Health Ethics

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Health Ethics

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1. Introduction

The concept of ethics is not limited to the area of health. Indeed, it is inseparable from many areas of human existence. Within the French health system, ethics is becoming increasingly noticeable. Since 2002, institutions have been required to *"reflect on the ethical issues raised by medical care and treatment."* **[1]**

Changes in hospital organisation, growing evolution of users' expectations and techno-scientific progress are contributing to the enhancing complexity of care practices. In this

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Droit Ethique Procedures

constantly changing background, the occurrence of Covid-19 pandemic has highlighted the tensions of a system aiming at preserving the continuity of care despite the shortage of human and material resources. *"Ethical destabilisation"* **[2]** experienced by healthcare professionals may explain the expanding request for ethics. Therefore, it is now necessary to question the meaning of actions undertaken and call for a change in practices.
During this 1st seminar of the Head of the AI Chair of the University of Artois, health ethics will be introduced and particularly its inclusion by health professionals within health and medico-social institutions. Then, the origin of ethics in health, its objectives as well as its implementation will be considered.

2. The origin of ethics in health

The 19th century remains the scientific medicine development era. Initially based on the observation of the subject, medicine radically changed its approach by reducing individuals to a physical-chemical dimension.
For Claude Bernard, medicine is *"capable of descending into the interior of the organism, and of finding the means of modifying and regulating to a certain extent the hidden springs of the living machine."* **[3]**
According to him, *"Sick people are in fact nothing more than physiological phenomena in new conditions that need to be determined."* **[4]** The scientific model has contributed to the rapid growth of knowledge, therapeutic discoveries and to the effectiveness of the fight against disease. Nevertheless, this has been to the detriment of an "objectifying" consideration of the human being.
In this respect, the expression *"medicine is inhuman"* rightly becomes a pleonasm. **[5]** The Nuremberg trials condemned the medical research methods used by Nazi Germany. Then the United States has experienced the revelation of scandals in the field of medical experimentation. **[6]** One example is the Tuskegee affair, in which a comparative study was carried out over four decades (from 1932 to 1972) on African-American people in a village of Alabama without informing the inhabitants.
After awareness was raised among the American scientific community, a series of reflections and works were carried out by a commission from 1974 to 1979. The conclusions were formalised in a document entitled The Belmont Report, which contributed to the drafting of a law regulating medical experiments on human beings.
This has also been the indirect feeding ground for the implementation of the National Consultative Ethics Committee (CCNE) in France. In 1979, Beauchamp and Childress identified *The Principles of Biomedical Ethics* **[7]**. It consists of four ethical principles guiding the decision-making process. These are: non-maleficence, beneficence, autonomy and justice.

Those ethical principles can be helpful when it comes to clarify the dilemmas encountered. However, they have certain limitations because they may sometimes crystallise aporic situations.

The scientific paradigm of medicine has strengthened its expansion, potentiated by technical progress, sometimes at the cost of people's subjectivity. Long subjected to medical paternalism, patients now aspire to more autonomy and active participation in their medical care.

The evolution of the user's position within the health system has been registered in successive laws. As early as 1974, the recognition of patients' rights and dignity **[8]** encouraged the emergence of the "subject of care". The latter has continued to gain autonomy, becoming fully involved in their own medical care, as illustrated by the *Hospital - Patient - Health – Territory Law (HPST law)* **[9]** or the recent developments in the area of the end of life and palliative care. **[10]** We could witness a "humanist" paradigm, granting the individual the full expression of their autonomy without compromise. **[11]**

In fact, a patient's refusal of treatment would become incongruous since people's free will would make a decision that would be different from ours if we were the patient.

Each major period in the great history of caregivers, probably dating back to the beginning of humanity, has favoured the emergence of various paradigms (maternal, religious, scientific, liberal, humanist) and the foundation of associated values. For instance, the *"mothering"* paradigm, attributed to women caregivers, concentrates the values of affectivity, generosity, sharing, gentleness etc. Similarly, the *"religious"* paradigm is associated with beneficence, charity, vocation and humility. The arrival of a new paradigm does not drive out the other. In fact, they are superimposed in successive layers, like geological strata. **[11]** It is therefore not surprising that a caregiver can find himself in different paradigms through his own values. A nurse may value working in an intensive care unit for the objectivity, method, expertise and technicality required by the position but it can also be for gentleness and care of the patients. The *"mothering"* paradigm is not only restricted to women. Some would have chosen this occupation as a vocation, even though those who do not identify with a religiously based value would be shocked. Others would be attracted to areas of care that are sensitive and subjective and would decide to go into self-employment because they identify with the values of the *"liberal"* paradigm. The Covid-19 health crisis might be a turning point for the profession. We could have witnessed the emergence of a new paradigm that we could describe as *"heroic"* and *"warlike"*. **[12]** The plurality of paradigms is a richness for the care professions. Articulating them together has become a challenge within institutions that are subject to major constraints, as it can create tension with each other and with other logics (medical, administrative, economic, etc.) and could generate conflicts of values.

