PRESIDENZA DEL CONSIGLIO DEI MINISTRI
NATIONAL BIOETHICS COMMITTEE

REFUSAL AND CONSCIOUS RENUNCIATION OF HEALTH TREATMENTS IN THE PATIENT – DOCTOR RELATIONSHIP

24th OCTOBER 2008

INTRODUCTION

The national Bioethics Committee (NBC) approved the opinion ***Refusal and Conscious renunciation of health treatments in the patient – doctor relationship.*** Due to an ample number of cases regarding the issue under discussion, the NBC deems it appropriate to deal with the issue of the refusal (request to not begin) and the *renunciation* (request to suspend) of life-saving healthcare by a conscious patient of sound mind, who has been suitably informed of the therapies and who is able to express his own will on the question. We have not, however, taken into account situations regarding patients who are unable to express a conscious and legally relevant choice (minors, mentally ill patients, patients in persistent vegetative state, etc.). In part, these issues have already been discussed by the NBC in other opinions, such as *Information and consent relating to medical acts*, 1992; *End-of-life issues in bioethics*, 1995; *Advanced care statements*, 2003. Within the situation under discussion we have also deemed it necessary to differentiate the position of the *autonomous* patient, able to avoid undesired therapy without involving others, from the position of the patient in such *conditions of dependence* that the doctor's intervention becomes necessary.

Different positions have emerged within the current Committee, both from a bioethical and a legal point of view, some shared and some not. This text has been drawn up by Prof. Stefano Canestrari, Prof. Lorenzo d'Avack and Prof. Laura Palazzani, with the contribution of all the members of the working group coordinated by Prof. Stefano Canestrari. Of particular interest for the drafting of the document are the written contributions of Prof. Salvatore Amato, Prof. Adriano Bompiani, Prof. Francesco D'Agostino, Prof. Antonio Da Re, Prof. Marianna Gensabella, Prof. Demetrio Neri, Prof. Andrea Nicolussi, Prof. Monica Toraldo di Francia and Prof. Grazia Zuffa. In the plenary meeting of the 24th of October 2008 the document has obtained the consensus of those present (Prof. Salvatore Amato, Prof. Luisella Battaglia, Prof. Stefano Canestrari, Prof. Antonio Da Re, Prof. Lorenzo d'Avack, Prof. Emma Fattorini, Prof. Carlo Flamigni, Prof. Romano Forleo, Prof. Silvio Garattini, Prof. Laura Guidoni, Prof. Aldo Isidori, Prof. Claudia Mancina, Prof. Demetrio Neri, Prof. Laura Palazzani, Prof. Rodolfo Proietti, Prof. Lucetta Scaraffia, Prof. Monica Toraldo di Francia, Prof. Giancarlo Umani Ronchi, Prof. Grazia Zuffa, Dr. Riccardo Di Segni), with the abstension of three members (Prof. Adriano Bompiani, Prof. Francesco D'Agostino and Prof. Maria Luisa Di Pietro). Prof. Marianna Gensabella, Prof. Andrea Nicolussi and Prof. Alberto Piazza, absent from the meeting, have nevertheless stated their agreement with the document. To better

clarify their reasons regarding some of the issues that have been discussed and some of the conclusions that have been reached in the opinion, a number of personal remarks have been drafted, respectively signed by Prof. Adriano Bompiani, Prof. Bruno Dallapiccola, Prof. Maria Luisa Di Pietro and Prof. Aldo Isidori; by Prof. Roberto Colombo; by Prof. Francesco D'Agostino, to which Prof. Assuntina Morresi has also agreed, by Prof. Antonio Da Re and Prof. Andrea Nicolussi, to which Prof. Salvatore amato and Prof. Marianna Gensabella have agreed, and by Prof. Vittorio Possenti. These personal remarks are published within the text of the opinion.

In conclusion, the document presented here is the result of ample discussion on the issue of refusal/renunciation of health therapies within the patient – doctor relationship, which is one of the most controversial issues in the current bioethical debate in our country, as demonstrated by the recent dramatic cases which have had a strong impact on public opinion, politics and the law.

The President

Prof. Francesco Paolo Casavola

DOCUMENT

1. The problem

The theme of the refusal or the conscious renunciation of health treatment is at the centre of a variety of problems that can be without a doubt listed as the most controversial in the current bioethical debate[1]. As demonstrated by recent dramatic cases which have had a strong impact on public opinion, because they have attracted interest to the problems and decisions we face at the end of our life, the issue presents profound challenges on a number of different but connected fields.

From a moral and legal point of view, the conscious refusal/renunciation of a health treatment profoundly involves both the idea of individual self-determination in health choices (informed consent to the medical act, limits in the length of human life, etc.), and the definition of the deontological statute and of the social function of the medical profession, with particular focus on the meaning of cure and to the role of the therapeutic alliance.

As already accepted, the informed consent can not be considered implicit and automatically inferred by the fact that the doctor's actions are determined by the patient's wellbeing. In the current medical ethics, the informed consent has a key role, allowing the full weight of the choices made by the competent patient, on the basis of the principle of autonomy. As known, modern medical and biotechnological science has instruments of intervention that are able not simply to extend, but to profoundly transform the very way in which we experience the illness up to the last moments of our existence, opening new areas of choice for the patient. He/she is in fact called upon to choose not only between the various typologies and methods of cure available, but also, consciously and within the law, to refuse or to renounce the medical treatments already in use.

From a legal point of view, the impossibility to outline a general obligation to cure oneself – the coercive imposition would be, in any case, generally excluded – has its basis in the Constitution. Especially relevant is article 13 of the Constitution, which ratifies the inviolability of personal freedom. Its minimum and incontrovertible content is represented by the possibility for the subject to have the exclusive control of his/her own physical body, even if within the limits and obligations imposed by the regulations; and especially article 32, co.2 of the Constitution, which ratifies: "No-one can be forced to undertake a certain health treatment if not so stated by law. The law can not in any way violate the limits imposed by the respect due to the human being".

The limits and the guarantees ratified in article 32 of the Italian Constitution can be found also in the ordinary rank regulations[2], as well as in various

[1] It must be clarified that both "refusal" and "renunciation" indicate a disagreement towards a therapeutic proposition. However, the NBC believes that it is important to use the term "refusal" when applied to the request of not beginning a therapy and the term "renunciation" when the request is to suspend a therapy already under way.

[2] L. 23rd of December 1978, n. 833, art. 33 (*Founding law of the national health service*); D.L. 24th of June 2003, n. 211 (*Law on clinical experimentation*); L. 19th of February 2004, n. 40 (*Law on medically assisted procreation*); L.21st of October 2005, n. 219 (*Law on transfusional activity and the national production of hemoderivatives*).

judgements by the Constitutional Court[3] and by the Court of Cassation[4], as well as on the level of the jurisprudence of merit[5]. In addition, they can be seen in various dispositions by the *code of medical deontology*, in particular the articles 35 and 37, item IV (titled *Information and Consent*).

Beyond the national level, the same principles inform both the *Convention on human rights and biomedicine* (1997 Oviedo Convention) – which in art. 5 establishes that "intervention in the health field can not happen until after the interested party gives a free and informed consent" – and the European Union's *Charter of fundamental rights* in 2000, which in item I, article 3, states: "The free and informed consent of the interested party must be particularly respected in the field of medicine and biology, in accordance with what is laid down by the law".

Despite the picture we have briefly outlined, some issues are nevertheless controversial. Firstly, the wish to avoid undergoing a health treatment can be brought back to two fundamental hypotheses: 1) when the treatment has not begun yet and the patient refuses to undergo it; 2) when the treatment has already began under the doctor's responsibility or the responsibility of a medical team, and therefore the patient shows the intention to renounce it when the patient – doctor relationship is in fully developed.

The first hypothesis, as directly linked to the theme of the informed consent to the cure, has already been partly discussed by this Committee (see Opinion *Information and consent related to medical acts* of the 20th of June 1992). The second, however, has not so far been directly taken into consideration.

On this point, it is especially about establishing the content and the limits of the right to consciously refuse/renounce health treatment, with particular focus, on the one hand, to deciding which treatments is lawful to refuse and, on the other hand, to question the concrete possibility to operate such right when on trial. To this we add the fact that, next to positions favourable to the broad interpretation of the right to conscious refusal/renunciation to health treatment, there is a different position in the legal and doctrinal thought which, by stressing the first subsection of the art. 32 Const. in particular, urges a different solution to the balancing of the values that come into play, reducing the possibility to recognise an unconditional and unquestionable right to refuse/renounce any therapy, no matter what the context might be. We will return to this point at length later on in this document.

1.2 The issue of the conscious refusal/renunciation to medical treatment can give rise to different issues according to the particular context that surrounds it. Various factors come into play: from the nature of the pathology the patient is suffering (light, acute, chronic, etc.), to the typology of the proposed treatment (of brief or long length, invasive or non-invasive, statistically efficient or of poor/uncertain efficacy, pharmacological or surgical, such that it requires hospitalisation or not, etc.); from the accessibility of the medical and welfare services to the quality/quantity of the available resources; and still, the existential

[3] Constitutional Court 161/1985; C. Cost. 561/1987; Constitutional Court 471/1990; Constitutional Court 258/1994 and Constitutional Court 238/1996.

[4] Between the most recent: Cassation 23676/2008; Cassation 5444/2006; Penal Cassation 38852/2005; Penal Cassation 14638/2004; Penal Cassation 26446/2002.

[5] Between the most recent: Appeal, Milan, 25th June 2008; Tribunal of Modena, 13th May 2008; Penal Tribunal Rome, 17th October 2007; Tribunal of Campobasso, 26th of April 2004; Tribunal of Modena, 20th December 2001.

situation the patient finds him/herself going through (situation that can in itself be quantified differently according to a variety of parameters: the age of the patient; the context of his/her family, as well as the socio-cultural, economic and ethnic contexts; the health and welfare context within which he/she should receive the treatment, etc.). Therefore, having considered the wide variety of concrete problematic circumstances that regard not only "extreme cases" (which have captured public opinion's attention) but also events that belong to everyday experience, a preliminary delimitation of the objective of this document becomes necessary, in order to avoid unwanted assimilations or arbitrary generalizations.

It is the intention of the NBC to examine a specific and well defined issue: the conscious refusal or renunciation, total or partial, of health treatments that have not yet began or have already began, expressed by an informed patient of sound mind, and directed to the doctor (or to the medical team), appointed with fundamental legal and deontological obligations and under whose responsibility the treatment is taking place. The NBC does not here intend to discuss problems that have already been examined: the general issue of bioethics at the end of one's life; the requirements for the informed consent; the problem of the refusal/renunciation expressed beforehand by the incompetent patient or by the patient who has not yet reached adulthood[6].

With regards to the field that we have identified, it is necessary to distinguish at least two different situations.

