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MEDICAL DECISIONS IN END-OF-LIFE SITUATIONS AND THE ETHICAL IMPLICATIONS OF THE AVAILABLE OPTIONS

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Unrevised translation

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INTRODUCTION

Given that, in the words of L. V. Thomas, "every society gets the death it deserves" (142) and that every society and every period of history faces its own specific paradoxes, this report will deal with **medical decision-making in end-of-life situations in Europe.** This subject is viewed in the context of three major features of the current European landscape:

1.   The universal natural phenomenon of death, which follows all births, raises questions for modern societies. Increasingly, death is medicalised and occurs in hospitals, prompting some patients to opine that "death is when medicine decides to stop". Who decides? How is the decision taken? What does such a view expressed by a health care user actually mean?

2.   The regular extension of life expectancy is accompanied by the ever longer preservation ("survival") of the lives of increasingly old persons with increasingly serious diseases. Western society is tempted to follow up this long life by shortening the end-of-life period, which is covered up and forgotten as quickly as possible, so much so that in some institutions we might wonder if an individual's death has not become a sort of "therapeutic side-effect". At the same time, patients and their families expect society to relieve their pain and to support them right up to the last few moments of their lives with appropriate treatment.

3.   Lastly, westerners are demanding more and more autonomy. However, within this autonomy the human being is both 100% biological and 100% cultural, while at the same time being irreducibly individual. "He bears within himself a genetic heritage and at the same time the imprinting[1] and the norms of a given culture[2]" (92). These three sources are central to the individual in his capacity as a subject. To be a subject is to unite egoism and altruism. The ethical approach to possible choices in the decision-making process must therefore acknowledge the essential nature of egocentricity and the basic potential for the development of altruism, which is a prerequisite for any society.

Medical decisions in end-of-life situations therefore take place in the context of our European fellow-citizens' demand for an improved quality of life, extrapolated into an improved quality of death. The debate on the end of life and the support provided for it in Europe thus lies at the crossroads of all demographic, social, medical, political and economic givens, because it primarily lies at the centre of every human life for *soi-même comme un autre* ("Oneself as an Other", also the title of a work by Paul Ricoeur) (121).

The aim of this report will be to:

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[1] E. Morin defines imprinting as "the indelible mark which is imposed first of all by family culture and then by society and which remains throughout adult life".

[2] Morin defines culture as "a set of items of knowledge, know-how, rules, strategies, habits, customs, norms, taboos, beliefs, rites, values, myths, ideas and achievements which are handed down from generation to generation, are reproduced in each individual and maintain the individual and the social complexities" (93).

1.   clarify terminological questions in order to home in on the underlying ethical problems;
2.   describe the operational modes behind clinical decision-making processes;
3.   analyse the European roots influencing these decision-making processes;
4.   highlight the ethical implications of these decision-making processes in present-day western medicine.

These various phases will highlight the need to work on "thinking well" (99), to quote Pascal, and to start work on a critical hermeneutic approach to medicine.

I.   TERMINOLOGY AND RELATED ETHICAL PROBLEMS

According to the specialist literature, **medical decision-making** terminology emerged over the last few decades, relating to various fields of medicine: neonatology, adult and child intensive care, geriatrics and palliative care (27; 139). In these services specifically there has been a radical change in practice, and an ethical debate has emerged in line with this new context. At a time when virtually all the patients concerned were dying either during or after the implementation of aggressive types of treatment, prior questions began to be asked about the value of implementing these types of techniques at all, and a debate was launched on reducing them, or even halting them after they had begun. In such cases, the services in question gradually brought in palliative care teams on the basis of a *transitional palliative care* approach, given that the patients, families and care teams confront together the conceptualised threat of possible imminent death and its whole panoply of grief and anguish. This was the point of collision of two different modern understandings of medicine, viz curative and palliative medicine. How were the two to be reconciled? It was during this "change of course" that the main ethical questions on the end of life began to emerge.

1.1 The concept of a medical decision

Etymologically, the word "decision" comes from the Latin *de* and *caedere*, meaning, *cutting off, cleaving, deciding.* In its standard meaning the word "decision" refers to choosing an action to effect or an attitude to adopt. A decision puts an end to hesitation, as the culmination of a process of reflection of varying degrees of intensity.   In its philosophical sense it refers to the analysis of will by the psychology of classical introspection: it constitutes the moment which precedes the execution of an act and succeeds its conception, followed by deliberation.   It involves rationality and responsibility (116).

In the medical field, the decision is the "heart" or the raison d'être of the medical act: it is the fundamental act in the exercise of medicine. The medical decision-making process, in the presence of a patient or a community, consists of choosing a mode of investigation, formulating a diagnosis and then proposing or deferring a type of treatment (62). Medical decision-making may follow two different methods: the traditional method, which is redolent of the whole history of the profession and is based on the recognition of forms (*Gestalt*), and the so-called "probabilistic" method which emerged in the 19th century, presupposing an inherently different attitude embracing the uncertainty that bests all knowledge (uncertainty of the data provided by questioning, uncertainty of the information expected from diagnostic investigations, uncertainty of the benefit expected from the therapeutic prescriptions to be applied, etc).   Incorporating the uncertainty

dimension into medical knowledge means acknowledging that the only possible medical decision is a probabilistic one, and therefore that error is consubstantial with any medical decision. In fact, these two methods are complementary in medical practice, and are combined in the current period of demands and justifications. The new constraints facing medicine today come from the economic market and a new type of customer-contract relationship with the patient. In this context, ethical conflicts emerge between legislation and practical wisdom, as in the following two examples:

• The first example concerns the laudable but illusory legislative requirement set out in the code of medical ethics to the effect that "all medical decisions must be taken in accordance with the current state of science". Doctors are required to read up in order to ensure the scientific credibility of the information on which they base their reasoning (evidence-based medicine and "levels of evidence"). Given that 20 000 medical science articles are published every month worldwide, we can see the practical difficulties of securing reliable information. Moreover, once the scientific information has been established, medical decisions are needed to "judge" the applicability of a treatment deemed scientifically valid to an individual case, and therefore to a relationship between two individuals.

• The second example of an ethical conflict between legislation and practical wisdom is the practical impossibility of meeting health care needs without imposing limits on them, raising certain questions:

o firstly, for each individual, where are the limits to be set and how are they to be justified? What are the priorities? Who and what should determine the latter? Health care needs are not invariants of human nature but are multiple cultural aspects in constant flux and evolution. They are linked to each European country's history, social and political structures, health care system, representation of individual health and illness, etc;

o secondly, in collective terms, what exactly is to be justified, to whom and on what basis? Will these questions change the modalities of medical practice, or indeed the ethical foundations and whole significance of the medical profession within our society?

