

Quality of life and human dignity: aims and criteria of medical prolongation of life

Calidad de vida y dignidad del ser humano: metas y criterios de la prolongación médica de la vida

Qualidade de vida e dignidade humana: metas e critérios do prolongamento médico da vida

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ABSTRACT: Modern health care is a complex system comprising different parts and dimensions each of which is determined by its own criteriology and governed by its own ethical norms. If in response to scarcity of resources a decision to limit access to health care has to be made, such a decision can only be judged as being ethically acceptable if all the ethical norms which are relevant for the various dimensions are brought into an adequate balance. When limiting access to health care this structural problem of combining and balancing different ethical criteriologies and codes seems to be one of the most difficult tasks. But what are the main criteriologies and codes which play a role in this area and what type of interdependence would result in an adequate balance? In this paper we want to discuss some relevant questions concerning problems inherent to these criteriologies on the basis of specific health care problems in order to determine at least provisionally whether these distinctions and interrelations can be considered as a helpful means for solving the problems.

KEYWORDS: Quality of life. Human dignity. Health care - medical prolongation of life.

RESUMEN: La asistencia médica moderna es un sistema complejo que abarca diversas piezas y dimensiones que son determinadas por sus propias criteriologías y gobernadas por sus propias normas éticas. Si en respuesta a la escasez de recursos una decisión para limitar el acceso al cuidado médico tiene que ser tomada, tal decisión se puede juzgar solamente como siendo éticamente aceptable si todas las normas éticas que son relevantes para las varias dimensiones estén en un equilibrio adecuado. Al limitar el acceso a la asistencia médica este problema estructural de combinar y de balancear diversas criteriologías y códigos éticos parece ser una de las tareas más difíciles. ¿Pero cuáles son las principales criteriologías y códigos que desempeñan un papel en esta área y qué tipo de interdependencia daría lugar a un equilibrio adecuado? En este artículo deseamos discutir algunas cuestiones relevantes referentes a los problemas inherentes a estas criteriologías considerando problemas específicos de la asistencia médica como para determinar por lo menos provisionalmente si estas distinciones e interrelaciones se pueden considerar como medios provechosos para solucionar los problemas.

PALABRAS-LLAVE: Calidad de vida. Dignidad del ser humano. Asistencia médica - prolongación de la vida.

RESUMO: Os cuidados médicos modernos são um sistema complexo que compreende peças e dimensões diferentes determinadas por suas próprias criteriologias e governadas por suas próprias normas éticas. Se em resposta à escassez de recursos se tem de tomar uma decisão para limitar o acesso aos cuidados médicos, essa decisão somente pode ser julgada eticamente aceitável se todas as normas éticas que são relevantes para as várias dimensões estiverem num equilíbrio adequado. Ao limitar o acesso aos cuidados médicos, o problema estrutural de combinar e de equilibrar criteriologias e códigos éticos distintos parece ser uma das tarefas mais difíceis. Mas quais as principais criteriologias e códigos que têm um papel nesta área e que tipo de interdependência levaria a um equilíbrio adequado? Neste artigo desejamos discutir algumas questões relevantes a respeito dos problemas inerentes a essas criteriologias com base em problemas específicos de cuidados médicos a fim de determinar pelo menos provisoriamente se essas distinções e interrelações podem ser consideradas meios úteis para resolver os problemas.

PALAVRAS-CHAVE: Qualidade de vida. Dignidade humana. Assistência médica - prolongamento da vida.

Modern health care is a complex system comprising different parts and dimensions each of which is determined by its own criteriology and governed by its own ethical norms. Health care plays a significant role for bodily life and for the well being of each individual human being; it is an integral part of social life determined by

the professional standards of medicine and governed by economical rules and political decisions. Therefore, if in response to scarcity of resources a decision to limit access to health care has to be made, such a decision can only be judged as being ethically acceptable if all the ethical norms which are relevant for the various dimensions are

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brought into an adequate balance. When limiting access to health care this structural problem of combining and balancing different ethical criteriologies and codes seems to be one of the most difficult tasks. But what are the main criteriologies and codes which play a role in this area and what type of interdependence would result in an adequate balance?

