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The Protection of the Patient's Private Life : a Vast Normative Landscape First part

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Key words. Bioethics ; privacy ; confidentiality ; medical secret.

Abstract. The debate on the protection of people's private life is stronger than ever, particularly in the health care sector, where choices have to be made in order to decide between the conflicting interests at stake. This Article gives an overview of the general provisions that aim, for the time being, at guaranteeing this protection to the patient. His or her right to respect for private life, which aims at protecting not only the confidentiality of his or her private realm and relationships with others, but also his or her freedom of choice regarding this private realm and these relationships, is indeed expressed, in various forms, in a large number of texts of every possible origin. It would be a mistake to regard these as a heap of redundant rules. These texts can be distinguished according to their content, the time of their elaboration and their authors. Although complex, the normative structure that they form is not void of effectiveness. A next article will examine how they are extended and supplemented by provisions trying to answer, at the level of the respect of private life, to the growing use of computers in medical practice.

The stir caused by the discovery of the Echelon network. The criticism against the measures taken in the wake of the terrorist attacks of 11th September 2001. The reactions following the socio-economic enquiry carried out in Belgium at the end of the same year. Court decisions on the control of electronic mail within the company. It is obvious that today more than ever society is faced with questions relating to the extent to which the private life of its members has to be guaranteed. The health care sector is not spared this debate. In this sector some new factors contribute to weakening the patient's private life. Other factors, on the contrary, invite to strengthen the respect that it deserves. This just shows that rules relating to the protection of the patient's private life are in search of a new balance. Choices have to be made in order to decide between the conflicting interests at stake. This Article does not speak for one orientation to the detriment of another. Its aim is more modest. It starts from the assumption that a choice can only be made with full knowledge of the facts. Therefore, it offers a global overview of the provisions relating to the protection of the patient's private life as they are today. It is in a way a snapshot of a changing normative landscape likely to change even more in the future. This undertaking does not claim to be exhaustive. It rather tries to give the keys for a right understanding of the relevant texts. To that effect, this Article first examines the right to the respect of private life in general. Then, it mentions and structures the corresponding provisions in the specific context of the doctor-patient relationship. Finally, it highlights the specificities that distinguish them from each other.

I. The right to the respect of private life

There are many texts that establish the right to the respect of private life in general terms.

At the international level, Article 12 of the Universal Declaration of Human Rights (United Nations, 1948) specifies that "no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour or reputation", being understood that "everyone has the right to the protection of the law against such interference or attacks". Article 17 of the International Covenant on Civil and Political Rights (United Nations, 1966) is worded in a very similar way. Article 8, § 1, of the Convention for the Protection of Human Rights and Fundamental Freedoms (Council of Europe, 1950) states that "everyone has the right to respect for his private and family life, his home and his correspondence". Paragraph 2 of the same article further specifies that

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"there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others". As for Article 7 of the Charter of Fundamental Rights of the European Union (December 2000), it reasserts the right of everyone "to respect for his or her private and family life, home or communications".

The right to the protection of private life is also written down in several national Constitutions. The Belgian Constitution, just as an example, states that "everyone has the right to respect for his or her private and family life, except in cases and conditions laid down by law" (Art. 22, al. 1er).

Though omnipresent, the notion of *private life* turns out to be difficult to define (1, 2, 3). The domain it covers is vast (4). Besides, its content may vary according to factors such as time and place or the person whose privacy is being protected — the private realm of the key figures of the political, economic, or artistic life tends to be more limited than that of the ordinary citizen (5, 6). Therefore, unlike other rights, such as the right to form associations, the *right to the respect of private life* cannot be defined precisely (7). As a result, our paper only gives general indications, being understood that the value of these points of reference remains all the more relative since each relevant provision gives rise to its own interpretation.

