almost all the PRHOs who took part in our survey had good legal understanding of the differences between competent and incompetent patients.[3] This may be interpreted as a positive result of the change in the curriculum at their particular medical school, which includes extensive sessions about informed consent. These embrace ethics, law, and communication skills. However, despite their understanding, the junior doctors in our study still experienced problems about their role in the consent process. The problems pertained to pressure of time and lack of support by senior doctors, as well as pressure on them at times to obtain consent in circumstances where they had been taught that they should not. This gap between the standards of informed consent currently taught to medical students and the clinical realities they face, and into which they are thrust, is an ongoing problem.[4]

If informed consent is to fulfil the purpose of respecting the autonomy and dignity of patients, sufficient resources are required to train young doctors to do the job properly, especially as regards their understanding of procedures for which they are providing information and their competence as communicators. One thing is clear: if they cannot complete the task in accordance with the guidance issued by both the General Medical Council and the Department of Health, they should not be doing it at all.[5 6] Trusts and colleges should ensure that all supervisory staff are aware of their responsibilities in this regard.

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Response to ''Patient organisations should also establish databanks on medical complications''

Gebhardt in his brief report[1] pleads for patient organisations to establish databanks on medical complications. Given the references (for example, an article by Paans, a journalist, entitled ''Medical errors to be kept secret'') and the lack of argumentation, there is substantial danger of misinterpretation of the current situation, which in turn may frustrate the process of increased transparency. We would therefore like to respond to this by giving background information and reasons for some of the choices that were made with respect to the registry of complications mentioned by Gebhardt.

First, a distinction needs to be made between an error and an adverse outcome, which are often confused. From Gebhardt's reference to the journalist's article which discusses the same registry of adverse outcomes, but with the title referring to errors, both Gebhardt and the journalist think errors and adverse outcomes are the same thing. However, an error refers to the process in which something has gone wrong, a substandard performance, regardless of the outcome. It has been explained by others that such a judgement may have a degree of subjectivity.[2] An adverse outcome refers to the outcome which is unwanted but does not necessarily imply that an error has been made. This is why the term ''adverse outcomes'' is used rather than the term ''complications'', since the latter term is often confused with an error being made. The registration of medical complications that Gebhardt refers to is a registration of surgical adverse outcomes guided by an unambiguous definition of the term ''adverse outcome'', of which only a small percentage is related to errors.[3] Furthermore, some errors will be missed in this registration—that is, errors which have not led to adverse outcomes.

Secondly, with respect to confidentiality, this is relevant in particular for the initial years of such a registry during which it is thoroughly tested and accuracy of the registration may vary widely between participants. Nothing is gained by false positive signals with respect to the high incidence of adverse outcomes in some hospitals, except perhaps by flashing headlines in newspapers. In this respect one may compare the development of such a national registry to the development of a new drug, in which case no one argues about confidentiality and thorough testing until proved safe. Moreover, a pharmaceutical company will probably be sued if it markets a new drug without proper research. It is intended that after this initial period, national adverse outcome data will become available to the public with respect to probability of an adverse outcome given certain types of surgery.

Box 1: Patients need information to make a well informed choice

Who is a good doctor and what is a good hospital? This simple question is not easy to answer for individual patients who need a good diagnosis and the best treatment. The NPCF (Dutch Federation of Patients and Consumer Organisations) and its member organisations have published several consumer guides for specific diseases to help patients find their way in the labyrinth of the healthcare system. Patients experience many difficulties in getting access to relevant information from doctors' organisations and insurance companies. Therefore the NPCF wants to cooperate with these organisations to create consumer information based on the important and relevant data that are available. A joint project for a databank on best practices started in September 2003.

Patients are not interested in black lists of doctors and malpractices, they prefer to know about good and best practices to make a well informed choice for a doctor or hospital. They need consumer information on objective measures such as the risk of infection in a hospital, the specific skills of a doctor, how many patients with this specific disease a doctor treats a year, etc. Patients would also like to receive subjective information on a specific hospital or doctor: How is the communication between a doctor and his or her patients? Does the team give enough information and support when needed?, etc. This experience based information is often available from patient organisations.

The NPCF has chosen to work together with organisations of healthcare providers and insurance companies to use parts of their databanks as a basis for consumer information. One task of the NPCF is to translate the data into consumer information that meets the needs of the patients, based on research and experiences of patients.

Joint efforts are needed to make this important information accessible for doctors and patients.