A first and most relevant distinction is the one between the patient independently able to avoid the undesired therapy and the patient who finds himself in such conditions of dependency that the intervention of another subject – the doctor – becomes necessary in order to concretely carry out the interruption of the cure. It is this last hypothesis that appears particularly problematic: the necessary collaboration of the doctor raises, amongst others, the problem of his deontological and legal qualification, and of the respect of the obligation to protect the patient with regards to the "position of guarantee" held by the health worker.

A second distinction can be highlighted between the hypothesis in which the refusal/renunciation to the treatment does not lead to the patient's death (for example simply a partial renunciation to the cure), and the hypothesis in which the renunciation seems to be, in a cause-effect relationship, the determining element leading to the patient's death or to a strong acceleration of the lethal process.

An additional profile that needs to be taken into account consists of the distinction between refusal/renunciation to a proportionate cure and a disproportionate cure (which comes into the notion of "therapeutic persistence"). The expression "therapeutic persistence", even if largely used, appears generic and in itself is contradictory when referred to cases in which the methods used do not have, in practice, any therapeutic effect anymore. For this reason the NBC believes that it is preferable to use the expression "clinical persistence", referring to a disproportion between the efficacy and the heaviness of the cure and the benefits that can be obtained in the concrete clinical circumstances (they are called, in this instance, "futile cures"), it being understood that each treatment must be evaluated balancing the potential positive (benefits) or negative (*neminem laedere*) contributions.

[6] Cf. the opinions: Information and consent related to medical acts, 1992; End-of-life issues in bioethics, 1995; Advanced care statements, 2003.

On the patient's right to avoid disproportionate cures and, even before that, on the doctor's *duty* to abstain from practicing them, there is unanimity of view. The discussion is about the acceptability, from a moral and legal point of view, of refusing or renouncing, in conditions of independence or dependence, cures that, even if not considered to be clinical persistence, do not improve the patient's living conditions but simply prolong his/her illness until its still inexorable outcome.

The issue of the possibility of accepting a conscious refusal/renunciation of the treatment therefore constitutes a problem of great relevance in a highly technological medicine.

2. The refusal/renunciation of treatment and autonomy

The NBC takes into account how the refusal or renunciation of the therapies by an autonomous and competent patient is legally legitimate – when the patient is self-conscious and aware of his/her own condition, as well as thoroughly informed about the illness and the consequences deriving from accepting or refusing/renouncing the therapies.

The constitutional and normative references already mentioned in 1.1 confirm that, if on the one hand a fundamental *right to care* is recognised, on the other hand a *general obligation to cure oneself* cannot be established, as healthcare can not be coercively imposed, if not within the limits and the guarantees provided for in the aforementioned article 32, subsection 2, of the Italian Constitution. The current regulations do not accept, therefore, the forced imposition of a treatment independently and consciously refused, even if it is necessary to keep the person alive. It is not possible to oppose the choice of who, exercising his/her own free will, requests not – this must be clear – to be helped to die, but simply to not be (further) subjected to unwanted care, accepting that the pathology that affects him/her will follow its natural course, even to its extreme consequences. Although, therefore, health workers are invested with a position of guarantee with regards to the patient's life and health, the legal obligation to act in order to preserve those assets is limited by the patient's conscious, free and informed opposition. The Italian Constitutional Court clearly expressed this point of view (sentence number 238/1996), observing that no-one can be forced to suffer unwanted healthcare in the absence of a law that explicitly imposes it, and that the right to not be subjected to unwanted medical treatments is an inviolable right, being included "amongst the supreme values, as the undeniable, essential core of the individual, non unlike the similar and connected right to life and to physical integrity, with which it joins to create the primary matrix of any other constitutional right protecting the individual"[7].

One thing, therefore, is the material *possibility/ability* to cure; another is the *power* to cure: in the absence of the patient's consent, the doctor, although concretely in possession of the professional ability to carry out positive therapeutic procedures, does not have a full power to cure. We must therefore keep the distinction between these two different levels: on one hand, the technical and professional ability to carry out the cure, based on the best science and experience available, and therefore linked to the continuous

[7] Sentence of the Constitutional Court number 238/1996.

progression of medical and biotechnological knowledge; on the other hand, the "authority" necessary in order to legitimise the concrete application of available treatments, an authority that only the patient can give to the doctor through his/her informed consent and is destined, therefore, to cease when the patient negates or withdraws such consent.

The NBC wants to highlight the fact, however evident, that the right to avoid the cure does not alleviate the doctor's duty to inform the patient in science and conscience, verifying also the understanding of the received information and the patient's awareness regarding the consequences of his/her choices: or better still, the correct and full information of the patient constitutes the very premise of the validity of the consent/refusal, that only in this case can truly be said "informed".

According to some NBC members, the conscious refusal of health treatment in conditions of autonomy, even if admissible from a legal point of view, cannot be accepted from an ethical point of view. We particularly refer to those therapeutic treatments that, temporarily applied, allow the patient to overcome his/her condition of grave danger, which can not be avoided in any other way for the subject's survival.

From this point of view we believe that the lack of the legal obligation to cure oneself does not count in order to give ethical legitimacy to an unconditional refusal or renunciation of care. From the point of view of an ethics that believes that human life is an asset in itself, we must distinguish the renunciation to proportionate care from the hypothesis of a renunciation to disproportionate care. The last one, being in effect an acceptance of imminent death, has its place within the area of respect for the value of life, of which it recognises and accepts the intrinsic limit. On the contrary, the renunciation of proportionate care goes against this principle, as it consists of a way of disposing, even if by omission, of one's life. Now, from an ethical point of view, this means withdrawing not only from a responsibility towards others (family, society), but also from a duty towards him/herself to defend and preserve his/her own life, a necessary condition to exercise freedom and morality.

In addition, according to this point of view, there is a risk that the refusal of therapies can lead to a de-evaluation, on a social level, of the people who live in similar conditions of illness (considered less worthy, as they are suffering a poor quality of life): we must instead declare a social responsibility to recognise the full value even of the person who is ill and in extreme conditions. In this sense the duty towards our own health has a social relevance. To this we add the observation that, when confronted with the renunciation of therapies, it arises on a moral level the need to investigate the reasons for this choice (generally due to the pain and suffering in conditions of extreme illness), with the aim to remove, within the limits of the possible, the causes. The elimination of pain and the human and psychological support can create the condition for a repeal of the refusal and a serene acceptance of the therapies. According to this vision, the only reason that morally justifies the renunciation of the therapies is sacrifice in the name of a higher good (it is the case, for example, of the pregnant woman who has a tumour and renounces the cure in order to bring the pregnancy to full term).

In conclusion, the *moral judgement* can present itself, case by case, more problematic in comparison to the *legal possibility* of a conscious refusal of care.

Other committee members believe, differently, that the ethical call to respect life is not incompatible with the request to interrupt all types of care. As the illness is an aspect of existence, to accept its progress renouncing all therapies does not represent the transgression of a moral imperative, but the conscious acceptance of the intrinsic limit of human existence.

Evidently the motivations and the principles inspiring this kind of choices change appreciably according to moral and religious convictions. In any case law and ethics, rather than criticize the validity of an individual's intimate convictions, or the motivations that are the basis of his/her actions, should promote, each in its field, the conditions for a fair access to the best possible therapies, including palliative support when the cure can not provide a healing effect anymore, in view of a social and human solidarity.

3. The renunciation of treatment and dependence

Let's now consider the case of the conscious renunciation of care by a patient who is in *conditions of dependence*, that means, by a competent patient (of sound mind and able to express an authentic, informed and present will), who lacks the physical autonomy necessary to carry out his/her intentions, therefore needing the intervention of a third party, in particular of a doctor (or of a medical team).

Regarding this kind of situation, different positions have emerged in the NBC, which are listed here as follows.

Some members believe that the interruption of care within the therapeutic alliance must be considered as ethically and legally right only in cases of clinical insistence. As expressly sanctioned by the deontological code (article 14), the doctor has a precise *duty* to abstain from a conduct of diagnostic-clinical persistence. The complex definition of clinical persistence happens principally on the basis of two parameters: on one hand, the doctor's in science and conscience evaluation; on the other hand, the patient's individual perception. It is based, therefore, on a mixture of objective data – only definable on the basis of parameters that are scientific and acceptable by the doctor – and the subjective data of the patient's personal perception regarding the "extraordinariness" of the procedure (the patient's "feeling" as it emerges through the dialogue of the therapeutic alliance). At times the renunciation of therapies can be the way to express a reservation towards using certain methods (for personal or religious reasons) but not a request to die: it is the doctor's responsibility to act in order to verify the availability of alternative methods (acceptable to the patient) to provide the patient with healthcare (consider the case of the Jehovah's witness who refuses hemotransfusions but does not want to die, and the possibility that the doctor can prepare bags of blood for self-transfusions or of hemoderivatives).

Having said this, from this perspective, even recognising the relevance of the patient's subjective experiences regarding the extraordinariness of the cure, in the case of proportionate care the possible refusal by the patient can not be acritically accepted. In particular, the request, addressed to the doctor, to become instrumental to the interruption of treatments necessary to survive seems bioethically problematic: there is in fact an evident link of cause–effect between the doctor's action (disconnection of the respirator, or of the means that allow artificial hydration or feeding, etc.) and the patient's death. It is true that such an action, as already pointed out, can be intended as a direct consequence of the cessation of the *power* to cure, but it is also true that it requires a kind of behaviour, from the doctor's part, that presents elements of friction with his duty of care to the patient, to protect his/her life.

We highlight that there are many regulations to protect life, health and physical integrity, which deem that the subject's self-determination that can become detrimental to such assets or even sacrifice them, is illicit. The article 32 of the Constitution inhibits any intervention that invades the sphere of the safeguard of health, reserved to the relationship between the patient and the doctor, except if differently stated by law and within the limits imposed by the respect for human life. There are however situations, as those relative to compulsory vaccinations or compulsory treatments for mentally ill patients, that highlight the need to balance interests, individual freedom and social solidarity, individual's autonomy and health policies of general interest. Health represents, in fact, a constitutional asset of primary importance that "the Republic safeguards as the individual's fundamental right and the community's interest, also guaranteeing free healthcare to the poor" (article 32, Constitution). From this, follows the doctor's social function and the reason why the medical profession itself is authorised, as health is both an individual and a social right, and as such it is subjected to the principle of solidarity. According to this principle, we must avoid a radical "privatisation" of the problem concerning the refusal or renunciation of therapies, as this would reduce the medical act to a mere variable depending on the patient's individualistic options. In addition, article 32 of the Constitution must be read not only as normative foundation to self-determination in healthcare, but also as source of limitations to the exclusive availability of the personal sphere. The limitation of the respect for human life, which is stated by the regulation under examination, backs the idea of a right *to* life and not *on* life, which excludes the absolute disposing power of the holder of such right. This is confirmed, at the level of Italian ordinary legislation, in articles 679 and 580 of the penal code (dedicated to the case of consenting homicide and incitement or help to commit suicide) and in article 5 of the civil code (which limits the actions to dispose of the body); this interpretation, in fixing the limitations to the availability of the physical body, brings together article 5 of the civil code and the discipline of the parting consent in article 50 of the penal code.

