

# 22

## What Ethics for Telemedicine?

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The development mode of digital technology innovations in the health-care field has been qualified by some as “hyperactive inaction,” which refers to an anarchic multiplication of experimentations and tools resulting in a certain inability to set up useful, desired, and sustainable products (Rialle et al. 2014, our translation). Actually, the development of such a field as telemedicine sparks the emergence of new techniques, new practices, and new organizations. It simultaneously involves new challenges regarding security, the respect for individual rights, the way medical activity is organized, together with economic and access challenges, as well as eventual public policy ones.

Through the example of telemedicine and of the related French regulations, we would like to show, from an ethical point of view, in

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what way the development of telemedicine requires a *reflexive governance* (Lenoble and Maeschalck 2011) permitting to match the various challenges induced by that developing field.

Although telemedicine has already been granted recognition through the August 13, 2004/2004–810 law related to the reform of the state health insurance, its true recognition results from the HPST law (Hospital, Patients, Health and Territory July 21, 2009 law), which recognizes and defines this practice. In the course of the following year, the October 19, 2010 decree states the characteristics required by the regulation of the practice. It defines its outlines, sets out the rules to be complied with regard to the patient and specifies the framework within which telemedicine projects have to be organized in agreement with regional authorities.

This framework is now very controversial and we believe that it reveals the challenges of a normatively controlled development of telemedicine. In this contribution, we would like to raise the question of a telemedicine ethics. Does telemedicine raise new ethical questions? Generally speaking, does the emergence of digitalization technology involve a new way of considering ethics, deontology, or the law in the field of health care?

Our reflection here will not be empirical: We are not analyzing a concrete telemedicine project. Neither are we giving any comprehensive list of the possible ethical challenges of telemedicine. Our questioning will be mainly methodological and epistemological: *How* should the ethical question be formulated regarding this development?

## 22.1 A Few Telemedicine Development Challenges

As a first point, we will try to identify the major lines of the questioning raised by the deployment of telemedicine, with no pretensions to being exhaustive. These lines are more or less directly linked to the technology through which this deployment is made

possible. Others are related to the insertion of that technology into medical practice and more besides, namely related to the territorial redeployment permitted by those new devices. The deployment of those projects raises security issues, access concerns, as well as questions related to the transformation of the medical relationship.

### **22.1.1 Challenges Directly Related to Information Technologies**

The use of digital technology is likely to give rise to several issues “directly” linked to the technique itself, such as security, the respect for private life, and the protection of data property. The notion of “directly related to technology” is to be relativized in so far as the technological aspect will never be freed from social aspects. The fact that we always have to make do with “socio-technical devices” in that field will be a major connecting thread throughout this contribution.

#### **22.1.1.1 Security Concerns with Telemedicine Systems**

Even though telemedicine relies on advanced and high-precision technologies, we should not minimize the fact that telemedicine devices rely on a relatively complex technical infrastructure which may include one or several quality internet connections, computers, cameras, screens, software programs, and medical devices that have to be adapted, compatible, and high-performance ones altogether. Each of the items included in the system, as well as the whole system itself, have to operate optimally to ensure the quality and sustainability of health-care deliveries. Thus, the functionality, quality, and security of the technical system are the minimal requirements for the implementation of telemedicine. The fulfillment of those first requirements is likely to raise all the more complex questions regarding coordination and responsibilities as these devices are seen as performing articulations between technical objects and human organizations.

### 22.1.1.2 Private Life and Personal Data Protection

Then, since what can be defined as socio-technical devices are widely relying on information and communication technologies, patients' confidentiality, and privacy questions are obviously raised. For some authors, the evolutions of the medical practice such as telemedicine “generate inevitable threats to privacy and medical confidentiality” (Béranger et al. 2012, p. 87, our translation). These authors remind us that “any IT system is violable—all the more so as it is connected to a network” (Béranger et al. 2012, p. 88, our translation).

### 22.1.1.3 The Data Property Question

Finally, and as an extension of the questions related to the protection of private life, the accumulation of data permitted by those devices raises the question of the property and use of the data, for instance for research purposes. There again, the question cannot be seen as fully new but its intensity and spatial dimension together with the multiplication of the actors involved in those systems will undoubtedly raise questions specifically pertaining to this field.