The evolution of users' needs is also characterised by easy access to information. It is clear that patients benefit from the popularisation of medical sciences. Media and the internet are permanent and inexhaustible sources of information, providing lay knowledge. As for the regular publication of hospital and clinic rankings, they contribute to the reputation of certain

facilities by displaying a ranking that guides patients in their choices regarding health management. Increased awareness of rights and access to information are leading to higher expectations from health system users. Patients are demanding more quality and safety, both in strictly medical care (diagnosis, adaptation of treatment, etc.) and in the ancillary services provided (hotel comfort, friendliness of staff, etc.). Finally, we can note a transformation of the modalities and purposes of care. The number of elderly people is increasing due to the rise in life expectancy and the "grandpa boom", i.e. the arrival in old age of the post-war generations. On January 2013, 17.5% of the French population was at least 65 years old and *"in 2060, 1 in 3 people will be over 60."* **[13]** The experienced pathologies are linked to age, lifestyle and environmental factors. The major public health issue is no longer based solely on the fight against infectious and transmissible diseases - although the current fight against Covid reminds us of this necessity- but it is also directed against chronic pathologies: diabetes, obesity, cancers, inflammatory diseases, cardiovascular disorders, etc. It seems important to specify that those illnesses are related to severe forms of Covid. Medical care actions are becoming more complex in view of patients' need for holistic support. In order to be effective, they cannot be focused on a physical dimension, along with desire to repair, but they must necessarily include the other aspects of the human being: the psychological, socio-cultural and spiritual ones.

3. The objectives and purpose of health ethics

In addition to changes in users' expectations and in the development of technosciences, hospital institutions have implemented major reforms that deeply affected their structure. Until 2004, they benefited from a global allocation, more precisely an annual and limited operating budget. *Price per activity (T2A)* has become the method of financing healthcare facilities for their medical, surgical and obstetric activities. *"Launched in 2004 as part of the Hospital 2007 plan, it is based on a logic of measuring the nature and volume of activities and no longer on an authorisation of expenditure."* **[14]** The introduction of *price per activity (T2A)* is part of a context of economic rationalisation aimed at encouraging the competitiveness of facilities by valuing the acts performed. In 2009, the *HPST law* **[9]** defined the modernisation of healthcare institutions by clarifying their governance and status as well as by improving cooperation between institutions with performance at stake. The pursuit of efficiency, which gives full meaning to the expression *"health has no price but it has a cost"*, influences the organisation of care provided in order to avoid the pitfall of counter-productivity identified since the 1970s. **[15]** Within the "hospital-company" that welcomes its "patient-customer", the duration of inpatients' stay is decreasing and alternatives to traditional hospitalisation are developing, such as home care and networks. **[16]** The just-in-time approach requires short average duration of stay and high bed occupancy rates. The number of hospital beds is reduced but bed managers ensure optimal regulation of supply. Additionally

to these transformations, training standards are evolving, particularly in nursing. They now are seeking to teach professional skills (another word taken from the business world), enable students to make relevant decisions, question the meaning of their practices and being morally and legally accountable for the consequences of their actions. With regard to the objectives of the training, *"the student develops a professional ethic enabling him/her to make informed decisions and to act autonomously in the field of his/her function."* **[17]** The access to quality care was reaffirmed in Title 2 of the *HPST law*. **[9]** Quality is a major issue for health care institutions. In 1996, accreditation **[18]** was introduced in order to allow and guarantee an independent evaluation of institutions. The procedure is now referred to as certification and its implementation is the responsibility of the *French High Authority on Healthcare (HAS)*. *"Certification consists of a global and independent assessment of the facility in order to promote the continuous improvement of patient care conditions. It is particularly concerned with assessing the facility's ability to identify and control its risks and to implement good practice.*" **[19]** Hospitals are therefore no longer only required to provide care but also to be economically efficient while guaranteeing the quality and safety of the care provided.

