Privacy and Confidentiality

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Introduction: The context

Regarding the themes of this chapter, there have been, under the auspices of several organizations, developments that constitute a substantial background. To quote some:

The UNESCO Universal Declaration on Bioethics and Human Rights. This Declaration (UDBHR), adopted in 2005 by the UNESCO General Conference, is of particular importance (UNESCO, 2005b; ten Have and Jean, 2009). It says:

> ***Article 9: Privacy and confidentiality***
> *The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.*

An Early Effort: The Declaration on the Promotion of Patients' Rights in Europe (1994). This Declaration was elaborated under the auspices of the WHO Regional Office for Europe in collaboration with governments and interested bodies. In the resulting publication, Dr. J.E. Asvall, Regional Director, writes: "Well informed patients are beginning to assert rights in their private dealings with professionals in the health field. Until the beginning of the 1970s, the health professional-patient relationship was defined primarily by the rules of medical ethics. During the last two decades, the relationship was gradually redefined in terms of a contract (. . .) It has been demonstrated that well informed patients make better partners in their care, and have quicker and more complete recoveries (. . .) Patients' rights are a reflection of the importance of human rights" (WHO, 1995, p. 8).

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The set of principles set forth in the Declaration include

> In the section "Human Rights and Values in Health Care": the right to respect of the patient's person as a human being; the right to respect for his or her privacy; the right of patients to be fully informed about their health status, including the medical facts about their conditions and alternatives to the proposed procedures. It further said that information may only be withheld from patients exceptionally, that patients have the right not to be informed at their explicit request, and to choose who, if anyone, should be informed on their behalf (WHO, 1995, pp. 38–39).
>
> In the section "Confidentiality and privacy": All information about a patient's health and all other information of a personal kind must be kept confidential, even after death; confidential information can only 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; all identifiable patient data must be protected; patients have the right to access their medical files and technical records, such access excluding data concerning third parties; patients have the right to humane terminal care and to die in dignity (WHO, 1995, p. 41 and 43).

The Council of Europe Convention on Human Rights and Biomedicine (The so-called Oviedo Convention) was adopted in 1997. It includes in particular:

> ***Article 10: Private life and right to information***
> *Everyone has the right to respect for private life in relation to information about his or her health.*
>
> *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.*
>
> *In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.*

> ***Article 2:***
> *"Primacy of the human being," of the same Convention, is worth noting as well: "The interests and welfare of the human being shall prevail over the sole interest of society or science." Article 2, paragraph 2, of the UDBHR has, with minor editorial changes, the same content.*

Privacy

Privacy is a major feature of medical care, particularly in the Western World, with roots in the Hippocratic Oath as it has arrived to us. Today, the right to privacy is, among other things, a consequence of the autonomy attributed to (adult, normally competent) individuals, their right to conduct their lives as they see fit.

Regarding the already-mentioned UDBHR, this issue is described as follows in a Memorandum of the International Bioethics Committee that developed it (Stiennon, 2009, p. 166): "A right to privacy restricts access to personal and medical information and provides a claim of non-interference in various private

spheres (. . .) Confidentiality refers to a special and often fiduciary relationship, such as that between researcher and research subject, or doctor and patient, and provides that the shared information shall not be disclosed to third persons, unless a strictly defined, compelling interest justifies disclosure." It goes on to mention international legal instruments that have recognized the importance of privacy.

Groups Whose Privacy Is Not Protected in Their Own Society

In Ancient Rome, to take a historical example, only a minority were Roman citizens and could participate in decisions of a political nature. The Roman *pater familias* exerted a right of life and death on members of his household (wife, children, and slaves). The latter had thus no autonomy or real power over their own lives, including as regards privacy. Similar situations are numerous today still; it is necessary to recall how often the autonomy and right to privacy of entire groups are not recognized and much less guaranteed. This is especially true for women (in past centuries their testimony was not accepted in courts or did not have the same weight as that of men). In fact, they remained *legal minors* in several respects (civically, politically) in European countries until the twentieth century and, in a number of regions, remain so today.

One point is of particular importance in medical ethics and bioethics: because of their inferior social status, formally or informally, women encounter significant difficulties in exercising their autonomy and privacy in matters of sexuality; their right/freedom to choose when and with whom to have sexual relationships, when and in which circumstances to bear children, is not at all universally accepted. This makes them vulnerable to various types of pressures and to violence. Moreover, contraceptive needs often include an element of urgency for the woman who might thus be, in various ways, at the mercy of the care provider and/or of others.