## 22.1.2 Impact on the Health-Care Relationship

The specificity of those devices (intensity of the technical presence, virtual relationship, multiplication of actors) are likely to transform the health-care relationship. Telemedicine may not bring fundamental alterations to the health-care relationship but it will transform a certain number of procedures in such a way that they will induce several challenges.

### 22.1.2.1 Is Medicine Being Dehumanized?

Many criticisms in the related literature evoke “the fear of human care and support being dehumanized” (Rialle et al. 2014, p. 135, our translation), the fear of a “depersonalization” of medicine. Let us first

make it clear that some ethical approaches would see the cause of that dehumanization in the technique itself. Indeed, those approaches emphasize an opposition between the technical medical gesture (cure) and a caring gesture (care) performed without any preset measurement or protocol. Besides, according to Mark Coeckelbergh, “technology has always mediated care practices” (Coeckelbergh 2013) Medical practices have always been both a technical and human compound likely to have dehumanizing effects as well as humanizing ones. The complexity of those systems is undoubtedly likely to multiply those effects which may rather originate from the technique itself or even from its use. Truth be told, we should rather say it comes from some sort of articulation between both. Then the major challenge mainly lies in our capacity to identify those effects and challenges. To this end, the emergence of questions about those techniques has to be made possible. In that respect, a full series of questions can be identified, which will obviously be raised throughout the deployment of those systems:

Any physician knows the importance of body language, bearings and hesitations during a face-to-face consultation. Telecom links and terminal units can only transmit and reproduce non-verbal messages imperfectly. Neither can they reproduce the numerous factors contributing to the ambiance in a healthcare room (people’s breathing, smells, the quality of the air, draughts, the participants’ stress), or what is going on beyond the scope of the cameras or microphones. (Parizel et al. 2013, p. 466, our translation)

In his work, *Télé médecine, Enjeux et pratiques*, Pierre Simon emphasizes that “the climate of confidence that sets up between a patient and their physician during their first meeting is based on the warmth of a direct face-to-face relationship, which can only be reproduced by a videoconference distance consultation” (Simon 2015, p. 79, our translation). This is the reason why, according to him, a teleconsultation cannot substitute for a face-to-face primary consultation, except if it is justified in the interest of the patient. Telemedicine thus urges to rethink the

conditions of the building up and sustainability of the confidence-based bonds between a physician and their patient.

According to some approaches, the relationship established by telemedicine seems to even question the possibility of a therapeutic relationship. According to Pierre Simon, again, the reason why the development of psychiatric teleconsultations has not been the same in France as in other countries is to be seen in “the mark left in French approaches in psychiatry by the influence of Pr. Jacques Lacan, a Freudian psychiatrist and psychoanalyst. According to psychoanalysts, the face-to-face contact is indispensable, which excludes any psychiatric care solution in which the physician speaks to their patient through a videoconference system” (Simon 2015, p. 50–51, our translation).

The recent opinion of the European Group on Ethics in Science and New Technologies (EGE)—*The Ethical Implications of New Health Technologies and Citizen Participation* (opinion n°29), puts forward the ambivalent effects of those new technologies (p. 31): On the one hand, they establish novel possibilities for sick persons and patients to exchange and share experiences; on the other hand, information technologies are likely to transform a rich and diversified experience into pieces of information that are transmittable but isolated and disconnected from the person’s social context and biography.

### **22.1.2.2 Participation, Empowerment, or Responsibilization?**

The EGE puts forward other impacts of those technologies on the health-care relationship. One of the key ideas of their opinion is that digital care new technologies contribute toward a “participatory turn” in the health-care field: Patients are participants in their own care continuum. They even mention an *empowerment* of the patient. Some eHealth applications or systems enable the patients to get an easier access to their medical data and to better control them. Telemedicine is likely to broaden some sick persons’ range of possible options. Thus, some chronic care patients may be able to stay at home,

while hospitalization would have been the only option. One may even think that on the basis of the data that the patient will get in real time, he or she will be able to make certain decision concerning his/her treatment.