The purpose of the right to the respect of private life is to guarantee the specificity of the person entitled to it, to protect his or her uniqueness with regards to anybody else, the limits of this private realm varying according to the collective feeling prevailing in the social environment and at the period of time under consideration (8, 9, 10). This right covers on the one hand the right to protect a *personal realm* not dedicated to any public activity from any external interference, and on the other hand the right to establish and maintain *relationships with others*, free from any external interference as well, these relationships being essential to the development of one's personality (11, 12, 13, 14). This explains why some provisions establish, along with the right to respect for private life, the right for inviolability of home, a place favourable to personal blooming, and the right for respect of correspondence and communications, both privileged sources of relationships (15, 16, 17).

The protection offered by the right to the respect of private life shows different sides. Some authors make for instance a distinction between the protection of the *confidentiality* of private life and the protection of the *freedom* of private life, insisting on the fact that these two notions are interwoven (18, 19). While the former implies that no information inherent to the private realm of the individual can be disclosed without his or her consent, the latter is aimed at guaranteeing "the freedom to make existential choices in the sensitive spheres of the private realm without any (…) interference" (20). Such a freedom derives from the individual freedom recognised by the declarations of rights (21). Its limits are not easy to define. The risk is precisely to give it such a large extent that it would make loose any specificity to the notion of private life (22), hence the need for the interpreter to be vigilant.

II. The right to the respect of the patient's private life : provisions to be listed

The concern to protect the private life of the patient involved in the health care relationship inspires a large variety of provisions peculiar to this relationship. It finds expression in a series of obligations for the physician and of rights for the patient.

Illness hits human beings at the deepest of themselves. The suffering it causes is, according to Ricoeur, "the very last retreat of their uniqueness" (23). The information concerning the health of an individual is therefore part of his or her private life. It belongs to this personal realm that he or she can justly protect against the outside world. However, an outsider, the physician, becomes the *guardian* of this information due to the very nature of his or her art. Moreover, this "necessary confident" is also induced to learn about factors inherent to the personality or the relationships of the patient, be they financial, familial or other, these factors having a greater or lesser influence on the patient's health. For those two reasons, the physician's intervention questions the *confidentiality* of the patient's private life.

This is why the physician has above all to see to preserving the confidentiality of the information that he or she has about the patient. To that effect, he or she has first and foremost to respect the *medical secret*, in other words, he or she has to refrain from disclosing this information to anybody.

This principle is reaffirmed in a great number of texts. Most of the time, it is worded in the form of an obligation for the physician. Such an obligation appears in the 1948 Declaration of Geneva and the 1949 International Code of Medical Ethics, both texts being from the World Medical Association (WMA). It is written down in the European Guide of Medical Ethics adopted in 1987 by the international conference of professional medical associations (art. 7) (24). It is repeated in Article 4 of the Declaration on the Promotion of Patients' Rights in Europe, also called Declaration of Amsterdam, which has been written under the patronage of the Regional Office of Europe of the World Health Organisation. In this declaration the above-mentioned obligation is described in precise terms : "All information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death" (art. 4.1) ; "Confidential information can be disclosed if the patient gives explicit consent or if the law expressly provides for this. Consent may be presumed where disclosure is to other health care providers involved in that patient's treatment" (art. 4.2). The obligation for medical secret is also mentioned in numerous national codes of medical ethics (art. 55 to 70 of the Belgian Code of Medical Ethics ; art. 4 and 104 of the French Code of Medical Ethics) and in the penal codes of several States (art. 458 of the Belgian Penal Code ; art. 226-13 and 226-14 of the French Penal Code) (25).

In exceptional cases, the respect of the medical secret is presented as a right of the individual (26). It appears in this form in the title of Article 8 of the WMA Declaration on the Rights of the Patient (1981), as well as in Article 9 of Quebec's Charter of Human Rights and Freedoms (1975) (27). So is it once more written down in Paragraph 1 of the recently adopted Article L. 1110-4 of the French Public Health Code : "Everyone followed by a health care professional (…) has the right to respect (…) for the confidentiality of the information about him or her" (28).