1.2 The "end of life" concept

At the international level, the WHO refers to "palliative care" as a practice implemented when a disease is gradually worsening and the patient is nearing death, and uses the term "end of life" to describe the so-called "terminal" stage of a disease or illness. However, what of the "relationship" between the illness and its host, the sick person drawing towards the end of life? Terminology becomes confused as death approaches, fancifully perceived as the "final illness to be overcome". And yet this "terminal" period has always constituted the main concern of medicine, since any disease confronts the patient with possible death. While there is life, even without hope, medicine continues its efforts. But when death comes, medicine is sidelined. The major problem of medicine therefore is indeed the dying process!

In France, an effort was made to clarify terminology in the end-of-life field with the parliamentary mission assigned to Dr Jean Leonetti, entitled *Respecter la vie, accepter*

la mort (Respecting Life, Accepting Death)[3]. A number of ambivalent and ambiguous questions were highlighted in the questionnaires for the relevant opinion polls. For instance, in the 1999 IPSOS survey the question asked was, "If you had an incurable disease which caused you extreme pain, would you like to be helped to die?", while the 1990 SOFRES poll asked the yes-or-no question, "Should very ill people be allowed to die if they so wish?", and the wording in the 2002 IFOP survey was, "Should doctors be allowed to put an end to the life of an individual who is suffering from an intolerable incurable disease if (s)he so requests?".

The fact is that these three situations can be interpreted very differently, as a rejection of excessive therapeutic zeal, in the first case (IPSOS), provision of palliative care in the second case (SOFRES) and an intentional and deliberate termination of another's life (euthanasia) in the third case (IFOP). Faced with this multiplicity of terms and expressions, the parliamentary mission proposed rethinking the end of life by banishing the word "euthanasia" as being too general and confusing because it covers widely varying realities on the clinical front. The following concepts were proposed: "medical abstention" to be used in the context of emergencies and intensive care in order to prevent excessive therapeutic zeal; "help with dying" in the sense of end-of-life support; and "deliberate termination of life" corresponding to the precise term of "euthanasia", without a qualifier (active or passive) to describe the voluntary, intentional and deliberate act of putting an end to another person's life, which, in the legal vocabulary of all present-day countries, is defined as "homicide".

In Europe, the legislative texts analysed highlight a lack of comparative studies, and those studies that have been conducted concentrate on comparing a limited number of west European countries (a maximum of six or seven) (LC 139/2004).

The terminology used here is that used by the *Société Française d'Accompagnement et de Soins Palliatifs* (French Terminal and Palliative Care Society). "End of life" means "in the natural development of a disease, that death is imminent and inevitable. It is a "tipping point" in the development of the disease as announced by the breakdown of the major vital functions, often triggered by an acute episode (intestinal occlusion, infection, pulmonary embolism, etc). Schematically, there are two very different moments in the end-of-life phase: the pre-agonal phase and the agonal phase. The **pre-agonal phase** relates to the breakdown of one or more of the main vital functions, viz the heart, lungs and brain. The corresponding neurological, respiratory and cardio-vascular signs can therefore be described. In other words, this is a condition which is sometimes reversible and can develop towards a palliative-phase situation with the corresponding therapeutic strategies. The **agonal phase** is marked by the appearance of the first signs of decerebration and the inexorable deterioration of the neurovegetative regulating functions. This phase is irreversible and leads to death." (137).

1.3 <u>Ethical issues relating to the beginning and end of life</u>

1.3.1 *<u>Life beginning</u>*

Historically, situations relating to end-of-life issues in neonatology have been on the agenda for some forty years now, ever since this new discipline emerged. Before this

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[3] Leading to the Leonetti law (*loi Leonetti*) of 24 April 2005.

time, all acute pathologies present in a neonate[4] at birth could only lead to its death. Having no means of intervening, it was fairly simple for doctors, apart from the human and affective aspect, to accept such natural deaths in ethical terms. Today, on the other hand, it would no longer be acceptable not to try every means of saving a child who is in mortal danger. However, is there not a risk of going too far, of venturing beyond the tolerable? Should all such neonates be resuscitated? Can we resign ourselves, in specific cases, to halting the resuscitation process, which in fact flies in the face of nature, so as not to cause a seriously disabled child to survive?

The main ethical dilemmas encountered are as follows:
- Resuscitation at birth of an apparently stillborn child.

In such cases, medical resuscitation is required for the child's survival. But should this be provided systematically? When should resuscitation stop? Within hours or days of being born, some neonates present a serious state of distress that endangers their lives. In such cases their survival depends on sophisticated technological resources. Are all such technological methods justified, and is there not a risk of therapeutic escalation, or even unreasonable medical zeal? If resuscitation is undertaken for the benefit of the doubt, what about the resulting mischief when a major disability is induced by medicine?

- Saving neonates suffering from multiple malformations.

Multiple malformations are still common because they cannot always be diagnosed or because no diagnosis was possible during the prenatal period, in spite of all the scans, foetal blood tests and amniotic fluid analyses. Ethical issues are raised only if the child's suffering is extreme, if the neurological prognosis is disastrous or if there is an accumulation of lesions which in combination will make subsequent life very uncertain, despite multiple major operations.

- The neurological consequences of perinatal cerebral anoxia.

Perinatal cerebral anoxia and its neurological consequences can be extremely serious, causing profound and definitive psychomotor and sensory disabilities, without leading to "brain death". It is currently impossible to prevent such lesions, raising the question of the limits of foetal viability. How far can we go in this field? Should we set limits in terms of weight or length of gestation?

1.3.2 *Life ending*

- Life ending and death

"End-of-life" practices in fact relate to "life ending", because when death occurs and we are left with a corpse, medicine no longer has any role to play. Within the "life ending" phase, in the context of medical decision-making, the following factors should be differentiated:

1. the representation of death as something possible, a universal experience, particularly when a diagnosis is awaited;

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[4] Neonate : a child from birth to the 28th day of life.

2.   the natural course of the end of human existence, which has its own specific physical, psychosocial and spiritual needs. It comprises a pre-agonal phase, with the breakdown or gradual extinction of one or more vital functions, and an agonal phase marked by the appearance of the first signs of decerebration and the deterioration of the neurovegetative regulating functions.

3.   the terminal stage of a disease, which combines the symptoms of the latter with their final evolutive stage and the signs of the natural course of the end of existence.

Each of these phenomena inherent in "life ending" situations necessitates separate medical decisions: the diagnosis of the anxiety surrounding the representation of death will require a suitable relational approach and recourse to philosophy, the diagnosis of "life ending" will obviously necessitate an appropriate psychosocial and cultural approach, and the diagnosis of the terminal stage will involve care tailored to a specific disease in its final stage of evolution and the psychosocial and spiritual effects of the latter on the patient and his/her family, who are associated with the cultural approach to the natural course of any human life.