Finally, establishing a parallel with the hypothesis of suicide, we highlight how this last one is a *private* act, whilst the request to a third party to interrupt vital treatments constitutes a mainly *social* act.

For the supporters of this position, from this follows the ethically problematic nature of the patient's request to renounce care that is keeping him/her alive, as well as of the execution of such request by the doctor, as much as it requires an active behaviour on his part.

Once the doctor-patient relationship has been established, it can only develop towards a full protection of the patient's life and health. To not accept the request to refuse or renounce the therapies by a patient in conditions of dependence does not constitute an unfair inequality of treatment in comparison to the autonomous patient: the unfairness would exist if there was a limitation to accessing a good, but death cannot be considered a good. From this point of view, the right solution lies in the protection of the subject in conditions of dependence exactly because he/she finds him/herself in conditions of vulnerability.

Other NBC members adhere to a different position. They believe that, despite the patient's conditions of physical dependence, his/her autonomy and informed

consent/dissent must take priority, including in cases of renunciation of vital treatments.

Every time we are witnessing a conscious renunciation, free and present, it is not possible to invoke limitations deriving from a duty of care founded on solidarity or public order reasons. By virtue of the protection of the individual, which permeates our fundamental Charter, every individual constitutes an end in itself, and can not be exploited for the good of the community nor be sacrificed in the name of general interest. Therefore, the possibility to consciously renounce a therapy cannot be limited by reasons beyond the individual: instead it is a subjective, constitutionally guaranteed right, to the concrete realisation of which the doctor is legitimately called to contribute, as long as he is allowed to abstain.

We also highlight how the argument of total and unconditional protection of life as an asset – an argument that certainly remains fundamental – must not however be subjected to an uncompromising interpretation, but needs to be updated with the most recent interpretation, even legal, according to which we must enhance the *ratio* of individual guarantee and protection, therefore the promotion of the individual's autonomy, and not of external reductions or limitations in the field of self-determination.

The same interpretation of article 5 of the civil code has been revised by the interpreters: this regulation does not forbid acts to decrease the body *tout court*, but only those motivated by lucrative purposes, in which, that is, the decrease of physical integrity is followed by an economic return for the disposing subject. What the law aims to avoid are lesions to the physical body in view of a financial gain. The *ratio* evidently is that of guaranteeing the weakest subjects, prepared to accept the sacrifice of their physical integrity in order to confront an economic need. Instead, article 5 of the civil code is not about the acts to dispose of the body that are freely and consciously wanted by the subject within the relationship of care, acts that are completely alien to any economical and financial considerations and are motivated exclusively by individual convictions and moral principles, by individual "critical interests". There is no reason why a competent subject must be deprived, because of his/her state of illness, of the right to keep control of what happens to his/her body and his/her life; we must instead support the "appropriation" of death (and of dying) by the patient. Overcoming the strictly paternalistic interpretation of the doctor-patient relationship, the criteria of the "patient's best interest" is articulated on a twin level of judgement: that is, it becomes important not only as an objective and knowable fact (entrusted to the doctor), but also as a subjective fact (the "knowing in himself" of the patient, starting with the awareness of the illness and of the pain as part of his/her own life story). Therefore, taking for granted the undisputed centrality of the medico-clinical evaluation, founded on science and the doctor's experience, the expression of the patient's will, through the informed consent, constitutes the end of the process of research of the "best interest" of the individual patient. An interest that can therefore be said "best" exactly because it results from the joint contribution of the medico-scientific knowledge on one hand, and of the patient's personal experience on the other. If the doctor acts in the patient's absence or against his/her will, he exposes himself to serious legal consequences (as it can be considered a crime of private violence, ex article 610 of the penal code); on the other hand, the same obligation of care exists and extends to the limit of the opposition advanced by the patient.

We also state that implementing the right to conscious renunciation to care can have positive effects also on the patient-doctor relationship: if the patient can be confident that his/her will (to be ascertained concretely and with due care and guarantees) is going to be accepted and respected, the trust at the basis of the therapeutic alliance is strengthened (see paragraph 5). In addition, the possibility to request the interruption can in itself encourage the patient's agreement to beginning treatments that involve the dependence on life support machines; treatments that, otherwise, could be refused *a priori* for fear of a definitive loss of self-determination.

Finally, there are those who state that to deny non-physically able patients the chance to consciously refuse an unwanted medical treatment leads, in effect, to discriminatory outcomes. In fact, it establishes a difference between the patients who are able to autonomously avoid care without the help of a third party, and the patients who, because of their illness, are not able to do so, and who therefore find that the right to exercise their will, guaranteed to the other patients, is in effect denied to them. This is in contrast to article 3 of the Constitutional Charter, which forbids any discrimination founded on "personal conditions".

To these considerations we must also add the statement that clinical persistence can not be the necessary premise - as *condition sine qua non* – of exercising the right to refuse or renounce care. In other words, the "renouncibility" of treatment is independent from the previous verification of a situation of clinical insistence. Care that does not present the characteristics of persistence can also legitimately be the object of renunciation. The verification of a situation of clinical persistence is relevant, at most, under a different profile: in fact it triggers a precise obligation from the doctor to interrupt the disproportionate treatment, as the code of medical deontology (article 14) expressly ratifies. Because of the lack of an objective and shared definition of clinical persistence, the patient's free and conscious will to interrupt a treatment – even if in keeping with "clinical good practice" – must be taken as a point of major importance. In other words, the subordination of the legitimacy of renouncing care to the evaluation of clinical persistence, in effect results in leaving the voice of the patient unheeded, and leads to an almost systematic negation of the patient's will, compared to the judgement of appropriateness and proportion formulated by the doctor.

4. Let die and bring about death

In examining the issue of refusal/renunciation of health treatment, the Committee highlights the possibility to distinguish or not between *let die* and *bring about death.* A distinction that can lead to another: between behaviour of omission and behaviour of commission.

It has been stated by some that the difference between action and omission, although naturalistically perceivable, tends to dwindle when a moral evaluation of the agent's behaviour is in question, as there is no morally significant difference between not beginning and interrupting life support measures. In fact in both cases, if we observe the end result, the behaviour's effect leads inexorably to the patient's death. Looking at the agent's behaviour, can also become difficult to clearly distinguish between acting and omitting: on this point, the variety of theoretical reconstructions proposed by legal and bioethical literature demonstrates that, especially in some borderline cases, a clear classification in terms of action or omission is not at all easy.

Because of such difficulties we can therefore state that, on one hand, the contrast between *bring about death* and *let die* is not entirely exhausted in the contrast between action and omission: the two expressions are on different planes and are not completely superimposable. On the other hand, a consistent and motivated school of thought insists on the need – social and legal as well as ethical – to keep a clear distinction between *bring about death* and *let die*: according to such point of view, the two hypotheses can not be considered as having the same quality of non-value. With regards to the agent's common sense and also to his/her psychological background, the hypothesis of omission appears in fact generally perceived as characterised by a lower offensive quality, in comparison with the "act" of euthanasia consisting in a *facere.*

To these considerations we can add that the pervasive role taken on by technology within the field of contemporary medicine, as well as at times making the limit between natural and artificial uncertain, can generate the risk of drifting towards technocratic medicine. In light of this, the renunciation of treatment could represent a reaction of the patient against an intensive recourse to technology, which is felt more as a "power" exercised *on* him/her than as a "power-possibility" *for* him/her. The renunciation can therefore represent the refusal of that third factor – technology – that comes in between the patient-doctor relationship and at times takes over; the same technical support that makes surviving possible can be *experienced* as an imposition-coercion.

From this point of view the renunciation of treatment by the patient does not correspond to a request to die, but it expresses the preference for a course of therapy characterised by less invasive medical procedures and supported, when necessary, by appropriate palliative care. Therefore, putting the renunciation of therapies on the same level as suicide appears unacceptable and simplistic. The distinction between *let die* and *bring about death* can also reflect upon a moral evaluation. On this, a variety of positions have emerged in the NBC.

Some members in fact believe that to *let die*, although it does not coincide with euthanasia, is in some circumstances nevertheless problematic (even if legally acceptable, given the patient's autonomy) as the doctor still has – as already highlighted – a medical duty of care and there's the patient's individual and social responsibility to care for his/her own life.

Other members of the Committee however, believe that the hypothesis in which the doctor *brings about* the patient's *death* must be distinguished from the hypothesis in which the doctor accepts the patient's conscious and informed request to renounce care, and therefore to go along with the natural course of the illness: in such cases, the – *negative* – duty to not act on the patient's body without his/her consent it thought as prevailing on the – *positive* - duty to give care.

5. Therapeutic alliance

The request to stop the course of treatment, when made to the doctor, stimulates a more careful reflection on the complexity of the relationship of care: it is not limited to the level of the single patient-doctor relationship, but it frequently extends to the patient's family circle, up to involving the very basic health policies' guidelines, and even the health system's organisation and functioning in its entirety. In the social change from the traditional patriarchal family model to the current nuclear model, the treatment and management of illness and death have undergone profound

transformations, mostly characterised by a tendency to anonymity, to bureaucratization, and in general to the dying patient's removal from the domestic/familiar context. Without, in this way, failing to appreciate the great benefits deriving from the progress of medical science, we cannot however ignore some problematic implications of contemporary technological medicine: procedures that are carried out with the intention of prolonging life can turn out to be simply a way of postponing the death process; the material availability of new technological resources can lead to starting treatments or procedures even when the circumstances do not let us foresee any margin for improvement or effective benefits to the patient's health. This picture invites us to reflect on a double risk: on one hand, that the renunciation to care could come from a sense of refusal towards attitudes of diagnostic/therapeutic aggression and of the patients' exclusion/alienation, amplified by the current tendency to an excess of rationalisation and commercialisation of the medical-health service. On the other hand, the risk that the patient might decide to refuse treatment in fear that the shortcomings of the health service for terminally ill patients – and the consequent transferral of the burden of care on a family circle that is unprepared to take on such a duty – would lead him to a situation of "loneliness" and of therapeutic and healthcare "abandonment". In short we need a lot of caution in evaluating, case by case, the reasons that motivate the renunciation of care: the daily drama experienced by patients subjected to cutting edge or highly invasive health treatments can without a doubt generate a situation of fragility that – even without affecting the individual's capability of self-determination – invites us to avoid employing the respect for the patient's supreme, autonomous will, acritically accepted, as a hurried buzz word. Respect for a truly free, personal and conscious will, in itself imposes us to avoid procedures that can incline towards an "abandonment" – bioethically unacceptable – of marginal patients.

The complexity of the issues at play and the extreme delicacy of the interests involved have provoked, therefore, a detailed reflection on this Committee's part, allowing us to reach the following considerations.

From a general point of view the act of renunciation is a way to connect and communicate: although it expresses a moment of crisis or conflict, the renunciation of care does not place itself outside the relationship, and it does not necessarily bring about a breakdown of it.

