LAW, ETHICS AND MEDICINE

The right not to know: an autonomy based approach

R Andorno

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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.

Correspondence to:
R Andorno,
Interdepartmental Center for Ethnics in the Sciences and Humanities (IZEW),
University of Tübingen,
Wilhelmstr. 19, 72074 Tübingen, Germany;
roberto.andorno@uni-tuebingen.de

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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