The Cultural Dimension

It is important to recognize how in different societies traditional rules interfere with privacy as understood elsewhere. UNESCO's International Bioethics Committee, in its *Report on Consent* – discussing Articles 6 and 7 of the UDBHR – says under the title "Communal and individual consent": "In many societies, the community is the entity in terms of which the individual is identified. The leaders make decisions on behalf of the community and its members and these are not questioned (. . .) There is a difficulty in aligning the autonomy of individual as embodied in Article 5 of the Declaration with certain cultural settings. The expression of individual wish that goes against these decisions can be difficult or impossible (. . .) The distribution of responsibilities and the decisional hierarchy in the family unit are such that the choice to be treated or not is not necessarily made by the person concerned. Health professionals must ensure that individuals should

not be subjected to coercive treatment, involuntary exclusion from available treatment or unwilling participation in research." (IBC, 2008, pp. 35–36).

Further, the Report says: "One of the most complex situations arises in societies where communal forms of decisionmaking may prevail. Seeking consent from an individual is indispensable even if his/her community is consulted [respectively informed, as regards privacy] (...) although it is important to observe and respect values of different cultures, these values should not infringe on fundamental freedoms." (IBC, 2008, p. 49).

Respect of Privacy by the Health Care Provider

Over the centuries, health care has been marked by a strong tradition of paternalism by care providers. In many societies, the priesthood and medicine were fulfilled by the same persons or were closely related functions. To be noted, however: paternalism is not always authoritarian or rigid, it may be benevolent and empathetic; admittedly there is, within limits, some reasonable use of paternalism.

One should know that the principle of patient autonomy is absent in Hippocratic writings. It is mostly since the emergence of modern bioethics, in the l960s and1970s and in Anglo Saxon countries first, that the diseased person has been seen as the *subject* of health care rather than its *object*. In the former quite asymmetrical state of affairs, privacy was not much of a concern. A few decades ago, in hospitals in Europe and elsewhere, even in university ones, it was customary to see consulting rooms with lines of patients queuing to be seen by the doctor at the end of the line, who would ask questions in front of others; adopting often in the conversation the "tu" when addressing them (in Latin and German languages, "tu" is the "you" used when talking to a child or person of inferior status). These manners were seriously encroaching on the privacy of the patients, and indeed on their dignity. Quoting from the above-mentioned WHO European Office Declaration on patient's rights: "Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy, particularly when health care providers are offering them personal care" (WHO, 1995, p. 42).

Such behavior might not have been basically ill-meant but corresponded to a power/authority relationship in medical care. The spontaneous provision of sufficient and understandable information to patients and the requirement of their informed consent, which are pillars of today's bioethics, were not given much attention – at best they were envisaged at the free, arbitrary, judgment of the physician. Things are changing, not always as rapidly as one would wish, however. There is a major need, in the training of all health personnel as well as in their practice, to underline the importance of attentive and tactful respect of patient privacy – and especially of his or her modesty.

This is an essential component of adequate care today, as expressed, for example, in the above-mentioned WHO Declaration on the Promotion of the Rights of Patients in Europe: "There can be no intrusion into a patient's private or family

life unless and only if, in addition to the patient consenting to it, it can be justified as necessary to the diagnosis, treatment and care. Medical interventions may only be carried out when there is proper respect shown for the privacy of the individual. A given intervention may be carried out only in the presence of those persons who are necessary for it" (WHO, 1995 p. 41).

It is important here to mention the issue of sexually suggestive or loaded behaviors by care providers, which is rightly receiving more and more attention. It is a fact that, due to the singular encounter situation, there might be temptation to express inadequate words or gestures, especially sexual in nature. Contrary to the autonomy of the patient, which does not appear in it, the prohibition of such inappropriate contact is expressly mentioned in the Hippocratic Oath**:** "In every house where I come I will enter only for the good of my patients, keeping myself far from all intentional ill-doing and all seduction and especially from the pleasures of love with women or with men" (English translation of the original by Michael North, National Library of Medicine – in Wikipedia, January 2012).

Such abuse of the care situation is strictly unacceptable. A number of professional bodies have included relevant dispositions in their deontological codes. For example, the Québec College of Physicians Code of Deontology:

> ***Article 22:***
> A physician must refrain from taking advantage of the professional relationship established with the person to whom he is providing services.

More specifically, the physician must, for the duration of the professional relationship established with the person to whom he is providing services, refrain from having sexual relations with that person or making improper gestures or remarks of a sexual nature (www.cmq.org – January 2012).

The deontological Code of the Swiss Medical Association says at article 4: In his professional activity, the physician does not exploit the dependence of the patient; it is particularly prohibited to misuse his authority on the patient, emotionally, sexually or materially" (www.fmh.ch – January 2012).

Of course, what is said here of sexually connoted behaviors holds true as well for any gestures or words that might be demeaning, insulting, scornful, or racist.

Finally, let us mention special needs, for example, when there is a particular risk of violence or escape by people under police custody or imprisoned. All efforts have to be made nevertheless to ensure maximum possible privacy and respect of the patient's dignity.

Privacy of the Care Provider

The professional is entitled to respect of his or her own privacy. Physicians and others, however, have a professional duty to be physically and mentally fit for their tasks.

