

Useful Ethical Principles during the Care of Patients with Cerebral Damage

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Abstract

This article reviews fundamental principles related to ethics and patient care, with an emphasis on neurological disorders. The respect of the principle of autonomy is essential for patients. This principle is now recognized as one of the fundamental rights of patients, not only in the legal field but also in the moral field. In ethics, other principles favour patients in their specific relationships with their physicians such as the principles of beneficence, non-maleficence and equity. Within the framework of their customary practice, doctors must also respect other ethical principles including proportionality, truthfulness and precaution.

However, for patients with cerebral damage, respect for the principle of autonomy must be subordinate to effective legal competences. Otherwise, the decisions could be made by third parties such as families or doctors, at the risk of drifting from the patient's own demands. A number of clinical situations may result in dilemmas or conflicts between the therapists or the nursing staffs and patients or their close relatives. Some specificities of Belgian law are discussed.

Keywords: Autonomy; Beneficence; Non-Maleficence; Equity; Precautionary Principles; Veracity; Proportionality; Legal Competence

Introduction

In medical practice, the relationship between a therapist and his patient is typically "asymmetrical" when the later invariably trusts the former. Indeed, a patient's confidence in his doctor is "fiduciary" in nature when the confidence is automatically granted, just as we instinctively trust a bank note as being a "fiat money" (derived from the Latin "fiat" meaning "let it be done" or "it shall be"). Therefore, today it is sufficient for a medical practitioner to comply with the laws of the civil code as well with the recommendations of the College of Physicians in order to claim that he acts "inevitably" and "in any circumstances" in the interest of his patient [1-6].

Although the situation is very simple with healthy and consenting adults, there might be controversy when the patient is a minor or when he does not have the adequate psycho-intellectual faculties to give consent. In these two particular cases, authorisation from the patient's family members may be required before proceeding with any therapeutic intervention.

Previously, most of the contentious issues within the framework of the fiduciary relationship between a patient and his doctor concerned either the failure to respect medical confidentiality or, in medical "emergencies", imposing treatment that is against the patient's philosophic or religious beliefs [7,8].

There is no penalty against a patient who refuses to follow a treatment, with the exception of civil commitment during serious behavioural disorders that are not the result of dementia. Additionally, even in this specific case, the fiduciary relationship ensures that the decision of civil commitment is made by a magistrate and not by the patient's physician himself [9,10].

Implications of Brain Injury

A diffuse cerebral lesion (trauma, haemorrhage, etc.) is generally accompanied by a coma, the initial intensity and duration of which foresee the chances of survival and recovery [11]. The changes of the resulting or residual cerebral function are numerous and complex: disorders of the motor system, sensory functions, language and writing,

psycho-intellectual function, behaviour, recognition of familiar faces, perception of the environment, and others [12-14].

Most often, quality of life is impaired. In some cases, the patient will be in a state of complete dependence for basic acts of daily life [15,16].

It should be remembered that in main legal systems, the magistrate is the only authority who can decide if a person is legally competent or not; therefore, each physician should proceed with the presumption that his patient is competent until otherwise stated by a court [17,18].

In addition to the financial, professional and medical after-effects, difficulties may also arise in the legal field if the patient becomes unable to manage his own financial and other personal affairs [19]. Furthermore, mobilizing financial and human resources can lead to changes in the family balance, with the risk of conflict or of legal separation.

Besides, the fundamental rights of patients have been enhanced with new rights: right to information, prior consent to medical care, respect for professional secrecy and privacy, and others [20]. With the public being more and more informed on so-called miracles and on the alleged capabilities of new medical techniques, many physicians are sometimes placed in uncomfortable moral situations. Many physicians generally share the families' point of view, but there can be great variability in their expectations when a parent is affected by a cerebral insult. Some will erroneously ask too early a cessation of treatment. Others, generally in the search for a miracle of some sort, will never

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admit an actual diagnosis of unlikely recovery and will refuse any legitimate interruption of treatment.

The repercussions for the society are essentially financial, as there is a constant claim that “health care” is hugely expensive to the community, and that this reality requires drastic savings in the name of efficient and rigorous management.

However, in health care management, the patients’ points of view are rarely taken into account because the “health care system” is typically developed and controlled by necessarily healthy individuals. Furthermore, moral implications resulting from issues such as the right to die have given rise to numerous legal debates in Court. Thus, families are more and more tempted to make their voices heard through the media and/or their lawyers within the courts and tribunals [21-25].

