

NEWS AND VIEWS

Comment on a View Favoring Ignorance of Genetic Information: Confidentiality, Autonomy, Beneficence and the Right Not to Know

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1. Introduction

In June 1999, the *European Journal of Health Law* published an article, by Graeme Laurie, on the right of the relatives of a patient not to know genetic information not only concerning the patient, but also information potentially affecting them, as relatives¹. I would like to discuss the crucial points of the article and offer a rather different view of the 'right not to know'.

This different analysis, though, I would like to point out at the outset, does not mean that I have reached different conclusions. But my reasoning and the reasoning of my esteemed colleague, are different; and there is value, in science, in different reasoning, even if the conclusion may be the same. In mathematics, the method, the reasoning, the way, to put it simply, we use to resolve a mathematical problem is obviously crucial, even if two methods come at the same conclusion in a particular case, e.g. that $a=1$. With this as a premise, I shall now begin my discussion.

2. The essence of Laurie's article

Laurie's main theme, as I understood it, was whether we should recognize the value of a 'right not to know', here genetic medical information. In the article this right not to know is examined not as a right of the patient, not to know medical information of herself, but as the right of the relative of a patient, not to know genetic information of the patient. In dealing with this question,

Laurie sustains certain ideas²:

- a. That genetic information is unique compared to other medical information, because it does not affect only the person from whom it is drawn, but may also alert family members to their own future medical status.
- b. That there is a notion of privacy, different from privacy as we know it now, a spatial privacy, protecting one's sense of self. Receiving information about ourselves 'which we did not previously have and for which we can do nothing' may invade our spatial privacy. If so, then it is better to remain in a state of ignorance, which is used in the article as a simple state of no(n)-knowledge.
- c. That, if a physician informs a relative that the patient suffers from a genetic form of breast cancer (Laurie's case example), so she, as a relative, may also carry the gene and be at risk, this does not mean that the physician manages to avoid harm (the ethical foundation of disclosure), physical harm, psychological harm or harm to (reproductive or other) choice; there is always the question of how to protect the relative's 'interest in not knowing', in cases where e.g. there is no cure for the disease.
- d. That confidentiality and autonomy as principles cannot protect the 'interest in not knowing'.

Laurie's case example, the 'mathematical problem', on which we will also work, is the following:

'Sophie discovers that she has a genetic form of breast cancer linked to the gene BRCA1. The disorder is dominant and multifactorial. There is a 2-3 fold higher increase if a sister is affected, but a clear family history is available in only 10% of cases. Cure is improbable and mastectomy is the most effective preventative measure. Sophie has two sisters, Katie and Sally. Katie is phobic about needles and hates hospitals. Sally is depressive and has recently discovered that she is pregnant. Sophie does not want to tell her sisters about her disease, but should Ivan, her doctor, do so, even if the knowledge might have adverse implications for their lives?'

Laurie's answer is that Ivan, the doctor, under the above circumstances, should not inform the two sisters of Sophie's disease, not because of Sophie's right to privacy, or to confidentiality, but because of the sister's right to spatial privacy, their own right not to know, a right, though, exercised by Ivan.

I would like to mention here that the answer cannot, should not be found in law, at least not only; the question is in reality a medical ethics question. It begs for the balance of medical ethics values, namely autonomy, liberty (of the sisters) versus privacy (of Sophie), and also of beneficence (for the sisters)

versus their freedom of choice. So, I think that the difference in reasoning, the difference in analyzing this case between Laurie and me is obvious from this starting point.

3. The uniqueness of genetic information: is it relevant to the obligation to disclose?

Before dealing with the balance of values question, we have to see whether it is correct to distinguish between genetic information and other medical information. That genetic information is unique could be proven by the number of Acts, Bills, Federal Bills, statutes and other laws concerning this type of information; there is a widespread fear that, if privacy is not protected in this field, individuals will suffer discrimination, by all sorts of sources: by insurers, who will decline to cover them³, once they know a particular genetic trait (e.g. a predisposition to develop cancer), by employers, who may dismiss or refuse to hire for the same reason etc⁴. Similarly, genetic information, unlike other medical information, like the results of a cholesterol test, does not change over time; there is really nothing you can do, at least now, when you carry a certain gene. Genetic information reveals our heritage and our connection to relatives and communities.