Dr I van Bennekom, Director, NPCF

Finally, what does the patient want? (see box 1). International research has shown that patients do not use public information on performance of hospitals or doctors for making a choice of treatment or hospital because, among other reasons, they do not understand and do not trust these data.[4] This also applies to adverse outcomes data. For interpreting the incidence of hospital specific adverse outcomes it is important to know the context—for example, since older, sicker, and more complex patients have higher probabilities of adverse outcomes.[3] It is therefore vital to establish a reliable registry which can be trusted and understood both by medical professionals and the public. For this reason, the Association of Surgeons of the Netherlands and the Dutch Federation of Patients and Consumer Organisations (NPCF) are collaborating with respect to the national surgical adverse outcome registry, in particular, to produce information that is relevant for patients about treatment and hospital choices. Supported by the international literature, the NPCF holds the view that patients are not primarily interested in data on adverse outcomes, since they are aware that these data need to be interpreted in the right context. Patients are more interested in the experience of doctors or hospitals to treat certain diseases or to perform certain operations, since the question they want answered is "What is the best place to go to for this type of problem?". That this doctor or hospital probably has a high adverse outcome record is not relevant, since this may well be explained by the complex patients who are referred to more experienced doctors. As argued in a previous paper,[3] it is essential that there is an increased mutual trust between the medical profession and patients' organisations that supports a combined effort to improve the quality and availability of patient information. Such initiatives will benefit both patients and doctors and are too important to be frustrated by references to "powers that must be kept under control".

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What do patients value in their hospital care? A response to Joffe *et al*

In the *Journal of Medical Ethics*, Joffe *et al* recently published an article titled "What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics".[1] This empirical study evaluates whether patients' willingness to recommend their hospital to others is more strongly associated with their belief that they were treated with respect and dignity than with their belief that they had an adequate say in their treatment.* Joffe *et al* go on to suggest that confirmation of these empirical hypotheses would constitute a prescription for elevating the principle of respect for persons to the level that the principle of respect for autonomy currently enjoys in our model of the ideal patient–physician relationship (p 104).[1] In other words, they suggest that by some means empirical findings could influence our ranking of the normative principles. Earlier in the article, they make an even stronger claim about the influence of empirical data on our acceptance of normative principles. They suggest that, if it were demonstrated empirically that some patients prefer to delegate medical decisions to health care professionals, a serious challenge would be levied against the normative assumptions underlying the principle of respect for autonomy, at least under the mandatory autonomy view, which holds that patients not only have a right but also an obligation to act autonomously (p 103).[1] In the light of many recent empirical studies challenging the centrality of patient autonomy and shared decision making in bioethical theory, I think it is instructive to evaluate the means by which empirical findings, like those offered in Joffe *et al*, strengthen or weaken our arguments for ethical principles. In particular, I would be interested in how these authors propose that their data led them to the normative conclusions they reached.

In the last paragraph of their article, Joffe *et al* write: "we do not recommend that patients' perspectives should unilaterally determine ethical frameworks. We do, however, believe that data such as those presented here can contribute to the search for reflective equilibrium in bioethics"(p 107). The term "reflective equilibrium", as the authors note, was introduced by John Rawls. At least in its first instance, it refers to a way of constructing a moral theory by balancing one's considered moral judgements against one's moral principles, until one's judgements and principles form a consistent set—that is, a moral theory (p 288).[2] Joffe *et al*'s idea seems to be that by surveying patients' perspectives they will be able to capture one side of this equilibrium, considered moral judgements, or moral principles (they do not specify which), and in so doing contribute to the desired end: a consistent ethical framework to govern medical encounters, built (at least in part) from the principles and moral judgements of the patient community. Whatever the merits of this goal, however, Joffe *et al* fail to capture either the considered moral judgements or the moral principles of those they survey and so fail to contribute to the moral theory they seek to construct.

Rawls defines considered moral judgements as those judgements in which our moral capacities, which he considers analogous to our linguistic capacities, are "most likely to be displayed without distortion"—for example, those offered without hesitation, given without strong emotions like fear, and made in the absence of conflicting interests (p 47).[3] The distinction between considered judgements and judgements generally is important. When constructing a moral theory for a particular community—for instance, the patient community—we want to use only those judgements that reflect the respondents' real moral sensibilities, and not those stemming from superficial prejudices or their mood on the day they happen to respond. This raises two important questions, however, for researchers, who, like Joffe *et al*, are using the concept of reflective equilibrium: (1) precisely how considered do considered judgements have to be if they are to count; and, more practically, (2) how can a researcher know whether he or she is collecting them—that is, what survey method, if any, is appropriate for the task?