Principles of Medical Ethics

If one considers that “ethics” is derived from the Greek words *ethicos* meaning “moral” and from *ethos* representing “the customs”, “ethics” would then correspond to a particular set of rules of conduct. As a result of the progress in the biological sciences since the 1980s, the word “bioethics” has rapidly spread in our language. “Bioethics” is generally used in medicine to express ethics in medical practice. However, its meaning has been profoundly modified. The term was invented in 1971 in the United States by the oncologist Potter [26] for whom bioethics meant “a project on the use of biological sciences intended to improve the quality of life”.

Nowadays, the connotative aspects of “bioethics” are numerous and varied. As suggested by KANT in 1788 in his Critique of Practical Reason, one should take into account the respect for the knowledge along with the respect for the person. In addition, advancements in the life sciences are constantly demanding new forms of commitment and guidelines.

Simply stated, bioethics involves, in addition to the present responsibility towards the future generations, actual reference to the mandatory respect that is due to every human being as well as to the biomedical sector and its applications.

Beyond the simplest disciplinary and technical references, good medical practice depends upon certain medical expertise for neurologists and for other specialists. It also requires efficient familiarisation with the value judgments related to ethical reflection. Therefore, physicians should have a clear understanding of basic ethical concepts when they are considering decisions to proceed with, refrain from or discontinue a medical treatment. These options concern many ethical principles and moral rules [20, 27-30].

The four basic principles of medical ethics

The Table describes the four basic principles of medical ethics and their corresponding Latin mottos and moral rules. (Table 1)

Ethical principles	Latin mottos	Moral rules
Autonomy	Voluntas aegroti suprema lex (the patient’s will is the most important law)	Do not deprive someone of his freedom
Beneficence	Salus aegroti suprema lex (The patient’s well-being is the most important law)	Do good
Non-maleficence	Primum nil nocere (First, do no harm)	Thou shalt not kill!
Equity	Iustitia (fairness and equality)	Fair adjudication between competing claims

Table 1: The Four Main Ethical Principles and Their Corresponding Moral Rules.

Principle of respect for autonomy

The first principle is the principle of respect for autonomy, which corresponds to the right of each person to make of his own volition decisions that others must respect (*Voluntas aegroti suprema lex*). The moral rule related to this is, “do not deprive someone of his freedom” [30].

One of the greatest ethical difficulties for any Department of Rehabilitation is the determination of the proper support of patients with severe brain injuries that prevent them from expressing their own feelings and options. Often, these patients suffer a severe cranial trauma, major stroke, or diseases mimicking a ‘locked-in syndrome’. Alternatively, these patients experience partial recovery in the wake of a post-anoxic encephalopathy. These patients are usually unable to make or express their own decisions, but physicians have a formal duty to inquire about the patients’ life choices and actual orientations, such as treatment initiation or supportive equipment discontinuation.

Practically, the principle of autonomy corresponds to each person’s right to govern his own body unilaterally and to participate through valid consent in every decision related to medical care. To this end, the physicians and surroundings should supply a competent patient with all useful information, and the doctors should support the patient’s decision even if it does not appear to be good or successful from the strictly medical point of view.

Principle of beneficence

The second principle, the “principle of beneficence”, corresponds to the duty to promote the good; the related moral rule is “do good” [31]. According to this principle, the physician should always favour whatever is most beneficial for his/her patient (*Salus aegroti suprema lex*).

Within the framework of the closest relationship based on both the physician’s professional and considered judgment and on the fiduciary confidence that the patient dedicates to his physician, the benefits are obvious when the patient sees that his desires are being realised or when he admits that his physician is actually taking into account all of his physical and mental sufferings, the risk of death or disability and the quality of his residual life.

This “asymmetrical” relationship is readjusted when the patient finds that his physician respects his suffering and his symptoms and that his physician in general demonstrates restraint, tact, understanding, empathy, and patience.

For the physician, it is advisable to ensure that “benevolence” is devoid of exaggerated paternalism [32], abusive dogmatism or authoritarianism, especially when the patient’s vulnerability is aggravated by excessive emotional weakness.

The “principle of beneficence” is bound by a balance of advantages and inconveniences, and it aims to benefit the patient and others. Therefore, this principle is the basis of organ transplants. Upon patient death, the ethical obligation contained in the “principle of beneficence” is superseded by the ethical duties that the doctor has towards society and the patient’s family. The obligation of charity towards society is expressed by the fact that the removal of organs will not adversely affect the dead patient but will save other lives or restore deficient functions in other patients [33]. Therefore, the doctor has an ethical duty to suggest to the family that the organs of the deceased patient may benefit other patients. Physicians also have the same obligation of charity toward the families because they can find some comfort in the idea that the organs collected from their deceased relative have saved the lives or nurtured other patients back to better health. In many cases, families are heartened by the belief that their loved ones continue “to live” in the bodies of other people and by claiming the right to donate organs even when the procedure is impracticable [34].