However, the above uniqueness of genetic information does not transform the duty of the physician to disclose information into a different one. Between A, a doctor, and B, her patient, the obligation to disclose does not depend on the nature of the information, be it genetic or not. All the same, between A, a physician, and C, the patient's sister, the question whether there is a duty to inform, on whatever legal basis, does not depend on the type of information. It is not the genetic character of the information which will force, or will release the physician from informing. What will determine the obligation is, first of all, the answer we will give to the balancing of interests, namely the (original) patient's privacy towards C's autonomy (simply, to allow her to make choices) coupled by beneficence for C (possibility of injury to C, hence need to attempt to protect her from harm). So, I think, the physician's obligation to disclose a genetic trait is no different from the obligation to inform a spouse that her husband is a HIV carrier, or suffers from AIDS⁵; nor, even more, is the obligation different from the case where your mental patient threatens to kill a third party (the Tarasoff⁶ case). Exactly the same principles are involved in all these cases: the patient's right to privacy/confidentiality, the third parties' right to autonomy/liberty and well being.

If the above is correct, the question whether the particular genetic information in each case will have an impact on this balance of interests is

irrelevant to the (need of, structure of) balance itself. We may accept that there is no disclosure obligation for the results of, lets say, Huntington chorea⁷, to the tested patient's siblings, because the time of onset of the disease varies immensely, and there is no cure; still, this argument in fact just means that there are no autonomy and/or beneficence interests of these siblings to be advanced by the disclosure-and, really, nothing else. So it is, if we accept that there is no obligation to inform a patient that her surgeon is an alcoholic or a drug user, if, on the facts of the case, it is proven that there are no risks for this patient⁸.

There is a direct and important implication of this irrelevance of type of information to disclose: that the way, the method, we will use to resolve the question of the duty to disclose is exactly the same, for genetic and non-genetic information. If this is so, we are in the realm of the duty to warn cases, like the famous Tarasoff case, cases and law dealing with the obligation to disclose medical information, and specifically an obligation with the purpose to warn against harm. And, lastly, even if looks like beneficence takes over here, autonomy interests are paramount, as it will be described.

4. The duty to disclose medical information and the duty to warn

I would like, therefore, to start the main part of the discussion differently from Laurie. As Sophie has declared that she did not wish the information to reach her sisters, the first problem is whether Ivan has the right to breach his confidentiality obligation to her, the 'original' patient. The reason Sophie does not want her sisters involved is, legally, irrelevant. We have to find, therefore, a legal reason why Ivan can proceed, in breach of secrecy (an extremely well founded principle in medical law and ethics), and inform the two sisters that they may be carrying a dangerous gene.

Which could be the legal basis for this duty to inform, against patient's wishes, or without asking the patient? There is obviously no contract, between Ivan and the two sisters; but, at least according to the Tarasoff⁹ reasoning, the 'original' doctor-patient relationship can be the source of obligations to third parties-it therefore could be negligent, not to inform them of danger¹⁰.

The question, therefore, now is: is there danger? Is there harm? And, furthermore, is there such harm and such danger, to identifiable interests of these sisters, so as to allow the breach of confidentiality? What we understand from the case-example is that, when the sisters are informed, the only thing they can do is elect a preventive mastectomy¹¹ (both) and have an abortion¹² (Sally). I have to point here, though, that these are real choices, choices that

an individual is allowed to make for herself. And I can also imagine a lot of other choices that these two sisters could make, had they known the information; from taking time off from work to take a trip to browsing the Internet for information of this gene, taking care of their sister or whatever else. (In fact, it is impossible to predict what these choices could be, medical or other). So, arguing that the mastectomy itself is harm is of no value, because the choice interest here is too powerful. I mean, if I elect this mutilation, to expect a life free from breast cancer, I exercise my freedom of choice. There is absolutely no room for another deciding for me that this is physically harmful, so I better be deprived of this choice. If I must be deprived of this choice, we need a much more powerful argument. And of course the same is true for the abortion decision. It is also degrading, in a way, to enter the domain of searching 'what would she do if she knew?', not only because it is impossible to know anything for sure, but because this also constitutes a real invasion of liberty. It is the same as in informed consent cases, this rule of altered conduct, where, in order to prove that you were misinformed, let's say, about a surgical risk (typical informed consent case), you must also allege and prove that you would have taken different decisions, you would have made different choices. But the choices you would have made is something precisely beyond the point, when we have a proven negligent omission of medical information¹³. Nobody said this better than Professor Katz that physical harm resulting from an operation on a misinformed patient 'only adds injury to insult'¹⁴.

So, in fact, the autonomy interests of these two sisters necessarily surpass in value their alleged interests in well being, in being free from physical harm. Should they also outweigh in balance, their interests to be free from psychological harm?