*Joffe *et al* also evaluate whether patients' reports that they had confidence and trust in their health care providers significantly predicted whether they would recommend the hospital to others. For simplicity's sake, I address only Joffe *et al*'s treatment of the respect for persons and the respect for autonomy principles in this response.

Although it is difficult to give a positive answer to these questions (and I will not attempt to do so here), some survey methods, such as the mailed questionnaires that Joffe *et al* used, seem particularly inadequate. Rawls suggests that certain external conditions favour the formation of considered judgements: ''the person making the [considered moral] judgment is presumed … to have the ability, the opportunity and the desire to reach a correct decision (or at least, not the desire not to)'' (p 48).[3] Very likely, however, many of Joffe *et al*'s respondents lacked the necessary ability, opportunity, or desire to reflect on their moral judgements when responding to the questionnaire they received in the mail. Furthermore, even if a number of patients did offer legitimate considered judgements, there is no way to distinguish these from those made by respondents who lacked the requisite ability or desire. Although the size of Joffe *et al*'s study is of value for its ability more accurately to reflect a population's response to its survey questions, because of the practical limitations that come with its size, the study falls short of capturing patients' considered moral judgements.

Any empirical approach using reflective equilibrium, as Joffe *et al*'s, faces a second challenge: why do we want people's considered moral judgements to influence our theories of ethics in the first place? In his influential critique of reflective equilibrium, D W Haslett writes:

> … given the wide differences between people's considered moral judgments, and given that these differences are, as we know, largely just a reflection of differences in upbringing, culture, religion, and so on, it would appear that, far from having a reason for giving people's considered moral judgments initial credibility, we have instead a reason for initial skepticism (p 309).[4]

If moral judgements are liable to reflect superficial prejudices, one could argue, considered moral judgements are liable to reflect deep seated ones. Surely this prejudice is something ethicists would like to overcome, not codify. While I do no think this challenge is insurmountable,†[5] it does demand that researchers justify the inclusion of considered judgements in ethical theory before using the method of reflective equilibrium. Joffe *et al* have failed to do this.

Joffe *et al*'s study is susceptible to a second line of critique. Even if the study's use of mailed surveys is appropriate, it fails to capture either patients' considered judgements or principles, because, put simply, it does not ask for considered judgements or principles. Instead, it asks patients whether providers respected their person or respected their autonomy, and then tests patients' responses to these questions against whether they report being satisfied with their care. If a provider's acting with respect for persons is a better predictor of patient satisfaction than him or her acting with respect for autonomy, Joffe *et al* conclude that the principle of respect for persons should be assigned as much importance, *ethically speaking,* as the principle of respect for autonomy. As should be clear, this conclusion does not follow from Rawls's conception of how one constructs a moral theory. In a Rawlsian view,‡[3 6] a moral theory requires knowing which principles patients hold, not whether those principles are associated with patient satisfaction. Joffe *et al* seem to be operating with an underlying utilitarian assumption to the effect that what we ought to do ethically speaking is whatever will lead to the greatest patient satisfaction. Although there may be reasons for accepting this utilitarian assumption (which Joffe *et al* do not provide), certainly there are others for rejecting it. For instance, although patient satisfaction may give a hospital a very good reason to change a policy, we probably do not want to say this reason is a good *ethical* reason. It is just good business sense. This is an especially important point given the principles that Joffe *et al* evaluate. Respect for autonomy and respect for persons are traditionally viewed deontologically—that is, it terms of duties or rights, which are valued for their own sake rather than the consequences (such as patient satisfaction) that they produce. In any case, these utility considerations take us far from patients' actual moral views, the very things Joffe *et al*, by invoking Rawls's reflective equilibrium, propose to capture.

