

The Constraints of the Right to Know

Thoughts on Presymptomatic Diagnosis

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The patient's access to information is viewed today as a fundamental principle in the ethics of health care. However, this essay shows that in the case of presymptomatic diagnosis, exercising one's right to know can in fact be working against the patient's liberty.

Many do express their wish to know, but a slight tension in their expression, an imperceptible nervousness in their voice suddenly betrays them. This is when the doctor must carefully "sweeten" the truth – "must", yes, for whatever might have been said on this topic, in this mysterious connection between the physical and the moral, who can say that the truth, once known, will not trigger a mechanism of despondency, of fear, of panic which has sometimes led patients to suicide, and does not in any rate promote healing. In truth, most patients only actually require from their doctor a light, banal word, said almost as an afterthought: "It's not serious," "It's nothing," which is more than enough to satisfy their pale curiosity¹.

These are words written in 1954 by Doctor Louis Portes, the President of the *Conseil National de l'Ordre des Médecins* (National Council of the Order of Doctors), on the subject of patients, which he elsewhere qualified as "toys that are just about completely blind, very painful and essentially passive, and who only have a very imperfect objective knowledge of themselves"². In short, in his view, medical knowledge was a kind of precious and rare potion, but also a dangerous potion if it fell into the hands of the uninitiated for whom it had been designed.

The Emergence of the Right to Know

If Louis Portes' words sound to us like the remains of an old paternalistic discourse, this is because, today, a patient's access to information seems to us to be a fundamental principle of the ethics of care. There are three essential reasons for this, which are all interconnected.

The first is the transformation of medical knowledge. Contemporary knowledge is a type of knowledge that, as we know, no longer applies only to the symptoms of diseases, but

¹ Louis Portes, *À la recherche d'une éthique médicale*, Paris, Editeurs Masson, Presses Universitaires de France, Paris, 1954.

² *Ibid.*, p. 159.

also extends to the numerous risk factors for diseases, be they genetic or environmental. This knowledge is all the more sought-after because it allows whoever holds it to anticipate the disease well before any symptoms appear, and therefore to gain some reassurance about his/her fate or, in situations where there is a clear risk, to protect him/herself against it or to reorganise his/her life accordingly.

The second reason for which Louis Portes' discourse seems old-fashioned to us is connected to a sociological development, which is entirely correlated to this epistemic development. This development is the advent of a "sentinel patient", to use the expression coined by the anthropologist Jean-Pierre Dozon, meaning a citizen who is able to equip him/herself with specific and individualised knowledge about health issues, in particular thanks to the Internet; this is a citizen who, before even he/she is diagnosed as being ill, will anticipate any health problems he/she may be facing.

Finally, these two developments are also connected to a well-known legal and moral development: the movement for patients' rights, of which the 2002 French law on patients' rights is emblematic. In this framework, a patient's right to be informed of a diagnosis, and possibly of any life-threatening prognosis and of the consequences of the treatments that are being offered to him/her, has appeared as a fundamental guarantee of autonomy.

In this way, the field of healthcare has come to accept an idea that extends largely beyond this field: that of there being a "right to know", which is close to another idea, that of "transparency". This invocation of a right to know or of transparency is based on a principle that is in itself difficult to disagree with: the necessity of providing to all citizens, in all areas of life, information that can equip them to decide their own fate, both as individuals and as members of a political community. Defending and laying claim to a "right to know" thus appears as a beneficial discourse, an apparently emancipatory discourse.

The Pitfalls of Viewing Knowledge as Sacred

However, should we sanction the systematic invocation of the right to know on the basis that access to knowledge makes us more free? We here defend the idea that, on the contrary, and in particular in the case of presymptomatic diagnosis, claiming and exercising a right to know risks turning against human liberty. We use the term "presymptomatic" to refer to a diagnosis that is made in the absence of any symptoms, mostly based on genetic testing or biological signs. In the case of Alzheimer's disease, which we will be using here as an example, the accumulation of neuritic plaques, which can be revealed through scanning, makes it possible to issue such a diagnosis without, in the majority of cases, predicting the necessary outbreak of the disease.