5. The therapeutic privilege aspect of the case-example

'Katie is phobic about needles and hates hospitals. Sally is depressive (and pregnant). These facts invoke what is known in medical law and ethics as the 'therapeutic privilege'¹⁵. This, here, is the motive behind their sister's wish that they are not informed. Could it be enough, just the same, for Ivan, to 'save' him from his duty to warn against danger? In other words, could beneficence ('do no harm') mean here that, since Katie hates needles and hospitals, and Sally is depressive, they should not learn that they may be carrying the gene that causes cancer?

Even if there is a trend, in Canada for example, against the application of the therapeutic privilege to release a physician from the obligation to inform¹⁶,

and very strong dissents against it¹⁷ exist, the doctrine of the therapeutic privilege could apply, in certain cases, against disclosure, this meaning that, depending on the facts of every case, a court could find that disclosure could be withheld¹⁸. But no matter how wide a therapeutic privilege could be accepted by a State, just 'phobic of needles and hate for hospitals' (Katie) will not be enough to invoke it. Courts all over the world now have stringent demands¹⁹ for the application of this highly controversial, to say the least, principle, especially when legal theory has attacked the privilege so strongly²⁰, as a menace to patient autonomy, even a way to cover up for malpractice.

On Sally's depression, the situation may be different if she is clinically depressed and close to, let us assume, a nervous crisis²¹. In these cases, the patient may be in fact incompetent to receive information, another exception to the rule of disclosure²². But because Sally is also the pregnant sister, who faces the reproductive choice among other choices, the decision to withhold the information should be extremely carefully weighed against her autonomy interests.

But since we have no reason to believe that Sally's depression is very severe and renders her incompetent to receive medical information, and since psychological harm as such is not anymore considered as enough to warrant non-disclosure of adverse medical news²³, we have to conclude that Katie's and Sally's autonomy interests outweigh here both their interests in freedom from physical and psychological harm. Their choices, reproductive or not, have to be protected-unless we accept that, apart from their autonomy/liberty interests in choice, they also have a right they probably never heard of: a right not to know, a right to spatial privacy, a right that, in balance to their well known interest in autonomy and choice, is declared more important, and forces Ivan to withhold the information.

6. The right not to know

If you have a right, you are the one to exercise it, and this my problem with Laurie's approach to the right not to know. Of course it is not the first time that a right not to know is discussed, and also a right not to know medical information in particular. Between a doctor and her patient, A and B, we accept that B may waive her right to information. Waiver is in fact one of the exceptions to informed consent requirements²⁴. And we know of other waivers too, in other laws, not medical laws: you may waive your right to a jury trial, sometimes your right to an attorney etc. Under the landmark US case, *Miranda v. Arizona*²⁵, a legal waiver is a voluntary waiver of known rights.

In this A-B case, doctor/patient, the problems of waiver have to deal with

the question of how we can ascertain both procedurally²⁶ and substantively²⁷, the legality of a waiver to be informed.

But how real is it, how true, how realistic, to say that, when Ivan decides not to speak, the right not to know of Katie and Sally is protected? How true is it to say that they have exercised this right? For I understand a right, if, only if, I may exercise it. At least legal jurisprudence, I think, has not yet accepted that there can be 'rights' which people cannot exercise. This is not the meaning of a 'right', as we know it, until at least today. So have Katie and Sally, by not knowing, exercised their right not to know? They don't even know that they have this right! And in law, we cannot allow another to exercise our rights, without us knowing that we have these rights. No proxy can ever assume this kind of power; no such authorization could ever be possible, let alone realistic. So, Ivan cannot be deemed to have exercised their right not to know, which they do not know they have, let alone decided somehow that he will exercise it for them.

Legal theory discussing waiver of the right to be informed was confronted with a real problem, a procedural problem²⁸ of ascertaining a valid waiver. As Laurie also mentions, it is difficult to obtain a meaningful waiver, when the question is so close to the answer: '...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...'²⁹. But this presupposes that the geneticist reached this point too late: in the very beginning of a physician/patient relationship, during which exam results will occur at some point, in the first appointment between a doctor and a patient, there could be a sincere and human discussion on what the patient would like to know and what not-what type, at least of information. Anyway, there have been some answers to this, truly tricky, problem³⁰.

Laurie draws arguments for the right not to know, as he sees it, from the European Convention of Oviedo, 1997, and cites art. 10(2). This article in fact deals primarily with the right to know ('everyone is entitled to know any information collected about his or her health', 10.1) and then it provides: 'the wishes of the individuals not to be so informed shall be observed' (10.2).