There is no doubt, in addition, that the patient-doctor relationship has undergone considerable changes over time: from a fundamentally dual relationship, it has progressively transformed into a plural relationship, in which the patient is put into contact with a considerable number of health professionals, doctors and nurses *in primis*. The process of specialization in a variety of branches of medicine, the refinement of the diagnostic technologies, the increasing complexity of the health organisation represent some of the principal causes of the change from the traditional "bipolar" patient-doctor relationship, to a relationship model that branches out and is composite, in relation to which the denomination patient-*doctors* seems even more urgent. This implies the risk of the therapeutic relationship changing from an interpersonal relationship to a depersonalised relationship, especially when accompanied by increasing forms of bureaucratisation and "marginalisation" of the doctor's role. Because of such considerations it appears evident that the patient-doctor relationship cannot be founded on models inspired to views that are, all considered, unilateral, even if articulated in a variety of ways. Therefore we must reject the idea, by now obsolete, of *medical paternalism* – where the patient is confined to a passive and subordinate position – and we must also reject those models centred on the

patient's *will* as abstract principle in contrast to its concrete realisation in the context of a person's life (and to the consequent retrocession of the doctor to the role of mere executor). This allows us to fully appreciate the central importance of the principle of trust within the patient-doctor relationship, as well as the necessary characteristic of confidence in such a relationship.

Through trust, we can maybe try to overcome the contrast, which often appears forced, between pursuing the patient's good, objectively intended, and his/her autonomy. As much as the illness itself causes a limitation on the patient's autonomy, then medicine, in its aim to cure the illness, contributes to the patient's autonomy. Autonomy, therefore, must not be reduced to the simple negative acceptance of "non-interference", but it must be intended also positively, both as source of the doctor's duty to inform the patient and to verify, in a true process of communication, the real understanding of the given information; and as the doctor's ability to listen and to understand the patient's requests, an ability that is necessary to identify the most appropriate and most respectful therapeutic choices for the individual patient. Information cannot be reduced to the neutral presentation of different options all considered equivalent, but it is aimed at counselling, supporting and – maintaining respect for personal autonomy – persuading the patient to make therapeutic choices that can offer the best chances.

From this clearly derives the need to overcome the procedure directed at a merely formalistic and defensive conception of informed consent, as already highlighted by this Committee in the aforementioned opinion *Information and consent relating to medical acts* (1992). The act of conscious renunciation/refusal of care, just as (and maybe more than) the act of informed consent, must not be reduced to a formality, but it must reflect the entire relationship between patient and doctor; the doctor – supported by other specialists (e.g. the psychologist) if needed – has the task to help the patient to form his/her own will in the difficult circumstances of the illness[8]. It goes without saying that in this dynamic of communication and relationship centred on the patient and on the doctor, the family and other people trusted by the patient have a fundamental role.

The awareness that the informed renunciation/refusal of a health treatment, by a competent patient, represents the exercising of a right (within the limitations of the above mentioned considerations) must not, therefore, be detached from a sensitivity (cultural even more that deontological and legal) towards the need to promote as much as possible the patient's agreement to the care necessary to keep him/her alive. From this point of view, as already mentioned, within the *lato sensu* duties of the doctor towards his/her patient we can list the one to promote – not in an ideological or paternalistic way – the consent to therapies, especially when medical science is able to use life-saving instruments or, at least, to introduce concrete health benefits.

This, naturally, maintaining both the principle of respect for the patient's decision-making autonomy, and the doctor's *duty* to abstain from any diagnostic/clinical insistence. The health worker, in short, must not escape either

[8] On this point, refer to articles 33 and 34 of the Italian *medical deontology code*, respectively titled "Information to the public" and "Information to a third party". The increased value of the principle of autonomy requires also to respect "the documented will of the patient to not be informed or to delegate the information to others" (*medical deontology code*, article 33). The *Nurse' deontology code* must also be mentioned, which in point 2.6. proposes this helpful synthesis: "In his/her professional behaviour, the nurse agrees to not harm, aims his/her actions to promote the patient's autonomy and interest, stimulates the patient's resources when he/she is in conditions of disability or disadvantage".

his/her role of health and life promoter, or his/her role of healer called to assist even the person who consciously rejects a certain therapeutic "proposition".

6. Palliative care

There is another aspect that the Committee intends to highlight. The patient's conscious renunciation or refusal of a particular treatment must not be automatically identified with the final act of the relationship of therapeutic alliance. It rather initiates a new phase of the care relationship, in which the doctor is called to give the patient *all* the care – different from the one that is the object of the renunciation/refusal – that can be helpful to guarantee the patient's best quality of life.

To refuse a certain treatment does not mean, in fact, to refuse *any* type of treatment; just as the interruption of a particular cure is very different from the interruption of "taking care" or *caring*. Moreover, except in cases presenting a state of grave depression, it is rare for the patient to want to renounce *all* care: in general, the refusal or the renunciation have as object a *specific* cure, that it is felt to be insufferable, degrading and intolerable. For this reason the doctor is called to illustrate to his/her patient the complete array of the available cures, with the aim to offer a course of therapy that is as much as possible suitable to his/her needs, in compliance with the maximum *standard* of clinical efficacy. We put the proposal of palliative care in this field, as it can allow a reduction of the symptoms and an overall improvement of the quality of life.

The increasing sensibility towards the palliative medicine sector is an indication of the, by now, widespread awareness that the doctor's deontological/professional duties do not end with the traditional preventive, rehabilitative and therapeutic field and its "healing" aims, but it is projected towards the protection of "health" in the widest sense, which includes also pain relief, psychological support for the patient and, where needed, for his/her family, support "in" dying and not "help to" die. In precise circumstances and conditions, therefore, the refusal or renunciation of care can highlight the trust element and the collaborative character that is typical of the "exchange" between patient and doctor.

Therefore, another aspect that the Committee wants to clarify is the necessity to distinguish between interruption of care accompanied by adequate pain therapies on the one hand, and euthanasic procedures on the other. The terminal analgosedation, if and because it *only* has the aim to relieve the patient's pain, has the same ethical, deontological and legal position that supports the palliative medicine statute. Therefore the recourse to adequate pain therapies, when the course of treatment is interrupted, with the only objective to relieve any possible pain suffered by the patient, represents not only a legitimate procedure, but instead a duty, as relieving pain is also part of the doctor's professional duties. The appreciation for pain therapies is not only consolidated at the level of general bioethical guidelines[9], but it has been accepted also in the Italian *deontological code*[10] and in the positive law[11].

The reasons that can lead to confusion between palliative sedation and euthanasia reside in the possible effects of acceleration of the course of the illness due to the

[9] The value of palliative medicine has already been highlighted numerous times by this Committee, as can be seen by the opinions *End-of-life issues in bioethics* (14th July 1995) and *Pain therapy: bioethical guidelines* (30th of March 2001).

[10] *Medical Deontology Code*, articles 3 and 39.

[11] It suffices to cite the Law of the 8th of February 2001, number 12, *Regulations to aid the use of analgesic opium drugs in pain therapy.*

preparations used for sedation[12]. The Committee deems necessary to stress, on this point, that the possibility of bringing death forward because of analgesic and sedative treatments, if not wanted and not criminally caused, must be evaluated as the consequence of a fully legitimate conduct, which is in keeping with the doctor's professional duties. The objective acceleration of the mortal outcome, in fact, does not constitute a valid element to justify improper assimilations between interruption of care accompanied by palliative sedation and euthanasia.

7. The right to abstain

7.1 When, to accept the competent and documented request to interrupt care by a patient in state of dependence, an action is necessary or in any case a positive intervention by the doctor and his team (for example switching off a life support machine), we recognise the doctor's right to abstain from this conduct if he/she feels that it contradicts his/her own ethical, deontological and professional views (cf. article 22 of the *Medical deontology code*).

7.2 The patient has in any case the right to achieve in other ways the realisation of his/her request to interrupt care, even in consideration of the possible abstention of the doctor or of the medical team.

7.3 Even if the doctor is not obliged to interrupt the course of care, he/she is nevertheless called to guarantee assistance to the patient, to supply him/her with palliative care, to share with other health workers all the information on the course of the illness, which is indispensable for the correct assumption of medical responsibility.

8. Conclusions

8.1 The reflection developed within the NBC has shown the complexity of evaluating from an ethical point of view the issue of the renunciation of care. The NBC intends to reiterate what has already been stated in a previous document: the "consent to medical procedure is – as known – the basis of the "justification" of exercising medicine itself and the foundation, for centuries, of the doctor-patient relationship"[13]. Having said that, within this Committee a variety of opinions have emerged, both on the bioethical and biolegal level, and with regards to the hypothesis of refusal/renunciation of care. On the one hand there's the position according to which human life constitutes a good that cannot be disposed of, which must be always protected and preserved, guaranteeing adequate medical care. On the other hand, the position that considers life as a good without question of primary importance and deserving of the outmost protection, but not for this subjugated to a system that totally forbids the disposition of it, having to take into account the value that the individual attributes to it, in light of the principles and of the moral choices that reflect the meaning each person gives to his/her own life.

8.2 Despite this difference of opinion, this Committee has reached the formulation of some shared observations, which can be synthesised as follows.

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[12] We refer to the *Recommendations by the Italian Society of palliative Care and on Terminal Sedation/Palliative Sedation*, where in paragraph 7.3 it is highlighted that the available data non only do not support the thesis of the anticipation of death due to TS/PS – which would nevertheless be irrelevant from an ethical point of view both because of a quality of life ethics, and because of a sacredness of life ethics – but they even indicate a prolonged survival of the sedated patients.

[13] Opinion *Information and consent related to medical acts* (20th of June 1992).

1) The doctor, as amply emphasised, holds a fundamental duty of guarantee towards the patient, and must always act in accordance with the patient's consent to treatment. One of the doctor's ethical, legal and professional duties is to ascertain that the need for a formal acquisition of consent does not result in the quick fulfilment of a bureaucratic duty, but is preceded by an adequate phase of communication and interaction between the subject who is able to give the necessary information (the doctor) and the subject (the patient) called to make the choice.
2) The patient's conscious refusal of a medical treatment that has not yet started, just as the renunciation of a treatment that has started, cannot ever be acritically accepted, or passively "recorded", by the doctor. Considering the seriousness – and often the irreversibility – of the consequences of a refusal or of a renunciation of care, what becomes necessary is a careful analysis of the patient's effective competence and of the presence, case by case and in concrete, of all the prerequisites and the indicators that allow the consideration of his/her will as certain, conscious and reliable.
3) From this derives that the doctor must always develop, at both an epistemological and bioethical level, a double awareness: on one hand, that any form of clinical persistence is illegitimate; on the other hand, that the stated "equality" between doctor and patient can be over-abstracted, obscuring the difficulties, the uncertainties, and the fragility of those who experience illness first hand. This does not mean that we need to go back to a position that emphasises the asymmetry of power/knowledge between doctor and patient and relegates to insignificance the patient's word: on the contrary, the doctor's duty to avoid assuming a paternalistic attitude or *latu sensu* authoritative towards the patient must be combined with a particular attention to the needs of *caring*, so that the patient's refusal or renunciation of care needed for his/her survival remains an extreme hypothesis.
4) Not uncommonly, it is particularly difficult to concretely ascertain the effective existence of a clinical-diagnostic persistence: in such cases, even the patient's possible and competent request to suspend treatment – supported by adequate counselling – can be useful and contribute to the doctor's adequate evaluation of the case.
5) When, in case of a competent patient in conditions of dependence, the renunciation of care requires, to be carried out, an active action by the doctor, we must recognise the doctor's right to abstain from actions he/she feels in contradiction to his/her own ethical and professional views. In large majority, the NBC believes that the patient maintains the right to achieve in other ways the realisation of his/her request to interrupt care, even considering the eventual and possible abstention of the doctor or of the medical team.
6) The need for a full appreciation of the importance of the therapeutic alliance, leads to stigmatise any procedure of therapeutic withdrawal, the risk of which seems to be particularly widespread – although not always accompanied by the operators' full awareness – especially in societies with highly complex and technologically advanced health systems.
7) We reaffirm the great importance of the widespread use of palliative treatments: through such statements medicine tries to offer the patient the support necessary to face the terminal phase of existence, in the respect of personal and human solidarity values.