•   Aging populations in Europe

Becoming "older" each year is the natural physical and mental process of the seasons of life: birth, maturity and death. Since time immemorial individual aging has been part of the human adventure, raising fundamental existential questions. Confronted with their mortality, old people reinterpret their presence in the world. In this story they are not isolated but maintain close solidarity-based links with the cultural, social and family group to which they belong. All societies implicitly or explicitly assign a role to their elders, and organise to meet the needs of their weaker members, particularly their very elderly dependants.

Nowadays, however, the individual aging of western Europeans is proceeding in line with trends in the world community of the 21st century and is accompanied by new ethical challenges. Ending one's life in the European community today raises questions because of the current demographic revolution. Experts have calculated that by 2025, 25% of the population of each European state will consist of elderly persons, who will be increasingly old and dependent. These persons will therefore need both assistance in their everyday lives and medical treatment of variable cost. In the case of the very old, who constitute a still expanding group in the privileged western societies of Europe, thanks to curative antibiotic medicine it is possible to prevent an old person from dying as a result of a commonplace infection. Medicine can also reduce the destructive effects of illness on organisms weakened by aging. Scientific progress and advances in the health field (diet, hygiene, etc) are the main factors in prolonging life expectancy.

This aging of the European populations is thus presenting our society with a number of challenges: is the prolongation of life expectancy confined to "good health"? Can the increase in overall health costs correspond to the hope of a longer life in better health? What type of medical care is best suited to their state of dependency and their specific pathologies? What types of prescriptions are need to suit their conditions? What are the limits of technological exploratory and therapeutic measures? How can we inform the elderly which treatment is possible and which impossible, while respecting their dignity as citizens, within a progressive dialogue continuing until the end of life, taking

account of their clinical realities? How can we improve training in this field, which requires a different approach to the new realities we have to confront?

- Is there a cure for Europe's aging?

Statistical laws speak of a "demographic revolution". Humankind has always had a fairly balanced demographic system thanks to a low rate of population growth. For a long time, death and birth rates were high and only a small percentage of neonates lived to old age. Progress in the health and medical fields in the 19th and 20th centuries disrupted this ancient system by lowering global death rates. The result has been rapid population growth. This imbalance between birth and death rates should not last, according to statistical experts, and a new system is expected, this time characterised by low death and fertility rates. What would be the "useful" approach to this current period of demographic crisis or revolution? Death has been medicalised: what kind of death do Europeans want?

- What ethical questions does the health profession ask itself where elderly patients are concerned?

In the clinical field, ethical questions concerning elderly patients are the same as for any patient. What are described as their main characteristics depend on western society's perception of both individual and collective aging. The joking question, "Can you cure aging?" might serve to depict the atmosphere in western Europe surrounding the representation of "living to an ever riper old age". In our "society of control", medical research and its practical application are based on the exclusive vision of the myth of eternal youth and "single use". The opinion which the modern citizen has of himself (self-esteem) and the fact of growing older is influenced by the current prevalence of biologism.

In this prevailing atmosphere, the concept of "quality of life" in old age challenges the usual quantitative aspects. In a culture where all things biological are considered sacred, we often end up believing that existence can be reduced to quantitative terms. In this line of thinking, human dignity is no longer an indisputable given, but a conditional concept which can be analysed alongside other ponderables (physical, psychosocial or existential pain, socio-family isolation, loss of psychic autonomy, economic insufficiency, etc). This simplification and confusion of the qualitative and the quantitative might give us food for thought.

Behind this interplay between the quantitative and the qualitative lurks the same universal quest for human happiness. The dominant ethic of "individual happiness" would currently appear to be establishing itself in society. This reduces the moral obligation of "proper living" to the seeking of personal fulfilment. Highlighting desire and subjectivity in this way relegates the Otherness dimension to oblivion. And it has considerable consequences for relations between the elderly and their families: "nowadays, taking charge of an elderly parent is seldom regarded as a duty; on the contrary, it is frequently envisaged as a threat to family members' self-fulfilment, accentuating their fear, as if were, of 'failing' in life. We feel that the consequences of this form of ethics raise serious problems. Such ethics seem quite inadequate for mentalising such feelings as that of moral indebtedness, which, despite all attempts at rationalisation, act unconsciously and can turn into crushing guilt; so much so that we might wonder whether hatred of one's elderly parent is not the only way out of such

guilt." (101). These comments about the contemporary family and aging parents highlight the paradox of our situation vis-à-vis the elderly both on the individual and collective fronts. The elderly person disturbs, and is therefore despised and excluded from our lives; his or her mere presence throws up existential questions which do not lend themselves to media treatment and are relegated to the subject area of euthanasia!

In western Europe today, medical decisions with ethical implications relating to the end-of-life situation of elderly people are analysed mainly from the biomedical angle, but this precludes any understanding of the real problems facing health professionals. A few examples of the broader questions addressed by professionals in this field can shed light here: how and when should a patient be prepared for the end of his or her life? Which prognostic factors are to be used? What types of professional references or recommendations should be put in place? How can we facilitate access by elderly persons to appropriate care (types of structure, home, city hospital, etc)? How are the "terminal phase" diagnosis and its "agonal and pre-agonal" components to be established? How are the optimum types of treatment to be deduced from this diagnosis? How are elderly persons who can no longer communicate verbally to be kept informed, and how is a relationship based on dignity to be maintained? When and how can we decide that a person is ethically "incompetent"? How can individuals unable to communicate verbally be involved in taking decisions relevant to them? How can we "manage" any secrets imparted vis-à-vis the family, and also within the team? What kind of secrets shared by a patient should be reported at team meetings? How are we to protect such vulnerable persons and at the same time respect their autonomy? What are the role and the limits of persons of trust? How can we help elderly persons to draw up advance directives tailored to the ethical questions which society asks in their regard? How can health professionals use these documents? In several European countries influenced by the philosophy of the English-speaking world, patients wishing to be admitted to a "hospice" or other institutions catering for end-of-life situations must sign a declaration on admission specifying that in the event of major cardiorespiratory problems they will not be placed in intensive care. Should this approach be used more generally? etc.

- How are medical decisions taken in the light of these questions?