None of them should drink alcohol when working; surgeons should not have any difficulty that might alter their dexterity. The author of this chapter had in his official capacity to ask two psychiatrists with serious bipolar syndrome to stop their practice.

An increasingly important issue is whistle-blowing. "Traditionally health care professionals have been reluctant to blow the whistle on an incapacitated colleague. This may have been out of misguided loyalty or fear of repercussions for themselves. Even when a colleague's infractions are serious, reporting such behaviours will not necessarily find peer support," writes in 1996 a practicing physician involved in medical ethics (Hébert, 1996 p. 62). Yet there is today no excuse for covering up inadequate abilities or professionalism. In the jurisdiction where this author worked, a legal provision, adopted in 2002, says that health professionals are obliged to inform the health authority of facts raising suspicion of abuse or malpractice by other professionals (Vaud, 2002).

In a recently published Casebook by the UNESCO Ethics Education Programme (UNESCO, 2011a), two situations regarding physician privacy are discussed (Cases 1 and 2 – the book describes real situations). The first case is about an accidentally cut obstetrics/gynecology resident, in whom immediate blood testing shows HIV seropositivity. Several hundreds of hospital patients had been involved with this doctor during their treatment. The question is to evaluate whether this physician's colleagues and patients have to be informed of his status and how. The second story is of a gynecologist who did not disclose to a patient that he was suffering from epilepsy. The disease, however, was adequately medicated and kept under control.

Such situations usually are delicate, do not have ready-made answers and need to be considered in depth under their various facets, by the professional concerned, by responsible deontological and public authorities, by the employers.

Privacy and Research

The rules and principles within a research endeavor are basically the same as those for the provision of health care. Any element touching on the participant's privacy has to be carefully explained. Any invasion of privacy, as the case may be, should be agreed upon by participants and strictly limited to what is imperative for the study purposes. There must be assurances that the participants may withdraw at any time from the research, without having to give motives. Also all research projects should be submitted to appropriate ethical review.

Relevant articles of the World Medical Association Declaration of Helsinki on ethical principles for medical research involving human subjects (1964, amended last in Seoul, Korea, in October 2008):

> ***Article 11:*** *It is the duty of physicians who participate in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects.*

Article 23: *Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity.*

A Particular Ethical Issue in Research with Data Anonymization

A delicate situation is raised in research in which (with the consent of the participants) data are anonymized: "Even after rendered anonymous or encrypted, data related to samples might still be associated to the ethnic or geographical origin, socio-economic level and lifestyles of specific populations" (Stiennon, 2009, p. 169). Furthermore, in some studies, it appears ethically necessary to be able to go back to the provider of (anonymized) samples, when, for example, the sample examination uncovers information of major importance for him. However, if such "back-tracking" is possible for a reasonable, well-meaning purpose, concerned professionals and institutions should make all necessary efforts to prevent that it may be unduly used.

Confidentiality

Medical Confidentiality

The notion of confidentiality in medical care goes back in the West to the *Hippocratic Oath*: "All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal" (English translation of the original by Michael North, National Library of Medicine – in Wikipedia, January 2012). Said oath regained visibility and vigor in eighteenth century Europe. During the Middle Ages, European medicine was hardly organized and there is no clear indication of a confidentiality duty then, although such a duty was present in Islamic and Jewish medicine (Morais, 2001, p. 725).

In Anglo-Saxon societies, confidentiality is mainly a deontological rule without legal protection (British common law gives a right to professional confidentiality to the barrister only). This flexible conception has been influenced by eighteenth century medical personalities such as J. Gregory and T. Percival. The latter said, "confidentiality must be strictly observed when circumstances demand it", but, if called to testify, "the physician must tell the truth, all the truth and only the truth" (Morais, 2001, p. 725).

This is very different from the French approach: in France, the 1810 Napoleon Code provides a basis to the "secret médical," imposed to any person who by virtue of his or her profession is depository of secrets entrusted to him or her. The Québec legal disposition is of the same vein. Medical confidentiality is more than a moral duty, it is a legal obligation. It is considered an element relevant to "public order"

and its violation is sanctioned by the Criminal Code. Several authors think that this particularly stringent definition is due to some assimilation of the "secret médical" to the Catholic confession confidentiality – "secret de la confession" (Hoerni & Bénézech, 1996). In Switzerland, the "secret médical/professionnel" is also ruled by the Criminal Code but the faculty of being lawfully freed from the obligation to keep confidentiality is more easily obtained, and in more circumstances, than in France (Martin & Guillod, 2000).

Medical confidentiality has in modern times followed three different routes: one, as said above, is *deontological* (professional ethics). One of its expressions is the Geneva Declaration (1948), the forerunner of today's Helsinki Declaration. The second one is the *legal* one (the French model). One might note that deontological texts, elaborated and applied by a professional body, do not have the democratic legitimacy law has – today an increasing number of rules linked to bioethical issues are inscribed in public law and regulations.