In certain circumstances, the “principle of beneficence” can impose that the physician does not intervene, particularly if the benefits of the procedure are manifestly considered minimal or futile.

Principle of non- maleficence

The third principle is the “principle of non-maleficence” or the “absence of malevolence”, which reflects the concept of “do no harm” [20,29]. The moral rule that refers to it is “do not cause suffering or injury”, and it results from the “Thou shalt not kill!” of the Judeo-Christian tradition or from the “Primum nil nocere” of the Hippocratic oath, which stipulates, for all physicians, “first do no harm”.

Thus, any “good” doctor will avoid causing any damage to his patient, practising any form of intensive diagnostic or medication, or applying any notoriously unnecessary invasive therapeutics. In most clinical situations, this “principle of non-maleficence” adds very little to the “principle of beneficence”, and the synergic effects of both principles were notably discussed in 1849 by Percival [35]. However, the “principle of non-maleficence” has proved to be useful in human experimentation or during the administration of a novel therapy.

European legislation does not allow research without reference to national legislation, “good clinical practice”, respect for subjects’ autonomy, protection against discomfort, risk or harm, and the prospect of some future exploitable benefit. Nevertheless, many authors consider that the randomization of patients with traumatic brain injury into trial protocols may be ethically justified in acute situations even if mentally incapacitated patients are unable to give consent directly [36,37].

However, it should be remembered that in cases of controversy owing to medical damage, magistrates in some countries like Belgium are now accustomed to condemning doctors who cannot defend the true necessity of their medical interventions [38-43].

Principle of equity

The fourth principle is the “principle of equity” (or “principle of justice”), which results from the reality that within society, the allocation of collective resources must be fairly divided for all patients [44]. Thus, our system of “mutual insurance” provides that patients in similar situations should have equal access to the same care and that when resources are assigned to a group of patients, the impact of that choice on the other groups should also be assessed.

This principle implies that every responsible physician’s decision

should take into account not only the correctness of their patients’ requests but also the implications of their options for others.

Other useful principles in medical practice

Other principles, rules and notions have proved useful for appropriate medical practice.

Principle of veracity

The ethical principle of veracity [45] applies to people and corresponds to the notion of “truthfulness”. It expresses the moral character of one who intends to tell the truth, and it establishes the good faith of the one who speaks.

The principle of veracity must always be respected, as suggested by PLATO in *Cratylus* (385b2) and *Sophist* (263b) and by ARISTOTLE in Book Γ of *Metaphysics* (1011b25) when they asserted:

Say that what is, is not, or that what is not, is, is false;

And say that what is, is, and that what is not, is not, is true.

The ancient Greeks equated ethical and moral acts to virtue as they regarded the resulting sense of well-being from acting morally as important.

According to KANT, “truthfulness” is an unconditioned duty and, contrary to the utilitarian moral, there is strictly no “right to lie” regardless of the situation or the implications; in KANT’s opinion, one has to strive to do the right thing even if the efforts got nowhere. The principle of veracity in human relationships implies a reciprocal confidence when people speak to each other because this forms the basis for their social links.

The principle of veracity has often proved useful in medical practice, especially in situations in which there could be a strenuous effort to obtain the patient’s or his entourage’s consent or approval. In accordance with this principle, the physician should always be careful not to exaggerate the benefits of a treatment or an experimentation protocol. Overall, families should always be duly informed on the success rate of a novel therapeutic procedure, and they should genuinely understand that not every medical intervention is always harmless.

The “precautionary” principle

The “precautionary” principle [46,47] is reflected in medicine in the consideration that the doctor-patient relationship is fundamentally asymmetrical, which makes the patient more vulnerable when he is old or unable to communicate decisions. In addition, even with the very best of intentions, it may sometimes happen that these particularly fragile patients’ own value hierarchies are not fully respected by others. The “precautionary” principle is the duty of any doctor to “proceed with restraint and moderation” according to the Hippocratic oath. It also provides that any “good” doctor must act with wisdom, must search for the “right” balance between dereliction and overprotection, and must take just and wise actions that are not supported by subjective or biased knowledge.

Through reference to these considerations, the practitioner can proceed to an intelligent assessment of the quality of care for each patient who is “vulnerable “ or “incapacitated” and to offer him the “fairest” treatments at the end of life or when the patient is faced with the fear of abandonment or carelessness [48].

The principle of proportionality

Inherited from mathematics, the “principle of proportionality” has

been widely used in the legal field as a principle of the adequacy of a researched purpose by applying tools to the objective [49]. Related to bioethics, the “principle of proportionality” attempts to comply with the means implemented to achieve the expected result [50].