In a Dutch retrospective study, G. Roenwound (125) sent 43,000 questionnaires to GPs asking them, some time after a patient's death, about their decision-making procedures at the time of the said death. The results show that 30% used no decision-making procedures before terminating treatment such as nutrition, hydration or antibiotic therapy. These attitudes vary in accordance with the GPs' place of work: 52% of GPs practising in nursing homes stop the treatment without any prior decision-making process, as compared with 35% of those in private practice and 17% of specialists. We should once again stress the semantic difficulties of this type of survey, because it would be interesting to gain a better understanding of what is meant by "without any prior decision-making process", since, as we saw in the section on terminology, this process is inherent in the medical act itself. No doubt it means that they did not wonder about the interest and rightness of their action, which is the first stage in any ethical reflection. Two further studies, one conducted in Germany (115) and the other in Canada (150), compare the attitudes of three industrialised countries to therapies for elderly persons in end-of-life situations. The results highlight an aggressive attitude in 86% of American GPs, 61% of Canadian GPs and 68% of German GPs. Does this suggest that the more

industrialised a country is, the more aggressive its GPs are in their therapeutic approaches? This suggestion requires some qualification.

Other ethical questions have been addressed by specialist literature on the elderly:

1.   Questions of violence, and even physical and mental abuse, involved in provision for the elderly (pain induced by treatment, discontinuation of personal hygiene care, injuries and various types of physical and verbal violence, etc), and the lack of human dignity in the approach adopted by some professionals to highly vulnerable patients.
2.   Questions of the usefulness or otherwise not only of treatment but also of care; more often than not, the difference between the two is rather confused in the teams involved: when and how should a given type of treatment be restricted? Should the patient be hydrated or not? Should a feeding tube, parenteral nutrition, etc, be used?
3.   Questions concerning paradoxes: how are we to understand the paradox of "a quality of life for a quality of death"? What is the point of "a life like that"?, etc.

1.4 <u>The "end-of-life" context yesterday and today</u>

The semantic fog here stems from the fact that death is a property of any life form, a natural fact, but one to which human beings ascribe a specific interpretation which conditions the meaning of life. While the death of an animal is purely natural, the death of a person is tragic, and this, throughout the history of thought since ancient times, has led to various affective and intellectual attitudes.

In the ancient world, human life was regarded as part of the life of the cosmos, so death was considered to be an event which should be met with wisdom. This situation changed radically with Christianity, which introduced the concept of the infinitely unique individual into our civilisation (69). Every life is that of a unique person made in the image and likeness of the Creator; his or her spirit is within a body that is destined to die, but for the Christian, as for the modern atheist who has inherited the Christian tradition, life will be lived in line with the adage that "we only have one life", a life inseparable from incarnation and therefore from the biological dimension sustaining it. Death, like birth, thus becomes a serious matter, one that we have now medicalised.

It is doubtless impossible to escape this living tension, which is the basis not only of our culture but also of our human condition: on the one hand death is indeed a natural phenomenon, is in the natural order of things, enabling the living to die so that others can be born; on the other, death is also an ordeal which does away with an irreplaceable, unique being, something which outrages and perplexes us in equal measure. The former approach is geared to making death less traumatic, while the latter leads us to seek an ontological understanding by exploring human existential questions. All of which goes to show that death cannot take on meaning by itself and that its meaning or lack of meaning is strictly dependent on the meaning or non-meaning ascribed by each individual to his or her life, which again splits into several tiers: we can decide to die to earthly life in order not to die to eternal life, or we can take the diametrically opposed decision to commit suicide, like Kirillov in Dostoevsky's "The Possessed" (33), in order to prove that we are God, in control of life and death.

These different representations of ideas of death weigh heavily in the medical field. The approach to death will vary widely depending on whether the emphasis is on a life based on full enjoyment of physical and mental capacities or on one that does not reduce "life"

to its mere biological "mortal coil". This means that medicine can only exist if it takes note of the tension between these two poles, viz the natural and the spiritual, whose dialectics combine to form genuinely human life. Even if medicine confronts deadly diseases, it does not confront death: it is confined to dealing with life. For the medical profession, every patient, even one who is dying, is an authentic living being.

In short, this foray into terminological questions and related ethical problems shows that the approach to medical decision-making in end-of-life situations can only be envisaged from the angle of "critical hermeneutics", that is to say an array of interpretations and comparative views combining clinical, demographic, economic, political, anthropological, philosophical and other approaches. This thinking process, which can be conducted on the basis of textual exegesis, is the one also adopted by the instigator of any medical act (the decision-maker).

Hermeneutics, or the art of interpretation, is a comprehensive method specific to the human sciences, which Michel Foucault defines as "the totality of the learning and skills that enable one to make the signs speak and to discover their meaning" (50). Without this hermeneutic approach, medical decisions in "end-of-life" situations might be reduced to a mishmash of procedural and utilitarian attitudes. This approach, via what Pascal called "work on thinking well", might help to open up situations of ethical crisis deemed "insoluble". The suggestion that critical hermeneutics might be applied to the medical field highlights the three shortcomings in the decision-making procedures implemented at patients' bedsides, in terms of meaning, obligation and being. We should therefore "launch full-scale efforts to restore, renovate and broaden ethics" (19).

2.   CLINICAL DECISION-MAKING PROCEDURES

Two procedures, both of them rooted in ancient medical traditions (9), are at work today in medical decision-making processes: one follows the Hippocratic tradition and the hypothetico-deductive model (from Hippocratic medicine to evidence-based medicine), while the other follows a holistic approach directly in line with ancient philosophy and its leading light Aesculapius. These two long-standing traditions are nowadays implicitly combined in medical decision-making on seriously ill patients, particularly during evolutive terminal phases in their diseases. Both traditions come from the Greek world (138) and are the main origins of western medicine.

2.1 Two "health"-related traditions: Hippocrates and Aesculapius

The Hippocratic tradition currently dominates western medical procedures. Hippocrates (460-377 BC) and his school concentrated on laying the rational and scientific foundations of medicine. This scientific approach disregards patients' individuality and focuses all its efforts on the commonality of diseases. The decision-making process is based on the axiom that all disease (not the patient) follows a modelable sequence in accordance with causality laws which medicine must unveil. Once these "laws" have been discovered, the doctor can deduce from them the treatment required by the disease. The basis of Hippocratic medicine is that each illness or disease, each symptom has a cause, and that if this cause can be elucidated the disease can be cured and the knowledge acquired during the process will become generally applicable. This is the intellectual approach used to this day in diagnostic and therapeutic reasoning and research.