But can we truly speak in our case-example for Katie or Sally's wishes? We do not know them. They never had the opportunity to express them. What I mean is that art. 10.2 cannot serve as a basis for the right not to know for people who have not even had the opportunity to know that they could be facing a choice, what this choice could be, and to express their wishes accordingly ('I wish, or not, to know').

The UNESCO Universal Declaration of the Human Genome and Human Rights article 5c, also invoked by Laurie to support the right not to know, as he sees it, is not helpful as well, for the same reasons: the article talks about

the right of the individual to decide whether or not to be informed of the results of a genetic examination³¹. But Katie and Sally never had the chance to decide anything, to know or not. What both the above provisions tell us is that you are not obliged to hear anyone who comes and 'throws' information on you, even if it is your doctor; you simply may refuse to listen to this information, you may, at the very beginning of any treatment or therapy, decline to receive information. Not that another may decide if you will receive them or not.

7. Last points on non-disclosure

I tried to show that it is wrong to base our reasoning for non-disclosure in our case-example on the balance between the sisters' interests in physical well-being and their autonomy, on the balance of their interest in psychological well being and their autonomy, again (in both cases, I remind you, I believe that the autonomy/choice interests are paramount), and as an exercise by another (Ivan) of their alleged right not to know the information involved. Is there any other basis to allege that disclosure could be omitted?

Confidentiality should be a great concern for us here. I do not, as Laurie, believe that confidentiality is ineffective against intrusions of (what he calls) spatial privacy³². It is exactly the same conflict we as lawyers have had to deal for centuries, for example with cases on freedom of press. So, we have learned a lot on how to balance the related interests. Laurie himself accepts that, when we balance Sophie's choice not to disclose the information against the sisters' autonomy interests, '...the invasion of Sophie's informational privacy cannot be wholly justified...'³³. And it is so, definitely, for this is not a case like Tarasoff, where there is a real threat to life of a third party, or a case like a major contagious disease, or the case of an AIDS infected patient who tells her therapist that she intends to continue having sexual relationship with her husband but not to inform him. These are clear cases where a breach of the duty to secrecy is warranted, up to the point of risking a lawsuit, if you, as the doctor, don't inform. It is here, I mean, that the nature of information, not genetic information, any information, comes into play.

But I do not wish to elaborate on the nature of the case-example's information here, and decide whether Sophie's right to privacy is or is not more important than her sisters' right to autonomous choices. Actually, I wholeheartedly agree with Laurie's analysis of the factors to be considered when deciding whether or not due cause to invade Sophie's privacy are present³⁴ (availability of cure, severity of condition etc.). And here is what I meant in the beginning, that different methods may lead to the same

conclusion. If we also look at the accepted circumstances where a physician may be allowed to omit information of the existence of certain diagnostic tests, the situations are similar³⁵.

What I want to stress, though, is that the result of this balance has nothing to do with a relatives' 'right not to know' information, but is directly relevant to the principle of beneficence. Even if Sophie authorized the disclosure, the physician could still, under some circumstances remain silent. Medical ethicists, though, will accept this decision, not as an exercise of another's right not to know, but as an exercise of paternalism, as an expression of the principle of beneficence.

Obviously, grounded like this, the choice of silence shall be much more difficult to defend, in comparison to the 'suspect' exercise of another's right. A 'right' is a strong notion, interwoven in the very fabric of our individual rights bread society. We have learned that we must protect 'rights', whereas the principle of beneficence (so closely connected with the idea medical lawyers have in a way learned to dread, paternalism) has been 'having' increasing difficulties to surpass a patient's autonomy.

But the difficulty to defend a choice to remain silent is desirable not only because of the autonomy interests involved, but also because, as a policy, it may have the effect to advance scientific knowledge. Perhaps this is just another 'romantic' idea, but, still, the obligation to defend a choice of silence may send researchers a message like: find out more about cure, find out more about the likelihood of the disease's onset, find out more of genetic disease. Find out more, because you are obliged to justify your own choices-and the more they learn, the better we will be equipped to fight out main enemy, disease.

Notes

1. In Laurie's article, genetic information is treated as an example for a generalized right not to know unsolicited or unwanted, as he describes it, medical information. But, as he uses genetic information as an example, I am also obliged to use the same example to comment.
2. See Laurie, 'In Defence of Ignorance: Genetic Information and the Right not to Know', *European Journal of Health Law* 6, 119-132, 1999.
3. In California e.g. the insurer may demand medical information (even) without the authorization of the patient to determine coverage, Cal. Civ. Code 56.10(c) (2).
4. See Lehman J. Daniel, 'Genetic Test Called Threat to Privacy', *Chicago Sun Times*, Oct. 10, 1995, p. 9.
5. See Beauchamp & Childress, *Principles of Biomedical Ethics*, 4th ed. p. 426.
6. *Tarasoff v. Regents of the University of California*, 1976, CA 131 CalRptr 14, 551, P.2d 334, CA Supreme Court.