In this context, ethics is becoming more noticeable. Healthcare facility must carry out *"an internal reflection on the ethical questions raised by the reception and medical care."* **[1]** This obligation appears as a certification criterion in the V2010 and V2014 versions of *the French High Authority on Healthcare (HAS)* guidelines. In 2013, the HAS published a guide whose title is *"Evaluation of ethical aspects at the HAS"* **[20]** in order to provide institutions with methodological recommendations. Ethics committees have gradually been set up in hospitals to meet expectations and *Regional Ethical Reflection Areas (ERER)* **[21]** have been created. As for social and medico-social facilities and services, which are subject to other quality standards, they are also encouraged to develop ethical issues within their institutions. **[22]**

Health professionals work in constrained environments aiming for better quality at lower cost. They are confronted with new questions regarding the development of technosciences and the changing health needs of users at a time when resources are limited. Also, the health crisis linked to Covid 19 has strengthened the tensions in the hospital system and has led to the emergence of new questions, such as the prioritisation of patients. The metaphor of the lifeboat **[23]** underlines our current concern on available resources (resuscitation beds, respirators, etc.). Another concern is their equitable distribution in the interests of distributive justice. Therefore, it will probably be necessary to question the conditions of navigation, or rather the strategic orientations of the last few decades in the field of health. Considering ethics offers health professionals the opportunity to question the meaning of their actions and sometimes to respond to real *"ethical suffering."* **[24]** They all act towards a common goal, which is the best interest of the patient, but sometimes with mutual misunderstandings while facing the complexity of the situations encountered (linked once again to different paradigms that are tensed with contradictory logics). The ethical question, which guarantees the meaning given to care practices, helps to limit the risks of professional burn out. This is almost a

public health issue since, according to a consultation of *the French National Order of Nurses* carried out in October 2020, 40% of French nurses would like to change their occupation.
In a nutshell, ethics is *"doing well"*, as Svandra says with a touch of irony **[25]**. Indeed, ethical reflection is actually needed in view of the increasing complexity of care and the articulation of dialogical thinking. Therefore, there is a possible instrumentalisation of the ethical approach which could be used as a guarantee by institutions. The word "ethics" is so frequently used that it could be overused due to multiple interpretations, at the risk of substituting the idea of value for that of service. **[26]**

4. How to make health ethics work?

Principles, values and norms no longer guarantee proper action to meet the new challenges of the health system which is now subject to multiple changes. The void created by the insufficiency of axiological and normative guidelines needs to be filled with a new approach to ethics. The identification of the conflict of values (and not the judgement of values !) is the beginning of ethical reflection, which *"aims at developing practical judgement in order to identify and establish the criteria for choosing the action that seems to us to be the most adequate in a particular situation, on the basis of one or more values."* **[27]** In its practical implementation, ethics attempts to reconcile norms with the singularity of the situations encountered. Normative approaches do not guarantee the best, or at least the least bad, decision when they are implemented per se. For this reason, an approach that would focus more on the voice of the stakeholders would make it possible to give meaning, in a collective manner, to clinical situations giving rise to an ethical dilemma. Each situation would be approached in its singularity in order to better understand the inherent issues. The ethical approach is now part of a contextual and reflexive **[28]** but also interactionist and transactional prospect. **[29]** The contextual approach is essential to identify the specificities of the course of action, with regard to the interactions between the stakeholders. Then, an actual transaction (which is not economic in this case) takes place between individuals and their environment in a mutual influence. Ethics, perceived as a reflexive, collective and deliberative process is, in this matter, an intrinsic resource that subjects must develop through experience. The learning of ethics is not innate and is made possible by the implementation of an investigative approach that aims at a *"controlled or directed transformation of an indeterminate situation into a situation that is so determined in its constitutive distinctions and relations that it converts the elements of the original situation into a unified whole."* **[30]** Investigating is a way to resolve a situation experienced by the stakeholders as discordant in order to get to a more harmonious situation through methodical reflection and the search for new viewpoints. It is necessary to pay particular attention to the stakeholders' narrative. Yet, above all, it is crucial to focus on the conditions to create solutions to the problems encountered in each situation.

More precisely and schematically, the ethical approach can be considered as follows:
- Explaining the situation: clarifying the elements of the context (people, place, etc.), identifying the decisions spontaneously taken and specifying the "problems" (dilemmas) encountered by the stakeholders
- Analysing the situation: identifying the normative frameworks (personal, institutional, social, but also legal, economic, social, religious, etc.) and the actions already carried out, trying to identify the "turning points" (why or for what reason did we decide to act in this way at this precise moment? What worked or didn't work in this situation?)
- Developing options: considering ethical perspectives on the basis of hypotheses for action and identifying the foreseeable consequences.
- Evaluating: testing the solutions contemplated by implementing the hypotheses and evaluating the result obtained.