But the patient's "empowerment" may also result in their excessive "responsibilization," which means that the responsibility of their situation may be more and more incumbent to them. Thus, "GEE warns against a deviation of health-related autonomy," "which either corresponds to a more general transfer of the public health services' responsibility towards individuals or let them bear the responsibility inherent in the risk as well as the regulating capacity, and which would eventually pave the way for lower standards and quality of the care delivered" (European Group on Ethics in Science and New Technologies 2015, p. 68).

This risk is relatively hard to control. However, the way the French regulation is set up reveals this issue. Indeed, the October-2010 decree<sup>1</sup> includes two sections: one referring to the patient's participation in those plans and the other one concerning their implementation and organization. This decree shows the need for what currently relies on the concept of governance, that is, "the setting up and running of institutions" (considered not so much as "organizations" but rather as the laws of the game), defining the various actors and their prerogatives in a cooperation to the benefit of the community as well as in the resolution of conflicts that are likely to occur.<sup>2</sup> A governance of those plans requires both to make a participation of the concerned actors—namely patients—possible and a capacity to take into account the questions raised within the scope of the "lifetime" of those telemedicine plans permitting to correct the issues faced, and even to revise the regulation framework by taking the purposes of that kind of plans into consideration. Such an approach could undoubtedly make up for a response

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<sup>1</sup> Décret n°2010–1229 du 19 octobre 2010 relatif à la télémédecine, *JORF* n° 02045 du 21 octobre (2010).

<sup>2</sup> Groupe de travail n°5, *Renforcement de la contribution de l'Europe à la gouvernance mondiale*, Rapport du Groupe, Pilote: R. Madelin, mai (2001).

both to the deviation consisting in over-responsibilizing the patients and to the dichotomy between telemedicine plans and more traditional medical practices which may induce discriminating effects.

### 22.1.3 Toward a Territorial Justice for Health Care?

In the current difficult economic context, with the decreasing number of physicians and their geographical distribution over the territory being sometimes far from optimal, with the growing demand in health care due to the aging population and the increase in chronic diseases, the questions of the access to health care and of its equity are more and more acutely raised. Telemedicine can be a response to this situation in terms of quality, efficiency, and equity altogether.

In a way, telemedicine represents a real possibility to redeploy the health-care system. That redeployment raises a full series of questions: What health-care distributive justice can be expected with technologies such as telemedicine? Can the fact of responding to a “medical desert” situation by just implementing a telemedicine system be considered as an equitable response to unequally treated areas and territories in terms of a health-care offer? How can the digital exclusion issue be avoided? How can the “digital divide” factor (regarding gender social backgrounds, ages . . .) be abolished? How can quality, efficiency, and justice be altogether guaranteed in telemedicine projects? The deployment of telemedicine definitely raises questions in terms of distributive justice.

The specificity of the questioning in this respect lies certainly in the entanglement of the questionings related to equity and access to health care with those regarding security, quality, and efficiency, all those questions being raised by an evolution which, according to some people, changes the way to do medicine completely. Considering these challenges, we understand why the French 2010-decree envisages to formalize telemedicine projects by contract with the public authorities. As a matter of fact, one may realize that this decree more generally reflects the various questions that we have raised here, including security, health-care relationship, and equity. In spite of the



number and diversity of the questions raised by telemedicine, is it still possible to consider that the development of telemedicine raises novel ethical questions? Does the development of telemedicine require a renewed approach of ethics and regulation?

## 22.2 What Response from Ethics?

As seen above, the law seems to take the questions raised by the development of telemedicine into account to a large extent. In France the 2009-law and its application decree define telemedicine, state the rules to be complied with by its specific health-care relationship, and makes allowance for those questions through a kind of contractualization tending to ensure a balanced deployment of this new medical practice procedure. Likewise, the deontological codes and bioethical principles seem to provide responses to the questions we have raised below. According to several authors, telemedicine would not require a new definition of ethical principles or of the deontological code which may need to be reinterpreted at the very most.