There is a simple reason why the right to know paradoxically turns against liberty in this way: the quest for knowledge can arise out of its sacralisation *a priori*, out of a tendency to ascribe to the knowledge desired a prophetic virtue, without examining the basis for this. Kant has however underlined the flaws in this passive and thoughtless acceptance of knowledge: "*Dare to know! (Sapere aude.)* 'Have the courage to use your own understanding,' is therefore the motto of the Enlightenment," he wrote³. Every individual

³ Immanuel Kant, "What is Enlightenment?" taken from the translation by Mary C. Smith available at: <http://www.columbia.edu/acis/ets/CCREAD/etscc/kant.html>.

must be able to throw his/her own light on knowledge, meaning that he/she must criticise it. And “criticising” is not necessarily equivalent to disagreeing with or discrediting a piece of knowledge. Rather, it implies that we should ask ourselves questions about our ability to know what we claim to know, and set limits to this ability to know. Without having a critical relationship with knowledge, we will always remain, out of “laziness” or “cowardice” in Kant’s terms, in a tutelary relationship towards it, or even in a relationship of mystification, quietly obeying the prescriptions of a “physician who prescribes (our) diet.”⁴.

This is why we might fundamentally view as equally misguided both Doctor Louis Portes’ medical paternalism and the insatiable quest of the sentinel-patient for knowledge about his/her risks of disease: in both cases, medical knowledge is endowed with an authoritative value that cannot *a priori* be called into question. Admittedly, moving from medical paternalism to the acknowledgement of there being a right to know for the uninitiated does constitute a certain kind of progress: that of the sharing of knowledge, of widening the circle of those who know or are able to know. But the sharing of knowledge is not always synonymous with its deconsecration. And indeed, there is no reason for it to be. The fact that the uninitiated are given access to the sacred need not imply that, by some sort of miracle, the sacred is then lowered to the level of the uninitiated.

Giving an individual the right to know without simultaneously providing him/her with the tools to call into question or at least put into perspective this knowledge is therefore in a way equivalent to alienating him/her, by entertaining his/her illusion that he/she is being given access to a sacred truth. Let us now return to presymptomatic diagnosis: it is extremely important to maintain a critical perspective on the knowledge that such a diagnosis provides.

The Traps of Presymptomatic Knowledge

This critical approach highlights four traps created by this diagnostic knowledge:

1) First, the knowledge of the diagnosis is never knowledge that is consented to from a position of absolute liberty. It is misguided to present it as being the result of an individual will that was free to know or not to know, and that ultimately chose to know. Paradoxically, the guarantee of a right to know hides an injunction to know, since, in order to wish to know or not to know, you must already know that there is something to know, meaning that you must already know that you do not know. And this “knowing-that-there-is-something-to-know”, without which neither the will to know nor diagnostic knowledge would be able to emerge, is not itself subject to prior consent.

In this regard, we must make a distinction between three stages in the knowledge of disease: a first stage during which the individual is not even aware that there is something to know; a second stage during which the individual knows that there is something to know without knowing what exactly; and a third stage in cases where the individual has agreed to know whether or not he/she carries genes that might put him/her at risk.

If I am in the first stage of this process, if I am entirely ignorant of the fact that I am at risk of developing Alzheimer’s disease, and if I am ignorant even of the possibility of

⁴ *Ibid.*

resorting to a diagnosis, then there is no reason for me to want to know. In this case, telling me that I have the “right to know or not to know that I have Alzheimer’s disease” is already to give me knowledge without asking for my permission to do this. It already means insinuating two nerve-racking ideas into my mind. The first idea is this: there is a chance, a greater than average chance, that I might be carrying risk genes. The second idea is no less nerve-racking: I have the means of knowing whether or not I carry these risk genes. These two ideas have been planted in me without asking for my permission.

At this first stage of total ignorance, it is not appropriate to talk about a right to know, since, in order to be able to talk about a right to do A, we must be able to talk conversely about a right to not do A. But this is impossible here: I cannot refuse knowledge that I do not even suspect is possible.