In the first part of my paper I shall try to identify the relevant criteriologies and their interdependence and discuss the inherent problems (I). In the second part I would like to exemplify the specific problems by using a particular case of health care, namely the treatment and care of patients in persistent vegetative state (II), and in the last part I would like to examine whether the proposed model of distinctions and interrelations can be considered as a helpful means for solving the problems (III).

I. THE RELEVANT CRITERIOLOGIES AND THEIR INTERDEPENDENCE AND DISCUSS THE INHERENT PROBLEMS

If the description of health care is to be correct, then at least four dimensions have to be mentioned: the individual human being with its fundamental rights and freedoms: the relation between the physician and this individual human being as patient; the structure of social life of which health care is a part and which is determined by political and administrative decisions and the economical system which is governed by the rules of the market. All four dimensions have their own ethical codes: (a) human rights ethics, (b) medical ethics, (c) social ethics and (d) ethics of economy.

a. Health care and human rights ethics

What human rights ethics aims to signify is not only the fundamental dignity of the human being, but the basic anthropological dimensions without which the well-being and flourishing of a human being is impossible and which have therefore to be protected by fundamental rights. If each individual human being as a human being has such inalienable fundamental rights and freedoms, the system of these rights must be considered as a framework for all the more specific ethical and legal norms. With respect to the area of health care some of these rights have a particular importance, for instance the right to self-determination (autonomy), the right to the integrity of life and body and also the principle of equity.

But it is important to keep in mind in what way these fundamental rights play their normative role: They are not sources from which more specific norms can be deduced. They formulate fundamental claims or entitlements, but they protect these claims or entitlements – as you can see in the classical catalogue of human rights and freedoms – only by drawing limits against offences i.e. by formulating general prohibitions like that to kill innocent human beings. They express the necessary conditions without which nobody can pursue what he or she thinks is a good life, but they are not the title for a formula of good life. In contrary, they protect the freedom of everybody to follow his or her idea of good life within the limits which are determined by the freedom of others. Therefore informed consent is a necessary prerequisite for any medical intervention; and to follow ones own conscientious decision or the personal vocation is one of the fundamental freedoms.

Problems arise with respect to the so called *positive* human rights such as, for instance, the right to labor or the right to health care. Because the possibility to exercise these rights is dependent on various conditions and the extension of such rights is difficult to define. With respect to the right to health care it is therefore necessary to clarify the nature of this right. In so far as the protection of health is a necessary condition for the protection of life, the right to life and to bodily integrity comprises the right to health care. But because in this context life is protected as a fundamental good, the basic right to health care includes only the right to a decent minimum (cf. Childress JF in *The right to health care*. *J Med Philos* 1979;4(2)). Since health and health care are necessary requirements for social life, they can be considered to be public goods. However, the right to health care expresses a social human right which is more a claim than a definite right. Because this claim can only be realized in a given society, the definition of the right to health care has to be in accord with the social ethics of that particular society. Whatever the status of health care may be, its application has to be governed by the principle of equity.

To sum up, in an ethics of limiting access to health care, human rights ethics has to play an integral role which is, however, restricted. First, the limits have to be drawn by formulating the general prohibitions have to be formulated, which have to be respected by any further systems of norms and cannot be transgressed by weigh-

ing up between competing goods. If within these limits it is necessary to prefer one need against the other we are therefore not dealing with distribution, but with triage; what we are allowed to do here is not weighing up goods, but only weighing up unavoidable evils. As a second task human rights ethics has to emphasize certain claims or entitlements such as the claim to adequate health care. But without relation to a given society and polity it is only a reminder of goals which have to be specified by the actual social order and its norms.

b. Medical ethics

Because the human being is to a large extent determined by individual genetical properties, living under contingent physical and socio-cultural conditions and acting and suffering as an acting subject with its own biographical identity and value history, health and disease cannot easily be defined by a description that would be universally valid. Health and disease are action-guiding i.e. practical concepts which comprise a lot of descriptive scientific parameters, but are deeply dependent on socio-cultural and individual factors. In a strict sense a disease can only be determined in relation to an individual patient in a concrete situation by a physician who is able by experience and empathy to understand the patient and to diagnose his or her disease. General descriptions of diseases are the result of generalizations of such individual judgements and related to the diagnosis and therapy of another individual patient.