So, according to Pierre Simon,

clinical telemedicine is a medical activity. It refers to ethical principles stated in the Code de la Santé Publique (public health code) which has integrated the deontological code and the decree concerning telemedicine. Four pillars of medical ethics apply to clinical telemedicine: the benevolence principle, the non-maleficence principle, the justice principle and the respect for the patient's autonomy. (. . .) The telemedicine activity is a medical activity as any other one and therefore does not require the implementation of a specific judicial system. The French national council of the medical order (Conseil National de l'Ordre des Médecins—CNOM) considered, in 2009, that the practice of telemedicine could refer to the Code of medical deontology. (Simon 2015, p. 111, our translation)

Actually, the French National Council of the Medical Order (CNOM) stipulate, in their 2009 recommendations regarding telemedicine, that “the patients’ rights are imperative with telemedicine just as they are

with the current healthcare framework” (Conseil National de l’Ordre des Médecins 2009, our translation). Likewise, “the physicians’ obligations within the context of telemedicine practices results from the application of the common rules of medical deontology. However, these rules acquire a new dimension due to the necessity for their interpretation to be stipulated in this application” (Conseil National de l’Ordre des Médecins 2009, p. 10). The CNOM’s position is then clear: “The use of information and communication technologies in the exercise of telemedicine does not justify a specific provision in the code of medical deontology since all the principles in force regarding the usual form of medical practice remain relevant and apply” (Conseil National de l’Ordre des Médecins 2009, p. 12).

The European Council of Medical Orders emphasizes in their turn that the use of information and communication technologies within the exercise of telemedicine does not impose specific provisions either in the medical deontology codes of the member states of the European Union or in the European chart of medical ethics since the ethical and deontological principles in force remain relevant and apply to that medical practice.

In an article entitled “*Ethique, jurisprudence et télé médecine*” (Ethics, jurisprudence and telemedicine), Jean-Louis Arné seems to have the same approach: “Telemedicine must comply with the ethical and jurisprudential rules stated in the code of deontology which manages the medical act on the whole (. . .). Physicians’ general duties, as stated in the code of deontology, must apply to telemedicine (. . .).” However, he admits that “a new technology should not necessarily generate a new legal or ethical theory. It may yet lead to a redefinition or a new clarification of the preexisting principles, in order to adapt them to the new situations induced by the emerging technology” (Arné 2014, p. 124, our translation). Among the specificities induced by telemedicine, Jean-Louis Arné points out the following:

- The specificity of information and consent-related questions induced by telemedicine
- The traceability of the medical report
- Specific responsibility-related questions, particularly the duties and responsibilities induced by technology, etc.

## 22.3 Limits of the Principlist Approach

How should the various views mentioned above be envisaged? It is clear that the major principles of bioethics find their application in front of the various challenges induced by the development of telemedicine, a brief outline of which has been presented in this article. These challenges have been identified within the scope of the development of modern medicine. As maintained by their promoters (Beauchamp and Childress 2001), they find their origin in contemporary morals (and somewhat recapitulate the history of the ethical line of thought by joining the consideration of an adequacy, a patient-centered, and a plurality principles) but they are also related to the major polarities of the medical practice (respect for the patient, health-care quality and humaneness, as well as the fact that any care delivery is to fit within the scope of a system aiming at matching the needs of the whole population equitably).

Even if these principles may reveal some orientations that converge with Hippocratic medicine principles, they definitely emerge from the contemporary society in which the central ethical challenge is to join efficiency and respect for the individual, all of which being considered from an individual (autonomy) or a collective (justice) point of view. Here are the definite cardinal challenges of medicine.

Does this mean that there is nothing new under the sun? To start with, as seen above, the ethics of principles clearly originates from a contemporary situation. This reveals in itself a form of the topicality of this ethics permitting to explain its relevance as regards medicine. Does it mean we should not go any further? No, it does not. Because principlism somewhat bears the mark of what constitutes the current criticism against this paradigm. Indeed, if the principles are relevant today, it is because they bear the mark of their contextual characteristic or, in other words, because they depend on the circumstances of justice. To put it even differently, today's core issue of ethics or of the regulation is *application*. The current major criticisms against principlism are precisely about the application modes of the principles: How to arbitrate between those principles? According to what method? Who is to apply those principles? All those questions not only show the incomplete

characteristic of the principlist approach but also, above all, the obliteration of the contextual challenges and of the consecutive evolution of those contextual dimensions through this approach or through the various regulation modes it inspires. The sector called *clinical ethics*, as a sector of excellence for the application of ethics to clinical situations, clearly reveals that problematics as related to the application and to the conditions of application. This problematics has given rise to an abundant literature in the field of ethical foundations as well as in the way clinical ethics is practiced (Doucet 1996; Cobbaut 2007).