Lastly, there is a question of their instrument's validity. As I have been arguing, Joffe *et al* claim to assess whether patients are treated according to the principles of respect for autonomy and respect for persons. Yet, their single item assessing respect for autonomy—the question, ''do you feel you had your say?''—does not do the principle justice. The principle of autonomy not only requires that the health care provider *asks* the patient for his or her opinion, but also that the provider *acts* on the patient's opinion. Their instruments are similarly inadequate for the principle of respect for persons, which, they suggest, includes ''autonomy, fidelity, veracity, avoiding killing, and justice'', as well as ''respect for the body, respect for family, respect for community, respect for culture, respect for the moral value (dignity of the individual), and respect for the personal narrative''(p 104).[1] How are we to know whether patients had all or any of these in mind when they answered the question: ''Did you feel like you were treated with respect and dignity while you were in the hospital?'' Joffe *et al* acknowledge that these ethical concepts are a bit unwieldy for a survey of manageable length. However, these practical considerations should be used not only to excuse the study but also to question its ability to clarify the ethical concepts it claims to assess. They should prod us to ask, regardless of the survey's scale and the limitations that its size produces: does this survey really address what we mean by the principles of respect for autonomy and respect for persons?

With any empirical study in bioethics, there is a gap between the empirical hypotheses the study confirms and the normative conclusions its authors would like to draw from it. In their article Joffe *et al* hoped to bridge this gap by invoking Rawls's notion of the reflective equilibrium. As I have explored, however, the study does not contribute to either side of the reflective equilibrium they imply, and, thus, they fail to demonstrate how their findings challenge the centrality of autonomy and shared decision making in bioethics.

Joffe *et al*'s failures are instructive, however, insofar as they suggest how we could better bridge the gap between research and theory. The use of the reflective equilibrium in empirical research has promise, provided researchers are clear about: (1) how to define considered moral judgements and/or principles; (2) how their methods capture these judgements and/or principles reliably; (3) how the inclusion of considered moral judgements strengthens rather than weakens bioethical theory; and (4) how their instruments are valid for the judgements or principles they mean to assess. In addition, empirical research can contribute to bioethics by questioning the assumptions implicit or explicit in our normative views. Joffe *et al* try to do just this when they argue in the introduction to their article (p 103)[1] that patients' desire to delegate decision making challenges the mandatory autonomy view. However, if empirical findings are to defeat a particular normative principle, the assumption that those findings challenge must be logically necessary for our holding that principle. For instance, without showing that patients' desire for autonomy is necessary for our holding the mandatory autonomy view, the studies that Joffe *et al* cite, even if valid, can be interpreted variously as devaluing the mandatory autonomy view or as recommending that we better educate patients on the value of autonomy. This normative question cannot be settled empirically.

Empirical researchers have the potential to contribute substantially to bioethics, but their work needs the kind of philosophical and empirical rigor that comes from truly interdisciplinary collaboration and must be informed by a careful reflection on the proper relationship between descriptive and normative ethics.[7] Joffe *et al* take us part of the way down that path. An exciting research itinerary lies ahead.

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† See, for instance, Delden and Theil,[5] in which the authors argue convincingly that a reflective equilibrium-like method may be valuable for capturing the norms of health care providers and that knowledge of these norms may guide individual providers.

‡I say ''a Rawlsian view'' rather that ''Rawls's view'' because, in his theory of Justice, Rawls advocates balancing a single person's considered moral judgements (for example, Rawls's or his reader's) with a single person's moral principles (p 50).[3] Although he later gestures towards reflective equilibrium as an exercise that involves the considered moral judgements of others (p 8),[6] it is probably safer to say ''Rawlsian''.

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How to be a ''good'' medical student

The public revelation in 2003 that medical students perform intimate examinations without patient consent has engendered much debate in the press and scientific journals. Using this case as a springboard for discussion, I will argue that medical schools should encourage students to raise their ethical concerns and call for a change of policy making it easier for students to do so. I will also address the question of medical students' moral obligations towards their patients, and conclude that medical students ought to express their discontent when faced with unethical practices or attitudes.

In early January 2003, a study appeared in the *British Medical Journal* revealing that nearly a quarter of rectal and vaginal examinations on anaesthetised patients were performed by medical students without patient consent.[1] Although the study did not generate the firestorm of controversy many expected, it engendered much discussion on ethical issues surrounding informed consent and patient autonomy, as well as stressing the need for greater ethics training for medical students. As an ethical problem, however, the case of intimate examinations is, to my mind, relatively uninteresting. If we agree that it is wrong for doctors to perform a vaginal examination on a *conscious* person without their consent, then it follows that it will still be wrong if that same person is merely asleep. Society would be somewhat chaotic if a person suddenly lost his rights when unconscious. The argument that the anaesthetised patient is unaware of the examination and so cannot be harmed is, at best, questionable. Suppose a newspaper revealed tomorrow that sociology students had placed hidden cameras in the cubicles of public toilets to study urination habits. Most people would be understandably outraged by this violation of privacy, even though the victims were not harmed by it at the time. This is based on the belief that a person's rights can be violated without that person's knowledge.