It should be noticed that the principle of medical secret is subject to exceptional mitigations and exceptions, irrespective of the form in which it is expressed. In particular, the concept of shared or collective secret, being understood as a secret "concerning all the members of the medical team" (29), becomes more and more common. It is echoed, among others, by the last sentence of Article 4.2 of the above-mentioned Declaration of Amsterdam.

Still in order to guarantee the confidentiality of his or her patient's medical data, the physician also has to take all the necessary *concrete measures* to protect these data against the excessive curiosity of anyone not involved in the health care relationship (30). Such an obligation is stated, among others, in Article 8.c of the WMA Declaration on the rights of the patients : "All identifiable patient data must be protected. The protection of the data must be appropriate to the manner of its storage. Human substances from which identifiable date can be derived must be likewise protected". This obligation also appears in a sometimes very similar way in Article 8 of the European Guide of Medical Ethics, in Article 4.3 of the Declaration of Amsterdam and in Articles 72 and 73 of the French Code of Medical Ethics.

Finally, and this time at the heart of the health care relationship, the protection of the confidentiality of private life compels the physician not to investigate into the patient's private life *more than what is necessary* to the practice of his or her art. This specific form of the principle of proportionality is most explicitly described in Article 4.6 of the Declaration of Amsterdam : "There can be no intrusion into a patient's private and family life unless and only if, in addition to the patient consenting to it, it can be justified as necessary to the patient's diagnosis, treatment and care". Other provisions, adopted or only proposed, go in the same direction when reminding of the obligation for the physician to respect his or her patient's private life (Art. 8 of the European Guide of Medical Ethics ; bills on the patient's rights introduced in Belgium).

As for the *freedom* of private life, it also appears in the context of the health care relationship. Its presence is examined insofar as it does not seem to be the result of an exaggerated extension of the notion of private life as exposed above. The freedom of private life is directly linked to the protection of the patient's privacy.

The physician gathers most of the information concerning his or her patient in what is usually known as the medical records. From the moment it is recognised that everyone has the right to have any information regarding his or her private life at free disposal, the patient should be entitled to receive information about the data recorded in his or her medical records, as well as, if need be, to ask for it to be corrected or withdrawn. This is at least the argument some put forward. It is partly questioned by others, defending the physician's freedom of diagnosis and therapy. These positions on the *patient's right of access to the data recorded in his or her medical records* can be found in provisions such as Article 7.a of the WMA Declaration on the rights of the patient, Articles 4.4 and 4.5 of the Declaration of Amsterdam, Article 42 of the Belgian Code of Medical Ethics, Article 6, § 2, of the Belgian Royal Decree of 3rd May 1999 laying down the minimal general conditions to be met by the medical records as defined in Article 15 of the Hospital Act, coordinated on 7th August 1987 (31) and Article L. 111-7 of the new French Public Health Code (32). It should be noticed that the above-mentioned right belongs to the prerogatives recognised to the patient by the Act on the patient's rights recently adopted in Belgium (33, 34).

Not only does the physician collect a set of data specifically relating the patient's privacy. He or she also carries out medical acts that have direct consequences on the patient's health, or that can even perhaps damage his or her physical integrity. The physician acts at the heart of the patient's personal realm. For this reason the freedom of private life has to be taken into consideration in this case as well. In principle, and with some reserves, it is going to be expressed through the *patient's right to information and consent*. The patient must be entitled to accept or refuse any medical act proposed by the physician. This implies that he or she has to receive all the necessary information about these medical acts (35).

Many texts establish or are about to establish such a right : the WMA Declaration on the rights of the patient (art. 3 and 7), the European Guide of Medical Ethics (art. 4), the Declaration of Amsterdam (art. 2 and 3), the French Code of Medical Ethics (art. 35, 36, 41 and 42), the Belgian Code of Medical Ethics (art. 3 29, 30 and 33), the Convention on Human Rights and Biomedicine (art. 10) (36), the French Public Health Code (new art. L. 1111-2 and L 1111-4) (37) or the Act on the patient's rights recently adopted by the Belgian House of Representatives (art. 7 and 8).