Besides, in the problematics we are dealing with, the evolution imparted by telemedicine to the medical practice alters the medical practice context and modes rather substantially. In that respect, we find the very recent report produced by the Conseil National du Numérique (French National Council for Digital Technologies) “Health, a social good in a digital society” very significant (Conseil National du Numérique 2015). According to the authors of the report, the new uses of digital technology change the traditional patterns drastically and give rise to new possibilities, whether it be a more democratized health-care system and patients’ better empowerment or to an individualization and increased health social inequalities as well as to a commodification of health care endangering our universal and solidarity-based health social pattern. In the context of a more and more extensive access to knowledge, actors, and infrastructures together with individualized innovative health services leading to patients’ increased responsibility and greater power over their health, health becomes a social good more than it has ever been, as well as the object of a political, social, and economic project requiring a three-front fight for the activation of health fundamental rights, for the reassertion of solidarity and universality values and the creation of spaces allowing each individual to be a tributary and a stake-holder of health as a social good.

According to this report, these perspectives are made possible in so far as the importance of information and of the matter of access to information, together with the new ways to cure and to take care

are taken into account (Conseil National du Numérique 2015, p. 98 and following). The point is not only to integrate the new temporality induced by digital medicine and leading to a more preventive, predictive, and individualized medicine but also to get to a networking medicine (Conseil National du Numérique 2015, p. 105) that requires to experiment new cooperative medicine methods mobilizing the health-care staff, the persons cared for, as well as the natural caregivers and requiring both a human support and new fields of expertise.

The perspectives launched by this report urge to think about a new way to envisage the governance of that development (Conseil National du Numérique 2015, p. 7). The report actually insists on the fact that “the conservation of the principles of our health pattern (quality, solidarity, universality) relies on our ability to turn digital technology into a leverage in the service of a consistent and ambitious political, social and economic project” (Conseil National du Numérique 2015, p. 8, our translation) relying on the determination of “the conditions for a management of health as a common good (Ostrom 1990) of which each individual is a tributary and depositary” (Conseil National du Numérique 2015, p. 9, our translation). The report thus comes into line with the notion of governance in as much as it opens to a pragmatic turn promoting the aspect of a cooperative action induced in the networking process and based essentially on the new possibilities to compare, exchange, and exert a mutual control in the search for solutions (Lenoble and Maeschalck 2011). Governance must refer to a type of action conducted by the society on itself, mediatized by the transformation of the collective relation to the norm, or, to put it differently, to an approach focused on the involvement power of the various actors concerned in their cooperation to a representation of the common good, that is, to making a living-together world possible (2014).

In the case of telemedicine, such an ethical and political governance certainly requires to pay attention to the technical object itself, to the temporality of its processes and to the many actors involved in those processes. We would like to conclude this article with the consideration

of those aspects which, in our views, constitute major challenges around which a reflection is to be conducted on a reflexive governance of telemedicine and with regard to which the inadequacy of principlism seems to be obvious.

## 22.4 Methodological Marks for a Reflexive Governance of Telemedicine

### 22.4.1 Taking the Technical Object into Account

First of all, we do find essential to integrate the technical object itself into the reflection on an ethical and political governance of telemedicine. Indeed, according to many authors, technical objects are not neutral instruments which would just be the support of our actions. According to such a view, the technical object is likely to be approached only indirectly, through the new obligations to which it may give rise or the redistribution of the responsibilities it may involve among health-care actors. Yet, for many authors, technical objects are far from being neutral or passive instruments. They rather represent true “mediators of our actions.” For Bruno Latour, norms “are delegated” to systems which impose moral involvements through their own structure and the way they operate. Some authors even pretend that certain values are “incarnated” in the design of technical devices: “the values of a design-team members, even those who have not had a say in top level decisions, often shape a project in significant ways as it moves through the design process. Beliefs and commitments, and ethnic, economic, and disciplinary training and education, may frame their perspectives, preferences, and design tendencies, resulting eventually in features that affects the values embodied in particular system” (Flanagan et al. 2008). Going beyond principlism by taking a broader account of the contextual conditions required by the application of an ethics of telemedicine first relies on a consideration of the values that the technical object can materialize.