PERSONAL REMARKS

Personal remarks signed by Prof. Adriano Bompiani, Prof. Bruno Dallapiccola, Prof. Maria Luisa Di Pietro and Prof. Aldo Isidori.

Our "abstention" vote – and not "vote of objection" – on the Document "Conscious refusal and renunciation of health treatments in the patient-doctor relationship", approved on the 24th of October 2008, wants to be a recognition of the Group's Coordinators effort to achieve, within the limits of the possible, a precise description of the variety of opinions on this issue and to identify a "point of convergence" between them.

The continuous reference to the patient-doctor relationship, to the so-called therapeutic alliance, to the recognition of the patient's right to express his/her thoughts and his/her therapeutic options, does not correct - however – the document's general formulation which exposes the risk of sliding from an undefined "refusal/renunciation of treatments" by the patient of sound mind to the legitimisation of the so-called "right to die", therefore triggering other people's obligation to kill or to help to kill and distorting the true essence of the medical profession, which is to assist and heal.

Evidence of the high risk of drifting into euthanasia is: 1. the forced interpretation of article 32, subsection 2, of the Italian Constitutional Charter, in which its inspiration to the *favour vitae* and to the *favour curae* is not mentioned; 2. the imbalance between the legal argument and the ethical argument; 3. the unmentioned definition of "euthanasia".

1. THE FORCED INTERPRETATION OF ARTICLE 32

The fact that the patient must be asked to give consent before proceeding with any health treatment is confirmed, as well as in the Medical Deontological Code of the National Federation of the Surgeons and Odontologists' Order ["in any case, in front of a capable person's documented refusal, the doctor must desist from following diagnostic and/or curative actions, as carrying out any medical treatment against the person's will" is disallowed (article 35)], also in article 32, subsection 2, of the Constitutional Charter ["no-one can be forced to undergo a certain health treatment if not dictated by law. The law can not in any case violate the limitations imposed by the respect for the human being"]. It is, on the other hand, known that the aforementioned regulation was approved precisely with the specific intention to forbid scientific experiments on the human body that had not been voluntarily accepted by the patient or – more generally – to protect the individual's health from illicit interferences by the public powers.

The constitutional provision on the issue of voluntary acceptance of health treatment, as discussed in article 32, subsection 2, does not however show the Constituent's will to abdicate the principle – already amply made positive in 1948 – of the impossibility of disposing of life as a good, even by the subject who owns it. Article 32 must be, in fact, read and interpreted in full, and it is not correct to isolate subsection 2 from the general context: instead, although we cannot deny that the NBC hints to this, it is clear that the entire formulation of it suffers from an unambiguous and forced interpretation of the article.

The option for the *favour vitae* and the *favour curae* of article 32 can be seen by reading subsection 1 [“The Republic protects health as fundamental right of the individual and as collective interest and guarantees care to the poor”], where the right to health is considered fundamental both as individual good and collective interest. On the basis of this principle it is logical to infer that care is a value that the individual must search for and that – consequently – the refusal of any health treatment is not a good for the patient or for society as a whole. The corollary is that the patient, even if in a strictly legal sense is not required to accept care, has however the moral (or maybe civic) duty to do so.

The last subsection of article 32 introduces a limitation even in the case that a compulsory health treatment is forced by law: in no case the limitations imposed by respect for the human being can be violated [“Law can not in any case violate the limitations imposed by the respect for the human being”]. Forcing a person to accept care and putting our hands on his/her body, is certainly something that offends human dignity and represents, at the very least, an inhuman and degrading treatment. There is, however, a great difference between the refusal of experimentation as formulated in article 32 and the refusal of treatments truly capable of guaranteeing, curing, assisting, helping and maybe saving a patient’s life. In both cases a patient can legitimately refuse health treatments, but in the first case there is no duty to participate to the experimentation, in the second case such duty persists at least ethically. As a consequence, although in the first case no action is allowed that is aimed at persuading the person to undergo experimental treatments, in the second case it is legitimate that the doctors, family and friends try – as much as possible – to persuade the patient to accept them.

It must be considered, finally, that article 32 is to be found under title II of the Constitution which is about ethical-social relationships, those, therefore, that must be inspired to a principle of solidarity. The primary aspect of article 32 is not, therefore, to protect the individual from a hypothetical oppression by medical technology, but, on the contrary, to ensure everybody’s health. This does not at all exclude the condition of informed consent. On the contrary, it strengthens and clarifies the content of it even with the objective of putting more effectively into action the adequate therapeutic procedures. The patient’s participation, in fact, through the dialogue with the doctor, ensures greater efficacy of the care, also with regards to the place, the timeline, the methods, the effects, and the alternatives. In any case the aim is health and health’s ultimate enemy is death. It appears, therefore, quite paradoxical to obtain the protection of a so-called “right to die” from a regulation aimed at ensuring the maximum public commitment to life.

We feel, therefore, that an interpretation of article 32, subsection 2, aimed at demonstrating that the “right to care” counts as the “right to not care” up to deciding death, is quite forced. Certainly the patient can refuse a certain health treatment, but in this case the reason is not that he/she has free choice of life or death, health or illness, but that he/she must not be subjected to inhuman or degrading procedures as the ones he/she subjectively believes will have to undergo in the proposed treatment. It being understood that, in addition, he/she is free to choose a different health treatment that – although less efficient – is not in conflict with his/her will.

2. THE IMBALANCE BETWEEN LEGAL ARGUMENT AND ETHICAL ARGUMENT

The document – inspired primarily by a positivistic legal interpretation – does not take into account all the ethical "nuances" of the clinical data about the various situations that can arise during the treatment of a "critical" or "terminally ill" patient. With the grave risk of legitimising – even inadvertently – euthanasia.

In fact, to justify the refusal/renunciation of health treatments from a legal point of view it is sufficient that the expression of will is free and conscious despite what the object of the decision is and the circumstances in which it is taken. The morality of a choice does not depend only on whether it is free and voluntary. For these reasons the right of refusal/renunciation of health treatments cannot be considered a generic right, but it is limited by specific clinical conditions and strongly conditioned by the illness, and it is not only the patient's will – although necessary and sought after – to legitimise it. It follows that, whilst there could be no problem in accepting a refusal motivated in terms of a morally legitimate choice, one that takes into account all the values at play, very different is the case of a choice we cannot easily agree with and that does not seem dictated by morally binding criteria.

In addition, the NBC's document does not adequately differentiate between exercising self-determination as making provisions "on oneself" and as making provisions "of oneself". If, in fact, exercising self-determination in terms of making provisions "on oneself" indicates the patient's involvement in the course of therapy and his/her will to accept the doctor's counsel or not, exercising self-determination in terms of making provisions "of oneself" inevitably leads also to recognising the so-called "right to die".

The "right to die"? A contradiction in terms, because there can be no self-determination where there's no chance to continue existing: at the basis of any right there is, in fact, life. And, even those who consider life as a disposable good cannot deny that – when it ends – no right can be exercised. A contradiction in terms, because the aim of a "right" is always to achieve a good: death is, however, a negative event for the simple reason that ends any possible achievement of valuable and good things.

The deliberate fluctuation between disposability and indisposability of life; the reduction of the cases' complexity to a generic regulation; the decontextualisation of the decisions: these and others are the factors that open any possibility, even hinting at euthanasia, in which social judgements on quality and dignity of life can come into play as undisturbed co-protagonists.

3. THE UNMENTIONED DEFINITION OF EUTHANASIA

In addition to neologisms of doubtful meaning, which bring further confusion in the patient-doctor relationship (the expression "clinical persistence", that is added to the already abused and technically imprecise "therapeutic persistence") and generic and imprecise terminology (the terms "therapies", "treatments", "care", are used indifferently), the document deliberately avoids explaining the meaning of "euthanasia".

From this follows that the stated a priori exclusion – by the NBC – of euthanasia (exclusion that we agree with) can appear to those reading the document only formal and not substantial. In other words, in weakening the doctor's duty of guarantee towards the patient and decontextualising the abstention/subtraction of health treatments that would not meet the disproportionateness/extraordinariness

criteria, forms of "indirect or per omission" euthanasia are legitimised. And, on the other hand, I highlight that in the current debate the term "euthanasia" is used to indicate only direct or active forms of killing the patient, whilst indirect or per omission euthanasia has been reduced to a generic refusal/renunciation of health treatments.

The confirmation of this deliberate ambiguity is given from what is reported in point 5 of the *Conclusions*, which takes into account the abstention or the suspension (which in the document is – a fact we don't agree with – morally assimilated to non-activation) of health treatments to the patient by a doctor or a medical team that do not agree with his/her request. This means that the object of such a request could be an action that contradicts a medical practice aimed at the protection of life and at the care of the person in conditions of maximum fragility, to the point that the possibility that the doctor or the medical team – in science and conscience – might refuse to intervene, is anticipated.

The NBC anticipates, in addition, that – in case a doctor or a medical team refuse to intervene – the patient's right to interrupt care must nevertheless be satisfied. We witness, therefore, the total loss of meaning of that same patient-doctor relationship that the NBC puts at the basis of the document itself: the doctor's *techne iatrike* is completely taken over by the patient's exercising of self-determination. This contradiction seems even more evident when joining point 5 to point 4 of the *Conclusions* where we read: "Not uncommonly, it is particularly difficult to concretely ascertain the effective existence of a clinical-diagnostic insistence: in such cases, even the patient's possible and competent request to suspend treatment – supported by adequate counselling – can be useful and contribute to the doctor's adequate evaluation of the case".