The “principle of proportionality” is useful in situations in which a balance is required between, for example, unreasonable therapeutic obstinacy and medical abandonment. It involves a structured decision strategy that favours the clarity of the information provided to the patient and his relatives as well as the positive exchange of points of view among the care team. In patients with brain injury who are vulnerable or fragile or debilitated, the “principle of proportionality” helps detect situations of unnecessary or unreasonable or futile therapeutic care. The “principle of proportionality” rests in the grand tradition of the “principle of equity” in the allocation of means and it presumes that the patient or his family has given prior informed consent.

The informed consent

Clearly detailed by Western medical codes and by the World Health Organisation, the “informed consent” refers to both the “principle of respect for autonomy” and the moral rule according to which any doctor has the duty to “not deprive a person of his liberty”. The patient’s preferences are important because they correspond to his/her own existential values, even when they are not always identical to those of the physician [51].

This is why any ethical foundation should correspond to the legal basis of obligation to respect the “principle of autonomy”, and it should respect the patient’s self-determination right: “any adult human being has the right to dispose of his/her body” [52]. The notion of “informed consent” is essential as a foundation of any medical practice that aspires to be in concordance with ethics. “Informed consent”, or refusal, presupposes adequate information and the absence of coercion on the part of the physician, as well as the legal competence of the patient [28, 53].

Thus, ethically valid consent must be obtained from a patient who is both legally competent and fully informed. However, the incapacity of the patients to provide informed consent in particular clinical situations that are characterized by the emergency nature of the medical decision may alter the inclusion process in clinical experimentation. Therefore, it has been suggested that randomization should be allowed under “deferred consent” or “waiver of consent” in some specific situations. In randomized controlled phase III trials investigating the safety and efficacy of agents in traumatic brain injury with promising benefit during acute emergency situations with short therapeutic time windows, it has been proposed that progress in the knowledge of treatment in acute neurological and other intensive care conditions requires that national regulations and legislations should allow a “waiver of consent” or “deferred consent” for clinical trials [54-56].

However, present ethical rules recommend that the physician should try to identify and meet the preferences that his/her patient might have decided previously when a patient is not legally competent to provide consent. These earlier directives may consist of a written document or verbal instructions that would have been made when he/she was competent to express his/her desired medical care in case of an occurrence of incompetency.

Furthermore, there could be a conflict between the ethical rule of consent and the opportunity to greatly improve the status of these patients without their mandatory prior consent in the event they would become medically incapable of giving valid consent because

of traumatic or vascular brain injury, post-anoxic encephalopathy, or Alzheimer’s disease, while their clinical status could significantly be improved by an experimental treatment. Some countries, such as the United States, already allow a narrow exception to the requirement for prospective informed consent from human research subjects in clinical trials investigating potentially beneficial therapies for acute, life-threatening conditions [57].

If it is obvious that research is necessary in the clinical testing of pharmacological neuroprotective agents [58], this matter deserves the utmost caution and physicians should consider that the allowance of clinical trials in some countries is still governed by national legislation [59, 60].

The principle of confidentiality

The principle of confidentiality is the pillar of the doctor-patient relationship, and it applies to the content of their discussions, even if it is becoming more and more difficult to preserve this confidentiality because of the increasing use of electronic data and computing. Among the many recommendations of the College of Physicians, there are the specific obligation of respect for medical secrecy and the obligation to provide care to any person in need; however, the physician is not yet obliged to obtain results corresponding to his patient’s own expectations.

As is the case for many other responsibilities in the area of ethics, the obligation of confidentiality is not absolute. In addition, it is the usual practice that the doctor does not disclose medical information without the explicit consent of his patient. However, in some cases, the interests of public health or of the community outweigh the protection of individual information when it is also necessary to protect the life or health of third persons [61]. Nevertheless, in these particular cases, it is expected that if the doctor proceeds, admittedly with discernment, so as to cause the least harm to his patient, he will also proceed with “veracity” in accordance with ethics.

Legal competence

Legal competence is a concept that refers to the legal capacity according to which a person is capable or not of exercising all rights and obligations in the legal sense. In addition to minors, it mainly concerns subjects who suffer from a mental disease [62,63].

In law, the term “competence” fills a precise role for which the continental courts “presume” that each healthy adult has full responsibility for his decisions and is therefore capable of making decisions of his own volition [64]. Children can acquire full competence when they reach what is called “the age of majority”, the time when minors are recognized as adults by the law; then, competence will allow them to make decisions regarding not only their health, but also all of the other spheres of life (managing their own affairs, including financial decisions, or deciding on eventual marriage).