## 22.4.2 Taking the Temporality of the Development of a Telemedicine Project into Account

A second methodological precept that we feel is important to express is to be careful of the temporal dimension of the ethical assessment that can be conducted on the practice of telemedicine and that is likely to be overshadowed by the focalization on just the deontological code of medicine and the four medical ethics principles. As Xavier Guchet emphasizes it in his book about nanotechnologies, technical mediations are characterized by a non-topicality aspect: “Technical mediation inscribes the non-topicality of a past but also of a future into human communities” (Guchet 2014, p. 21, our translation). Talking about the non-topicality of techniques means referring to the fact that they open, make way for temporalities other than the temporality of the present of our interactions. Indeed, “techniques always bring with themselves the world in which they will make sense” (Guchet 2014, p. 22, our translation). They give birth to the power to transform reality.

It is thus essential not to confine oneself to an ethical judgment that would be limited to the *present* of a medical procedure. One should both take its consequences into account and feel concerned by the *downstream* part of the project but also consider the way the object is being designed, that is, the upstream part of the project.

*Opening the reflection on the upstream process of a telemedicine project* is the point because, as mentioned by Andrew Feenberg technique is characterized by a form of “interpretative flexibility.” It may be submitted to interpretation forms in the same way as a poetical writing or a work of art. To put it differently, “technical functions are not pre-given but are discovered in the course of development and use” (Feenberg 1999, p. 86). It necessarily follows that “there are always viable technical alternatives that might have been developed in place of the successful one” (Feenberg 1999, p. 10). Making a telemedicine ethics effective thus implies the opening of a refereeing procedure between the principles of bioethics concerning the temporality of technical developments.

*Opening the reflection on the downstream process of a telemedicine project.* According to the philosophers of technology, it is important to consider

the fact that a technique shapes the world into which it is inserted. But the effects are not directly visible. They often remain unspotted before the *aftermath* they provoke and on the basis of which ethical views are established. The point is then also to organize an “ethical reflection in the future,” despite the real methodological and epistemological difficulty of an anticipation of the effects of a technique. More fundamentally, some authors have drawn our attention on the fact that new technologies are part of a real “techno-scientific promise-based regime,” to quote the words used by Pierre-Benoît Joly in one of his articles (Joly 2010). Today’s technological innovation takes place in a promise-based economy structuring all actors’ expectations. Many speeches produced along with the scientific development suggest a staging of the evolution of technologies. *Roadmaps* anticipate the capacities of technologies and those scenarios can be seen as strategies aiming at “confiscating from citizens the mastery of the time in which the problems arose” (Guchet 2014, p. 19, our translation). This opening onto the future may then take the form of imposed “*scenarios*” which, rather than opening to a reflection about the potentiality of the technical development, are more likely to *naturalize* the technological development.

### 22.4.3 Taking the Multitude of Actors into Account

Finally, the opening onto whether the downstream or the upstream side of a telemedicine procedure necessarily requires to consider the related actors. A multitude of actors are involved in all the various stages of the development of a telemedicine project: industrial actors, health-care professionals, patients, public authority representatives, etc. Does not the development of an ethical reflection on telemedicine, in terms of security, accessibility, or of the alteration of the medical relationship, imply the consideration of the plurality and diversity of the actors concerned by a telemedicine project? Can this reflection be conducted without involving those actors in some way or other? Besides, an author such as Pierre Simon, stipulates that “telemedicine is not a therapeutic innovation. *It is an innovation within the*



*organization of care*” (Simon 2015, p. 129, our translation). This point is a reminder of how telemedicine ethics must always be understood as an “organizational ethics” too.

In this article, we have concerned ourselves with some of the ethical challenges of the development of telemedicine by showing that if the law, the code of medical deontology and the principles of medical ethics delimit the legitimate framework within which telemedicine must be exerted, the matter concerning the application of that deontological framework or of the principles at the heart of medical ethics cannot be approached satisfactorily on the sole basis of a principlist methodology. Principlism overshadows many of the contextual challenges involved in the application of a telemedicine ethics. In our views, overstepping those limits seems to require the development of a telemedicine project and a commitment of telemedicine actors.

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