Since the 1970s and the emergence of modern bioethics, confidentiality tends to follow a third route, the *human rights* one – similar to major evolutions in public and community health thinking. Below, we mention that the late Jonathan Mann, then head of the WHO AIDS program, championed the importance of human rights in the struggle to contain the epidemics. Would all concerned human beings be free to exercise their rights (especially autonomy, capacity to refuse unwanted relations), the spread of HIV/AIDS would not have been the same.

Goal of the Confidentiality/Secrecy

Fundamentally, the overarching objective of medical confidentiality is the *protection of the patient's interests* (and not the protection of the provider's – see below). It exists to protect the sick person from undue curiosity from a variety of others.

It is considered a cornerstone of good therapeutic rapport between the person cared for and the caring one. Louis Portes, a French physician who was (in the mid-twentieth century) president of the *Ordre national des médecins*, had the famous sentence: "There is no medicine without trust, no trust without confidence and no confidence without secret" (Hoerni & Bénézech, 1996, p. 12). The French doctrine insists strongly on the notion that, would patients not be fully confident about the strict secrecy of what happens in the therapeutic encounter (*colloque singulier*), they would not readily come for treatment anymore.

In principle, the doctor and other professionals have to be released from the confidentiality obligation *before they can talk to any other person* about the patient health condition. This holds true also for the patient's loved ones, wife/husband, partner, or children. The recognition of that principle has become more effective in recent decades. The consent of the patient needed before informing others usually does not require a formal procedure like a signature. Instead, it might be governed by common sense – as many things ideally should be in the relations between care givers and patients. In routine situations (fracture, appendectomy, common cold…), one

can often assume a tacit agreement that the provider informs family and loved ones. Yet, every time that there might be an unwelcome breach of the patient's privacy (information allowing to deduct questionable contacts or behaviors, e.g., sexually transmitted disease; this is an issue also in psychiatric care), the provider has to ensure that the patient gives clear and explicit consent, or mandate, to inform others. These aspects have been very significant, during the first decades of the AIDS epidemic.

Secret of the Doctor or "Secret of the Patient"

This is a significant terminological question. In German-speaking regions, one speaks today of the secret of the patient ("Patientengeheimnis"), which comes closer to the actual meaning of medical confidentiality, that is, to protect the person's privacy and data.

Over the last decades, a major evolution in a number of countries has been the recognition, and inclusion in the laws, of patients' rights. These imply the duty for the provider to inform the patient, spontaneously, without delay, and in a sufficiently complete fashion, about the medical observations made, laboratory and other para-clinical exam (imaging, etc.) results, about diagnosis and the various possible therapeutic avenues with their advantages and disadvantages, and about prognosis. This information is a *sine qua non* condition in order to obtain a valid informed consent from the person. Another patient's right is access to the medical file (in principle, to all that is in the file).

In this modern context, it is said that "the patient is the master of the confidentiality/secret," the health professional being the one who maintains it and stores it. Doctors who would refuse to their patients access to their medical data arguing that they are entitled to deny access "based on the medical confidentiality" would be grossly perverting the legal and deontological principle. After all, the patients should decide about the secret and its keeping or opening. Regarding their own medical data, they are to say to whom it may be given/transmitted, how and when. Case study 3 of a UNESCO Casebook in ethics education (UNESCO, 2011a) presents an actual example.

The Particular Situation of Teenagers Having Competency, the Capacity to Consent/Judge

Different systems have here different ethical and legal provisions. In several countries where the legal age of majority is 18 or 20, it is considered that teenagers have, some years before that age, the ability – the "strictly personal right" as the Swiss Civil Code has it – to request, accept, or refuse medical care, even without information being given to their parents or legal guardians, or against the will of their parents/legal guardians (see Martin, 2009). This allows, in Switzerland, for example, a 15-year-old girl to consult on her own a gynecologist to request

a contraceptive prescription, or even an interruption of pregnancy, without information of the concerned adults or against their will. Case 7 of the UNESCO Casebook on Benefit and Harm (UNESCO, 2011b) deals with that issue: the law, in the actual situation described, does not recognize any rule of absolute parental authority until a fixed age.

That "psychological/social age of competency" is not fixed by law, in general, it is a matter of appreciation by the care provider, in view of his or her professional experience. Understandably, it depends of the specific situation and in particular its severity.

The above has much to do with the principle of autonomy but is fully relevant regarding confidentiality. While for younger children the care provider has to thoroughly inform the parents, the provider has to be careful to protect the youth's privacy. By the same token (see preceding section), the youth is the one who decides about "secrecy" regarding their own medical data and the provider must have the patient's consent before informing others.

Shared Confidentiality Among Members of the Care Team

The need to share data among a variety of persons involved in the patient's treatment (the care team) is undisputable and now well recognized. The realization of this need required a change in mores and habits among the professions over the second half of the twentieth century. Physicians has been earlier rather possessive of the information they had ("information is power"...).