If it is correct to say that health and disease are practical concepts in a relation between an individual patient and his or her physician and which are leading to an action called diagnosis, therapy or prevention, then health and disease have to be governed by the norms which are the constituent parts of that teleology. And these norms not only comprise the pragmatic standards defined by the state of the art and governed by the code of right or wrong, but also the ethical norms which are defined within the framework of human rights by the ethos of the physicians and which governed by the code of (morally) good or bad.

The main principle of such a medical ethics is to follow what is required by medical teleology in accord to the patients informed consent within the individual patient-physician-relationship. Each of these two criteria is necessary, but none is sufficient on its own. Obviously, with respect to an individual patient, the criterion of medical

teleology is only fulfilled if treatment can be based on a concrete indication, i.e. on diagnosis, therapy or prevention of a particular illness, according to a certain medical standard (*lex artis*). The patient's consent should be guided by what we could call the 'ethos of the patient'.

The particular indication has to be considered as result of an individual practical judgement, a practical syllogism into which among others the various premisses enter: scientific parameters, medical standards, technological imperatives, disposability of means, expected effects, benefits (quality of life) and costs (physical, mental, spiritual) regarding the individual case, the preferences of the patient etc. The judgement itself has to be governed by the principle of proportionality (cf. Taboada, Schotsmans). If most of the parameters are related to the individual patient and his or her situation, then the adequate proportionality of a particular medical action can only be stated for the individual case. General criteria can only be given *ex post*, i.e. as the result of a generalization of particular judgements.

The difficulties of medical ethics with respect to limiting the access to treatment have their roots in the nature of practical concepts like health and disease. It is difficult to distinguish between therapy and enhancement, and it is also difficult, to establish an order of preference between different types of medical interventions. There are fewer difficulties if the teleological focus of medical intervention is not health, but disease. It seems to be no question that futility is a prohibitive reason, but it is difficult to get evidence about what can be effective and what will be futile in a particular case. However, this is not an argument against the criteriology of medical teleology, its impregnation by socio-cultural factors, its relation to the concrete situation of an individual human being and its practical character. In most cases the significant function of medical teleology is similar to that of other practical concepts. As in many other cases of practical concepts the difficulties are problems of demarcation. With respect to the question of limiting access to health care, medical teleology determines limits, but this in itself is not sufficient.

c. Social ethics

Human rights ethics tells us that health is a fundamental good from the viewpoint of the individual and a public good from the point of view of society. In both dimensions modern health care is dependent on resources

which can only be provided by the particular society. In overriding these resources the society resp. the bound by human rights ethics to the principle of equity, but this alone does not answer the question how equity of access to health care has to be concretized. Medical ethics demands that the physician has to do what is medically indicated and wanted by the patient, but tell us not what part of the actual resources a particular society have to spent on health care (macroallocation) and how then resources have to be distributed to the different sectors of the health care system (microallocation). What human rights ethics and medical ethics permit is to prescribe the decent minimum, to postulate an adequate proportion within the macro allocation and to demand equity in access to the particular health care system.

Beyond these demands and postulates the particular society confronted with the necessity of limiting access to health care on the level of macro allocation has to follow the ethical rules of social ethics. Because health care is answering to one of the basic needs of human beings and closely connected with the contingent conditions of human life, distribution has to follow the principles of solidarity and of subsidiarity. In realizing these principles, closeness and distance in the particular human relations are to be respected. It is the old idea of *ordo amoris* that under conditions of scarcity resources may be distributed according to the closeness or distance in human relations.

d. Ethics of economy

Under the condition of scarce resources economical effectiveness is an ethical demand. As an aspect of the cost-benefit-relation this effectiveness belongs to the professional duties demanded of the physician by medical ethics. But it is not only an obligation for the individual actors but also a duty of the public authority. If market is the most appropriate means to reach an optimal allocation of scarce resources, it would be an ethical demand to open the distribution of health care as much as possible to the rules of the market. In this case it would be an additional ethical demand to to guarantee the openness of market and to avoid failures of market. Incentives for the various actors, closer links between decision and liability and strengthening of competition could be helpful means. With respect to the large number of add-on-technologies in modern medicine which have a very restricted efficiency a catalogue according to the criteria of medical ethics is recommended.