7. Furrow et al. *Health Law*, 2nd ed., 345.
8. See Medical Law US, *Encyclopaedia of Laws*, only one judicial opinion supports that there is a duty to inform a patient that the surgeon is alcoholic (*Hidding v. Williams*, 578 So.2d 1192, LaApp 5thCir. 1991), '...The real issue is how the physician is likely to perform generally, regardless of an impairment or other personal characteristics...'
9. See above note.
10. See also *Lipari v. Sears, Roebuch & Co*, 497 F.Supp.. 185 (D.Neb. 1980), also *Hedlund v. Superior Court of Orange County*, 669 P.2d 41 Cal. 1983, *McIntosh v. Milano*, 403 A.2d, N.J.Super.Ct, 1979.
11. This is in the facts of the problem itself.
12. I deduce this from Laurie's comment that '...the decision to give pregnant woman knowledge of this sort can only be to facilitate or even encourage an abortion decision. Availability of a pre-natal test for a condition for which there is no cure or treatment only allows for a more 'informed' abortion decision...', Laurie, id, p. 124.
13. See generally Katz, 'The Silent World of Doctor and Patient', 1983.
14. Katz, 'The Silent World of Doctor and Patient', 1983.
15. This expression was first found in an 1942 article by Smith, 'Therapeutic Privilege to Withhold Specific Diagnosis from Patient Sick with Serious or Fatal Illness', 19 *Tenn.L Rev* 349, 1942.
16. *Meyer Estate v. Rogers*. 1991, 3 OR 3rd, 356, OntGenDiv.
17. Among others, see Katz, id, Veach, 'When Should the Patient Know', *Barrister Magazine*, Vol. 8 n. 1 (1981), Bok, *Lying: Moral Choice in Public and Private Life*, 1978.
18. 'Medical Law US', id, p. 97 citing *Nishi v. Hartwell*, 473 P.2d 116 (Haw. 1970).
19. E.g. Supreme Court of Canada, *McInternay v. MacDonald*, 1992, 2SCR 138, only in very special cases will the privilege be accepted, per Justice LaForest, *Canterbury v. Spence*, US, 1972 464 F.2d 772, DC Cir., landmark decision on informed consent, '...the physician privilege to withhold information for therapeutic reasons must be carefully circumscribed...'
20. Among others, see Veach, id., Katz, id.
21. The only case of application of the therapeutic privilege accepted by Veach, id.
22. A careful analysis of the exceptions of informed consent, Meisel A., 'The Exceptions to the Informed Consent Doctrine: Striking a Balance between Competing Values in Medical Decision-making', 1979 *Wisc.LR* 413, 1979.
23. Katz, id, p. 216.
24. See, among others, Meisel, 'The Exceptions to the Informed Consent Doctrine: Striking a Balance between Competing Values in Medical Decision-making', 1979, *Wisc.L.Rev.*, 413, 435,
25. 384 US 436, 1966.
26. Pe, when the patient declares she does not wish to be informed, then the doctor may be obliged to explain possible consequences etc, see Glass, *Restructuring Informed Consent: Legal Therapy for the Doctor-Patient Relationship*, 79 *Yale LJ*, 1533, 1970.
27. See Beauchamp, id, p. 163.
28. There is also a substantive problem with waivers, because it has been argued that there are at least some cases where we have an obligation to be informed, see Ost, 'The Right Not To Know', 9 *The Journal of Medicine and Philosophy*, 1984, 313.
29. Laurie, id, p. 127, citing Wertz and Fletcher.
30. See Note, 'Restructuring Informed Consent : Legal Therapy for the Doctor-Patient Relationship', 79 *Yale LJ*, 1533, 1970 Beauchamp & Childress, *Principles in Biomedical Ethics*, 162.
31. See Laurie, id., p. 125.
32. Id., p. 126.
33. Id., p. 124.
34. Id., p. 127.

35. See Kolker, 'Advances in Pre-natal Diagnosis: Social-Psychological and Policy Issues', 5 *Intl.J.Tech.Assess. in Health Care*, 1989. '...The very existence of techniques for prenatal diagnosis produces stress to potential parents...', see Furrow et al., *Health Law*, id., p. 345.