The Aesculapian tradition preceded the Hippocratic one, even they did coexist in Ancient Greece. Aesculapius (or Asclepius) practised medicine in the philosophical context of human existence and the conditions thereof, viz birth and death. Patients who came to him had been declared "incurable" by doctors applying the known therapies. The objective of Aesculapian medicine was to relieve symptoms resistant to the Hippocratic approach. They were declared "incurable" on the basis of this Hippocratic "failure". The atmosphere of the temple, with whose blessing this medicine was practised, the environment of repose and the doctor's interest in the patients' dreams contributed to the "healing" process. The basic hypothesis in this approach was that **the patient is the protagonist of his own healing.** This marks a fundamental difference from the Hippocratic approach and modern medicine. The latter **centres on the disease** rather than on the patient as the protagonist of his own healing process. This **complementarity of objectives** (the disease AND the patient leading his or her own healing process) shows **their slow, gradual integration** during the evolution of contemporary medicine. Today, "patient participation in health" is promoted by the concepts of health education, rehabilitation, physical and otherwise, behavioural psychology, life choices, patients' rights, patient participation in the relevant decision-making processes, etc. Does this mean that we should retain the distinction between "curative" and "palliative" medicine, given that there is A SINGLE clinical approach, viz that of the medical "art"? Wherever possible, in effectively dealing with illness, Hippocratic medicine is accompanied by a holistic approach, whenever the disease, rather than the patient, is incurable. In such cases it centres on the patient as the protagonist of his own "healing" process, targeting his quality of life. This is the fundamental palliative approach described by Cicely Saunders (131). This means that there are similarities in the work of the organic chemist and the "medical artist": both have the same aim, ie to complement nature and do what it cannot. This objective is achieved, according to M.T. Southgate, when the organic chemist heeds the patient and the artist heeds nature. She says that, if we are careful to observe and listen and are able to wait, sooner or later something will rise out of the depths of our being and we will find replies or solutions to things which used to seem insurmountable (138). Surely this is the key to the decision-making process itself?

2.2 Health and the consumer society: a confusing situation

How can this type of medicine, secretly combining "the curable and the incurable", be exercised in western European societies where care is provided.

The term "consumption" provides food for thought. Etymologically, this word comes from the Latin *consumatio*, and the verb *consumare* means "add up". "Consumption" has two separate meanings: (1) in the initial sense (12th century) it means the bringing of something to fulfilment, making it the equivalent of completion, accomplishment, end, termination; (2) in a secondary sense (17th century) it means the using of things in a way which destroys them or makes them subsequently unusable. The latter is now the usual meaning. "Consumption is destruction not of matter but of usefulness", as J. B. Say put it in 1968 (132).

This dual meaning of the word "consumption" highlights the challenges to the health system in the modern world. The risks of losing sight of the very objectives of medicine are very much present: what kind of medicine do we want in Europe? Do we want a system in which the patient/customer receives a systematic standardised service? Or a non-paternalistic "doctor-patient" relationship in which the doctor is in the service of a

sick person, who is the protagonist of his or her own "healing" or "quality of life"? Wait and see…

A number of unfortunate shifts of meaning can already be observed. Ever since the 1970s the Kantian doctrine of autonomy (*auto-nomos*) has been the subject of a consumerist interpretation that has led to the unwarranted view that you can have whatever treatment you want (patient self-determination). By "autonomy" Kant (79) means the capacity of all individuals to distance themselves from their own desires and to act accordingly in terms of maxims likely to be impartial or generally applicable to others: in other words, autonomy helps make the perception of events more objective and realistic. In this shift of meaning, Saunders' phrase, "You matter because you are you" (130), which is based on Kantian doctrine, is taken to mean that you must receive the treatment that you yourself choose. The consequences of these shifts of meaning in decisions in end-of-life situations which have ethical implications are significant, because reason is no longer the main factor in the face of affective drift. It is "as if consumerist conformism were busily paralysing the human function of reflection" (9).

Within this twofold Hippocratic and Aesculapian medicine and their UNION in practical reality, we can discern a landscape of two European faces of humanism, one domineering and the other fraternal. These two faces in ONE are leading to major confusion at the beginning of the 21st century. According to the first face of European humanism, man, taking the place of God, is considered as the only subject of the universe with the sole mission of conquering the world, disease, etc. This was the mission conferred on science by Descartes: making man the master and owner of nature. Since the 1970s, however, this message of Promethean omnipotence has been crumbling. We now realise that mastery of nature is impossible, that any attempt to control it leads to deterioration of the biosphere, and, as a knock-on effect, to the deterioration of human life and human societies; and that it is basically suicidal. European humanism has a second face, one that fully realises the smallness of our planet and the fragility of human life. It posits respect for all human beings, whatever their age or sex, race or culture. Would there not now be room for a third face, emerging on the basis of a dual identity (Hippocrates and Aesculapius) and the feeling of belonging to two different modes of existence in order to form a new entity, viz the "medicine of the curable AND the incurable"? Science is triumphing while simultaneously undergoing crisis: "This is no longer Science as Absolute Truth, Science as the Solution, Science the Shining Beacon, Science as the Guiding Light of the end of the last century. This is Science as a Problem." (93). Nevertheless, even within and via this crisis a type of knowledge is emerging which claims to be more suited to the complexity of the actual and whose central problem is to formulate the requisite paradigms for thinking about complexity: what Pascal called "work on thinking well".

2.3 Features of the European "spirit"

Sociological surveys (32; 42) on European values and culture consider the "disenchantment of the world" to be one of the key elements of the European spirit characterised by the drive to improve our understanding of things and a reasoned and relentless search for the reality of ideas and facts. The studies highlight the following features of the European spirit:

- Pluralism, as witness the European conception of truth:

The truth exists: we can and must try to gain access to it, but no one can ever claim to possess it definitively. Truth is an objective towards which we can progress, provided that we do so collectively and in co-operation/competition with others. According to Quigley (105), this liberal, non-authoritarian ideology is to be found throughout western history in the scientific, political and religious spheres.

- "Cultural secondarity"

This expression, coined by Brague (16), reflects the feeling that members of this culture have of belonging to outside cultural sources: Greek, Judaic and Roman. These are external because Europeans cannot consider them as their own roots, but nevertheless regard them as "fundamental" and therefore do their utmost to appropriate them. This results in a desire to understand things properly, to reflect on the relevance of alternative viewpoints and to ponder the advisability of potential borrowings both from the external founding sources and from sources beyond, from other cultures encountered by historical accident.

- New thinking

This characteristic concerns modern western social life and designates (57) the examination and constant revision of social practices in the light of new information on these very practices. The main feature of modernity is not support for things new as such, but the presumption of reflection on the ethical nature of medical practices, and also "thinking" about how to teach in the relevant training programmes.

- Individualisation

Ester's (38) definition of this term refers to the increasing autonomy of individuals in forming their own values and norms. "In Europe, the emancipation of individuals in the political and religious spheres and in private and public life is proceeding apace in all fields". The emphasis has been placed in this environment on patients' rights and desire to participate "autonomously" in taking decisions relevant to them.

Sociological surveys of the European spirit therefore point to an ongoing European ethical reflection.

2.4 Comparing the Hippocratic and Aesculapian operational models

In order to target the subtle differences between the models established by Hippocrates and Aesculapius, we shall describe the ethical approaches currently applied to seriously ill patients on the basis of a question put by a patient's son. The son asked the doctor the following question: "My father isn't drinking enough fluids; why don't you put him on a drip?".