Since, however, the unlimited market seems not to function properly with respect to come to good health care, other means for distributing the scarce resources have to be found. This a difficult problem for which so far a convincing solution seems not to be available.

Ethics of limiting access to health care

If it is correct that the four different ethical codes are relevant, the requested ethics of limiting access to health care could be understood not as a foundational system, but as a matrix built by a mutual determination of these four codes. This matrix permits to establish limits and to identify claims and entitlements, but it leaves open in which particular way these claims and entitlements have to be concretized. This would be the task of the particular health care system.

II. EXEMPLIFY THE SPECIFIC PROBLEMS BY USING A PARTICULAR CASE OF HEALTH CARE, NAMELY THE TREATMENT AND CARE OF PATIENTS IN PERSISTENT VEGETATIVE STATE

Coming to our particular case: How do we deal with people who have survived a brain injury but not regained consciousness and who, on all medical accounts, will never regain consciousness either?

There are few problems of medical ethics which are more difficult to solve, few which are met with such puzzlement by the experts. However, the puzzlement is understandable; for the fact that patients can be in such a state is a relatively new and uncommon one. It is the result of using modern medical technology – which leads to immediate recovery and cure for many, which opens up the possibility of gradual rehabilitation for some, and which leaves a not negligible number of people in a permanent state of being unconscious.

There is no agreement as to the the correct definition of their illness; the means for diagnosis are limited and prognosis will remain uncertain for a long period of time. Experience which could yield insight into the right way of dealing with such patients is as yet very limited. Comparison with other, more familiar states is doubtful. As a result, it is difficult to develop criteria and attitudes which could guide our actions in dealing with such patients. However, secure and accepted limits are necessary,

for no other group of patients is more vulnerable and thus reliant on appropriate protection and care.

In situations of such uncertainty, we are well advised to return to the basic self-interpretation of humanity and to reassure ourselves of some fundamental principles in order to obtain the criteria which can guide our judgments and actions. What is that basic self-interpretation, and which are the fundamental principles to guide us?

It is a hallmark of modern society that there are a number of different answers to these questions. This is true for each individual society, and even more for the cultural diversity of Europe.

In view of this situation, I consider it sensible to begin the search for suitable criteria by taking an approach which is anchored in European history and which forms the foundation of the legal consensus between the European states. It links the principle of human dignity and its consequent rights with the accepted teleology of medical practice and the demands which arise from the relation between doctor and patient.

What generates the “complete apallic syndrome” (or “persistent vegetative state” as it is more commonly called amongst English speaking authors) in the first place is the use of modern intensive care techniques commonly employed in cases of severe brain injury. Techniques are of a functional nature. Their employment is based on a functional understanding of life and aimed at the restoration or optimisation of certain life functions. As a means they are directed towards an end, and their efficacy is designed to achieve that end. They gain a relationship to the totality of human life only through the doctor, who must integrate them into his actions which are directed at that totality.

The use and application of certain means which the doctor indicates to be employed usually gain their legitimacy through the patient’s consent. What happens to this legitimacy if the patient cannot give his consent and if the means employed lead to a state which does not fulfil the hopes associated with their employment, a state with an uncertain prognosis?

III. THE PROPOSED MODEL OF DISTINCTIONS AND INTERRELATIONS CAN BE CONSIDERED AS A HELPFUL MEANS FOR SOLVING THE PROBLEMS

What significance does the resulting state have for the person concerned? How does the doctor, in whose care

the patient has come, regard such a state? How do relatives and the society at large regard it?

To advance an answer to these questions we need clarity about the following aspects: What is meant by the notion that a person can be ascribed (human) dignity and how is this dignity related to the integrity of body and life? How can we interpret the right to life and the right to a natural death and what role should the quality-of-life criterion play in this context? How does the teleology of medical practice determine what has to be done?

a. What is meant by the notion that a person can be ascribed (human) dignity and how is this dignity related to the integrity of body and life?

According to the notion of basic human rights, every human being must be ascribed an inalienable and unlimited dignity as well as the corresponding protective rights, regardless of all qualities or achievements of that person, especially of his or her health or state of consciousness. For the basis of such dignity and the criterion for its ascription constitute an undissolvable unity. According to the unambiguous testimony of our moral and religious traditions, that human dignity is based on the fact that a person is a living being with the capacity to determine its own goals. Because the person is a human subject which can say “I” and which interacts with others, it constitutes a good which cannot be offset against other goods and which – in the words of Kant – is an end in itself. What the notion of human dignity seeks to protect is this capacity for self-determination.

