

**Opinion n° 87**

**Treatment refusal and personal autonomy**

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## I. Introduction

The values on which medical practices are based presuppose that curative or preventive treatment offered to a person, sick or well, or sometimes imposed on an entire community, can only be beneficial to that person or community. However, although the intention may be benevolent, therapeutic action is never innocuous. It always assumes a symbolic quality which accentuates in the extreme the asymmetry of the doctor/patient relationship and for this reason, an intervention involving the body of a person always requires unlimited mutual trust. It is equivalent to a pact for which the ethical justification resides in the primacy given to the best interests of that person. That has always been the way in which the relationship was understood and how it was written into laws and codes and practised throughout history. Consent to care and treatment is at the core of this relationship.

Today, however, the increasing complexity of therapeutic options and a greater degree of autonomy of decision granted to patients (law dated March 4, 2002) as regards medical care, have led to a situation where **the patient's consent is no longer simply implicit. It must be explicit with, as a consequence, more attention being devoted to what the patient has to say, even when it is in opposition** to medical purposes. Clearly, if the principle of consent to treatment is accepted, then it is no less clear that this **logically implies the possibility** of refusing therapy. At a time when medical efficacy is reputed to be constantly improving, the medical profession always experiences such refusal as a constraint and a **contradiction of the principle** of benevolence. This **failing in the duty of optimising a patient's chances of recovery** (or sometimes of protecting society) raises **ethical issues which are all the more acute** if rejection of therapy can be attributed to a lack of discernment on the part of a patient who may be in pain, or particularly vulnerable because of weakness, or in some cases aware of imminent death. Refusal can also be perceived as a rejection of the very concept of benevolence according to a strictly medical and unilateral point of view.

### I.1. The ethical dilemma

In certain extreme **circumstances**, these **issues amount to an ethical dilemma for the physician**.

The right to freedom of decision which is expressed by refusal of treatment often seems paradoxical to healthcareers who are spontaneously inclined to see disease as a form of isolation. However, the expression of an individual liberty does not concern exclusively the person who makes use of it. It also involves:

- The medical profession which is invited to share with the patient and the patient's family reflections on the natural finality of care and relief.
- Society taken as a whole, challenged in its role of benevolence toward one of its members, and since solidarity is not always respectful of liberties, cultural differences, when a complex and precarious ranking of values make a decision difficult to understand.
- The Law, which is also required in the last resort to choose between contradictory imperatives, both justified by legitimate arguments: respect for

a person's consent on the one hand, rendering assistance to a person in danger (who may not be consenting) on the other. These difficulties explain why recent administrative and judiciary bodies have taken decisions which may not be contradictory but are at least very different as regards the interpretation of the attitude to be adopted in the event of refusal of treatment.

The paradox of contemporary medicine is that a constant expansion of therapeutic options makes decoding these options increasingly difficult. In legal terms, this new situation has been transposed into a growing demand for patient participation in decision making which seems to express the notion that anxiety caused by being subjected to some kind of medical dictatorship creates the need to even out a relationship which is by essence asymmetrical. To this recent culture is added a growing trend to judicialisation (although this is less prevalent than is generally thought to be the case) which challenges medicine to respond to contradictory imperatives: give the best possible care, but within mandatory limits and constraints, or confronted with hostility.

The purpose of ethical reflection is not to establish a more or less satisfactory legal solution but rather to analyse and understand the value judgments which have been expressed and the involvement of all participants: the persons concerned, their families, society and the medical profession, with full respect for the dignity and beliefs of everyone.

## **1.2. The various meanings of refusal of treatment**

The exact significance of refusal of treatment is particularly difficult to apprehend.

◆ As regards the patient:

Was the demand formulated by someone whose judgment was at least partially impaired, perhaps under pressure from friends and relatives or from what could be an excessively restrictive culture, in search of secondary benefits? Or was it the result of enlightened decision and awareness of possibly particularly severe consequences? Or were the actual consequences of the situation simply misunderstood?

◆ As regards friends and family:

Was there excessive, or even unauthorised, cultural or spiritual pressure from friends and family speaking in the name of the patient, or was there a difference of opinion between healthcarers and the patient's loved ones regarding what was or could be beneficial?

◆ As regards doctors:

Was the medical profession being excessively paternalistic or authoritarian, or was there a breakdown in communications, clumsy or incomplete information, a misunderstanding, so that refusal of therapy was interpreted as denial of a doctor's primary mission which is to give the best possible care?

◆ As regards society:

And finally, should society accept and respect the collective secular or religious values of solidarity which are sometimes screened by rituals? Was collective pressure annihilating the freedom of choice of an individual or should society review its own symbolic tenets instead of paying excessive attention to an erroneous concept of personal liberty?

Refusal of treatment is always a point where multiple issues are involved and only rarely a dialogue between a single individual and a single physician. Generally the patient's family and a whole medical team are concerned, as are sometimes contradictory interpretations of the law and an entire social context. Healthcare is never limited to treatment since there must be support, understanding and respect for the patient, which are not rejected, but which are a necessary part of true medical care. Treatment refusal must never be understood as meaning refusal of care, even though it must also be realistically considered.

The following reflection is limited to particularly tense situations which may sometimes lead to legal proceedings, since in the ordinary run of medical practice, practitioners share or should share with patients all the information needed to understand the consequences of decisions concerning them and participate to the fullest extent possible.

## **II. Some examples of treatment refusal**

Doctors face a number of specific but very diverse situations which require discernment as regards their severity. There is no comparison between refusal of immediate life-saving therapy (emergency transfusion or Caesarean section) and many therapeutic options offered by the medical profession which may be rejected by patients in a situation of lesser urgency. Treatment refusal may concern one person, an unborn child, or a family, a group or an entire society – which raises a problem of public health – but can also be expressed by a third party or the physician himself. This diversity of situations can be such that the interests of a third party in the broad meaning of the word, may enter into conflict with those of the patient. Depending on circumstances, issues must be viewed from very different angles.

### **II.1. Refusal by the patient**

#### **II.1.1. Urgency and extreme urgency**

For the sake of example, we shall consider two particularly dramatic sets of circumstances for the patient, the unborn child, or the child's mother, where the risk is severe and would be immediately life-threatening in the absence of appropriate medical care.

##### **◆ Refusal of transfusion**

Refusing transfusion of any kind is a core belief for certain spiritual communities, however life-threatening the situation (obstetrical haemorrhage, accidents with severe haemorrhage, leukaemia, digestive tract haemorrhage, etc.) and this prohibition may even be the expression of community unity. In such an emergency, doctors may be

confronted with a very grim choice: transfuse or allow someone to die. If the patient is adult, refusal of transfusion amounts to an insoluble moral dilemma for the doctor: on the one hand, existing legislation does not welcome therapeutic intervention without consent from the person concerned; on the other, the doctor's professional responsibility – and in particular the legal obligation to provide assistance to someone in danger – points to transfusion. Obstetricians have pointed out that haemorrhage during labour is the primary cause of maternal death in France and that (according to an American study published in 2001) mortality during labour for Jehovah's Witnesses is 40 times higher than for women who do not belong to that community<sup>1</sup>. Confronted with death that could seemingly be avoided by transfusion, the most commonly accepted opinion in France is that the doctor has good grounds in an emergency – but only in an emergency – to disregard the rule of consent and transfuse the patient against her will. This opinion is reinforced by the collective nature of the decision to refuse: the fact that the persons concerned live within a community which may exert considerable influence on their apparently autonomous power of decision cannot be ignored.

In the case of a child or under-age adult, after consultation with other doctors on whether transfusion is required, cases of refusal are submitted to the Public Prosecutor who may override the family's wishes and instruct the doctor to proceed. There is, as always, the difficulty of evaluating the actual threat to life and the degree of urgency.

#### ◆ Refusal of an urgent caesarean section

Caesarean section is increasingly frequent. However a great deal of discernment must be exercised for this indication since in nearly 15% of cases motives may be more concerned with issues of safety or organisation than strictly medical ones. For reasons which are often anthropological and ethnological, but sometimes of a more social nature (loss of status) or practical (risk of uterine rupture for later deliveries in the country of origin) a caesarean can be considered in some cultures to be irreversible or unacceptable damage to the body and/or flouting of a birthing ritual. At the last moment during labour, some women or more often than not their husbands, refuse the procedure. This dramatic emergency can lead to the obvious consequence: not just maternal death but also death of the child. Some obstetricians consider that a woman who refuses a caesarean during labour is no longer in a situation where she can give informed consent or refusal. Refusal involving an unborn child cannot be viewed as an expression of total freedom that must be respected. In such circumstances, society must protect the defenceless unborn child.

In any event, it would seem essential that such a situation should always be considered, if at all possible, **well before** birth rather than at the last minute, while recognising that one's attitude in a purely "theoretical" and therefore a "general" situation, may change if the situation becomes real. In this case also, there is no ideal solution.