- The ethical reasoning in Hippocratic palliative medicine today is based on applying four principles: (1) providing a benefit (calculating benefits against risks): would hydration improve the patient's condition?; (2) preventing harm: would hydrating the patient be likely to harm him?; (3) autonomy: does the patient actually want to be put on a drip?; (4) (distributive) justice: this is not an issue here because a drip is not expensive and does not require any sophisticated technology.

The decision-making procedure is based on general medical arguments, relational and emotional arguments and ethical arguments.

(1) General medical arguments

Since time immemorial, feeding and hydrating have been considered as "basic care" for a sick person. Scientifically, hydration is demonstrably "useful" in specific clinical situations such as hypercalcaemia, profuse diarrhoea and vomiting. It may "usefully" be envisaged where the patient's prognosis is of his general condition returning to normal. In the case of a "terminal" stage" (process of dying) in the illness, hydration is not recommended because it can generate oedemas and/or prolong the agonal phases. Medical decision-making will therefore centre on clinical arguments facilitating an estimation of the patient's prognosis and the current stage in the evolution of his disease. In these fields, however, science faces profound uncertainty and must rely on probabilistic data.

(2) Relational and emotional arguments

In the eyes of the patient, his or her family and many care teams, the decision not to hydrate is a difficult, highly emotionally charged one, because symbolically it involves "an END-OF-LIFE DECISION", ie the anticipation, forecasting/prediction of the time of death! If hydration is not provided, the patient and his or her family will be informed of this withholding of treatment, which may be taken as a "therapeutic abandonment" or a "verdict of imminent death". Information and the means of providing it are always difficult in this context. If the decision is taken not to provide hydration, one alternative is to hydrate the patient's mouth locally, with or without the family's help.

(3) Ethical arguments

Appropriate explanations will be provided for the patient, the family and the care teams that the palliative care administered is geared neither to accelerating nor to delaying the dying process. In situations of ethical crisis, a balance must be struck between the medical advantages and drawbacks of hydrating the patient or not doing so, taking account of the family's emotional distress and discussing with them the various points with which they have problems: reassuring the family and using professional competence to guarantee, for both the patient and his family, that the former will receive attentive and appropriate health care right to the end.

This approach consists of a rational and logical hypothetico-deductive procedure but, even though it is perfectly valid, is it not sometimes liable to lead to an excessively structuralist ideology whose watchword is "closing the sign"? According to P. Ricoeur, the work of opening up language, which is the key to interpretation, demands rigour and prioritisation of semiology (clinical observation) over excessively structuralist ideology (criteria of binary evaluation) (117).

- In Aesculapian medicine, the logical tools used to describe the situation will be the same (general medical arguments, relational and emotional argument and ethical arguments). The difference is that they will be integrated by means of mediation and the supportive relationship. This supportive relationship is specific (although not exclusive) to the palliative approach and is rooted in each team member's specific experience with the patient. This mediation relationship means that that the technical representation of hydration is a "living metaphor. The metaphor is a work on language… the metaphor is the rhetorical process whereby discourse liberates the power of certain fictions to **reformulate reality**" (118).

In the supportive relationship, during the mediation, the human being regains a footing in his/her human story and can emerge from the conflict between the forces of life and

death. As D. Mallet puts it, "the person providing the support is the third person, the Other in the dialogue. (S)he occupies a position of respect for what was, and perhaps still is, when life goes or the body seems uninhabited. **A position as witness, sometimes an expression of belief, postulating the maintenance of the subject beyond the horror of the countenance. The person providing the support postulates that the 'enigma' remains in the human realm.** By his/her presence the supporting person reintroduces time. By supporting desire, (s)he encourages the link-up of suffering and hope. (S)he frees us from the instant and introduces the present. (S)he authorises the future. (S)he is the temporal Other.

"However, if the patient cannot speak, are others reduced to silence? Can anyone speak for another? The obvious answer is no, unless we wish to negate his/her words. It is not a case of speaking for the other, speaking in place of the other. Idle chatter, encouragements and 'fine words' obstruct the possibility of listening and block the supportive function. The most that can be done, carefully and respectfully, is to dialogue about the other. Put into words what we feel about him/her. Express what (s)he evokes in us. Get together with others to alter the perception and representation which we have of him/her (which is the aim of the multidisciplinary palliative care meetings). Surprisingly, certain patients do emerge from their silence after others have spoken about them.

"Yet beyond these sudden improvements, the optimum alternative is surely to maintain an environment of presence, attention and listening when the human being is confronted with his or her enigma. The poverty of our responses vis-à-vis the extent of the suffering should not be offset by a surfeit of action or alleged knowledge. This poverty is a call for a presence, a solicitude which is very often silent" (89).

Aesculapian medicine thus adopts the same scientific references and follows the same scientific approach as its Hippocratic counterpart (medicine of the curable), but it also incorporates into its "palliative" dimension (medicine of the incurable) the shared experience of patients, families and care teams based on the mediation of the living metaphor. It therefore bases its reflection on the critical hermeneutic method and its decision-making process on what Ricoeur has called *ontological vehemence. Ontological vehemence* is the **experience of intuitive evidence** (and not just rational evidence) which guides the ethical act and the decision-making process in the work of interpreting several different points of view. The ethical act is thus tailored to a situation which is unique in time and space and to a uniquely individual person.

In response to the words of the patient's son, from the angle of Aesculapian medicine or the palliative approach, an initial period of time will be set aside for experiential analysis of this complex situation. At this level, the son's suffering clearly highlights the shortcomings of the provision made, and palliative medicine is often described as "the medicine of failure". The experience of suffering destabilises all our reference points. "Time is reduced to the instant, and the promise of life takes on the appearance of a lie, and the language of hope that of mockery. The Other is powerless; at worst, he is a threat and a tormentor. In this deteriorating relationship, speaking and listening can be liberating experiences" (89). Experience associated with proper observation, taking account of multiple interpretations and their interfaces, constitutes the crucible for the alchemy of ethical decision-making and the specificity of the supportive relationship.

Experience shows that when properly implemented, **the supportive relationship** is a full-blown therapy in itself, as well as the starting point for an ethical approach within the decision-making process. It involves a constant exercise in self-awareness, based on universal experience. It accordingly forms part of every individual's private life experience. In fact, those implementing the supportive relationship can experience specific states, specific internal dispositions which completely transcend scientific or philosophical discourse. Ancient philosophers were conversant with these states: Platonic love, Aristotelian intuition of simple substances, Plotinus' experience of The One, whose specificity was inexpressible because whoever tries to speak of the experience after it is finished is no longer at the same psychic level as when he had the experience. "There was a before and there is an after…", say patients involved in the supportive relationship. But this is also true of the Epicurean, Stoic and Cynic experiences. Living experience of pure pleasure or of coherency with oneself and nature is completely different from any external prescription or description. These experiences are not in the nature of discourse or propositions, whatever the recommendations or rules on "proper professional conduct".