If the result obtained is satisfactory and leads to a more harmonious situation for everyone, then the investigation is over. Otherwise, it needs to be repeated in this situation, which is already different from the initial context due to the first level of investigation.

Ethical reflection is not only carried out in situations where the technical dimension is important (e.g. therapeutic limitation in intensive care). It is not limited to palliative care or oncology departments or to exceptional events. Ethical reflection is encouraged and draws its source from the daily practice of caregivers.

As an example and to illustrate the suggested ethical approach, here is a brief clinical situation:

Mrs A is 85 years old ; she is a widow, she has been living in an Accommodation Facility for Dependant Elder People (EHPAD) for two years and has a daughter who visits her every Sunday. Mrs A has no cognitive problems. She enjoys taking the bus, alone, in the morning to go to a hypermarket located two kilometres from the facility and do some shopping. Three months ago, she fell while getting off the bus and suffered a fractured shoulder. Recently, Mrs A got the bus lines mixed up twice and joined the EHPAD very late, which worried the caregivers. Her daughter, who was informed of these incidents, is very angry. She spoke of the total irresponsibility of the EHPAD, which, according to her, did not ensure the safety of the residents and was considering a transfer to a more secure facility. The nursing staff, the coordinating doctor and the management are divided as to the attitude to adopt.

The conflict of values is easily perceived. The challenge is to reconcile the obligation of security and respect for individual freedoms within a living environment. The identification of the principles of security and autonomy is essential to initiate the reflection which does not spontaneously offer any viewpoints. Giving voice to the stakeholders allows them to express their experiences, the expectations as well as the identification of constraints and responsibilities.

Each view of the situation will be different. However, which voice counts most? Should Mrs A and her daughter be included in the discussion? Is it necessary to consider meetings at different times to include the family? Why do the resident's outings become problematic at this time? Has anything been tried to make it safer to walk outside their home? Once the situation has been clarified, hypotheses for action will be put forward: can a specific "contract" be drawn up for outings and consideration given to limiting trips? Can Mrs A be equipped with an electronic device (mobile phone, GPS watch, etc.) to alert or monitor her? No solution, however surprising, can be ruled out spontaneously, as its effectiveness can only be demonstrated once it has been implemented. It is essential to ensure freedom of speech and to guard against certain prejudices with regard to the suggested solutions which may "work" in a particular context.
Ethical reflection can be carried out *a priori* ("in the heat of the moment") or *a posteriori*. This method permits a more distanced view of the situation so that it does not remain "meaningless" in the experience of the caregivers. Looking for meaning is probably the best guarantee offered to caregivers to ensure that their support is sustainable. It seems necessary to repeat here the importance of initial and ongoing training to learn the ethical approach **[31]**, which can be considered through different teaching methods. **[32]** Eventually, ethical reflection is not only dedicated to hospital ethics committees, since it is encouraged whenever professionals question the meaning of their actions. Nevertheless, it needs to be supported, not by an expert who already knows the right solution, but by a qualified professional who would simplify the reflection process in a methodical way.

5. A few leads to go further...

Ethical reflection represents an opportunity for intellectual, individual and collective emancipation, while facing the limits of moral universalism and institutional rules. These rules have sometimes been agreed upon for a long time between the stakeholders and without any real basis. Ethical reflexion makes it possible to redefine collective and institutional modes of operation. It is part of a search for coherence by suggesting other alternatives often expressed by the stakeholders of the health system. Apprehending ethics as a method of investigation creates an approach accessible to the greatest number of people, provided that the dilemmas encountered are identified and, above all, that the institutions accept and encourage changes. When dealing with a plurality of statements and reasoning, there is no last word *"or, if there is one, we call it violence"* **[33]** because ethics leads us to question normative frameworks and to move the lines in order to offer new ways of *"being in the world"* as Heraclitus said. Health ethics does not focus on medical approach exclusively. It is the joint between multiple dimensions: medical, sociological, anthropological, philosophical, legal, economic, etc. Ethical reflection requires, in a holistic and systemic perspective, to see the situations encountered from different viewing angles, microscopically or macroscopically, according to certain degrees of extension and collective involvement, exactly as in the health

crisis we are currently experiencing. Barbara Stiegler, drawing on the reflections of the editor of the prestigious medical paper *The Lancet*, states that the crisis linked to Covid 19 is not a pandemic but a syndemic, "*a disease caused by social inequalities and by the ecological crisis understood in a broad sense.*" **[34]** In other words, our societies are ill because they were already weakened and medical treatment will not be enough. Our health, educational, economic and societal models need to be questioned and probably re-invented.

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