It appears, therefore, evident how the persistence of ambiguities and silences does no good to the correct patient-doctor relationship and risks to produce or to amplify feelings of mutual distrust and/or suspicion, especially in situations like those presented by the case of a patient affected by a serious and irreversible illness or even terminally ill. As these are the situations that mostly recur in clinical practice and for which the issue of the refusal/renunciation of health treatments arises, it would have been more correct to formulate the NBC's document on the basis of two principles: on one hand, the duty to "accompany the dying patient" and, on the other hand, the principle of "the treatments' proportionality/ordinariness". In this context it should also be included – with its own specific value – a criterion of appropriate judgement of the patient's autonomy to be balanced with the doctor's duty of guarantee, also on the basis of the provisions made by the Oviedo Convention. The aforementioned Convention states, in fact, in article 8 that: "When, because of an urgent situation, the appropriate consent cannot be obtained, we can immediately proceed with whatever medical procedure is indispensable for the benefit of the interested person's health".

We hope that the NBC will complete, in these aspects too, the document that has been approved on the 24th of October 2008.

Personal remark signed by Prof. Roberto Colombo

The signatory of this personal remark, although expressing appreciation for the work carried out by the NBC members who have drawn up and revised the *Opinion* and for the respectable effort to present a clear and synthetic picture of a variety of ethical and legal positions, does not agree with the text for the following reasons.

1. The absence of an explicit reference to the category of the objects of refusal or renunciation that they intend to legitimise – objects that qualify, from a caring and ethical point of view, the action that the patient does not want to be subjected to or of which he/she requires the interruption – does not allow us to completely agree with one or the other of the positions reported in paragraphs 2.2, 2.3, 3.2 and 3.3. According to the conception of the human action I am referring to, the first and principal source of morality is the object chosen by the subject's deliberate will, object that ethically qualifies that will, because reason recognises it as being a good or not.

2. In the text, the fluctuation between the terms "treatment", "care", and "therapy" has taken the place of a presentation and resumption of the debate, still lively, on the relevance, looking at the legitimacy of refusing or renouncing them, of the distinction between "therapeutic acts" on the body (actions that are specifically medical or surgical, whose objective is contrasting or containing the pathology, new or in course, and whose aim is resolving, improving or stabilising the clinical case history) and "acts of care" of the body (actions that, depending by the patient's physical conditions, can coincide with daily life's common actions, executed by the patient him/herself or by his/her family, or requiring the intervention of qualified health personnel, whose aim is nevertheless the maintenance of homeostasis within physiological parameters compatible with life through the availability of air, water, electrolytes and organic nutrients for essential metabolic processes, and whose aim is to allow the subject's survival). The refusal to begin or to continue a therapeutic action directly implies the renunciation of the fight against the disease (with the possible indirect effect of shortening life), whilst the refusal of an act of care indispensable for the body's physiological functions directly implies a renunciation to life.

3. The choice to laterally tackle the issue mentioned in the previous point, recurring to the generic expression "life-saving treatments", and the lack of reference to the considerations put forward in a previous NBC opinion (*Nourishment and hydration of patients in persistent vegetative state*, 30th of September 2005) make even more difficult to take position with regards to the conclusions proposed by the *Opinion*, whose normative indications and implications become susceptible of different interpretations. Even if "life-saving", the renunciation to some therapeutic procedures whether pharmacological, resuscitative or surgical can be legitimate (for example, because of the procedure's extraordinariness, the scarce efficacy or the particularly negative way in which it affects the patient) and an eventual continuation of such treatments *contra voluntatem aegroti* on the doctor's part would be unjustified. On the contrary, daily and indispensable care, like – but not only – hydration and nourishment (even if administered enterally or parenterally), when available through the health system and for as long as it really is effective, because of the patient's favourable clinical conditions, in supplying substances that are essential

for the human body's metabolic processes, always represent an ordinary and proportionate way to achieve the patient's survival. Those who want to deprive themselves of this in order to prematurely end their lives, cannot demand the doctor's collaboration in such an act. The continuation of such care of the body by those who assist the patient, except when they become futile because they do not contribute to maintaining his/her body's homeostasis, is not an "persistence" and represents a human and professional duty. On the contrary, to not begin or suspend such care (always with the exception of the abovementioned case) would be a type of human and professional "abandonment" of the patient, even more serious in a society that does not lack the people and the means to put this essential care into practice, without burdens for the patient and his family as well.

Personal remark signed by Prof. Francesco D'Agostino

1. The NBC's document *Refusal and conscious renunciation of health treatments in the patient-doctor relationship,* approved on the 24th of October 2008, can be fully agreed upon *for what is said in it*. It can be agreed upon much less *for what is intentionally not said in it* and that instead, in the opinion of the person drawing up this personal remark, should have absolutely been said. It is for this reason that in the plenary meeting, when the NBC members are called to ratify with a definitive vote this text, I did not vote against, but I simply abstained, giving advanced notice of this personal remark, to show how the will to elaborate a text as much as possible *shared* has inadvertently led those who have drafted it (with merit, as it is a very well written document) and those who have approved it, to overlook or to minimize very tricky bioethical problems. I believe it is absolutely indispensable to focus public opinion's attention in an honest and direct manner and not to remove or simply cite through allusions or quick observations, which inevitably end in hindering the perception of the importance of the issues at play.

2. Also as a preliminary, I confirm in this little personal remark what I have more than once stated during the Committee's debates: this document does not manage to avoid – instead it confirms – the tired and abstract dichotomy between life intended as "indisposable good" and life intended as "disposable good". It is an *abstract* dichotomy, because for the simple fact that we use it we presume the possibility to define in a conceptually correct manner the idea of *life* itself, without thinking that this idea is instead characterised – as it is been subtly stated – "by ancient and consolidated convictions and by recent and fast-growing uncertainties". It is a *tired* dichotomy, because it leads to giving stereotypical answers to *bio*ethical problems, as the answers that unfortunately emerge from the document and that can be summarised in expressions intrinsically very meaningful, but that are by now worn out and have almost acquired the validity of slogans. In the current bioethical debate, as we well know, the dignity of life depends for some on its *sacredness* and for others on its *quality* (almost as if the two categories are intrinsically in contradiction with each other). Those who abide by the principle of the *sacredness of life* expect that life is always considered non-disposable (not only ethically, but also legally), by the interested subject him/herself as well and it arrives to the limit of denying the legitimacy to suspend therapeutic persistence, even doubting the plausibility of this category. Those who instead support the theory of the *quality of life,* rapidly end up denying that a life, affected by an illness that takes away its quality, deserves moral respect and legal protection and in any case they are fully convinced that only the interested person, as long as he/she is autonomous and competent, can judge the dignity of his/her existence. Both positions in the end give in to the temptation of the *deductive* argument, also because this, although icily formalistic, is the simplest to use when we need to find a solution to controversial issues regarding the end of human life. So, some settle for arguments like: *as life can not be disposed of, then surely it is not possible…* (e.g. "that it is legitimate that the doctor pulls the plug on the SLA patient, even if this is his/her will"), whilst others state that: *as life is disposable, then certainly it must be possible…* (e.g. "that it is legitimate that the doctor pulls the plug on the SLA patient, as long as this is his/her will").

3. It is clear that the two positions cannot be reconciled and because, as medieval people said, *contra impugnantes principia non est disputandum*, it is understandable that the NBC's document, with resigned tones, does not go into the issue more in depth and simply recalls, with polite correctness, the conflicting principles. What however the document fails to focus attention on (and here is a first criticism of elusion) is that the principle of the indisposability of life is strongly coherent, which does not seem to be the case for the opposing principle. In fact, those who believe that *life* as a good is really subordinated to the person's mere authoritative will and that the person is in any case the only one who is legitimised to attribute to this good any value he/she wants, should, to be coherent, recognise the *right to suicide* as a logical progression (recognition which is, in addition, quite widespread), the right to *assisted suicide* and finally the illegitimacy of any help given to those who, having tried to commit suicide but not yet having been able to die, could be saved with medical procedures or maybe quick and appropriate health procedures. We can not avoid this difficulty by stating that the will asking respect is not the one of the suicidal or possible suicidal, but only the will of those who are *terminally ill* or in a state of absolute dependence. In fact, the will of ill subjects, and in particular the will of the terminally ill, is much more difficult to ascertain (as deserving of respect because of being *competent, lucid, informed*) than the will to die of those who, to use a well known expression loved by Anglo-Saxon bioethicists, intend to commit a *rational suicide*. The truth is that the supporters of the quality of life theory are convinced that the disease objectively *weakens* the *good of life* and in some cases arrive at the conclusion that the patient's will to be helped *in* dying can – if missing or of doubtful assessment – be supplemented or replaced by another subject's will (family, fiduciary). But at this point euthanasia, at least *passive* euthanasia, which materialises in the suspension of life-saving therapies, could be legitimately practiced, independently from the request of the patient him/herself: it is what happens, although in a peripheral manner, in those European countries where children who are born with heavy physical or mental handicaps are not reanimated.

4. Moving our observation to a slightly more abstract level, we must stress that life must be considered *ethically* and *legally* non-disposable, not because it is *sacred* (this is a more than legitimate opinion, but it is valid only for believers and at times only for some of them), but because this *indisposability* is the premise and the foundation of all human rights (saying this, I recognise that this argument can not have a value for those who deny the existence and/or the absoluteness of human rights). If life is considered disposable, if this "good" is considered subordinate to the person's authority, we should, to be coherent, ask ourselves why we cannot accept the same subordination to the will of the State, which could subordinate life as a good to an administrative/health decision (finalised to suppressing patients who cannot be healed), or to a legal decision (finalised to practicing the death penalty) or to an eugenic decision. These are issues that cannot be minimised and I believe that, wrongly, the NBC's document has chosen to put them aside, despite being aware of their importance.

5. The point is that very often, although not always, the right way to formulate problems in *bioethics* is not *deductive*, but *inductive* and we must avoid as much as possible the lazy reference to general principles (which appear, to those who support them, very noble and not to be renounced, so that they are in effect taken away from the rational debate) in order to resolve problems. *In bioethics we must start from experience* and from the truth of experience emerge both the problems (those that really exist as problems, as in bioethics we often call "problems" situations that are

not at all problematic, but – unfortunately! – tragic and dramatic), and the solutions to adopt (if they are at our disposal or, more in general, if solutions really exist!). More simply, in the majority of cases bioethical work must accept the challenge of analysing the *record of cases*.