An authentic approach to the supportive relationship is self-regulated on the basis of coherency[5], as in the different mathematical theories based on wagers which are behind the construction of QALYs[6] (108). However, in the case of QALYs, the coherency is of a mathematical nature, while in the case of the supportive relationship, the coherency concerns the link between living experience and discourse. Such coherency in the relationship is what is known as authenticity, ensuring proper dialogue. In dealing with a clinical situation the Aesculapian physician must base his arguments not only on scientific discourse but also on a type of discourse that focuses on himself as someone Other than the patient, who analyses the latter's situation and will implement the ethical act vis-à-vis a patient with whom he shares the supportive relationship. Like his Hippocratic colleague, therefore, he will need to adopt a rigorously rational attitude; however, in addition to this, drawing on multidisciplinary meetings, he will have to accurately pinpoint the presuppositions, highlight the implications and consequences of the choice envisaged, and place the latter within its social, economic, political and existential perspective. This exercise will establish the ethical approach firmly at the centre of the clinical method, with an eye to formulating and therefore determining "an ethical act".

This corresponds to the thinking exercises which Marcus Aurelius conducted throughout his political career. The thinking exercises which he performed, which he had devised for himself, were not mere formulae designed for mechanical, systematic application. The aim of the exercises was not to solve abstract or theoretical problems, but to revert to a position in which an obligation was felt to live with dignity, and therefore in a "committed" manner.

The Aesculapian and Hippocratic approaches to medicine are therefore complementary, and incorporating both into medical practices makes the ethical approach a vital and

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[5] Coherency = close combination of disparate elements.

[6] The Ramsey method was used to construct QALYs (Quality-Adjusted Life Years), which are used to evaluate and compare the consequences of medical decisions in terms of individual well-being.

promising tool. Medicine today is still an art and must therefore benefit from hypothetico-deductive reasoning in order to analyse diseases and a hermeneutic approach to complex clinical situations[7], of which ethical decision-making is a prime example. This presupposes learning to dialogue with all the requirements of such decisions: acknowledging the interlocutor's presence and rights, basing the response on what the interlocutor himself acknowledges knowing, and therefore seeking agreement with him at each stage in the discussions. The main thing is to submit to the requirements and standards of reason, the quest for the truth, and lastly, to recognise the value of another immanent dimension, that of nature. The aim is therefore to get away from one's own "individual" point of view to tend towards a universal one, endeavour to see things in perspective and thus transform one's world view and one's own internal attitude. It is a case of experiencing all the aspects of human and universal reality as an adventure within a relationship committed to the other; or quite simply experiencing, or testing, life.

2.5 Description of decision-making processes in Europe today

Analysing comparative studies of European countries is simultaneously simple and complex. It is simple because few studies have in fact been conducted, and it is complex because the vocabulary used reflects the ambiguity in today's Europe in the face of end-of-life situations: the subject addressed by specialist literature is the making of "medical end-of-life decisions" rather than of "medical decisions in end-of-life situations", the literature on which has not been the subject of comparative studies. Furthermore, the comparative data concern either end-of-life decisions in intensive care units (ETHICUS) or end-of-life decisions studied on the basis of the death certificates of patients identifying the latter. Every certifying doctor received a retrospective questionnaire on the medical decisions (s)he had had to take during the patient's end-of-life period (EURELD Consortium). This facilitates a review of the decision-making processes implemented in end-of-life situations.

2.5.1 End-of-life decisions in intensive care units in Europe (ETHICUS)

The importance of these data resides in the fact that nowadays it is customary for patients or their families to request, or even demand, intensive care for the end-of-life period, so great is the refusal of death. Moreover, intensive care units are having to deal with so many palliative care patients that some spontaneously use the expression "terminal palliative care", because many patients in non-terminal situations of palliative care do actually benefit from the intensive care. The main ethical questions arising in respect of all types of patients admitted to intensive care are: When? What are the criteria for admitting a patient in a serious palliative situation? When and how can we reduce or discontinue treatment? And with more particular reference to end-of-life situations: how are we to inform families in the run-up to possible, but uncertain, death, and how in particular should we inform children or vulnerable persons about this long, uncertain waiting period? Teams often request ethical decision-making assistance from the palliative care teams.

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[7] Complex situations are situations that require multiple interpretations, eg anatomy, biochemistry and medical imaging, etc, but also anthropology, ethnology, sociology, mathematics, philosophy, etc.

The ETHICUS prospective study was conducted between 1 January 1999 and 30 June 2000 (covering 18 months) in 37 intensive care units in 16 European countries, namely Austria, Belgium, Czech Republic, Denmark, Finland, Germany, Greece, Ireland, Israel, the Netherlands, Portugal, Spain, Sweden, Switzerland, Turkey and the United Kingdom. It covered a total of 31,417 adult patients admitted to 37 adult intensive care centres in the 16 countries. Of the 4,248 patients who had died, 72.6% (3,086) had been the subject of treatment restriction. Treatment had been restricted in the case of 38% of patients, and discontinued for 33%. However, there were major variations among countries (145; 146): termination of treatment is less common in southern Europe (Greece, Israel, Italy, Portugal, Spain and Turkey) than in the north (Denmark, Finland, Ireland, Netherlands, Sweden and the United Kingdom), namely 17.9% in the south compared with 47.6% in the north. The "active shortening of the dying process" (SDP) uses opioids, possibly associated with benzodiazepines, myorelaxants and/or barbiturates, and is more widespread in central Europe (Austria, Belgium, Czech Republic, Germany and Switzerland), where it precedes death in 6.5% of patients (0.9% in northern Europe and 0.1% in the south). Statistical regression analysis shows that the option of reducing life-sustaining treatment rather than continuing it depends on the patient's age, the diagnosis, the number of days in intensive care, and the patient's and doctor's religion (144; 146).

* Field of end-of-life decisions in intensive care

* Reducing or terminating life-sustaining measures
In most cases western (English-speaking) ethicists consider that there is no ethical difference between restricting (refraining from initiating treatment that is not indicated) and terminating treatment (reducing and then stopping treatment which is having no beneficial effect on the patient: medication, dialysis, mechanical ventilation, etc) (2; 152). The same reasons are used for refraining from initiating the treatment and for terminating it. Even though ethicists consider that there is no difference between "restricting and terminating", in practice, restricting is considered less difficult, comparable to a "passive" attitude; on the other hand, where a treatment has been initiated, stopping it is seen as a "failure". However, no medical team should ever refrain from initiating treatment for fear of having subsequently to discontinue it (1). In either case, restriction or termination, the patient will die as a result of the decision. According to intensive care specialists, this should not be considered as homicide, because the patient dies of his or her illness. In fact, continuing a futile treatment is contrary to four ethical principles, ie benefit, autonomy, refraining from harm and distributive justice (costs in terms of time and human and financial resources).