III. The right to the respect of the patient's private life : provisions to be differentiated

The above-depicted normative landscape is vast and dense. At first sight, it appears *heterogeneous* and full of *redundancies*. It seems to be a disorganised accumulation of rules of every possible origin, all of them aiming at establishing the guarantees that the protection of the patient's private life deserves. However, after a deeper examination of these provisions, this first judgement can and should be reconsidered. This examination can be carried out in the light of three criteria : the content, the time of elaboration, and the author of the provisions. Each text so examined turns out to be unique.

1. *The content of the provisions*

A self-evident fact needs reminding. The relevant provisions can be distinguished by their objects. While some establish the right to private life at a general level, others relate to the preoccupations peculiar to the health care relationship. Among the latter, distinctions can be made according to the various sides of this relationship, although these distinctions do not directly appear at the reading of the provisions. This variety of objects is partly due to the adaptation of the texts to the changes occurring in this field.

2. The time of elaboration of the provisions

The rules relating the protection of private life do not all date back to the same period. As a matter of fact, the context they lie within has undergone deep changes, particularly during the 20th century. These changes are basically due to the evolution in technology and in the way of thinking, both typical for this period. In the specific field of health care, they appear under different aspects.

The respect of the *medical secret* has been imperative since time immemorial ; doesn't the Hippocratic Oath date back to the 4th century BC ? It has always been admitted that without the guarantee of confidentiality the patient would hesitate to confide in the physician, which would have consequences on the effectiveness of the health care relationship, and therefore on the health of the community as a whole. For about fifty years, though, new factors have contributed to weakening the medical secret. The practising of medicine becomes more and more technical and specialised, and therefore more and more multidisciplinary as well. Above all, the health-related data arouse the covetousness of a growing number of participants : the medical world wants to have an accurate picture of its practice ; government is trying to control the costs of the health care system ; as for employers, insurance companies and the next of kin, they want to be informed about the current, or future, health status of their employee, insured or relative. These people and organisms being anxious to reach their respective goals, they tend to pressure the physician, the guardian of the medical data.

Various factors also prompt to promote the *freedom* of the patient's private life. At a general level, the human rights movement insists, to a greater or lesser extent, on the primacy of the individual over the State or the institutions (38). At the level of health care systems the complexification of medical practice goes along with its dehumanisation, while traditional medical paternalism is being more and more questioned. All these phenomena incite to stress the patient's right to self-determination.

So dramatic changes cannot go unnoticed at the normative level. *New provisions are adopted to meet the new needs.* They replace, or more often add to, the older texts. This can be observed in the field of the general protection of private life : first guaranteed by the rules of civility, then by law, it was made into one of the fundamental rights after the Second World War (39,40,41,42). This phenomenon can also be noticed in the more specific frame of the health care relationship. It is worth going further into it with three observations.

First, in order to answer to the potential rise of factors threatening the patient's privacy and, at the same time, of considerations encouraging him or her to deal with the decisions relating to it, rules are adopted, *reasserting* the patient's right to private life in general terms. Some provisions even go further. They show the concern to *strengthen* or *extend* the protection of the confidentiality of private life. This is the case of recent texts that solemnly highlight the importance of the medical secret—sometimes making it into a fundamental right—or that remind the physician that he or she cannot investigate into his or her patient's private life more than is necessary for the practising of his or her art.

Secondly, the rules meant to protect the patient's private life show a tendency for *diversification*. There is a diversification at the level of the confidentiality of private life : the positive obligation to take "pro-active" measures in order to avoid that the very attractive medical data fall into undesirable hands adds to the traditional medical secret. There is also a diversification at the level of the freedom of private life : the patient having the control of him or herself, there appears to be a need to give him or her a new place in the relationship with the physician. He or she is being granted new subjective rights, be they about the data recorded in his or her medical records — right of access and to correction — or about the medical acts to be performed — right to information, right to informed consent.