These two situations illustrate the conflict between beliefs or special social and cultural circumstances (the risk of uterine rupture during a later delivery in the country of origin, for example) and medical procedures. In an emergency, such conflict may be the source of serious tension.

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<sup>1</sup> cf *Libération*, Thursday April 22, 2004

Several other situations, on the contrary, can be the subject of reflection which throws a less dramatic or provocative light on refusal of therapy.

### II.1.2. Therapeutic situations experienced as invasive

- ◆ The first of these is **refusal to go to hospital**. In such cases, physicians in both the private and the public sector are concerned that patients may not benefit from their full chances of recovery.

- ◆ **Refusal to eat**

Doctors can understand patients wishing to reject treatment, but they find refusing to eat much less acceptable particularly since, if doctors were to concur, they would be in a situation where they were failing to assist a person in danger, although the patient may be fully aware of the possibly lethal consequences of such refusal. To force a patient to eat can, paradoxically, be an act of extreme violence; but to let a patient starve to death is also an act of violence against the medical profession and society. Several situations may arise.

- **Anorexia nervosa**. For most psychiatrists, anorexia nervosa which mainly affects women, is a borderline psychiatric condition. But “borderline” means that some anorexic women are exercising a freedom that must be respected, with all that this entails in terms of a need for psychological assistance and multidisciplinary management. As always, the real problem is the necessarily subjective judgment of psychiatrists and somatic specialists regarding an anorexic patient’s ability to recognise his or her own best interests and the point at which a patient’s life is in danger.

- **Hunger strike and failure to assist a person in danger**. A doctor may sometimes be confronted with a pathological situation brought about by someone – in prison or at large – who is on a hunger strike militating to attain some objective which may be personal (such as release from detention) or the success of some enterprise or political cause. As a persistent hunger striker’s health deteriorates, it may become life-threatening. What can a doctor do in a situation where the person concerned is endangering his own life and taking no action to preserve it? The hunger striker’s cause bears no relation to his state of health and this has some influence on the coherence of his action. When a hunger striker resists healthcare, he is not rejecting beneficial treatment, he is seeking a result which is not connected to regaining health. In these circumstances if a doctor steps in, he is thwarting an action which could lead to death. But he is also playing into the hands of the striker’s political adversaries or the judicial authorities he is resisting. Frequently the doctor has to choose between respect for the striker’s lonely battle with himself and against society, in an ultimate attempt to regain his personal dignity, and therapeutic intervention in the last resort. Here again, the timing of such intervention can be an agonising decision. Treatment and parenteral nutrition may come too late to prevent serious consequences, but if provided too early they become a form of injunction which imperils personal freedom.

In a prison environment, refusing food is not the only expression of rejection of prison healthcare. A sick prisoner may refuse essential treatment such as insulin, treatment for hypertension or cancer on the basis that he is free to do as he wishes and possibly put an end to his own life or wishes to exert pressure on the judicial system.

- **Refusing food on the part of elderly people or those who are dying.**

Almost total anorexia on the part of the dying may mean resignation in the face of death that is accepted or even desired. In such cases, attempts at intravenous nutrition or gastrostomy may appear exceedingly violent.

When feeding through the mouth is impossible or is associated with food being ingested into the bronchial system, the possibility of using a gastric feeding tube that brings nutrition directly into the stomach is often mentioned, but this method of artificial feeding is frequently a source of anxiety for patients or their families and may be rejected. Force-feeding is sometimes experienced as a **form of violence** rather than therapy or care.

◆ **Refusal of tracheotomy**

A large number of patients suffering from chronic obstructive pulmonary disease need tracheotomy (i.e. a tube is inserted into the trachea through an incision) at some point in the progress of disease to improve ventilation. However, for some of these chronic patients whose condition is in any case worsening progressively, the very idea of tracheotomy is repellent since it further alters relations with the outside world by modifying or suppressing the voice and creates an unwelcome loss of autonomy.

◆ **Refusal of chemotherapy** for reasons which appear to be rather trivial to a doctor since they are connected to quality of life issues which are of course very subjective. Fear of collateral effects (loss of hair, or the name itself is perceived as a threat) must be not only heard but also respected. Rationality can also be non medical. As always, attention followed by information in the simplest and most comprehensible form possible is the way to obtain **postponement** of a final decision or to avoid irreversible refusal.

◆ **Refusal of infusion.**

Infusion is often necessary to rehydrate a patient or administer drugs which have no or little efficacy when they are ingested orally. This procedure is more frequently rejected than one might think. Here again, therapeutic objectives must be weighed in the light of how the person concerned perceives this form of treatment.

◆ **Except in an emergency, refusal of transfusion** is acceptable, whatever the consequences (transfer to another hospital is a legitimate option). The problem cannot be solved by force. Forcing a transfusion on a Jehovah's Witness does not solve the problem whereas listening to what the patient has to say and wants after being given the clearest and most respectful information about the major consequences that the decision entails, in a suitable environment (dialogue in privacy, absence of emotional blackmail, confidentiality of final decision).

It is true that refusal is frequently the result of pressure from the patient's community. Dependence of this nature, however, must not be allowed to obscure the best interests of the person concerned who may well be a member of a community but is no less an individual whose autonomy must be presumed or better still aroused or provoked. It is surely that individual's right in the final analysis to escape the group's dogma and accept transfusion as well as the consequent risk of excommunication. Of course, this is an "asymmetrical alternative"<sup>2</sup> since a choice has to be made which is not between good and bad but between two "evils". The person concerned must renounce one of two highly valued principles (his own life or belonging to a spiritual community). However, although the choice is very restrictive, it still exists as is shown by believers who decide

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<sup>2</sup> with reference to the pertinent concept in the Belgian Committee's Opinion N° 16 on this subject on March 25, 2002.

to accept transfusion while at the same time accepting that they will be excluded from their group.

### **II.1.3. Refusals in a psychiatric context**

Tension is particularly acute in this domain since patient discernment may, with some justification, be viewed as impaired or absent altogether. The subject, however, does raise some very unique and radically different issues since by nature, judgment on patient competence, capacities and capabilities are connected to the psychiatric condition. In any event, for both ethical and legal reasons, there is no case for considering that refusal of treatment should automatically lead to enforced hospitalisation. It has become apparent that hospitalisation following a request from a third party, sectioning or involuntary commitment can lead to abuse despite supervision as prescribed by the 1990 law. There are still issues regarding emergency procedures, considerable disparity between one part of the country and another and a growing concern for security. Some thought must be devoted to the subject to ensure that people are properly protected by law.

Situations where care is refused (for example surgery) for psychiatric reasons or when a psychotic patient is involved, raise extremely difficult issues since forced hospitalisation in these circumstances does not have a very clear status. “Taking advantage” of a psychic condition to enforce physical treatment or care is prohibited, but there are obviously many ambiguities in a situation where the protection of people from risks of their own making is more concerned with the mind than with the body. When a delirious patient refuses surgery for life-threatening peritonitis, the medical profession is in an extremely awkward position. Enforced hospitalisation does not in fact apply directly to this kind of situation.

### **II.1.4. End of life situations**

Discussions on what attitude should be adopted at the end of life are much too inclined to binary radicalisation about positions labelled “euthanasia” or “futile and aggressive therapy”. Although CCNE has already expressed itself on this subject<sup>3</sup>, some points are perhaps worth repeating:

- A patient’s refusal to continue living, expressed by refusing treatment, must not always be understood as a wish to die. It can also be a wish to regain some semblance of freedom from medical demands. The concepts “unreasonable obstinacy” and “unreasonable perseverance” must be a matter for the judgment of both patient and doctor.

- A person at the end of life is as vulnerable as it is possible to be and assistance, in whatever form, is a requirement which largely transcends refusal of treatment. Respecting refusal of treatment necessarily implies an obligation to assist and counsel<sup>4</sup>. That is why refusal or withdrawal cannot be solely concerned with therapy and why

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<sup>3</sup> See Opinion n° 63 (January 27, 2000) « End of life, ending life, euthanasia », available at <http://www.ccne-ethique.fr>

<sup>4</sup> “To assist someone does not mean leading them or showing them the way, nor imposing a route nor even knowing in what direction they will go. It only means walking beside them and leaving them free to choose their path and how fast they will travel.” P. Verspieren : “Face à celui qui meurt: Euthanasie, Acharnement thérapeutique, Accompagnement”, Paris, Desclée de Brouwer, 1984

other aid strategies must be implemented. A law recently adopted by Parliament confirms the role of a “trustee” to whom a patient can explain his wishes in case he later loses consciousness. Medical decisions must take them into account if they have been expressed less than three years before that time.

In situations of prolonged vegetative coma, a patient’s family may request that even quite elementary therapy should not be provided (for example antibiotics to treat pulmonary pathologies). The medical profession is in a predicament when faced with external demands which diminish the patient’s chances of survival. Such situations should be dealt with in advance by establishing a good relationship between the physician and families. Taking such radical decisions in a crisis situation is never advisable; it is far preferable to anticipate the possibility by sharing a process of strategic planning.