It is the *living being* which is the human subject; in the sense of a diachronic identity it is both a living individual and a subject, nature and person. However, if the subject and its body constitute an inseparable unity, then the specific *living being* is the *human being*. In other words, if being a subject is the basis on which we ascribe dignity, and if the living being and the subject are a unity, then the criterion for ascribing dignity is being human. Thus the notion of basic human rights not only incorporates the idea that human dignity is inviolable; it also contains a prohibition to ascribe that dignity on the basis of anything other than the quality of being a human being.

If subject and body constitute an inseparable unity in such a way that life is the condition for the possibility of being a subject, then the right to have one’s dignity

respected entails the right to have the integrity of one's body and life protected. The human being's right to life is something which we acknowledge, not something which we ascribe. It is therefore a right which precedes all positive law; and the resultant prohibition to kill human life is of an equivalent general nature.

Following this idea and taking the unconscious human being for what it is: a human being which is bereft of certain functions but which, at its core, is still a living human being, we arrive at a first conclusion. *The permanently unconscious human being is a human being which has the same dignity and right to life as any other human being.*

This conclusion is often disputed on the basis of a distinction between being human and being a person and an ascription of dignity and right to life to the person only. However, such a distinction contradicts the diachronic identity which we ascribe each other in all practical and theoretical contexts. What is more, its moral consequences are in contradiction to the consensus contained in the idea of basic human rights: that the ascription of dignity is made dependent on nothing other than being human. At the very least, anyone taking this position must take on the onus of proof.

As far as the patient is concerned, our first conclusion entails that the unconscious patient, like any other sick person, has a right to treatment and care which meets the therapeutic and palliative necessities of the illness. Indeed, if we interpret the prohibition to restrict the notion of basic human rights not merely as the foundation of an ethics of fairness, which is governed by a reciprocity between participants of equal strength, but also as the foundation of an ethics of solidarity with the weakest, then the right of the especially needy human being to get help gains particular weight.

b. How can we interpret the right to life and the right to a natural death and what role should the quality-of-life criterion play in this context?

Reference to the protection of dignity and the integrity of body and life, however, only stakes out a claim and marks a border; it does not provide the differentiation which is necessary in view of the concrete problems. Such differentiation only appears as we take a closer look at the human condition.

When I experience myself as completely identical with my physical and physiological nature I also experi-

ence myself as someone whose nature, transcending the physical and physiological, finds its fulfilment as a talking, acting and suffering subject in communication with others. Because I am a subject which is *identical* with its own body and at the same time *owns* this body, I can make that body the object of examination and therapeutic intervention as long as I relate such intervention to the totality of the human being. If subject and body constitute a unity of "mediated immediacy", to use a phrase of H. Plessner's, it becomes clear why mere living and survival have to be viewed as a necessary condition for the possibility of a successful life, though not as identical with it.

Thus, the question remaining is, how the good of living is related to the goods which make a fulfilled life. A *first* answer takes the relationship to be an instrumental one: Living is a value inasmuch as it is the instrument to support a personal life. This solution is based on a dualistic anthropology in which living remains external to the personal life and only has functional significance. However, any interpretation of personal identity as a unity of consciousness which excludes the dimension of living fails the consistency test; this is demonstrated by the fact that even John Locke had to supply a theological justification for the prohibition to kill. In addition, such an interpretation contradicts the practical experience of our diachronic identity. A *second*, quite different answer assumes that living is so much part of the person that it has absolute value. However, this solution, too, does not agree with our basic moral experience. If living was an absolute value, it would have to be prolonged at any cost, even that of greater suffering and pain; any withholding of treatment would be tantamount to killing. Risking one's life for others or dying as a martyr would be a violation of life; even the freely chosen abstinence from life prolonging treatment would be illegitimate.