Legal capacity is therefore based on the presumption that adults have the capacity to make health care decisions [53,63]; legal decisions determine who no longer has the legal capacity to assume his/her rights and duties [65]. In this matter, the decisions of courts are often based on specialised medical evaluations, but these are never mandatory because the magistrate has no legal obligation to follow medical opinions [66].

Assessment of Capacity

With the doctor-patient relationship being founded on the principle of respect for individual autonomy, any patient’s decision is facilitated through the process of consent. As a result of the “principle

of autonomy”, “informed consent” is a corollary of the moral rule following which the doctor has the duty “to not deprive any person of his freedom”. According to Culver & Gert [28], the decision-making process begins with the patient’s informed and valid consent.

When a physician finds that his patient is medically unable to express his volition in case of brain damage resulting from a tumour or a vascular lesion or a severe head injury, he should refer to the patient’s family or surroundings in order to identify the patient’s previous preferences. Any patient’s prior directive must be respected and can consist of a written document or verbal directives formulated by the patient when he was competent [50,67] or in the designation of a person with the authority to participate in all medical decisions in case the patient becomes incompetent [68]. Known as “the doctrine of substituted judgment” [53,69, 70], this process has the advantage of adapting the patient’s own value system to any particular medical situation.

In Belgium, once a guardian or conservator has been appointed by a court, all of his decisions are mandatory, and the physician must respect them; conflicts may arise however [71]. When a close relative makes the decision, the doctor has the moral duty to respect it because siblings can give a valid substituted judgment [69,70]. In accordance with the same ethical reasons (respect of autonomy, beneficence and non-malevolence), a member of the care team may act as a close relative to assist the patient in decision-making when he is completely and socially isolated. The role of surrogate medical decision makers is an extension of the principle of autonomy.

From a medical outlook, the patient’s ability to give informed consent covers a set of skills that enable them to make health-related decisions independent of anyone else [72,73]. A patient’s competence or decision-making capacity involves the ability to participate in medical decision-making. There is no fixed set of capacities [65,74,75], but there is a consensus on the primacy of four of them [76] which include understanding one given information, assessing the situation, capacity of logical and abstract reasoning, and ability of decision making with adequate communication of it. Practically, a legally competent patient regularly understands the advice of his physician, is able to determine if a specific decision will be favorable for his health or not, is able to consider the consequences of a decision, has the faculty to understand causal relationships as well as other theoretical notions such as arithmetic and has the ability to correctly communicate decisions.

However, standards of care are not always available to guide clinical decision-making in patients with severe acquired brain injury resulting in prolonged disorders of consciousness and inability to communicate through word or gesture [77]. Patients with traumatic brain injury, regardless of injury severity, need continued monitoring of medical decision-making capacity for at least six-months after injury [78]. Caring for these groups of patients as well as for patients with brain tumour condition is multidisciplinary in nature, with necessity of rehabilitative, psychological, and social support interventions [79]. Because of the ethical principle of autonomy, it is obvious that no pressure should ever be exerted on any patient with cerebral damage during the decision-making process [80].

Conclusions

In this era of the technological and computing evolution, bioethics should necessarily agree with both the patients and the physicians themselves because the latter have an ethical tradition which customised their profession since the time of Hippocrates. Furthermore, clinical practitioners have the moral duty to define and adopt appropriate

ethical guidelines and to consider them priorities in their medical practice.

The “asymmetry” of the fiduciary relationship between a therapist and his patient has been mitigated over time. Respect for the fundamental principles of bioethics guarantees, for each patient, the most appropriate care in return for indispensable valid consent that allows the right to health-related decision-making.

Through respect for the ethical principles of autonomy, beneficence, non-maleficence and equity, each patient can entertain the hope that the provided care will be of proper quality and he or she will be fairly treated by a compassionate and empathetic team that will take into account both his human dimension and his own hierarchy of values. If the patient is unable to make a decision in case of cerebral damage, the decision-making process may temporarily be transferred to third parties such as a family or a doctor, and procedures exist to lessen the risk of drifting from the patient’s own demands. Physicians should be adequately trained to identify good grounds for specifying a time-frame for monitoring decision-specific capacity.

Indeed, respect for the autonomy of each patient, capable or not of making decisions, is now a priority for every clinician because the need to restore and maintain the rewarding capacity for self-determination has today become the essential purpose of good medical practice.

Ethics committees could play a new role in cases where substituted judgment and best interest standards for surrogate decision making are problematic or require a specific set of interventions guided by morality and ethics. Universities could help in limitations of current clinical training and practice within current ethical and legal framework.

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