### **II.1.5. Situations where refusal has consequences for a third party**

#### **- Caesarean section in a non urgent context and the unborn child**

The question of risk to mother and child when a caesarean section is refused is a persistent problem. Although French law does not recognise the status for an unborn child, in ethical terms he most certainly can be seen as a potential third party.

The mother’s liberty to refuse a caesarean while fully understanding the consequences (that is, after having been informed of them in her native language if needs be) is subject to the scrutiny of society which may consider that the decision commits society itself and cannot be left to the mother alone. The same would be true for a pregnant woman refusing surgical intervention for the foetus she is carrying. No one has the right to force an intrusion into her own body, but here again, society may give vigorous expression to the notion that protection of the child she has chosen to put into the world and who is in her care must also be a consideration. For example, treating HIV contamination in a pregnant woman seems to be an obligation insofar as this treatment has almost eradicated transmission of the infection to newborn children, but it cannot of course be imposed by law...

The issue in general terms is the degree of liberty that a given society can accept or refuse an individual when a third party, even an unborn child, is involved. By taking her beliefs seriously and considering the consequences for the mental stability of a woman forced to undergo a caesarean section, the medical profession can be on the way to more detachment. It is important to view one’s own system of medical values with some degree of objectivity and consider other values, those of the expectant mother in particular, so that situations of complete blockage are avoided and negotiation in a spirit of mutual respect can begin.

#### **- Unidentified or collective third parties. For example:**

- **Refusing vaccination.** Refusal can of course be the entirely legitimate expression of an individual position, but a society confronted with refusal to vaccinate by a minority group is in danger. Countries for example who have not been able to convince their entire population that immunising against poliomyelitis is necessary are allowing this virus, which is only carried by human beings, to persist as a threat. To respond to that risk,

society exerts strong pressure through conditions for enrolling in schools. A person's individual right to exercise freedom is therefore limited by the security of the group as a whole.

- **Refusing treatment for tuberculosis** is also a threat to public health. A diseased person infected with TB bacilli refusing treatment continues to disperse contaminating bacilli into the environment. In this case, two forms of adaptation enter into conflict, society to the sick and the sick to society. It is perfectly obvious that absolute freedom for a sick person constitutes a major danger for everyone else, but can the threat justify going to the length of detaining those who refuse treatment? In the name of public health, quarantine can be made mandatory, even by physical force, in the case of some particular dangerous transmissible diseases such as avian influenza, SARS, smallpox, the EBOLA virus, the plague or cholera. But there is no comparison between the abrupt epidemic proportions of the mode of transmission of these infections and the endemic nature of tuberculosis. Simplifying to an extreme and placing them on the same footing is a possible source of confusion.
- **Refusing multitherapy for HIV contamination** because of social and financial precariousness. Such a situation, which also applies to other diseases, requires that great attention be devoted to social circumstances since refusal is in fact a call for help from society. Even if refusal voiced by a pregnant woman is difficult to accept, there can be no constraint.
- The question also arises of **anticipating blood transfusion for elective surgery or organ grafting**. In the latter case, the absence of blood transfusion has consequences that vary a great deal with the organ being transplanted. The problem is not that transfusion would be necessary for the transplant procedure to be fully effective; in some cases, it is in fact totally essential for the transplant to take place at all (heart, heart and lungs, liver), or else it could become necessary to save the patient's life in case of haemorrhage. This is something which must be fully explained in a written document providing the basis for securing consent from patients waiting for transplants. Otherwise, they cannot consent to the procedure. For transplants which do not always necessitate transfusion, a kidney graft for example, the consent form of the French transplant authority (Etablissement français des greffes) reads as follows:  
"If an organ becomes available for you, you will be undergoing a surgical intervention. We have taken good note of the fact that you object to the transfusion of whole blood and blood derivatives. We undertake to use all medical procedures compatible with your state of health to avoid transfusing products you reject. However, we are informing you that if, during or following the operation, a transfusion becomes necessary and urgent in view of a life-threatening situation, we shall use that procedure. You are certifying that you have been informed of this by the medical and surgical staff and that you maintain your wish to be placed on the national waiting list for attribution of a graft."

This wording is equitable. It does seem illogical to put someone down on a waiting list for a graft if he or she refuses from the outset conditions which ensure the best chances of a successful outcome. Furthermore in such a

case, refusal has obvious detrimental effects for other patients on the waiting list. In a situation where grafts are very scarce, one cannot afford to waste the chance of a graft being used successfully through excessive respect for individual and subjective views.

## II.2. A doctor's refusal

### **Can the medical profession also refuse to initiate a test, a treatment or an intervention that is being requested?**

In some circumstances the healthcare provider may be the one to refuse treatment. The reason could be that the test or other investigation requested by the patient is considered to be excessively costly or futile. With economic constraints<sup>5</sup> at issue, doctors may be asked to proceed with investigations which they consider to be unnecessary or unnecessarily costly whereas procedures which are simpler, just as efficacious and much less of a financial burden on the community, are available. Obviously, a doctor must always do his utmost to give his patients the best chances of recovery using the most up-to-date scientific methods and the least likely to produce side effects or other risks. But this theory depends on a number of very subjective decisions. It must be kept in mind that a doctor is an actor on the public health scene<sup>6</sup> and must be able therefore to refuse a request that he judges to be unnecessary or unnecessarily costly. Such requests are sometimes relayed through patient support groups and what they have to say must always be considered with care and submitted for critical examination. Some requests of this nature are the result of not fully identified manipulation by interest groups or based on information found on internet or in the media, more often than not unproven. The ethical issue is not refusal of a useful treatment because of its cost but rather to avoid an offhand attitude as regards economic dimensions when the choice and end purpose of treatment is in question.

The same is true of a treatment option which the medical profession judges to be futile and aggressive. To obstinately persist in maintaining life – and not quality of life – at the price of excessively burdensome treatment, without the least hope of gaining any benefit in the short or medium term, is not an obligation. The independence of medical choice must be preserved on the condition that transparency remains the rule and attitudes are agreed.

Refusal to practise assisted reproduction technology on the part of a gynaecologist or a medical team may be another example where medical considerations (such as age or state of health) are poorly or badly understood by the couple concerned. Medical responsibility does not consist in fulfilling wishes whatever the cost; it must also be explaining, with respect, the unrealistic or even harmful nature of some projects.

Refusal to engage in neonatal resuscitation in view of a very poor outlook for the foetus must be the subject of clear explanation to the mother and her partner<sup>7</sup>. Refusal to practise a termination on the part of a doctor is equivalent to the attitude of certain patients who are expressing religious convictions which determine behaviour, demonstrating through the tacit acceptance of it by society, the fundamental asymmetry

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<sup>5</sup> CCNE is considering the economic dimensions of healthcare in an Opinion to be published shortly.

<sup>6</sup> Article 2 of the French Code of Medical Ethics states: "Physicians, at the service of the individual and of public health..."

<sup>7</sup> On this subject, see also CCNE Opinion n° 65 "Ethical considerations regarding neonatal resuscitation". Report. September 14, 2000

of the care relationship. It also demonstrates the existence of cultural values held in some cases by carers which should incite them to allow other carers to take over. It is a fact that refusals, expressed by the patient and expressed by the physician, are not mirror reflections of each other. A patient's refusal is a right (further reaffirmed by the law dated March 4, 2002); a physician's refusal, which may take on the appearance of a safety clause, can only be based on experience or conviction expressed in the light of the duty to care.

### **II.3. Refusal by a third party<sup>8</sup>**

There are numerous situations where a third party refuses a care procedure on behalf of the patient. A spouse may refuse delivery by caesarean section whereas the mother would have accepted. A family may seek to impose its own views when one of its members is seriously ill and is either incapable of expressing his or her views or has not previously expressed them. This refers to the status conferred on a "trustee" by law. However, as long as refusal is expressed by a third party, it must be considered with great caution.

### **III. Summary of situations**

Be it rebellion against what is perceived as the medical "order", or a claim for absolute freedom of choice or a misapprehension of the true situation, refusal of treatment is never simply a confrontation. In the wings, there is always a misunderstanding, something left unsaid, on the part of the doctor, the family, or a person who may, or may not, be ailing. But perhaps it is in just such situations that the medical profession must show the true colours of its ethics.

Discrepancies between several different perceptions raise, as they always do, the issue of the status of that information and relates to the balance between a paternalistic model of medicine and a contractual model, with the attendant risks of medical militancy through excessive certainty or medical neutrality brought about by an insufficient sense of responsibility. All the situations considered frequently cause anguish, or even torment, for patients and their loved ones. Through an analysis, necessarily complex, of the situation and by respecting the wishes of the person concerned, a relationship will emerge. Refusing treatment is often an expression of courage. Recognition of this fact sometimes brings more serenity.