Stiennon notes, "Scientific and technical development has resulted in the need to accommodate the imprescriptible duty of confidentiality. Indeed, confidentiality is complicated by the fact that the flow of information is in the very interest of the patient. New confidentiality problems have also arisen from the computerisation of health administration. In the management of health problems and the prevention of diseases, government can intervene in the confidentiality domain" (Stiennon, 2009, p. 168).

In a time of high sensitivity to appropriate protection of personal private data (medical data are particularly sensitive), the desirable practice of "shared secrecy" has limits to be observed. The main one it that each member of the team has access only to the information needed in order to fulfill adequately his/her role/mission in the diseased person's treatment. Shared confidentiality shall not mean that everybody on the team can peruse any part of the file. This represents challenges and demands strict measures (passwords, etc.) in an age of computerized medical documents – see also what is said above of the respect of patient privacy by care providers.

Waiving Confidentiality When Others' Interests Are Seriously at Stake

There are situations where it appears desirable or necessary, as the case may be, to give others information covered by medical confidentiality. Flowing from the principle that

the patient is the master of the secret, the golden rule is to first obtain consent before the data is forwarded to others who have a significant interest in being informed.

Both the public authorities (health authority especially) as well as private individuals might have such an interest. The following examples are meant to illustrate this point:

- A number of communicable diseases need to be brought to the attention of the health authority in order to take appropriate treatment, control, or prevention measures.
- It is today generally considered necessary that violence and ill-treatment of persons, especially minors and others who are under the responsibility, rule, or pressure from others (including parents and close ones) and not in a position to adequately defend themselves and their interests, should be reported to an appropriate service or authority.
- The patient might be a danger for himself/herself but also for others, especially in psychiatric situations. In most countries there are legal texts allowing hospitalizing (committing) persons even without their consent.
- There might be cases where the declarations or behavior of a patient raise the fear that he might seriously harm others. The care provider has then to judge to what extent the danger is such that information should be conveyed to persons or offices concerned.
- There are countries where by law physicians or other care providers have to report to the appropriate authorities, if they come to know of a crime (in others, and by analogy with the confidentiality duty of ecclesiastic persons, this is not the case).

From an ethical point of view, one should generally oppose a duty of health professionals to denounce persons having committed a delict or crime (while the professional keeps the faculty, if they deems it necessary, to be freed – according to the relevant legal or deontological rules – from the confidentiality duty in order to give information to concerned third parties). In 1832, the famous French surgeon Dupuytren, asked by the police to give the names of rioters, answered famously "I don't know rioters in my wards, I see only wounded persons."

This issue is similar to the one raised by the ethical principle that physicians should not participate in any way, in acts of torture or other harsh and inhuman treatments, including the death penalty.

Confidentiality and Public Health: The Balance to be Struck Between the Individual's Interest and Privacy and Possible Community Interest and Wellbeing

In a book providing explanations about the UNESCO Universal Declaration on Bioethics and Human Rights, aimed at worldwide understanding and application of its principles, Jeanine-Anne Stiennon writes, "In practice, the rights and freedom of individuals are in conflict with the exigencies of the 'common good' and with the potentialities of information technology. Examples are : screening of pathogenic

agents or diseases, genetic or immunological typing, identification of potential offenders, codes of public health, interdependent social situations (social services, social insurance, preventive medicine, hygiene, and psychiatry) The interests of certain economic sectors linked to the exploitation of data are also involved" (Stiennon, 2009, p. 167).

In the future, deciding when medical confidentiality (may) have to be opened to others, private or public, will present many questions and challenges. They are to be dealt with by considering carefully the private and public interests concerned. The next sections provide illustrations.

Practical Issues and Examples in Today's World

A Major Challenge: Confidentiality and AIDS at the Outset

AIDS was described in 1981, first as a medical rarity and enigma, and became a worldwide public health problem around 1985. Public health authorities had then to ponder a number of difficult ethical questions, as it became apparent that it was an infectious disease, transmitted mainly through quite private behaviors (sexual intercourse, intravenous drug use), which raised alarms in the public.

There were demands for the promulgation of certain legal obligations in order to limit the spread of the disease. There were discussions in the 1980s and early 1990s about compulsory and universal testing (for HIV seropositivity) in the population, of exclusion of seropositive children from kindergartens or schools, of limitation of the freedom of persons living with AIDS to move around and even of their internment in closed institutions or camps. Several countries (including the United States) required an HIV test before delivering a visa! The problems were made more acute as medicine remained practically helpless for several years. There were many fears that one could catch that terrible disease unknowingly ("without deserving it").

With society faced with a dangerous communicable disease, it was logical that professionals were required to report whether they had seen cases, how many, in which types of patients (in order to advance epidemiological research, among other things). But did public health surveillance require that the names of the patients be known? With the possible exception of particular situations, the answer is no.