If we do not wish to deny the moral legitimacy of such phenomena, there is only a *third* way which appears to be consistent. Like the moral tradition, it distinguishes between basic and higher goods; it views living as an inherent good which, as a necessary condition of all other human enterprise, has a *fundamental value* but does not therefore as such already represent the ultimate good. Being fundamental it yields the integrity of body and life from the protection of human dignity and turns it into the basis for the right not to be killed. However, this right to life must be interpreted such that it does not exclude the

right to die a natural death. As nobody has the right to dispose of someone else's life, any intervention by the doctor requires the patient's consent; this implies that the patient has a right to place his own limits on any intervention.

However, it does not follow from the relationship described that the fundamental good of living is at anyone's disposition where a relationship to the higher goods is difficult or impossible to detect from the outside. Why not? If life is given to a human being and if this gift is the seat of the dignity of moral existence, then it is part of a person's freedom to decide for himself what he regards as a fulfilled life. This freedom must be protected. The protection of his dignity therefore demands the inviolability of the freedom of conscience. This does not determine one particular form of dignified human existence, but it marks a limit in order to guarantee the conditions and open up the space for a person's own decision over the fulfilment or otherwise of his life, and to protect it from outside interference.

Every judgement of a third party, which regards a certain state of living as no longer worth living, would be a judgement about the quality of this state and its relationship to a fulfilled life which is open only to the patient himself. This applies in particular to any judgement or reasoning which restricts the right to life because certain qualities of life are lacking. On the other hand, we must preserve the space for the patient's freedom to reject a certain intervention in view of a quality of life which he no longer considers to be meaningful and which he experiences only as full of suffering and pain.

However, if a judgement about the quality of a certain state of living can only be gained from the perspective of the person who is in that state, then that person's will is the ultimate deciding factor. Applied to the case of a patient who, due to his permanent lack of consciousness, cannot exercise or at least utter his will, this means that the legitimacy of all actions must be assessed relative to what can be regarded as the patient's presumed or previously expressed will as it appears from the circumstances, the guiding attitudes and the value preferences which can be gleaned from the patient's life.

This yields my *second* conclusion: *Living is a good which as a condition for the possibility of higher ranking goods has a fundamental value; what quality a certain state of living has in view of such higher ranking goods can only be decided by the person concerned. This includes the legitimate*

decision to reject intervention which in one's own judgement only serves to prolong a state which is no longer experienced as meaningful but only as full of suffering and pain. Any decision which is not based on the presumed judgement of the person concerned and which is based on external criteria would be a violation of the person's right to self-determination.

c. How does the teleology of medical practice determine what has to be done?

How can the patient's right to appropriate treatment be met if an assessment of his quality of life on the basis of objective criteria alone and without authorisation from him, that is a purely external assessment, is morally problematic, whilst the doctor has to make decisions and take the responsibility for action or the lack of it?

The only answer, it appears, which preserves the limits already drawn seeks the criteria for decisions in the *teleology of medical practice*. No doubt, the doctor has to make judgements about the present and future quality of life for his patient; for without them he cannot determine any therapeutic action. However, such judgements are limited by the structure of medical practice which make them appear acceptable, unlike judgements made on the basis of external criteria.

For it is part of the structure of medical practice that it establishes a relationship with an individual patient; such practice is determined by the dual goal of cure and pain relief. Diagnosis and prognosis are essentially related to the individual case; the therapy is to be developed from such diagnosis and prognosis. It must reflect the patient's will, or at the very least, not contravene it; and it must therefore, as a kind of "shared action", be supported by the relatives of or an advocate for the patient. Even judgements about the present and future quality of life for the patient, which are contained in the diagnosis and prognosis as well as the resultant therapy, are limited to the individual case and related to its context.

The doctor's judgement in a doctor-patient relationship differs from a judgement based on an objective catalogue of criteria as practical deliberation differs from rule-following. Whereas in a case of rule-following the treatment of an individual patient appears and is treated only as an instance under a rule which makes certain actions obligatory, in a case of practical deliberation it is the individual instance itself which leads to the appropriate rule, the criteria for decision making and the action. The

criteria of rationality and legitimacy are no less strong in this case, but they are not subject to a simple calculation, unlike when the action is determined by a fixed rule.