### **IV. The concept of recognition**

All the above examples, which are far from being exhaustive, show that ethical reflection cannot be applied identically in all situations. The variety is endless: surviving suicides refusing resuscitation, parents refusing procedures for the survival of their new born disabled child, etc. To simplify in the extreme, taking the decision to apply a compressive bandage to a bleeding wound without agonising over metaphysical issues, and all the more so in the presence of a doctor, is one thing, but refusing chemotherapy or vaccination is quite another.

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<sup>8</sup> On this subject, see also CCNE Opinion n° 70 "Consent for the benefit of another person » December 13, 2001

Except in an emergency, refusal expressed as regards various therapeutic options must always lead to consideration of ethical issues taking into account respect for the patient's dignity, not forgetting respect for the doctor's professional dignity and for his attachment to the founding values of medicine.

Refusing treatment is always an event situated at the centre of a profusion of concerns. The need for **recognition** is probably one of the most significant of them. This need for recognition that Paul Ricœur<sup>9</sup> analysed with great precision exists in both patient and doctor.

- Patients want doctors to recognise their individuality and their complexity. Refusal can be an expression of this need and a request for euthanasia is frequently a call for help rather than evidence of any real desire to end life.
- But doctors also need recognition from patients, not so much in the form of gratitude, but in terms of recognition for their competence, their sense of responsibility and the legitimacy and specificity of the values which the medical profession upholds.

To these two components could probably be added the expression of a need for social recognition, recognition of a need expressed by a public call for help from both protagonists in the act of caring. One specific characteristic of caring is the statement of an act of solidarity so that the “private” dialogue between patient and physician is frequently part of a quest for social harmony. When these demands are claimed by both parties, it is easy to understand that the two (or three) recognitions may not coincide. This may be the case when a sick person entertains iron-bound convictions that do not allow him to take account of the concern for professional – not to mention legal – responsibilities that inhabits the doctor. Or a doctor who is excessively infatuated with some therapeutic project and resents criticism from the patient.

Or it could be also recognition that medicine is a culture that finds it unacceptable that traditional beliefs which they consider to be irrational be allowed to challenge their modern practices backed by scientific evidence.

As can be seen from all these examples, solving the issues on a pragmatic case by case basis is not the way to developing guidelines.

Before attempting to provide some ethical answers to the problems that arise out of refusal of treatment, it is perhaps necessary to consider the history of treatment refusal in connection with the law and judicial precedent.

In fact, although the debate is increasingly topical due to scientific and medical progress and increased awareness of the need to respect totally autonomous expression of will, the notion of free and informed consent (which is at the core of any account of medical ethics in the therapeutic relationship) is far from having always gained recognition in its full complexity. The notion of “failure to assist a person in danger” may have led to censoring any basic reflection, leaving the medical profession with enough space to exert medical paternalism.

We shall attempt to analyse the legal situation before considering ethical issues.

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<sup>9</sup> P. Ricœur, *Parcours de la reconnaissance*, Paris, Stock, 2004

## V. Legal analysis

An analysis of law and legal precedents reveals the gap between the legislator's clear-cut intentions and case by case interpretation.

### V.1. The Code of medical ethics and the law

Although it may seem justifiable to state that patients may wish to be and remain at all times in complete control over matters regarding their personal health, this simple statement of principle bears little relationship to reality. People who are confronted with pain, disease, approaching death, are bound to feel diminished by the awareness of their own weakness and therefore lose some of their autonomy to the extent that they no longer know what it is they want or can accept and are not even able to express themselves. By their side, or more often than not, facing them, are physicians or carers whose strength is reinforced by their own science, despite some doubts and hesitation at times, and who wish to accomplish their mission which is to apply in full treatment which they consider to be the most appropriate in the circumstances to alleviate, cure, or delay the advent of death.

But what is left of patient autonomy, of the notion of consent that the patient is requested to give and of the need to create conditions in which freedom of consent – which everyone agrees must be “informed” – can be exercised? Can there be consent if, as we have seen, there is no possibility of refusal? This was the question that the law dated March 4, 2002 attempted to answer, by reviewing and extending the Code of Medical Ethics, so as to provide patients with more autonomy of decision as regards medical care and ensure more equality in the relationship between doctors and patients.

The law enshrines the notion that patient consent must prevail and clearly states that:

*“In the light of information and advice supplied by healthcarers and in consultation with them, patients are entitled to take decisions regarding their own health. Doctors must respect wishes expressed by patients after informing them of the consequences of their decisions. When refusing to undergo or continue treatment represents a threat to life, physicians must do their utmost to convince patients that they should accept essential treatment. No medical act nor any treatment may be applied without securing free and informed consent from the person concerned. Consent may be withdrawn at any time”.*<sup>10</sup>

Recognition of the patient's right to refuse treatment is stated with total clarity in the above. The article is witness to the legislator's desire to create a dialogue (or, as others would express it, equality of power) between a doctor's duties and a patient's rights in the decision making process. Patients are no longer simply required to acquiesce; they are clearly expected to participate in the decision by the medical profession. In this way, legislators were seeking to even out the relationship between doctor and patient and ensure greater respect for the principle of consent. This process of restoring the balance seems to be all the more difficult, and therefore all the more necessary, because scientific progress increases the gap, as we have previously mentioned, between patient perception of their body and what the medical profession knows – or believes it knows.

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<sup>10</sup> article 1111.4 of the “Code de la Santé Publique”

But legal precedents, both prior to the law and after it was voted, are ambiguous or even contradictory. The law states a principle, but in practice opposing views enter into conflict.

## V.2. Contradictory court rulings as regards respect for patients' wishes

### V.2.1. Respecting patients' wishes and its limitations

Respecting a patient's refusal arose mainly when life was at stake; the law remains ambiguous on the doctor's response in such a situation.

In the specific situation where parents refuse transfusion for their under-age children, French law postulates an obligation to provide care in an emergency<sup>11</sup> or, in the absence of urgency, subordinated to the possibility of obtaining authorisation from a juvenile court judge<sup>12</sup>. However, in situations where an adult patient is in danger, physicians cannot disregard patient refusal although they must do their utmost to persuade the patient to accept treatment. Article 36 of the Code of Medical Ethics (following the decree dated December 6<sup>th</sup> 1995) states that: "...if a patient is able to express his or her wishes, refuses treatment or investigation as offered, the physician must respect that decision after having informed the patient of the consequences".

The law therefore recognises the patient's right to simply reject care outright. The Code of Medical Ethics instructs the physician to respect the patient's wishes and the law dated March 4, 2002 gives patients ownership of a right to refuse care which has been further reinforced by articles in the recent law on "Patients' rights at the end of life".

The obligation to secure consent is reinforced if refusal is based on the patient's religious convictions. **Freedom of religion** is guaranteed by the French constitution and by the European Convention on Human Rights. The issue has been raised as to whether forced treatment in an emergency constitutes a violation of the freedom of religion. The question was answered in the negative by the Paris Court of Appeal in its decision on June 9, 1998.

Consent to a medical act is related to the principle of respect for the integrity of the human body, in the name of the dignity of the human being. This principle is included in the Universal Declaration of Human Rights, the Human Rights principles of the European Commission and the Charter of Fundamental Rights which devotes Article 1 to the subject and states the principle of integrity of the human body. Individuals are entitled to the intangibility of the human body and no one is allowed to violate that principle without the individual's consent even for curative purposes. Articles 16.1 and 16.3 of the French *Code Civil* assert the principles of inviolability and integrity of the human body. The *Cour de Cassation* (French court of last resort) therefore took the view that, apart from cases provided for by law, no one can be forced to undergo surgery<sup>13</sup>. Similarly, the Oviedo Convention on Human Rights and Biomedicine (not yet ratified by France), although it authorises restrictions when these are prescribed by law and are necessary for the protection of public health or the protection of the rights

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<sup>11</sup> Decree dated January 14 1994 – art. 42 of the "*Code de Déontologie médicale*"

<sup>12</sup> art 375 "*Code Civil*"

<sup>13</sup> Cass Civ II March 19, 1997

and freedoms of others<sup>14</sup>, nevertheless states that “*the person concerned may freely withdraw consent at any time*”.

However, this principle is not absolute since the law sometimes imposes submission to examination or to treatment (mandatory vaccination, treatment for mental disorders, some infectious diseases which may or may not be sexually transmissible, drug addiction, etc.).

On the other side of the scale, court orders have considered, long before the law voted on March 4, 2002, that a doctor is not committing a fault when complying with the patient’s wishes and therefore incurs neither penalty nor sanction. In the same way, physicians are not violating the law on failure to assist a person in danger and incur no disciplinary action when therapy as proposed cannot be applied because of obstinate, and even aggressive, refusal by the patient<sup>15</sup>. The *Conseil d’Etat* (French Supreme Court for administrative justice) made its position on this point absolutely clear when it sanctioned for incompetency a decision by the *Conseil de l’Ordre* (Medical Association) to declare faulty a prescription for palliative medication for a patient with uterine cancer who was refusing to submit to the only treatment likely to be efficacious<sup>16</sup>.