6. Never like in the case of the refusal or of the conscious renunciation of health treatments, are bioethical problems revealed as issues dramatically linked to the record of cases. If we start from the "bottom", as is appropriate when looking at the record of cases, we cannot avoid admitting that the problem of the *informed refusal to medical treatment* radically changes according to the typology of the pathology suffered by the patient (voluntary – as in the case of attempted suicide – or involuntary) and of its seriousness (light, acute, chronic etc.), according to the typology of the treatment proposed (of short or long duration, statistically efficient or statistically of unsure efficacy, invasive or non-invasive, pharmacological or surgical, such that it requires hospitalisation or not, experimental or consolidated, etc.); according to the patient's existential circumstances (circumstances that can also be qualified in a variety of ways according to a variety of parameters: the patient's age, his/her emotional nature, his/her family's circumstances, his/her social, cultural, ethnic and economic circumstances, the hospital and the health context in which he/she should receive the treatment, etc.), according to the doctor's ability to share an empathic relationship with him/her. The list could go on.
7. In the document, it appears evident that the context of reference which they chose to adopt is that, *absolutely very rare*, of fully autonomous patients, emotively balanced, who fully intend to know and correctly understand the information that regards them, who are not affected by other circumstances (family circumstances, economic circumstances, health circumstances, etc.) that could push them in one or the other direction and assisted by enlightened doctors who are gifted with a strong sense of humanity. It is evident that such cases exist and that *they must be taken seriously* and that, *for these cases*, the document's conclusions cannot be faulted. But it must be recognised that such hypotheses are absolutely exceptional. Generally, patients who are affected by even only relatively serious pathologies, but especially those subjected to cutting-edge or life-saving health treatments, are scared, fragile people, mostly elderly, alone, distressed by economic and family problems, unsure about their future, more than anything in need to be relieved of the weight of making serious decisions, often in a state of mental confusion, ready to value not the best opinion, but the last opinion or in any case the opinion presented in the most rhetorically convincing way. These situations must also *be taken seriously* and, as they are much more common than the ones previously discussed, must be taken even more seriously, to avoid the risk that, hiding behind the respect for the patient's presumed *sovereign, autonomous, informed* will, we open the door to a medical practice of *abandonment* of marginal patients, that is – I repeat – of people who are *scared, fragile, mostly elderly, alone, distressed by economic and family problems, unsure about their future, more than anything in need to be relieved of the weight of making serious decisions, often in a state of mental confusion, ready to value not the best opinion, but the last opinion or in any case the opinion presented in the most rhetorically convincing way.*
8. In my opinion, the NBC's document should have *first of all* stressed the risks of therapeutic abandonment and denounced how, too often, to justify such

abandonment we hide behind the respect of the will (informed, competent, sovereign!) of those patients who are terminally ill or in any case in need of costly and heavy life-saving therapies. The document certainly mentions the problem of therapeutic abandonment: it is however coldly formal and therefore *bioethically correct, but inadequate*. If in fact we must believe, as the document states, that the patient's refusal or renunciation of the care necessary to his/her survival must remain an *extreme and exceptional hypothesis*, it is indispensable to raise the problem of how to prevent situations in which refusal or renunciation can in effect take shape as or turn into a request of *passive euthanasia* (a problem that is not only bioethically but also legally relevant, given the criminal unlawfulness, in our penal system, of any euthanasic practice). The document, however, intentionally avoids talking about euthanasia, almost as if the issue of euthanasia and the issue of *refusal/renunciation of care* were on different and non-communicating planes. This is not true. It is proven by the fact that the ghost of euthanasia, laboriously kept out of the way, inevitably comes back when the Committee, reasonably, mentions the doctor's duty to continue practicing palliative and compassionate therapies on the patient who (legitimately) should refuse life-saving care, but it did not want to discuss the more thorny issue: *how much, that is, the doctor's promise to the patient to continue administering robust and early sedative therapies can objectively be an incentive, for the patient him/herself, to refuse life-support care.* These types of events have happened in our country and have featured strongly in the media.

9. Now, it is completely clear that it would be not only absurd, but even morally abhorrent (as well as unlawful, criminally too!) to "threaten" the patient to stop giving him/her the necessary sedations, in order to "extort" his/her consent to onerous and invasive life-saving therapies (a consent that should in any case be considered invalid, because "extorted"). This, evidently, is not the question. In fact, honesty demands that we recognise that promising the patient complete sedation, to give him/her the courage to request the suspension of therapies or in any case to more easily obtain this request from him/her, is in effect an *instigation to commit suicide* and in any case it simply means guaranteeing the patient *euthanasia*, that is, literally, a *sweet death*. Urged to engage all of its intellectual and moral resources on this terrible, controversial and mostly *unavoidable* point, the NBC, in great majority, has preferred to turn its head the other way. I note this with great sadness.
10. At this point I can synthesise my observations. The theme of the NBC's document could be summarised as a dialectic reasoning, which starts form a preliminary hypothesis, it progresses along the lines of a *thesis* and an *antithesis* and it concludes with *two syntheses*, one biolegal and one bioethical. Point 10.4 (the *biolegal synthesis*) summarises, in my opinion correctly, the point the NBC's observations have reached and where they have stopped. Point 10.5 (the *bioethical synthesis*) summarises instead, always according to my opinion, a conclusion which is much more correct than the previous one and which the NBC could and should have reached.

PRELIMINARY HYPOTHESIS: in our legal system, and in the more widespread sensibility in Italy, euthanasia (active or passive) has no legal or moral legitimacy.

THESIS: every citizen who is *of adult age, properly informed, competent and free from any coercion*, has the constitutional right to renounce any therapy (except when this in not allowed by law) or to deny his/her agreement to the continuation of a

therapy that has already started. *The non-activation of therapies or their suspension after the patient's renunciation or refusal does not take shape as euthanasic hypothesis.*

ANTITHESIS: in the case of life-saving therapies and of highly disabling and terminal illnesses, except in cases of absolute exception, it is extremely difficult to state and prove the competence of the patients who renounce care or refuse it: this is hindered by difficulties involving age (in the case of very elderly patients), psychological difficulties (depression induced by the illness or the invalidity), cultural difficulties (the complexity of the medical and scientific information to receive and elaborate), existential difficulties, economic difficulties, family difficulties, etc. *In such cases, the non-activation of therapies or their suspension after the patient's renunciation or refusal are also euthanasic hypotheses.*

BIOLEGAL SYNTHESIS: The right to renounce and refuse care must be recognised, stressed, protected and promoted. It is necessary to steer, in the process of their biolegal function, the doctor's conscience to a profound respect for the exercising, on the patients' part, of such tragic right.

BIOETHICAL SYNTHESIS: the patient's renunciation and the refusal of life-saving care must be interpreted not as the exercising of a right, but as a sign of an extremely tragic psychological and existential situation (at times induced by a *therapeutic abandonment*). It is necessary to steer the doctor's conscience, in the process of his/her biolegal training, to the acquisition of this awareness and to constantly acting to protect life.

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Prof. Assuntina Morresi supports this personal remark.

Personal remark signed by Prof. Antonio Da Re and Prof. Andrea Nicolussi.

We want to recall attention to points 4 and 5 of the conclusions of the document *Refusal and conscious renunciation of health treatments in the patient-doctor relationship*, and in particular to the necessity that point 5 is interpreted in coherence, and not in contradiction, with point 4, which immediately precedes it. For clarity, we quote the text of point 5: "In large majority, the NBC believes that the patient maintains the right to achieve in other ways the realisation of his/her request to interrupt care, even considering the eventual and possible abstention of the doctor or of the medical team". Point 4, in the light of which we must read point 5 quoted above, is so formulated: "Not uncommonly, it is particularly difficult to concretely ascertain the effective existence of a clinical-diagnostic insistence: in such cases, even the patient's possible and competent request to suspend treatment – supported by adequate counselling – can be useful and contribute to the doctor's adequate evaluation of the case".

These last statements highlight the centrality of the relationship between doctor and patient, even when the patient considers the health treatments which he/she is subjected to particularly heavy and therefore asks the doctor to suspend them. Now, it would be in contradiction with the recognition of the importance of such relationship if what stated in point 5 should be mechanically translated in bureaucratic procedures, which, instead of helping towards the protection of the patient within the logic of the relationship between patient and doctor, in which the document from the beginning identifies the problem, should try to find it outside such relationship, misrepresenting it. This would happen if a legal subject (the health service or another body) should be given the right to "supply" an anonymous service to interrupt life-saving health treatments, through recruiting professionals available to substitute the doctor on demand, that is, without any consideration for the reasons why the doctor deems appropriate not to interrupt the treatment. In this way, as well as admitting that a doctor can commit acts of mere execution in contempt of the professional nature of the act he/she carries out, the relationship between patient and doctor appears weakened: the formal manifestation of the patient's renunciation would in fact be conceived as a request without appeal of the act of interrupting treatment, to be executed always and in any case, that is, in an automatic way, by the doctor him/herself or by a third party, forgetting the "adequate evaluation of the case" mentioned in point 4.

The protection of the patient, especially in the case of the weakest people, demands instead that we give more value to the relationship with the doctor or with the medical *team* who is responsible for the treatment and in general for the patient's care, avoiding the introduction of extrinsic elements, which instead steer the relationship towards an *adversarial position* which would exacerbate disputes and distrust. It is necessary, in other words, that the ethical and legal basis of the relationship between patient and doctor is based on the objective of helping the dialogue between the patient's knowledge about him/herself and the doctor's professional knowledge, a dialogue that is an indispensable condition of a truly personalised care. On one hand the patient, offering his/her point of view, allows the doctor to subjectively evaluate the therapy's appropriateness and to formulate in this way a judgement that is not abstract and purely objective, but depends on the attention directed towards the person him/herself; on the other hand the patient can count on the doctor's professional evaluation, that is, a skilled and expert evaluation. Just as the doctor could recognise the inappropriateness of the treatment, he/she could also suggest waiting a bit more in order to overcome, for example, a temporary moment of difficulty. On the other hand, the hypothesis we

are considering is that involving treatments already started with the patient's consent and proposed as appropriate by the doctor. Therefore it is not appropriate to cite article 32, subsection 2, of the Constitution, which forbids compulsory treatments not dictated by law or in any case contrary to the human being: in the case in question we refer instead to free treatments, which the patient has consented to, unless we think that for any prolonged life-saving treatment it is necessary to consent "minute by minute". In fact, it is wrong and trivial to put on the same level the initial consent and the subsequent repeal of the consent to the life-saving treatment. Could we imagine as appropriate to act upon the request of a patient suffering from a heart complaint, who wants to have a cardiac implement, already surgically inserted with his consent, removed only because he/she wants to renounce the technical implement?

Rightly, the document underlines the difference between the *refusal* to start a health treatment and the *renunciation* of a treatment already started under the doctor's responsibility and with the patient's consent. Whilst the refusal demands the doctor's mere abstention from the professional act and even the doctor who deems such an act appropriate cannot violate the patient's body, the renunciation – when the patient cannot carry it out him/herself – implies, positively, the request of the doctor's intervention to interrupt the treatment. To accept the relevance of the renunciation means to prevent the choice to start the treatment from turning into a condition of imprisonment for the patient with regards to the technical instrument and at the same time to recognise that his/her request can make the doctor understand, in relation to the circumstances of each concrete case, the inappropriateness of the treatment (that has become excessively onerous). However, making the relevance of the renunciation absolute, means to deny the value of the relationship and of the dialogue between patient and professional and, in this way, to put on the same level a renunciation expressed soon after the start of the treatment, in a possible moment of weakness, and a renunciation that follows a long and heavy treatment, and which is also manifested in circumstances that seriously concur to redefine the doctor's judgement with regards to the concrete case. In final analysis, by making the renunciation absolute, we leave the patient alone (consider the weakest people, like the elderly who have a long-term illness), without being able to exclude the hypothesis that a doctor, to "liquidate the issue", could simply ask to be substituted by a colleague bureaucratically able to interrupt, on simple request, the treatment.