Apart from the relationship to the individual case and the connection with the concrete context, the legitimacy of a doctor's actions also depends on the dual teleology which is characteristic of medical practice. This dual teleology consists in cure and pain relief. According to medical tradition, cure encompasses the preservation and restoration of the condition for a fulfilled life. As a goal for therapeutic action it is not identical with the fulfilled life; at the same time, it cannot be thought of without reference to the conditions for a fulfilled life. To determine the goal itself it is therefore necessary to ask whether and how the cure can put the patient in a position where he can pursue the goals and aims of a human life. If, in the opinion of the doctor, it can no longer achieve such a position then the therapy has reached its limits and the doctor's actions must be limited to appropriate care and pain relief.

If the process of dying has already begun, the withholding of life-prolonging measures can be justified. At any rate, the second goal: pain relief, excludes the prolongation of life which is alien to the therapy and leads to unreasonable pain for the patient. On the other hand, pain relief appears justified even if it has life-shortening side effects.

However, medical practice as it relates to permanently unconscious patients is usually not medical practice as it relates to dying patients. It usually requires action under an uncertain prognosis without the possibility to refer immediately to the patient's will. The doctor will therefore have to act according to a careful diagnosis and a presumed prognosis; and he will have to judge the expected circumstances of life for the patient "according to his best knowledge" (Swiss Guidelines), and consider whether the "intensity and strength of the intervention inflicted on and the effort expected of the patient" are adequate for the "presumed therapeutic success and the life expectation for the patient". The doctor's responsibility in this consideration is total. Acting according to orders would contradict the teleology of medical practice. On the other hand, the remaining uncertainty of the diagnosis demands a consideration of the patient's presumed will. The decisive factors in this are: any expression of a wish to continue living, earlier instructions from the patient,

his moral and religious beliefs and the value preferences contained therein. If one can expect the restoration of a state in which the patient can lead "a life of inter-human communication", then one usually has to assume the patient's consent to any measure necessary to achieve such a state. It follows from the relation between doctor and patient that in the case of a patient who is unable to give consent any action must be supported by the relatives of or other advocates for the patient.

My *third* conclusion is therefore: *Medical action related to the permanently unconscious patient results from the teleology of medical practice as it appears in the circumstances which apply to the individual patient; it must follow the criteria which result from that teleology. The judgement about the expected life for the patient, which follows diagnosis and prognosis and which is necessary to determine the therapy, must be made relative to the individual case, according to the best knowledge and with respect to the presumed will of the patient. The decision about the therapy, which is the responsibility of the doctor, should be supported by the relatives. It is suggested to refer the individual deliberation and decision to an independent body.*

Certain consequences follow from this third conclusion. As long as there is no unambiguous evidence that the state is irreversible, the doctor must employ all diagnostic, therapeutic and rehabilitative measures which are suitable for the restoration of the patient's health. As long as the prognosis is uncertain, he must act according to the principle *in dubio pro vita*. A conscious withholding of what is demanded by the medical goal would be tantamount to killing.

I will forego the opportunity to develop the further criteria which result from the teleology of medical practice for this area of medical endeavour; they are the subject during the third section of our conference. My final remarks are these:

If a permanently comatose person retains his dignity and right to life without restrictions, and if it is part of the notion of human dignity to be able to determine for oneself which state of living is worth living with respect to one's concept of a fulfilled life, then we must rule out any guidelines which enshrine general criteria which depend on an 'external' judgement about the patient's quality of life and as a consequence may even restrict his right to life. On the contrary, in this case dignity and right to life establish a special right to protection and care. If this right is to

be claimed effectively we must make every effort to achieve methods for a more accurate diagnosis and a more certain prognosis as well as improve rehabilitation facilities.

The patient's right to life, however, also includes the right to a natural death. This is the right to forego therapeutic intervention and even life-prolonging measures. It is not the right to seek active assistance to cause death, a right which would, against the medical teleology, force or authorise the doctor to kill. Even with respect to a permanently comatose patient, the relation between doctor and

patient remains the seat of any therapeutic decision. That decision must presume the patient's will to live. The patient's right to a natural death can only justify appropriate medical action if the patient's instructions indicate that he wants to claim that right and if the doctor's actions are supported by the relatives of or an advocate for the patient. If the patient's instructions relate to the withholding of life-prolonging measures after a certain prognosis has been made, it would appear appropriate to refer the doctor's decision to an independent third party.

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