A later decision appeared to contradict that principle. A cancer patient had rejected both surgery and radiotherapy. Her doctor had prescribed homeopathic medication and acupuncture and had only referred her to a specialist when she was terminally ill. The *Conseil d’Etat* considered that the doctor had committed a fault when he consented to fight the disease with illusory therapies which had deprived her of a chance of survival<sup>17</sup>. It must also be said that in the event, judgment included the opinion that the doctor had not tried to convince his patient of the need to use more appropriate therapy. That was the only exception to the principle that a physician is absolved of blame when he follows the wishes of his patient.

The issue of the doctor’s fault in ignoring the wishes of his patient was also raised by other court rulings, in particular when the patient was unconscious. The *Conseil d’Etat* postulated the principle that when a doctor is faced with repeated and clearly expressed refusal of care, he must abstain from action<sup>18</sup>. The *Cour de Cassation* also condemned a doctor who had proceeded with surgery (which was not made essential by any vital or urgent need) without securing prior consent from his patient who was unconscious at the time the doctor decided to operate<sup>19</sup>. Theoretically, the doctor concerned could also be sued in a criminal court for violation of the physical integrity of his patient.

### **V.2.2. Limits to the principle of supremacy of the patient’s wishes**

Since the adoption of the March 4, 2002 law, court rulings have followed the same lines as those adopted previously. When a life is in danger and a patient refuses treatment, the law chooses to consider that the doctor may, or may not, respect the patient’s

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<sup>14</sup> art. 26§1

<sup>15</sup> Cass. Crim. January 3, 1973 ; also Crim October 30, 1974

<sup>16</sup> CE March 6, 1981

<sup>17</sup> CE July 29, 1994

<sup>18</sup> CE January 27, 1982

<sup>19</sup> Civ. I October 11, 1988

wishes. This amounts to considering that the doctor's subjective ethical tenets prevail over those of the patient.

By way of example, the LILLE Administrative Tribunal ruled on August 25, 2002 that a doctor's refusal to respect his patient's wishes can be justified by immediate danger to life. It would not seem that there is any major difference of approach to the problem compared to a now ancient decision on February 15, 1971 by the TOULOUSE appellate court which considered that a doctor was guilty of negligence and liable if he showed indifference in the face of refusal of the care he was offering. Similarly, the *Conseil d'Etat* in an interim ruling on August 16, 2002 set out some limits to the respect of treatment refusal. Furthermore, the law itself recognises that there are urgent situations where care should be applied forcibly, in particular as regard prison inmates on a hunger strike (article D364 of the *Code de Procédure Pénale*).

The problem therefore has not been solved since "*This ignores the fact that ethics and science are profoundly different in nature and that the doctor's ethical opinions are no more pertinent than those of the patient. It also ignores the elemental truth that the body in question belongs to the patient and not to the doctor*"<sup>20</sup>.

The March 2002 law and legal precedent therefore provide no definite answers. The only criterion is the observation that patient autonomy is now becoming dominant. But it is clear nonetheless that the consequent shift in prominence that this entails cannot overlook the greater or lesser degree of certainty and uncertainty of medical offers.

## VI. Ethical issues

In the cases under consideration, the relationship between doctor and patient is the source of tension or in some cases represents a conflict of viewpoints and values between which it is very difficult to choose. This is the core of the ethical problem. On the one hand are expressed values which go beyond the medical institution and dominate society as a whole: solidarity, respect of life, assistance to those in danger. On the other, the right of patients to distinguish their own (subjective) notion of what is good for them amid what others consider (objectively) good for them. The protagonists of therapeutic action are not necessarily in disagreement over values: the respective modes of ranking values are the problem. For example, in the eyes of a patient, *length* of life may seem less important than *quality* of life, whereas the doctor might be inclined to favour the number of years gained rather than how that life is experienced. Because patients are sometimes particularly weak and vulnerable, their competency may be more easily doubted than the doctor's.

In the circumstances, it is prudent to take into account two inevitable components:

- The difficulty of evaluating other people's judgment which always involves a large measure of subjectivity;
- A degree of determinism of conduct which renders complete autonomy rather improbable.

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<sup>20</sup> Jocelyn Clerckx : Une liberté en péril ? le droit au refus de soins, (Freedom in danger? The right to refuse care). *Revue de droit public*, 2004, n° 1

These practical questions would be an encouragement to refer to the rather more theoretical reflections of modern philosophers on the question of human freedom and more specifically on autonomy and the requirement to respect it.

## **VI.1. The various facets of individual autonomy**

Respecting treatment refusal by a patient acts in accordance with the ethical requirement to recognise personal autonomy. However, there remains the question of knowing exactly what the word “autonomy” covers: is it the capacity to adopt a rule or the capacity to adopt values?

There are, in brief, three increasing levels of complexity in the concept of autonomy.

**VI.1.1. Autonomy of action** which refers to the possibility of physical mobility. To be autonomous means being able to move through surrounding space using one’s own physical resources.

**VI.1.2. Autonomy of thought** which qualifies the power to conduct coherent and organised reflection. More specifically, in medical matters, this form of autonomy defines the state of patients who are able to participate in consideration supported by the acquisition of knowledge regarding their medical condition. Autonomous individuals are those who are capable of understanding medical information and exercise critical reflection on the subject. Autonomy then, quoting Kant, is the capacity to “use one’s own capacity of understanding”. Defective discernment which subjects one person to the conduct of another, deprives that person of autonomy of thought, despite possession of autonomy of action: “an autonomous person is one who is capable of reflecting on personal objectives and deciding independently to act in conformity with that reflection”.

Respecting autonomy of thought in concrete terms means that a physician is bound to make sure that those who refuse treatment have fully understood the information they have been given and the foreseeable consequences of refusal and that no other person or community restrict their freedom of action.

### **VI.1.3. Autonomy of will**

#### **VI.1.3.1. Its two meanings: self limitation and individual sovereignty**

Autonomy of will defines the capacity to suspend impulsive spontaneity which determines action mechanically and instead, decide as a result of conscious and individual resolution.

Such autonomy of will can be defined in two different ways: self limitation or sovereignty.

- Autonomy of will defined as self limitation integrates a dimension of rational control of sensitivity. It does not define anomie (lawlessness), but self-rule (auto: self, nomos: law), i.e. the capacity of an individual to submit only to his own rules. The defect of this “deontological” concept, inspired by Kant, is rejection of conflicts of values. Reason should every time, put an end to conflict. The doctor (in the name of reason) could overrule the “autonomy” of the person concerned.

- Autonomy of will as individual sovereignty. This concept was put forward in the 19<sup>th</sup> century by the philosopher John Stuart Mill: *“That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. (...) Over himself, over his own body and mind, the individual is sovereign”*. (On Liberty). The greatest possible latitude is therefore left to individuals, so that the sense of autonomy extends to all personal actions which were not constrained by others. The autonomy of will as a “sovereignty” consists in the possibility of having personal preferences and to take decisions on the basis of a conception of what is right that every individual must freely determine for himself. The physician must therefore respect his patient’s freedom, beliefs, choices and requests, even if he believes they are aberrant (taking disproportionate risks, drug abuse, refusal of blood transfusion or treatment considered to be necessary).

This extension of the meaning of autonomy is justified today even in the eyes of the English speaking authors who do not subscribe to utilitarianism, by the fact that we are in a context of moral pluralism (T. Engelhardt speaks of a “polytheist culture”<sup>21</sup>). There is no universal system of reason to resolve dilemmas. For this reason, a patient who refuses care need not be protected from himself (from his insanity); he must only be protected from a destabilising and stressing environment.

If treatment, therefore, is refused, the doctor’s sole duty is to make sure that his patient’s decision is not taken under the threat of psychological constraint exercised by a third party. The logic of that model of liberty leads to stating that if the doctor finds no evidence of external pressure, he may consider that the patient’s refusal expresses his autonomy and that it must therefore be respected.

### **VI.1.3.2. Autonomy and methods of persuasion**

Informing a patient is therefore the natural preliminary to a situation of consent or refusal. But of course, there are many ways of informing. It is often the way in which information is imparted (the tone of voice, the choice of words, etc.) that explains why one doctor is able to persuade whereas another will meet with refusal of treatment. “Persuasion” may well be an ambiguous practice. There is often a call on the emotions by addressing sensitivities.

Perhaps persuasion can be likened to pressuring a patient to consent by creating an emotion that the threatening prospect of death did not suffice to raise. A doctor might, for example, associate a refusal of consent to a threat of no readmittance to hospital in the event of a return of the “rebel”. However, article 7 of the Code of Deontology stipulates that the physician’s “attitude to the patient must never cease to be correct and

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<sup>21</sup> Engelhardt T., *Foundations of bioethics*, New-York, Oxford University Press, 1986, p.20

attentive”<sup>22</sup>. A physician must therefore convince his colleagues to accept the idea that patients who have refused treatment may return to the hospital if their condition (predictably) worsens. Should the physician manage to gain consent by the force of clever argumentation, he would surely be putting the patient in a position where he must bear the brunt of treatment in a state of moral suffering aggravated by the guilt of initial refusal. There is also the possibility that the efficacy of treatment can be diminished by the very fact that it was accepted reluctantly (for example, what is the impact of an antidepressant drug on a patient who does not really want to take it?). This is germane to ongoing scientific research on the possibility that a placebo effect might be a beneficial adjuvant in some cases to treatment already known to be effective on its own.