The problem of practically putting into action the renunciation must therefore be resolved without paying the high cost of a depersonalisation of medicine and of taking away responsibility from the doctor, who, when confronted by a patient's renunciation must neither coldly ignore it nor just as coldly go along with it, without expressing his/her own professional evaluation. From this point of view, in order to avoid the doctor becoming entrenched in his/her position, we could make provisions for the doctor's obligation to consult, in some cases, other doctors, in addition to the patient's right to substitute one doctor with another, who however should not avoid the task to give judgement in science and in conscience on the treatment's appropriateness or not, in light of the consciously expressed renunciation. In these cases additional reflection, which defers a solution that can be remedied, is preferable to the automatism of a solution without remedies.

Finally, we express the hope that the NBC will re-examine the issue of the patient-doctor relationship, not only in light of the possibility of a refusal or of a

renunciation of health treatments, which are hopefully extraordinary situations, but also in relation to the most frequent and positive aspects involving this delicate relationship, whose essential function is the protection of the good of "health as fundamental right of the individual and as collective interest" (article 32, subsection 1, of the Constitution).

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Prof. Salvatore Amato and Prof. Marianna Gensabella support this personal remark.

Personal remark signed by Prof. Vittorio Possenti

1. This additional note recalls and widens the considerations sent to the NBC members on the 20th of October 2008, anticipating the inability to participate in the plenary meeting of the 24th of October due to illness.

The document that is the object of this personal remark is drawn up with clarity and competence: for this we must thank the members of the working group, who have laboured to try and reach shared conclusions, even where this has been impossible in part because of the theme's difficulty and in part because of the variety of bioethical and anthropological perspectives of reference.

In the opinion's *Conclusions*, the conscious refusal/renunciation of health treatments remains in an uncertain state. This is true not only for life-saving care and the situation of patients who are unable to express their will if not in the early form of authentic and current declarations – an issue explicitly excluded from the opinion -, but also for the text's clear theme: the situation of patients of sound mind, who are conscious, informed, autonomous. The conclusions recognise that it has not been possible to find consensus within the working group with regards to the fundamental and in some way the only problem on which the opinion is focused; for good reason it describes the terms and the positions in which the variety of opinions manifests itself. This outcome is legitimate but worrying, because it decreases the NBC's "counselling" role towards the government and the parliament, especially on a theme that has been for a time at the centre of the bioethical, political and cultural debate.

A variety of reasons lead us to hope for a less hesitant outcome than the one recorded in the conclusions.

2. No absolute duty/obligation of care and of self-care exists at any cost, in particular when medical technologies' increasing invasiveness of the human body goes beyond any form of respect that is due to it, and it becomes confused with a fiercely technological idea of life and death, which violates the limitations imposed by the dignity of the human being. This important element is not specifically developed in the document, but it deserves more consideration in relation to the serious risk of violation and expropriation of the patient's body by an invasive, disrespectful and at times gone-mad technology. To live and die are not absolute and atemporal elements, to the point of making us insensitive to the way in which medical technology relates to the human body.

3. The opinion's carelessness regarding this point seems to stem from the fear, by some NBC members, that any small "opening" about the refusal /renunciation of health treatments would open the way to euthanasic procedures, which is, without a doubt, something to be averted. However, clarity demands that we point out that the "right to die" and the "right to refuse/renounce health treatments" are very different things. The "right to die" is a false right or a non-existing right, not because it is contradictory – as it has been at times hastily stated – but because it is something that is not due to the person. It is for this reason also, that it is not part of the commonly recognised list of human rights. Each authentic right gives voice to what is due to the human being, it expresses the *suum* that others must acknowledge. At the basis of every right there is not mere life, but human nature and human beings. Although the right to die does not exist, it is instead reasonable to acknowledge some autonomy in the way the subject faces death naturally and not as a fight to the death. If death is the ultimate human limitation that must be acknowledged, the interruption of treatment is not a refusal of life but an acceptance of the natural limitation that is inherent to it. It is not a renunciation of life, it is not a refusal of life, but an acceptance to not being able to prevent death or to not having to procrastinate it further.

Therefore, indirect or per-omission euthanasia and conscious refusal/renunciation of health treatments are not comparable, as the action's subjects are different: in the first case it is the doctor who abstains from care, in the second it is the patient who expresses the will to not be subjected to (further) care. In brief, there is no request of euthanasia in the refusal/renunciation of care. And we can easily imagine a disposition of self in the sense of avoiding care that is felt as invasive and useless, without in this way exercising the right to die. Naturally we must distance ourselves from therapeutic abandonment with all of its sad consequences, which, nevertheless, I believe – I'd be happy to be refuted by the experts in this field – is less frequent than cases of therapeutic persistence, towards which we are pushed by current, highly technological medicine. More negative than therapeutic abandonment is accompaniment abandonment, that is, the presence of too many machines and of few people in the patient's course of care. And once that, within the doctor-patient relationship, all the connections and the necessary information have been analysed, it is wise to put aside the claim that we, healthy people, know better than the patient what is truly in his/her best interests.

4. Almost fatally, the problems we are discussing involve the old issue of the disposability/indisposability of *one's own* life (I underline one's own, to define the problem, as the indisposability of other people's life is obvious). The opposing views that, quite ritually, refer to the criteria of the sacredness or of the quality of life, are well known. Personally, I have never used such doubtful categories. The starting point is the dignity of the human being in his/her concreteness, every time new and unrepeatable, with his/her recognisable and lovable human nature. The right to life is without a doubt the basis of any other right, even simply because to have rights we must exist, but from the right to life we cannot derive as its original character its absolute indisposability even by one's own self: in other words, from the issue of putting as foundation of all human rights the primordial right to life does not follow the indisposability of our "own life" as a good, which would involve a jump from the legal and compulsory level to the level of life and its absolute indisposability.

The agnostic and non-religious perspective gives the subject a high power of self-disposition, whilst the religious one sees human life as a "fortune" or, better, a good given as commodity or in use by the Creator to the creature, of which the creature is answerable. From this point of view, sometimes life is seen as a gift, in the attempt to justify human life as a gift from God the creator and therefore as indisposable. We could observe that the conclusion of indisposability is not so certain with regards to life as a gift, as a gift is something that does not belong to the giver anymore but to the recipient, who can dispose of it as he/she wishes. About the disposability/indisposability of one's own life, the opposing positions are profoundly and directly linked to a religious/creation-led vision or to an autonomous/liberal vision. Personally, I have often said that the expressions "catholic bioethics" and "secular bioethics" in their clear dichotomy are inadequate, except on one point: rational suicide, where in effect the religious/deistic perspective and the agnostic/anthropocentric perspective greatly differ.

5. The criteria of the indisposability of *one's own* life cannot be considered in the light of an absolutely abstract universality, which in effect ends up putting such indisposability in the hands of others. These people would end up assuming the role of decision-makers of such indisposability, which in the end would be taken away from the subject and given to others. Therefore it would not be a total indisposability but disposability in the hands of others. The criterion of absolute indisposability of one's own life in its abstract universality does not take into account the innumerable

contingences and particularities that surround it in such a way that this criterion cannot be taken as only guide *sic et simpliciter*. Instead, it is about not irremediably repressing the conscious and informed self-determination of the person in the relationship he/she has with his/her own health, body, life, encouraging instead the construction and establishment of a more authentic relationship with these realities. I mean to say that the criterion of self-determination, in all of its scope potentially without limitations, it is not in any way the absolute value that changes into licit what is illicit – as stated by the libertarian to the bitter end – but it is still an essential criterion within the subject's relationship with his/her own health and with the relative care, and it is expressly recognised by the Constitution.

6. Article 32 of our Charter, which certainly cannot be interpreted as a foundation for euthanasic practices, must be read as attributing to the personal body an extraterritorial value with regards to invasive acts by others and to therapeutic insistence. As this is a Charter that establishes the ethical-legal foundation of our cohabitation, I don't see why we need to surround its interpretation and its putting it into practice with a thick curtain of suspicion and exceptions.

To exemplify a case of life-saving therapy, I cannot see any ethical and legal reasons that are contrary to the decision of a patient that, finding him/herself in dialysis for a time without improvements and without decline, feeling as extremely painful and heavy the situation of total dependence, and having the doctor's confirmation that the situation is not reversible, would avoid the therapy or ask and obtain its suspension, even in the certainty that the outcome is lethal. The same can be said for SLA sufferers, who refuse the tracheotomy and the attachment to an iron lung.

It is still our duty to accompany the dying patient with palliative care and a humane relationship.

7. The fact is that current medicine is not anymore and not only Hippocratic medicine, but it completes it and it adds value to its persistent validity through the criteria of therapeutic alliance, of informed consent and of patient's self-determination. What does the proposition that the patient's self-determination must be respected mean, as Pope Benedict XVI has said in a recent speech to the Italian Surgical Society? Even accepting that the choice in favour of life and of healing is well founded, we cannot interpret the criterion of self-determination in relation to our own life in such a restrictive way that in effect the proposition of the indisposability of our own life becomes an event of disposability in the hands of others, as already mentioned. What's needed is dialogue, accompaniment, sympathy, help, life choices, but always in the respect of the patient, who can say: "the possible has been done, now let me go". This instance, already very important today, will become more and more frequent and decisive when the doctor finds him/herself alone to decide on *borderline* cases, in which technology is able to keep patients alive (like in the case of very serious accidents), who would very likely be condemned to a persistent vegetative life. This outcome comes into play in a very limited amount of time during which the medical team tries everything, without maybe wisely considering the limit and the possibility to "let go".

8. A large amount of cases involving patients in vegetative comas of various type, come from trying every possible medical treatment. This also means that any eventual law on the end of life will always be shaky, because it will not be able to take into account an unlimited amount of cases and will still have to leave to wisdom, to humanity, to the relationship between doctor and patient, an area of dialogue, avoiding excessive interferences by the law and by society. The doctor's role as

guarantor, which some strongly and maybe excessively insist upon, cannot become a kind of supreme and final tribunal. Article 8 of the Oviedo convention, which states: “When, because of an urgent situation, the appropriate consent cannot be obtained, we can immediately proceed with whatever medical procedure is indispensable for the benefit of the interested person’s health”, does not take into account that such benefit can not uncommonly (I speak about very serious events-accidents) turn into an evil. In case there are valid early declarations of treatment, it is necessary for the doctor to justify in writing any action contrary to the patient’s will. The obligation still persists to ensure life-support therapies to the patient in a persistent vegetative coma.

The case of the autonomous, informed and conscious patient only covers, naturally, a small amount of cases. It is therefore desirable for the NBC to return on the theme in the future, in a wider and more comprehensive way, also considering the fundamental guidelines of the NBC’s document (December 2003) on Advanced care statements.