As for the conflict between the educational need of students and the respect for patient autonomy, it would only arise if an overwhelming number of patients refused to be examined. This is an unlikely scenario. In a commentary on Dr Coldicott's study, Britt-Ingjerd Nesheim, a professor of obstetrics and gynaecology in Norway, affirms that obtaining patient consent to student examinations is not difficult, as long as the patient feels comfortable with the arrangements.[2] Yet for me the study raises a more interesting question which extends beyond the recondite sphere of intimate examinations. It concerns the moral obligations of medical students faced with ethically dubious situations. In short, what should a ''good'' medical student do?

In an article on the scope of medical ethics, Professor Raanan Gillon recounts two experiences from his days as a medical student.[3] The first describes his teacher's refusal to grant an abortion to a 14 year old girl on the grounds that she was ''a slut''; the second his own refusal to examine a scrotal lump on a patient whose testicles had already been examined by five other students. Gillon's objections were very much the exception. When these events took place in the 1960s, medical students were simply expected to follow their teachers' orders and to absorb their evident wisdom without question. Since then, medical ethics has developed from an ill defined embryonic subject to an academic discipline in its own right, with specific journals and associations, and a place in the medical curriculum.

Judging from some of the comments from students at Bristol, however, the growing emergence of medical ethics has not dispelled the awkward climate of unquestioned reverence towards teachers. Many of the students felt uneasy about the examinations, but were too intimidated to voice their concerns: ''You couldn't refuse comfortably. It would be very awkward, and you'd be made to feel inadequate and stupid'', commented a fourth year student who participated in the study. It seems clear that medical schools should strive to foster a climate more conducive to open discussion on ethical issues between students and teachers. Students should not have to perform heroic acts of courage to raise ethical concerns. In light of medical ethics' place in the curriculum, the situation is deeply paradoxical. Students may be taught the importance of respecting the patient's autonomy one day, but witness an obvious violation of this principle by their teachers the next. For the subject to be of any use, students must not only be allowed, but positively *encouraged* to put into practice their knowledge without the fear of appearing ''inadequate and stupid''. If a student's ethical concerns remain unresolved after discussion with the teacher, there should be formal methods of complaint, perhaps through a committee specifically set up for that purpose, or through the school's medical ethicist, who would then investigate the matter thoroughly. Medical ethics is, after all, an applied discipline.

It is nonetheless all too easy to blame the medical establishment and individual teachers for the unethical behaviour of students, as if the appellation ''medical student'' shielded individuals from moral fault. In Nick Hornby's novel ''How to be good'', the narrator, an adulterous GP and mother of two, resolves her moral conundrums by mechanically repeating ''I must be good. I'm a doctor''.[4] It is only later that she acknowledges that her justification is too facile: ''it's not enough to just be a doctor, you have to be a *good* doctor''. Students, however wide eyed or intimidated, are still capable of independent thought. Their personal values should not vanish as they put on the white coat, just as a patient's rights should not evaporate when under anaesthetic. Although the reluctance of many Bristol students to perform the examinations is comforting, it seems that none acted on their qualms by declining to perform the procedure or asking that proper consent be obtained. Neither the diminished responsibility of the medical student, nor his status as an apprentice, removes the need for ethical reflection in daily proceedings. Indeed, far from absolving him from moral inquiry, these factors should encourage a process of ethical questioning. This exercise is, to my mind, crucial to a student's flourishing as a morally responsible future doctor. To paraphrase Nick Hornby: ''it's not enough to just be a medical student''.

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NOTICES

JME editorial office has now moved

The JME editorial office has now moved to BMA House. The new contact details are: Journal of Medical Ethics, BMA House, Tavistock Square, London WC1H 9JR. Tel: +44 (0) 207 383 6439. Fax: +44 (0) 207 383 6668. The point of contact is Nayanah Siva, Editorial Assistant.

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Successful applicants will be informed by 31st March 2005.

CORRECTION

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An error has been pointed out in the affilliation for R Andorno, author of The right not to know: an autonomy approach (*J Med Ethics* 2004:**30**;435–439). The correct affiliation is Interdepartmental Center for Ethics in the Sciences and Humanities (IZEW), University of Tübingen, Tübingen, Germany. The journal apologises for this error.

The right not to know: an autonomy based approach

R Andorno

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