The usefulness of this concept of “sovereign” autonomy is that it precludes the risk of excessively paternalistic inclination to override a patient’s refusal to “bring him to his senses”.

But there is still the concern that by respecting entirely this spontaneous concept of autonomy, that *“medical practice could suffer a massive loss of the sense of responsibility (...)As long as he has done what the patient wanted, the doctor can consider himself absolved of any responsibility should there be an aggravation that he had himself foreseen and could have avoided”*<sup>23</sup>.

Seen from that angle, respecting refusal of care may seem like a form of hypocrisy. The end result is to condone the attitude of a physician whose rule of ethics would be to always behave as though the patient was free (“sovereign” would say J.S. Mill), including in circumstances when the physician is convinced that this is not the case, insofar as he believes that an excess of psychological factors which he deems irrational are present and are therefore responsible for the decision to refuse treatment. A practitioner, should he confine his decisions to following this “utilitarianist” model of individual sovereignty, would need to respect every choice –including those he considers to be totally aberrant – as long as his patient was not incompetent in law (children under the age of 18, or incompetent adults, i.e. individuals under the protection of a conservator).

## **VI.2. Obligation of care**

In itself, the obligation raises immediately an ethical issue: how can society abolish an individual’s ontological freedom by forcing him to submit to treatment against his will? The question is particularly acute in a medico-judiciary context where people are obliged to accept treatment designed to protect them from a recurrence of behaviour, essentially focused on sexual delinquency, either during incarceration or after their release. If treatment is not the result of voluntary acceptance on the part of the person concerned, it may well be experienced as an unbearable constraint from which the subject will seek to escape. It is also understandable that the law would see this forced therapy as a measure for the protection of society. Such obligation to care is at its acme when forced hospitalisation follows a request by a third party or by the medical profession itself. The conditions for admission are perhaps less crucial than conditions for release or continuation which should be subject to speedy, renewed and pluridisciplinary expertise. How can a pregnant woman be made to follow treatment to

<sup>22</sup> <http://www.conseil-national.medecin.fr>

<sup>23</sup> A. Kahn, *Et l’homme dans tout ça ? Plaidoyer pour un humanisme moderne*. Paris, Nils éditions, 2000 p.330

protect her unborn child? All kinds of recommendations can be formulated, using arguments as persuasive and respectful as possible, but the bottom line still remains the informed dissent of the pregnant woman herself.

Finally, as noted above, obligation of treatment may be opposed by an individual, but there are legal limitations that permit the opposition to be overruled. Although no one can oblige a sick person to accept treatment against tuberculosis or HIV, even if there is a strong probability that the contaminating agent will be disseminated, the situation is different for certain highly contagious diseases for which the law requires notification and quarantine.

Obligation of care becomes entirely significant in a situation where treatment has been refused. Respecting refusal of treatment must not, quite obviously, extinguish the obligation to continue care.

### **VI.3. The concept of respect**

Legitimising refusal of treatment in the name of respect for individual sovereignty may seem like a less than credible hypothesis in several kinds of medical situations if it rests on the basic premise that the individual concerned has full freedom of choice, cognizance and is independent of any external pressure. How should one consider for example a patient's refusal of appropriate treatment for the reason that he is aware that it could interfere extensively with his professional career. Is it not the case that refusal in such a case is expressing a form of subjection to economic and social constraints? A patient is always caught in a network of contexts – personal, social and cultural – that determine his reactions. Freedom to refuse treatment, because society does not provide the possibility of a minimum social status or of work is a major ethical problem. Can the doctor accept the obligation to behave as though he was dealing with a free individual simply because there was no obvious pressure from the patient's family? Can it be said in such a case that the doctor "respects" strictly speaking, the patient he is dealing with?

For the doctor, respecting a decision which is clearly unreasonable is a challenge to his moral and professional responsibility. He will never cease to feel remorse at having failed to persuade or of seeming indifferent or insufficiently concerned of those in his charge. To respect a patient is above all to make him feel that whatever decision he may take, he will not be left to his fate unaided. A carer must care to the end.

If he meets with refusal, he cannot force his patient. Quite frequently a patient may *appear* to be irrational or seem to obey incomprehensible psychological imperatives, a doctor's duty is nevertheless to continue caring. When a patient is totally lucid and seems to be fully autonomous, the doctor's only recourse is to acknowledge the existence of an insoluble moral dilemma: the doctor is still responsible, but is powerless to act. The patient has his *own rationale*, although it may lead to his own death.

### **VI.4. Has technological progress modified the apparent freedom of the individual?**

It is an illusion to believe that individuals are in a position where they master contemporary medicine. The notion of evidence-based medicine, by its very concept, is no encouragement to questioning therapeutic projects. Although in quantitative terms, it is still in the minority, evidence-based medicine, which is increasingly effective, does

not take kindly to contradiction in the name of subjective motivations which, by definition, cannot be made objective. There is a growing gap between what the doctor knows and proposes as a result of objective norms and the patient's subjective impressions. Sometimes there are other reasons for rejecting therapy than because it could be ineffective. However, it must be remembered that the very notion of "evidence" of medical efficacy is complex, inconclusive, and depends on the possibility of verifying the quality, reliability and exhaustiveness of the scientific and medical publications that provide that "evidence", as has been recently demonstrated by withdrawal of drugs or of their indication for certain age groups.

The growing compartmentalization of medical practice is also leading to a situation in which specialists are becoming incapable of judging the validity of a therapy if it is not used in their own special field. Biological parameters or imagery are become less and less disputable — and less disputed — in confrontation with subjective criteria.

This tension between two points of view justified on the basis of reasoned arguments, expressed or tacit, is becoming much more frequent at a time when medical practice, which used to be based on medical paternalism, evolves in the direction of a therapeutic alliance with the patient. Without wishing to embrace the systematic opposition to paternalism that would be typified by a logic entirely based on contractual notions, the defects of which have already been mentioned, present trends call for better mutual acceptance of the views of both parties. Viewing in a common perspective the "objectivity" of the one and the "subjectivity" of the other sometimes reveals behind the veil a doctor's subjectivity and a patient's objectivity! Understandably, on both sides, an original blend of rebellion and freedom may be sought, specifically in the name of what one sees as freedom but the other experiences as constraint.

#### **VI.5. Does the asymmetric nature of the doctor/patient relationship play a role in treatment refusal?**

To solve a conflict, the person who is in a situation of strength or power, in this case the doctor, to be able to recognise the asymmetry of the situation and the degree of constraint inherent in the conflictual circumstances. To view the conflict in perspective and to recognise that it exists can be in itself beneficial by creating a situation where opposing points of view can be expressed. Attempting to discover the underlying source of antagonism and its impact on each of the actors may help to solve the conflict or at least to reduce the amount of stress and resentment.

Exploring together the differences of opinion that are expressed and recognised can also, paradoxically, have beneficial effects. The attention paid, recognition of the other's values and a spirit of cooperation make it easier to understand that refusals, far from being a simple binary (yes or no) opposition to a question, in fact express a process. Decisions are triggered but only taken after interaction with the person's various psychological filters. The fact that the initial question becomes a stressful or conflictual experience is quite frequently only the result of the particular situation in which the individual, patient or carer, finds himself.

Some of the components of the situation are mirrored within medical practice itself. When the profession investigates the reason why the results of guidelines are not followed by some practitioners, the solution is to be found in the fact that the situation, the environment and the recognition of subjective factors within the entourage or environment weigh on the decision in a direction which was not always the one expected by the question which had been put objectively to factual medical practice.

Refusal on the part of a patient must therefore necessarily lead the doctor to analyse in cooperation with the patient the differences in kind and degree that are observed. More than a difference, it is frequently a matter of asymmetry of points of view, so that the doctor who seeks an honest and equitable resolution of the divergence, must tread the path of reciprocity. Precisely because the practice of medicine has become increasingly scientific, so that the notion that decision to treat and the choice of treatment are objective and obvious decisions gain greater credibility, doctors must integrate a greater degree of doubt than previously and must learn to handle the new forms of consent they require from the patient. Authorisation, assent, permission, acquiescence, approval and endorsement, are all closely allied to consent, but are nevertheless different concepts that are so many new avenues for relationships between the parties.

As regards informed consent, the situation corresponds to the definition given by Jean Bernard: consent is by essence an issue of deontology, whereas the fact that it is informed is a matter for ethics. But we are also in an entirely new situation which cannot be defined as some kind of automatic consent; a question put to the patient for which the only expected answer is “yes”.