Thirdly, all changes do not favour the protection of the patient's private life. On the one hand, that protection is not the only element that enters the lists. Other considerations are being taken into account. For instance, practical reasons explain the emergence of the concept of shared or collective medical secret : the growing collectivisation of medical practice makes it inescapable. On the other hand, changes do not go without difficulty. On certain issues new provisions opt for contradictory solutions. This is for instance the case of provisions relating to the extent and details of implementation of the right of access to the medical records. Obviously there is still no consensus on these issues. It is likely to be reached with even more difficulties when it comes to solve concrete problems pragmatically, rather than stating theoretical principles.

3. *The author of the provisions*

Provisions in terms of the protection of private life have to be examined in the light of a third factor : they come from different authors. Some are of *professional* origin. They have been drawn at the *international* level by non-governmental organisations such as the World Medical Association, or at the *national* level, particularly by the Association of the profession. Other are of *State* origin. They can come from several States ; this is the case of *international* rules adopted either by the organisations of which these States are members or within the context of a treaty. They can also come from the authorities of one single State ; this is the case of *national* rules of constitutional, legislative or regulatory nature. In *Common Law* countries High Courts decisions have the status of legal rules and therefore belong to the above-mentioned national rules (43).

One can wonder whether this brief classification has more than a theoretical interest. Shouldn't all these rules be considered on an equal footing, irrespective of their authors ? It is worth asking this question, particularly regarding the provisions guaranteeing the protection of privacy in general. In this field as in others, one can often find state rules with a *similar content* but coming from *different authorities*. There is no doubt about the answer. These provisions are not interchangeable. First of all each of them is addressed to different people and has its own legal effects, depending on its author. Moreover texts appearing to be redundant have their grounds for existence. Their aim is sometimes to *give effect*, at the national level, to provisions adopted at the international level (44) ; sometimes to *adapt* rules set up in a wider circle to the specificity of a smaller circle (45). Or their aim can also be to *introduce* into a given legal order provisions inspired from a separate legal order, these provisions being inapplicable as such in the former (46).

In connection with this, another, tough less frequent, phenomenon has to be highlighted. It can happen that provisions with nearly the same content are adopted by the *same* authority. This way of doing is not unjustified either. In this case the aim is to emphasise the legal significance of principles stated in a first time (47).

The above observations also apply to the provisions specifically relating to the health care relationship. An additional remark, relating to a particular feature of this sector, should be made, though. In this sector the normative role played by medical and health care professional associations is not insignificant. The provisions that they adopt are addressed to a particular group of people, namely the members of the profession in question. They have varying effects : ethical rules are mandatory for professionals because they are accompanied by disciplinary measures, other rules are given for information only. In every case they try to define the duties imposed upon the members of the profession by the very practising of it. To this effect, they sometimes have to adapt to the most recent developments in medical practice before rules of state origin, to which they open the way. This is the case, for instance, in the field of the patient's right of access to his or her medical records.

So, the material of the protection of the patient's private life shows several constituent layers of relevant provisions. This normative construction is characterised by its *complexity* as well as by a certain form of *effectiveness*.

Complexity ? If the rules to be considered as legal are those "enacted by authorities formally empowered to do so and having a legally binding effect potentially accompanied by compulsory enforcement and sanctions" (48), it must be acknowledged that the provisions examined cannot be classified into two clear-cut categories. Some of them are indisputably legal. Others are not. Many of them, be they of state or professional origin, are somewhere in between (49), although their own characteristics make some look more like legal provisions and others more like non-legal. In short, *the traditional categories are not sufficient to describe the configuration of the normative landscape*, which does not make the understanding of it easier. Moreover, the interaction of these provisions, their subtle reciprocal influences are often not easy to grasp.