Medical confidentiality was at stake from another perspective, too: what was the physician to do about the (most reasonable) wish to make sure that partners of a person with HIV seropositivity be informed of that fact – at a time when full-blown AIDS killed in 1 or 2 years. The French medical profession never admitted that it was understandable, and in a way morally compulsory, to inform at least the regular partner (entitled to expect that his/her consort not be sexually nomadic), and that medical secrecy had to be waived. French physicians went on with a rigid legal view of confidentiality, arguing that if giving such a information, even to a directly endangered person, was accepted, then the seropositive patient

would lose all trust in the health system and not seek care anymore. That might very well be true, argued others, but what about intentionally letting another person be at a mortal risk? In Switzerland, ways were devised to achieve the goal of informing regular partners; first through efforts to convince the patient to allow information to be given, then if necessary by asking the relevant authority to waive medical confidentiality.

In the UNESCO Casebook on Benefit and Harm (UNESCO, 2011b), cases 27, 28, and 30 focus on situations that went before courts in relations with HIV seropositivity having been hidden, either from the patient or from an interested third party, or on the contrary disclosed to others without the consent of the patient.

It was not easy thus for public health professionals and decision-makers to strike the right balance in a novel situation, with a number of unknowns regarding the spread of the disease. As forceful intrusions in the private sphere of individuals were talked about, one had to evaluate when and to what extent it was legitimate to invade privacy. Should there be compulsory testing? If so, of the whole population? Or, in certain groups like children in school? What about patients entering hospitals, as clinicians also were afraid? Should it be routine in persons with multiple sexual partners, in IV drugs users? In retrospect, one may say that, thanks to courageous positions by the WHO (including the late Jonathan Mann, a great advocate of human rights issues in AIDS and in public health in general), by National AIDS and Bioethics Commissions and other bodies, and by public health professionals, one could in most places avoid unjustified authoritarian measures which would have seriously jeopardized privacy and confidentiality.

Privacy and Genetic Testing

Progress in medicine, especially in genetics, poses new challenges, for example in respect to Huntington disease (known as Woody Guthrie's disease in the US), a dominant hereditary disease leading to early dementia (in the forties) and death, for which there is no therapy. Today, it is possible from childhood on to know whether a person carries the responsible gene, which represents a first ethical difficulty: may one propose to young persons that they be tested when, should the result be positive, it would mean a terrible burden for the rest of their (rather short) life. For these reasons, it is considered unethical to propose testing before the legal age of consent. In any case, prior enlightened and tactful genetic counseling is indispensable, after which the decision to test or not is taken in all liberty by the person.

Confidentiality – or disclosure – comes into play in relation with the children of a person tested positive. Should they be informed that one of their parents is a carrier, is going to die prematurely with dementia, and might have passed on to them the Huntington disease gene, which they might later on transmit to their own offspring? The person tested positive has the right to refuse that their close relations be informed but one readily sees that this opens serious questions. Similarly, one would have to ponder these questions in relation to the fiancé of a young person who has tested positive.

Similar challenges and difficulties are encountered as a result of other current advances in genetics. In the recently published UNESCO Casebook on Benefit and Harm (UNESCO, 2011b), case 26 describes a situation of a woman found with a genetically transferable disease where physicians did not take measures to have her threatened children informed.

In 1997, UNESCO adopted the Universal Declaration on the Human Genome and Human Rights (UNESCO, 1997). Articles related to privacy and confidentiality include:

> *Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.*
>
> *The right of each individual to decide whether or not to be informed of the results of genetic examination and the resulting consequences should be respected.*
>
> *Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions set by law.*
>
> *In order to protect human rights and fundamental freedoms, limitations to the principles of consent and confidentiality may only be prescribed by law, for compelling reasons within the bounds of public international laws and human rights.*

Medical Confidentiality and Daily Life

Other questions are common and may touch everybody's existence. Thus, employers have a (legitimate, per se) interest to have employees who enjoy good health. Should they be allowed to get information out of the medical file of applicants for a job? No, in principle. According to the above-mentioned golden rule, job applicants have the right to ask their doctors to inform any others, including a prospective employer, but one is well advised to be careful here; one would want to be sure that there is no undue pressure involved. Is the employer even allowed *to ask* health-related questions (about physical or mental conditions) to the candidate? This is much debated.

On the other hand, there are cases where such queries are logical: one very much wants a bus driver or a pilot to have good vision. One may understand as well that, before offering an expensive additional training to a collaborator, the employer wishes to have a reasonable assurance that the person will not in the short term be limited by medical conditions. Yet, there is here a contradiction with the notion of equal chances for all which we would like to maintain and promote.