The impossibility of refusing this knowledge preceding diagnostic knowledge is particularly problematic. Let us imagine that my sister has discovered that she is carrying risk genes for Alzheimer’s disease and that she decides to tell me that there is a non-negligible probability that I could also be a carrier – as, indeed, she is obliged to under the terms of the 2011 bioethics law⁵. What right does she have to wake me up from my ignorance and, in so doing, to put an end to my carefreeness? We see here how, paradoxically, it is the defender of the “right to know” who is being paternalistic. It is he/she who is deciding for me that I would like to have the choice to know or not to know that I may be at risk. It is he/she who is deciding that he/she needs to “make me responsible”, to use a term that is frequently used in public reports. “Making responsible” means making someone “responsible” for a choice that he/she has not chosen as if, without this possibility of choice, the person were not really “responsible”.

More precisely, the idea of “making people responsible” implies a “positive” concept of liberty, to the detriment of its “negative” concept, to use Isaiah Berlin’s distinction. It consists of “making (someone) free”, including through force, in situations where respecting negative liberty would exclude any third party intervention, whether it is aimed at endowing an individual with knowledge or depriving him/her of the knowledge he/she desires. Curiously, this “right to know”, which is often presented as the expression of a “liberal” ethic, relates to a positive liberty, which Isaiah Berlin viewed as a sham liberty put forward in the name of political liberalism...

It may of course well be that the decision is experienced positively and appreciated by the individual who is thus being “made responsible”. In addition, it is true that the access to knowledge is a social justice issue, and that individuals are not equal, particularly depending on their social background, in terms of their desire to know. Finally, it would probably be pointless to call upon people to resist this quest for “transparency” given how much the opportunities for knowing that there is something to know are multiplying both in the public and private spheres. Nevertheless, it must be acknowledged that the individual who has thus been “made responsible” did not choose to enter into the dilemma of “knowing or not knowing”.

⁵ “The individual is obliged to inform any members of its family who may potentially be concerned for whom he/she or, as the case may be, his/her legal representative, has or can obtain the contact details, if it is possible to offer them any preventive or healthcare measures” (Article L1131-1-2 of the French Code of Public Health, Law no. 2011-814 dated 7 July 2011 - Art. 2).

The first trap set by this diagnostic knowledge is therefore that receiving it cannot be freely consented to. It implies the intervention of external forces and pressures that are motivated by a desire to know and that aim to awaken in the individual a desire to know. Who is behind this injunction to know? Family pressure, certainly; insurance companies and banks could soon get involved; and definitely medical research, the requirements of which are in fact absolutely defensible.

The right to know is therefore only meaningful in the second stage, when the individual knows that he/she may be at risk and that he/she can check this through genetic testing. At this stage, it is possible for the individual – as well it should be – to refuse to know. While the choice of the question – to know or not to know? – has been imposed on him/her, the individual at least has a choice in terms of what answer to give. But is it really reasonable to think that individuals who know that they are predisposed to developing a certain disease will want to remain in the dark about it? To what extent can they put up with the uncertainty and the ever-present fear that their cognitive abilities might progressively start to disappear? And there is another problem: to what extent will they be able to bear the guilt of taking the risk of bringing children into the world who could potentially carry the same genes as them, or the guilt of opting to stay in the dark when this might be viewed as being disloyal by the people closest to them?

2) This knowledge is “performative”. It claims not only to tell me what I am, but also to tell me how I should behave. It not only assigns an identity to me, but also a direction to follow. In fact, it is as though this potential to develop the disease, just because it is known and highlighted by a genetic test, should take precedence over all the other potentials in my life. It is as though, once the verdict of the diagnosis has been issued, I should view my identity and my life through this limited prism. And this injunction to change one’s life and one’s world is all the stronger in the case of neurodegenerative diseases that radically transform, not just an individual’s life, but also their identity, which undergoes a metamorphosis.

3) The third limitation of this predictive knowledge is that it is a type of knowledge that, instead of generating certainty, generates uncertainty. This is the whole paradox about this so-called “predictive” medicine. In the vast majority of cases, except in those rare cases of genetic or hereditary diseases where the transmission of the disease is almost certain, predictive medicine does not deliver entirely certain information in response to the questions being asked. On the contrary, the exact opposite is true: predictive medicine provides uncertain information in response to questions we were not asking in the first place.

So, for a start, predictive medicine delivers uncertain information. It is clear that, in the case of Alzheimer’s disease, I may very well never develop the disease to which I have been told I am predisposed, and, conversely, it is possible that I may develop the disease without the biomarkers associated with the risk genes having been identified. This is therefore a type of knowledge that, instead of announcing an existing reality that is already present within me, like a virus or a tumour might be, announces a reality that is merely possible. It is a type of knowledge that brings with it a grey zone and a host of questions, which the individual concerned is incapable of answering: will I develop this disease? When will I develop this disease? Will treatment be available? How will the first symptoms of the disease appear?