#### **VI.6. Ethical issues raised by refusal of treatment by and for a third party.**

Refusal of treatment **by** a third party is always also refusal **for** a third party.

When a third party refuses treatment for a patient, he not only puts himself in the place of that person, he also takes that person over, since refusing treatment for oneself and for a third party are two very different matters. Personal convictions, emotional relationships and interests may overshadow or contradict the interests of the patient. The difficulties encountered when there is a transfer of consent from an incompetent person to the family or a trustee are well known. Proximity may be in contradiction with the patient’s true interests. Refusal by a patient and refusal expressed by a third party can never be deemed to be one and the same. Nor is the issue confined to interpreting the refusal expressed by a third party; the central issue is the legitimacy of that third party, a subject on which controversy is endless. Who is this third party? Is he or she a member of the family, a friend, a legal representative? What interests come into play, known or concealed? Is the third party competent to judge the best interests of the patient and to make known his true wishes? These questions become all the more acute in a sectarian environment when the third party steps in without debate or hesitation to take over any true or apparent patient autonomy.

CCNE has already made its views known regarding the ethical consequences of consent for the benefit of another person<sup>24</sup>. One of the key elements was to attempt to differentiate between what was specific to the patient himself compared to the third party from whom consent was being requested. In the event of refusal, the doctor must seek to discover the difference between “what do you think” and “what do you think that the patient thinks”. Applied to the difficult issue of consent (or refusal) to organ donation after brain death has been duly certified, this approach has been found helpful to attenuate the state of tension which sometimes exists at first within a family.

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<sup>24</sup> Opinion n° 70, Consent for the benefit of another person. December 13, 2001, <http://www.ccne-ethique.fr/english/start.htm>

In the particular case of a mother delivering a child and refusing a caesarean section at the last moment, the issue of a third party arises in the presence of partner or father. Is it really possible to accept an injunction on the part of a third party not to proceed with a caesarean for a woman who is obviously weak and vulnerable?

#### **VI.7. It is possible to evaluate the reality of freedom of judgment? Is there such a thing as free will?**

Apparently, apart from situations of incompetence as recognised by law, free will is presumed. But in fact, it is very much of an illusion in a number of situations<sup>25</sup>.

When a patient's consciousness is impaired by disease, denutrition, or birthing, is it possible to make sure that capacity of judgment is still sound and to make sure that the person concerned has fully understood the gravity and importance of the issues? Is it possible to consider that an opinion once expressed has permanence and stability although volatility of the will to live in a situation of distress is well known? How does one set about finding out whether the perpetrator of a suicide has really relinquished the wish to live?

In such circumstances, the medical profession is in a serious predicament. Doctors must take care to avoid considering such refusal of treatment to be equivalent to freeing them – most conveniently – from obligation. There is a difficult moral path to tread between excessive intrusion and the risk of not easily acceptable laxity. In Opinion n° 84<sup>26</sup>, CCNE recommended training in medical ethics in higher education.

An in-depth analysis of treatment refusal is always necessary. Is the problem related to **understanding**, or **perception** by the patient of the impossibility of effecting a cure, **disturbed reasoning**, or the **expression of opposition** to healthcarers? Or is it in fact a rational and reasoned refusal?

This semiology always deserves examination to avoid reducing refusal to a simple statement of opposition.

The concept of failure to assist a person in danger does not solve all the problems. It can serve as a pretext on the part of the carer to apply constraint in the name of possible legal retribution. This legal concept was designed to fight society's indifference to a person in distress, not for the protection of physicians in all their activities.

The very notion of failure to assist a person in danger cannot be used automatically to allow resuscitation of a new born child at 21 weeks of gestation or to systematically proceed with tracheotomy in the case of respiratory failure at the end of life. Similarly this applies to those who would seek to invoke this principle against doctors who had decided not to provide care which they considered futile. It is important that the principle of failure to assist a person in danger should not be allowed to exacerbate existing tensions in the field of treatment refusal.

The medical pact recommended by Paul Ricoeur can generate ethical dilemmas. The rights of patients may contradict the duties of physicians. Society's demands for ever more security, compensation, limitless observance to the principle of precaution whatever the circumstances, create a defensive attitude on the part of physicians who may feel that they must defend themselves from the reproach of never doing enough. This attitude is encouraged by judiciarisation which sometimes is detrimental to respect

<sup>25</sup> The issue of free will and determinism of behaviour is under review by CCNE.

<sup>26</sup> Opinion n° 84, Opinion on education in medical ethics, April 29, 2004. <http://www.ccne-ethique.fr/english/start.htm>

for autonomy. Starting from intrusive absence of recognition of the autonomy and liberty of patients, the progression leads to feelings of guilt for not having responded to distress by technical efficacy. Nor should it be thought that such dilemmas are the monopoly of the medical profession. Patients themselves may be confronted with a choice between acceptance and refusal on the basis of fairly fluctuating argumentation. Our society, which refuses death and considers that there must be a therapeutic remedy to any condition and that medical technique can always come up with an answer, also feels with some justification that excessively invasive medicine may need to be kept at bay.

In serious and significant cases, the moral dilemma is acute. Someone's body is at stake, someone's life or health, but it is also the meaning, with all its deep-seated values, that the person concerned seeks to inject into this episode of his life that is in question. In such a situation, the issue is to keep patients and doctors well within the truly significant human relationship that has always been sought after and retain the quality of trust that should pervades the medical relationship despite a diversity of views.

Beyond these philosophical considerations, the necessary medical action (or absence of action) limits the true scope of pure philosophical reflection. A physician will always be called upon to act and this constraint makes it all the more necessary to reflect on the authority he holds de facto. This need to act makes it all the more essential to provide training on reflection and humanity.

## VII. Recommendations

The Committee therefore offers the following recommendations:

1 – Make every effort to avoid having to take important decisions in a time of **crisis**. Be it in the field of somatic or psychiatric medicine, whenever possible, it is necessary to **anticipate** situations to the fullest extent possible, so as to avoid serious conflict arising when a new treatment, which could motivate refusal, needs to be adopted.

2 – Promote feelings and attitudes of mutual recognition. Except in an extreme emergency, doctors should never force a therapeutic option onto to a patient, nor should they adopt an attitude of evasion, desertion or emotional blackmail. Professional responsibility is to continue caring whilst respecting as fully as possible the decisions of patients who should be able to understand on their side the moral obligations of those caring for them.

3 – Not bow to the **medical and legal obsession** of the “failure to assist a person in danger” principle which should not obstruct a physician to patient relationship based above all on trust in the help that a doctor can be expected to provide to his patient, although the doctor must protect himself from rare but nevertheless possible situations of refusal by securing written mention of it.

4 – Be aware that information must, whenever possible, be a **progressive** and **evolutionary** process which can be **reviewed** if needs be, so as to take account of the occurrence of psychic sideration.

5 – Be aware that information is the expression of facts or opinions explained in apparently objective terms, based on knowledge specific to the person providing the information, but addressed to another's subjective understanding. Information cannot therefore ever be completely objective, because the **subjectivity of the provider and the subjectivity of the receiver interact in the process of communication and continually modify the conditions of the exchange.**

6 – Be aware that in the mingling of two freedoms, compassion carries the danger of **abuse of authority**. Physicians must be aware of this and be trained to hear the expression of a patient's freedom, as CCNE stated in Opinion n° 84 of training for medical ethics: appreciation of the degree of autonomy must be under constant review.

7 – Not presume total absence of liberty to avoid taking into account refusal of treatment; the physician must not take advantage of this vulnerability. A vulnerable person must be respected by providing information in such a way that the matters at stake can be understood, while avoiding both emotional blackmail and indifference. One cannot force people to do what is good for them in the name of the need for human solidarity and the obligation to assist a person in danger.

8 – Reflect on a new appreciation of medical deontology which could take account of a growing demand for autonomy. The unreasonable nature of obstinacy must also be judged by the patient and not by the doctor in isolation.

9 – As always in a crisis, not only call for a **second opinion**, but also for a **mediation process** or function, so that patient and physician or physician and family are not left in a confrontational situation on their own. Through such a process, third parties can make patient or physician aware of the **recognition** they may have one for another and all that it implies. The notion of trustee, included in the March 2002 law, attains its full expression in this procedure. The contribution of psychologists, or in some cases psychiatrists, and of healthcarers, cannot be overemphasised. The aim is in fact to not only receive a statement of refusal as being truly significant, but also to judge the degree of derangement, if there is one. This does not imply that a third party should be left with the responsibility of making a decision; it signifies helping individuals to govern themselves.

10 – **Accept the need to disregard refusal of treatment in exceptional circumstances**, whilst maintaining an attitude of modesty and humility which can help relieve tension and launch a dialogue. Although it is impossible to set precise criteria, some situations could arise where this transgression would be permissible, when time constraints endanger the life or health or a third party. For instance:

- A situation of urgency or extreme urgency where medical decisions must be taken immediately in the presence of an unconscious person or one who is in no position in practical terms to give consent at that time. The presence of a third party, even though the third party is in possession of anticipated statement of will, is not a decisive circumstance.