Medical Confidentiality and Health Insurance

In countries with universal social security and/or health coverage mandated by law, it is unacceptable that risk factors linked to health or disease be invoked to reduce or

diminish what the legal mandate fixes. But the situation is very different where there is no such coverage, as well as regarding complementary insurance on a private basis: in many countries those who can afford it contract additional coverage to get better than basic care. Then the insurer may ask questions – and demand answers – before agreeing to an insurance policy. In fact, in that private industry (including life insurance), the name of the game, the researched goal is to propose to the customers the most advantageous premium, as figured on the basis of the risks they represent – or not – to get sick or die prematurely. Insurers are advised to learn as much as they can about an applicant, in order to offer a low premium to good risks and high premiums – or offer a refusal – to bad risks. There is no consideration here of social solidarity, which is in principle the rule for universal coverage. Applicants may of course refuse to provide information or allow their physician to transmit medical data, but in that case they will most probably not have any proposal by the insurance.

Such situations have been frequent, and difficult, in respect to HIV/AIDS. When effective anti-retroviral therapies were introduced, a number of young seropositive persons were able to pursue professional careers, in which they often needed to contract life insurance, for example, to get loans from banks. In those circumstances, physicians faced serious dilemmas when answering insurers' questionnaires.

Medical Confidentiality and Duties of the Public Hand

Within any health care system today, there are strong pressures to contain the cost of care. Authorities and bodies supervising insurance programs ask for medical data justifying the prescriptions and acts performed, aiming at ensuring that money is efficiently used, and for the purposes it is supposed to serve. The goal is to eliminate unnecessary procedures, redundancy, and waste, wherever they may be. From a social ethics point of view, this is legitimate; we all have an interest in the relevant and economical use of means made available by the community. Confidentiality should certainly not serve to hide any wasteful use of resources. On the other hand, this objective should not allow excessive curiosity by others, which would be contrary to the interest of a patient and their treatment. A reasonable balance is to be found between what the insurer might ask and undue breach in the privacy of the care relationship.

There are requests for medical data that are justified by other tasks of the State, where one expects the authority to take adequate measures. For example the control of the driving capacity: there is a clear public interest in reducing the number of dangerous drivers on the road – be they dangerous because of drinking, some physical or mental problem, or other reasons. The right to privacy and confidentiality of the individual is thus superseded by the desirable security in traffic. Either one agrees to be medically examined and the conclusions are transmitted to those in charge of road safety or one should accept not to drive anymore.

In summary on this point: confidentiality is established to protect/preserve the privacy and interests of the patient. However, there are situations that make it necessary to waive the confidentiality when others' or the community's interests are seriously endangered.

Privacy and Confidentiality Are Threatened by Difficulties in Communication and Integration

It is increasingly recognized, all over, that persons living in an area where they were not born, and of which they do not know the socio-cultural mores and language, are for that reason quite vulnerable. They are migrant workers who, legally or not, moved to the new country, or refugees and asylum seekers, or people displaced within their own country. They are at a much greater risk of not being able to explain what their health problem is nor to understand recommendations of health personnel, and consequently not to be treated adequately. In the UNESCO Casebook on Benefit and Harm (UNESCO, 2011b), case 3 describes difficulties rising from such misunderstanding.

These situations demand the collaboration of interpreters, or cultural mediators when the problem is to understand the way things work in the new residence. In several countries there are valuable efforts in this direction. As regards our topic, one should be aware of a potential side effect of this basically useful development, that is, the threat to the patient's privacy through the presence and intervention of a third person. The interpreter or mediator, though knowing the person's language and culture, might be reluctant to render exactly declarations which he or she finds awkward or even offensive (because "these are things which are not said or done in our original culture"). Also, a woman might very well not be willing to talk of a gynecological problem through a male interpreter. An adult might not accept translation by a youth. Interpreters must be aware of and respect the confidential character of what happens in the care relationship. They must understand that they have to transmit the message neutrally, without modifying it. Furthermore, the translation might simply be inaccurate or the health provider might misunderstand. There are here growing challenges in today's increasingly diverse and mobile societies.

Confidentiality and the Health Status of Persons Assuming High Office or Other VIPs

On several recent occasions, there have been rumors, concerns, and questions around the health of elected officials, including heads of State (e.g., President Georges Pompidou in France in the 1970s). The issue is to evaluate whether there is a *public interest* of the concerned citizens to be informed when a person with major political duties is hampered in his or her capacity to carry out the responsibilities they have been elected to. Does the public have a right to know, and if yes, to what extent? The main opinion today is that there is such a right. How rapidly it should be done and with which degree of detail should be evaluated in the particular case. Whether the same might hold true too for members of the "people crowd," movie stars, singers, writers is of less momentous importance. There, the potential unfortunate consequences of not knowing appear more related to the fans' sorrow or of a commercial nature. Contrary to the situation of major political decision makers, the reasons to request a "right to know" do not appear compelling at all in these cases.

To What Extent Is the Intervention of the State Legitimate in Highly Private Situations, for Example, at the End of Life?