It is still a surprising paradox that, as the sociologist Ulrich Beck underlined in his work on risk, at a time when technologies, and in particular biotechnologies, are claiming to

anticipate the future, and to abolish accidents and chance events, uncertainty has never been so strong. Biotechnology gives birth to an infinity of possible outcomes.

In addition, this uncertain knowledge constitutes an answer to questions that the individual has not even been asking and that, we might almost be tempted to say, do not belong to him/her. The reason for this is that the announcement of a diagnosis of predisposition is not a piece of knowledge that is experienced, but rather a piece of strictly abstract knowledge. The individual cannot feel it in his/her body, and has no privileged access to it. Essentially, his/her doctors and loved ones can have the same knowledge of it, even if their perceptions of it might differ.

In other words, not only is this knowledge the purveyor of uncertainty, it also comes and meddles with us without us having asked for it. It is as though uncertainty were replacing ignorance.

4) The last trap set by this early predictive knowledge is that it seems to us to be infinite, at least in the short and medium term. This perception of there being this infinite knowledge is mainly connected to its object, the genome, which is like a bottomless well. We will always be able to go further in genetic research and refine our knowledge about the probabilities of someone developing Alzheimer's disease.

But this perception of there being this infinite knowledge is also connected to the subject of this knowledge, man, whose infinite desire to know comes up against the obstacles constituted by the finiteness of science itself, which is only able to formulate provisional truths, and by the interference of other interests, in particular interests of a financial order, which is always a possibility. Finally, we are never really able to judge whether our right to know is being respected. This is what is so difficult about the concept of transparency. Transparency is not verifiable; suspicion is always possible. Therefore, the right to know cannot really be honoured. And all the transparency measures imaginable, however necessary they might be, will never get rid of suspicions and worries.

Counter-Weight and Counter-Knowledge

These are therefore the main limitations of this early knowledge: this knowledge is not consented to; it is a performative knowledge; it is a knowledge that generates uncertainty; finally, it is an infinite knowledge. In these conditions, the right to know translates more into a desire to know and, through this desire, reflects the psychological and social forces that have created it more than a free choice to know.

How should we deal with this new knowledge? Should we close our eyes, and attempt to return to the age of ignorance by prohibiting access to it? This would be impossible, and would in addition be equivalent to giving up on research into treatments. At a time when the veil of ignorance hanging over our genetic predispositions is inexorably being torn⁶, the only resort we have against this injunction to know – an injunction that is alienating in many ways – consists more in carrying out critical work that can highlight its constraints and which should be carried out both by the people issuing it and those receiving it. It is only by carrying out this exercise in self-criticism that we may create the conditions for the preservation of

⁶ Pierre Rosanvallon, *La nouvelle question sociale. Repenser l'Etat providence*, Paris, Seuil, 1995, p. 155.

liberty, understood no longer merely as the enjoyment of a right to know, but as a right to the criticism of knowledge, which is an essential complement to the former.

It is therefore important for a culture of criticism to spread throughout society, so that it can act as a counter-weight and as a “counter-knowledge” to this predictive knowledge. This democratic counter-weight must, at a strictly political level, allow for the motivations of the agents that are behind this injunction to know to be made explicit, so that this knowledge does not appear, or does not appear as only being the free expression of subjects who have a desire to know. Moreover, these motivations should not in all cases receive public blame. For example, scientific research into new treatments, in particular for Alzheimer’s disease, is not a shameful aim. The idea of establishing a citizen’s duty to contribute to scientific research, for the good of present and future generations, is perfectly defensible in itself. Conversely, this injunction to know can be the expression of mercantile interests that are the vectors of social discrimination: those of the pharmaceutical industry and of the insurance and banking sectors.

As for counter-knowledge, it should allow for predictive knowledge to be demystified, and not to present itself as a certain answer to a question that people have always been asking themselves, but rather as the uncertain answer to a question that has been invented and triggered by a provisional and culturally constructed desire to know. This pedagogical duty is incumbent on political authorities just as much as on medical ones.

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