- An emergency delivery when the life of the unborn child is at stake. Ethics in such circumstances must not be a screen for spurious good conscience excessively respectful of patient autonomy.
- Situations where the safety of a group is in question, as in the case where there is a risk of a serious epidemic, when the liberty of one individual must be considered responsibly in the light of the duty of solidarity with others.

**11 – Respect individual liberties as long as they do not encroach on the liberty of others.** Refusal of a caesarean or a transfusion must be discussed in situations which are not emergencies.

**Refusal of treatment clearly expressed by an adult still of sound mind can only be respected, even though it will lead to his or her death.** To provide medical care does not mean only taking into account a person's medical situation; the person as a whole is involved. **To help someone does not necessarily mean imposing treatment.** This is the paradox that the medical profession sometimes misjudges, but they must accept confrontation with a "grey area" where the concept of beneficence may be questioned.

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## Annex : historical analysis

The history of refusal of treatment as expressed by the patient, is bound inevitably with the history of individual rights and autonomy.

Since Hippocratic times, there have been fluctuations depending on the degree of power that society was willing to grant to medicine and members of the medical profession.

Hippocratic writings do not mention the possibility of rejecting medical prescription. They do however touch upon efforts to be made by the doctor to achieve the best possible relationship with patients.

Hippocrates sought equality in this relationship. He went so far as to recommend two seats of identical height when examining a patient so that he who knows should not dominate he who suffers!

The possibility of joint decision is not therefore ruled out, all the more so since the Hippocratic physician makes an effort to “*penetrate the intimate custom of beings*”<sup>27</sup>, the better to understand them.

The Hebrews also prescribed such particular attention to patients. The Talmud, in the tractate *Baba Kamma*, encourages the physician to seek the patient’s opinion before an intervention. If consent is not given, there can be no action. There again, it is safe to deduce that refusal of treatment is “acceptable”.

Centuries later, Christianity developed “another arrangement of what pertains to life and death”<sup>28</sup>. The world of medicine was disturbed at first but then changed in meaning and function. It became a kind of secular arm of the God who tries mankind through disease.

The patient, to save his soul, must submit to the rules of religion. The physician is encouraged to make sure he conforms. Confession for example is part of care to the extent that in France — in 1712 — it became mandatory by royal decree. The sick are doubly subject, in their soul and in their body.

The law is just as binding for those who consult a healer or a sorcerer because they cannot afford to see a doctor<sup>29</sup>.

In every situation, patients are kept in a state of “disquieting dependence”.

In the long centuries that made up the Middle Ages, there were no signs — in France at least — of any favourable progress to patient autonomy and the possibility of refusing care.

Yet, at the same time, it would seem that the idea was gaining ground in other cultures. Physicians, for example Avicenna in the 11<sup>th</sup> century or Maimonides in the 13<sup>th</sup> century, both insisted on the central role to be played by patients. It does not seem too far fetched to consider that these famous physicians considered the sick person as a subject for attention and not simply an object of care.

It was in fact at the end of the Middle Ages, in Spain, that the notion of refusing treatment began to emerge.

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<sup>27</sup> J.P. Peter, *Hôpital et utopies*

<sup>28</sup> *id*

<sup>29</sup> Michelet, *La sorcière*

In the 16<sup>th</sup> century, in treatises on “temperance” and “homicide”, the Spanish theologian Francisco de Vitoria – known for his defence of the rights of Indians – considered the obligation to save life at all costs. To the question “Is it suicidal to refuse what will permit a continuation of life?” he responded clearly that refusal is not necessarily suicidal and that consideration must be given to the burden and efficacy of the means to achieve this purpose. This approach to the end of life, taking into account the patient’s wishes not to have his days artificially prolonged, was shared by many other moralists, such as Cardinal de Lugo in the 17<sup>th</sup> century and Saint Alfonso de Liguori<sup>30</sup> in the 18<sup>th</sup> century.

In their reflections on refusal of care, these Renaissance theologians did not elude the issue of suicide that such refusal might be concealing. However, placing their trust in discernment, they tended to welcome rather than reject the wish not to prolong “at any cost” the life of those confronted with an extreme situation. In fact, they only considered prohibition in respect to *means*, making a clear distinction between *ordinary* and *extraordinary*. “Ordinary means” are those that allow any human being (sick or well) to stay alive, such as food which it is not allowed to refuse, except at the time of death if revulsion is too potent. “Extraordinary means” are those which a man may judge to be too costly or trying. He may, therefore, refuse them if he so wishes.

In his doctoral thesis (1989), on “Conserving human life”<sup>31</sup>, the American scientist D.A. Cronin points out the convergence in views between these thinkers from different centuries. He considers that the more difficult of access, costlier in every sense of the word, of more doubtful efficacy and causing more suffering a treatment may be, the less a patient is bound to accept it.

This position is explicable by the tragic nature of a number of situations: unbearable pain akin to torture, as in the amputation of a limb; the impoverishment of families entailed by the burden of a seriously sick relative. Considering this latter case, one moralist goes so far as to state that: “No one is bound to ruin his family to gain a few days”.

*“This distinction has persisted throughout history, nourished by a tradition that maintained its initial meaning. It was used in 1957 by Pope Pius XII to justify the legitimacy, in many cases, of ceasing resuscitation. This position helped French physicians to decide on the appropriateness of interrupting treatment of patients presenting signs of death and greatly facilitated recognition of the paradoxical status of brain death”*<sup>32</sup>.

However, this statement should not be understood as having any bearing on refusal of treatment. It was simply related to an evaluation of the proportionality between care and its finality. The patient was not concerned as such.

During the 20<sup>th</sup> century, doctors in the West, nourished on scientific and technical progress, transposed into their practice the age-old distinction which had to a great extent preserved patients’ freedom of choice. Thus, “ordinary means” suffers a change

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Although some authors consider that there was a time, a golden age of medicine, when the patient’s wishes were always respected, this has gradually ceased to be the case, step by step, and surprisingly long after the “therapeutic break” which Michel Foucault uses to describe the Pasteurian era with its cohort of major discoveries that profoundly changed medical science.

In fact, it was between 1930 and 1950 that another view of the relationship between doctors and patients emerged.

It is epitomized by the words of Dr. Louis Portes, the first President of the French Medical Association:

*“Since the normal medical act is essentially based on trust in free association with conscience, a patient’s informed consent, at each step of this minor human tragedy, is no more than a mythical notion that we have vainly attempted to infer from the facts”.*

This paternalistic attitude however is not common to all physicians, as testified by Professor G. Payen in his work *Déontologie Médicale*: *“We presume, as is commonly thought, that a patient need not use extraordinary or painful means to save his own life. It follows that, more often than not, he remains entirely free to accept or refuse serious mutilation or a hazardous procedure”.*

However, as emphasised by Patrick Verspieren, there is no real opposition in terms. These apparently contradictory statements can be explained by the difference in the degree of intrusion between a medical act and a surgical procedure. The more invasive the procedure, the more patient consent is required.

After the Second World War, contrary to Anglo-Saxon countries where the patient’s wishes continued to prevail and the boundaries of medical science remained under discussion, France intensified its paternalistic logic.

During the thirty prosperous years until the early ‘70s, patients’ wishes were ever more rarely heeded by doctors whose confidence was constantly shored up by extraordinary progress in the fields of science, genetics, medical imagery and pharmaceuticals.

But boundless admiration for progress was not the whole story. In fact the medical profession exercised a complete monopoly by reason of the role of social regulator that political leaders allowed them to play. In some rare but tragic cases, this led to abuse such as the case of sterilisation performed for reasons of “social hygiene” involving 13,000 people between 1941 and 1975, in a country as democratic as Sweden.

The creation of the French national health system (*Sécurité Sociale*) and the media reinforced this influence on society until quite recently, as underlined by Professor Bernard Hoerni.

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The questions touched upon both the nature of the patient-to-doctor relationship and the boundaries of medical competence. They were amplified by confrontation with new realities: the temptation to prolong life beyond its natural limits, the impossibility of dialogue between people from different cultures or opposite lifestyles and the exponential cost of care.

Since 1996 and the publication of the "the hospital patient's charter", many signs indicate that patients are gradually returning to the state of "subject" and not simply an "object of care". Does that mean that patients are "actors in their own treatment protocol" (and therefore entitled to refuse care), as encouraged by the spirit of the law dated March 4, 2002? Ongoing debate on the first three years of enforcement of this law highlights the difficulties healthcareers face in adopting it and patient impatience to be heard. Conclusions of the debate more often than not seem to be a call for dialogue and mutual understanding. It is probably the quality of that dialogue and understanding that will be the start of a new phase in the history of refusal of treatment. Dialogue and understanding, once established, could transform the outlook and attitude of carers and those they care for.

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