There is an ongoing and necessary ethical debate about the extent to which the public authority is entitled to take compulsory measures vis-à-vis certain diseased persons (e.g., with psychiatric or addictive conditions). When, how, and in which circumstances might the State pretend to know better than the individual what is good for him or her? This is an important issue regarding the individual's right to privacy.

Until a few years ago, France had a law mandating premarital medical examination. As a measure ordered by the State, it came to be considered an inappropriate intrusion in the private life of individuals and was abolished. Needless to say, engaged people who freely decide to undergo a premarital examination show responsibility and are perfectly welcome. But, then, they are well advised to agree beforehand that the physician(s) are authorized to transmit possible pathological information both to the person concerned and to his or her partner. Case 30 of the UNESCO Casebook on Benefit and Harm describes the unfortunate consequences of a situation where the sick member of the couple did not inform his partner of the finding and where the doctor had not been given the mandate to inform her (UNESCO, 2011b).

Suicidality presents another illustration. Health care providers and society generally, have a general "mandate" to prevent suicide. However, putting an end to one's own life is also, in a way, a right. Almost all countries that earlier criminalized suicide (attempts) have abrogated such laws. Further, there is agreement that some suicides are understandable, "reasonable," given heavy and painful life circumstances – with a high degree of dependence, despondency, and no hope for recovery. One may talk of "stock-taking suicide," In some states in the US and in several European countries (Belgium, Luxemburg, Netherlands, and Switzerland), people with intractable suffering have the right to seek assistance for a suicide (though no right to require that it be given), and such assistance by third parties is not punished. The need there is to define a reasonable balance between the measures that public health might take to prevent suicide (e.g., of young persons under the effect of transitory stress or misfortune) and possibly undue and authoritarian limitations of the right of persons to decide over their own lives – their privacy.

About the Right Not to Know

Sigmund Freud is said to have told his physician, when the latter announced that he had diagnosed a cancer of the tongue, "Who authorized you to tell me that?" The right not to know is a generally recognized right. It follows from the principles of autonomy of the person, of consent (or refusal) and is linked to privacy. The patient is free to say, "Doctor, I trust you to do the best for me, whatever the diagnosis and available treatments, but I don't want to be informed" (especially, one assumes, in the case the findings and prognosis are severe). There are, however, cases where this raises questions. As mentioned above, the AIDS epidemic,

particularly when no therapy was available, generated much discussed ethical dilemmas. One is confronted with comparable issues in relation with less symbolically loaded communicable diseases as well as with hereditary conditions.

There might be other dilemmas for the physician and care team: suppose the discovery of a severe condition with bad prognosis in a young 40-year-old entrepreneur full of perspectives and projects. It is this patient's right not to be informed; yet he might have wife and children and the consequences of an announced death may be less devastating in several respects than if unannounced. Not knowing the threat to his life, he might engage in new investments that might become wasted; his business might lose much of its worth would he insist on managing it with a severely altered health. While the care provider's mission is not to take responsibility for all aspects of the patient's life, he is concerned with his general wellbeing.

Summarizing: patients are entitled not to know and to leave their close ones in ignorance but, in situations like the one described, for the professional to think of ways to discuss the possible consequences of deliberate ignorance is at least legitimate.

And After Death?

An important point is that the requirement for medical confidentiality is not cancelled by the death of the patient. Ethical and legal provisions remain the same, as well as the possibilities to be released from it – as mandated by law or if specific circumstances demand it (with no possibility then to follow the above-mentioned "golden rule" of the patient's consent as he or she is no longer in a position to give it).

Conclusion and Perspectives

The whole domain of privacy and confidentiality in health care and research has been marked in recent decades by the emphasis put on human rights. First, with the emergence of charters and laws about patients' rights, whereby the former deontological rules, elaborated and applied (arbitrarily as the case may be) by a profession, were replaced by public law – with therefore a democratic legitimacy.

Future challenges are, in particular, at the interface between traditional confidentiality, with the primary goal to protect the patient's interests, and the consideration of the interests of third parties. In some cases, these third parties are family members and close ones, in others cases they are persons the patient comes into contact with – in areas as diverse as communicable diseases, ill-treatment and battering of others, especially children, or traffic safety – or the community at large (public health problems).

There are delicate questions around the right not to know and whether to hide from concerned close ones information that is of importance for their own lives.

With increased emphasis on the respective rights and duties of patients and care providers, the latter might now more than in the past insist on protecting their own privacy. On the other hand, whistle blowing about incompetent professionals is now asked for. Others whose privacy is in jeopardy (unwillingly or sometimes willingly) are persons in very visible and looked upon positions: elected officials, people of the business or media worlds. For some of them, a legitimate public interest to know may be invoked.

In research, the widespread use of computerized banks, including biobanks, results in storage of ever larger amounts of data and samples of many sorts. This poses challenges in terms of informed consent for their use – when, for example, a new study is envisaged, which was not foreseen when they were collected, as well as questions in terms of privacy. Use of anonymized material has its own delicate issues.

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