Effectiveness ? The complex structure of these provisions shows a *common* (in space) and *continuous* (in time) tendency to protect the patient's private life to a sound extent, even though the diversification of these provisions, made necessary by the evolution of the social and technical context, could harm this harmony. Indeed, some issues remain difficult to get agreed on. As a matter of fact, texts of professional origin and state Act on the patient's rights recently adopted by the Belgian House of Representatives rules, international provisions and national rules form something of a *set of mirrors* (50) ; they reinforce each other. So, even national state rules, i.e. rules accompanied by the strongest institutional constraint of all and therefore indisputably legal, will gain in effect if they are supported by provisions of another nature. These can be international state rules, giving them a legitimacy that is far from being insignificant in the field of fundamental rights. These can also be professional provisions, allowing them to find the support of the professions first concerned by what they impose. How can these two other categories of rules be regarded but as a stimulus to the legal rules in the full meaning of the word ? The passing of these legal rules requires time since they "are aimed at providing fundamental choices for all of the citizens, while at the same time having a greater power and assuming the symbol of what a society wants to give itself as a model of mankind" (51).

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34. It should also be noticed that, with some reserves, this right can be deduced from the general texts that aim at protecting private life within the context of the processing of confidential data.
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36. This convention, also called "Convention for the protection of the Human Rights and dignity of the human being with regards to the application of biology and medecine" was adopted by the Committee of Ministers of the Council of Europe on 19th November 1996 and opened for signature by the States on 4th April 1997.
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42. More recently it has been reasserted with regards to the rapidly developing computerisation of confidential data processing.
43. Common law countries are countries that take to a greater or lesser extent from the English legal system, which is set apart from the so-called *continental* systems. In the latter, laws enacted by legislative bodies (statutes) are the main *formal source* of law.

Court's decisions are only an *authority*. In other words the only task of the judges is to apply statutes, which are supposed to have made provision for everything ; they do not create law — even if, in practice, they often have to innovate when they interpret obscure or inadapted texts. As for Common law countries, they recognise the primacy of statutes (Statutory Law) but give the decisions of High Courts of justice (Case Law) the status of *source* of law . Therefore, these decisions have the status of *precedents* : they are binding, following specific rules, for the courts of justice that have adopted them and for the lower courts of justice.

44. This is necessary when these provisions do not have a so-called "direct effect" : they require enforcement measures to be taken at a national level, among other because they do not reach a satisfactory level of precision. (See Verhoeven J. Droit international public. Bruxelles : Larcier, 2000 : 412-415 et 451).
45. The European Convention for the Protection of Human Rights and Fundamental Freedoms, for instance, goes deeper, at the level of the European continent, into the protection of the human rights set forth in the Universal Declaration of Human Rights — and in the subsequent International Covenant on Civil and Political Rights — : the provisions it contains are more precise ; it institutes an effective international control. (Kayser P. *Op. cit.* : 20-21 ; Wachsmann P. Les droits de l'homme, 2e éd. Paris : Dalloz, 1995 : 26-27).
46. This is in particular the case of the Charter of Fundamental Rights of the European Union : it states rights taken from the European common tradition expressed, for instance, in the European Convention for the Protection of Human Rights and Fundamental Freedoms, to which the Union is not a party. (See Bribosia E., De Schutter O. La Charte des droits fondamentaux de l'Union européenne. *Journal des tribunaux*, 2001 : 281).
47. After adopting the Universal Declaration of Human Rights, which is not legally binding, the UN got down to the drawing up of an International Covenant on Civil and Political Rights and an International Covenant on Economic, Social and Cultural Rights, both treaties being legally binding for the States that ratified them.
48. Meulders-Klein M.-T. La production des normes en matière bioéthique. *In* : Neirinck C. De la bioéthique au bio-droit. Paris : L.G.D.J., 1994 : 24.
49. This is for instance the case of some WMA declarations, of the Declaration of Amsterdam, of the Code of Medical Ethics, of the Universal Declaration of Human Rights.
50. Lenoir N., Mathieu B. Les normes internationales de la bioéthique. Paris : P.U.F., 1998 : 42.
51. Meulders M.-T. La production des normes en matière bioéthique. *Op. cit.* : 24.

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