In Sweden, 50% of doctors state that there is no difference between restricting and discontinuing life-sustaining treatment (55). In Israel, treatment may be restricted but not discontinued (56). In 1996, a European survey (144) showed that 93% of practitioners answering the questionnaire sometimes restricted treatment, while 77% said that they had had occasion to discontinue treatment. However, in reply to the question "do you think you should have … ?", the respondents said that they should have stopped the treatment in more cases than they actually did. This shows the extent to which "stopping" life-sustaining treatment is regarded as the cause of death. According to a French study (46), life-sustaining treatment dispensed in intensive care is restricted in 4.6% of all cases, while it is discontinued in 6.4% of cases. However, it should be noted that in 76% of cases, termination is preceded by a period of treatment restriction or

reduction. According to the ETHICUS study, 95.4% of patients underwent either treatment restriction followed by gradual discontinuation, or immediate discontinuation.

* Restricting/terminating life-sustaining measures versus SDP
While English-speaking medical circles see no difference between restricting and stopping treatment, because the outcome is death (utilitarian reasoning), is there a difference between restricting/stopping treatment and "active shortening of the dying process" (SDP)? According to the ETHICUS study, 6.5% of deaths were preceded by an injection of products for the purpose of shortening the dying process, but the doses of products used were the same as those prescribed for relieving pain. In Vincent's ethical questionnaire (144), 40% of the doctors replied that they sometimes administered lethal doses of products for the purpose of accelerating death when the patients no longer had any chance of survival. This report will not go into the debate on euthanasia, although, in the light of these data, we should emphasise the vagueness of the vocabulary and terminology on death, which remains "unthinkable", and how this vagueness is reflected by vague limits: what is "intention"? (106); and how is intention to be evaluated in a questionnaire?

- **The decision-making process**

* Patient typology
The pathologies subject to decision-making with ethical implications are mainly respiratory (22%: 937/4248), cardiovascular (17%: 730/4248), neurological (15%: 656/4248) and gastro-intestinal (14% (591/4248).

* Options
Decision-making procedures in end-of-life situations are commonly used in European intensive care units. Life-sustaining measures are restricted in 73% of patients, and cardio-respiratory resuscitation is initiated in only 20% of them. The commonest restriction concerns the reduction of such life-sustaining measures as mechanical ventilation and/or vasopressors, followed by their complete discontinuation.

European countries implement a wide variety of procedures for restricting treatment, stemming from many different factors:
1.   European religions and cultures differ from one country to the next and exert a heavy influence on medical decisions (106, 145; 146);
2.   Doctors' practical and ethical benchmarks vary from one country to the next in terms of the use of vasopressors and mechanical ventilation. For instance, the 48% rate of cardio-respiratory resuscitation and the 5% rate of active measure restriction in one country may bear witness to excessive treatment, but conversely the 5% rate of cardio-respiratory resuscitation and the 69% rate of active measure discontinuation in other countries may indicate under-treatment. These differences would appear to reflect a divergence in professional cultures according to country.

The ETHICUS study highlights the fact that the autonomy concept, which takes pride of place in American decision-making procedures, plays a much less important role in Europe than reflection. This would not appear to be ascribable to the fact that most of the patients are unable to communicate, since only 50% of patients communicate, and yet the autonomy principle is used in the decision-making. During the decision-making procedure, patients' personal wishes remained unknown (whether they were communicating or not); their families were unaware of their wishes or identified them

with their own desires. Where the families took part in the medical decision-making, it was a case more of the doctor providing them with information or of the doctor asking the family about the patient's wishes. The authors noted that the lack of real dialogue was due to the fact that the interpretation in English-speaking countries of the principles of benefit and non-harm was difficult to apply where the patient was not responding well to current treatment. The doctors interviewed considered that it would be unhelpful for the family to be asked what the patient wanted if the doctor was "incapable" of saving him! However, this reasoning in no way justifies the absence of discussion between the professionals and the family on the grounds that the latter is incapable of understanding, as stated in the replies to he questionnaires. Moreover, doctors find it difficult to ask families to consent to the different medico-surgical treatments for the patient when the latter cannot communicate, and doctors hardly ever ask the families for their opinions for the purposes of end-of-life decision-making.

According to this study, doctors retain a paternalistic attitude in their intensive care practices vis-à-vis end-of-life decision-making. Their primary decision-making criterion is based more on *good professional practice* than on ethical principles of benefit, non-harm and respect for the patient's autonomy, criteria hardly ever seeming to be used at the European level, and deemed inoperative.

These comments should be interpreted within the boundaries of this study, ie the patients covered may be considered as non-representative of actual practice in the various European countries: the persons involved in the study were already familiar with ethical issues and practices. Since then, many countries have issued recommendations specific to intensive care situations. However, additional comparative work is required on these recommendations at the European level.

* Factors influencing decision-making processes

In any case, the main factors taken on board in this study of end-of-life medical decision-making in intensive care units are:

1. The variations among European states play a major role: culture, health care systems, religions, aims of medicine in the present context and professional codes;

2. The inability of most patients in this study to conduct dialogue on end-of-life decisions. In fact, the patients' wishes are not known at the time the decision is taken, and advance directives are very uncommon.

3. The lack of discussion with patients, even communicating ones, for which the excuse is that the patient is not responding to the maximum treatment administered.

4. The lack of discussion with families, because they express the same fear as the doctor vis-à-vis a patient who is not responding to treatment (feeling of failure). Medical staff consider that the family cannot understand… In the study, 11% of end-of-life decision were discussed with the families. In Spain this figure was 28.3% (37), and in Italy (56) families were not consulted at all for 18.7% of decisions and seldom for 22.9%. And yet families could provide intensive care units with a great deal of useful information.

5.   Intensive care unit doctors are wont to take end-of-life decisions without discussing them with nurses, family doctors or families. Several countries (including the USA and France) have issued specific recommendations on compliance with "best practice" in intensive care. According to this study, doctors hold discussions with nursing staff on only 49% of decisions, which they usually take on a "colleagues only" basis. In the French study conducted by Ferrand (46), 44% of decisions had been discussed with nursing staff. Most of the time, the doctors and the care team (particularly nursing staff) agree on the end-of-life decisions, but there are occasional divergences, and in such cases the nurses often adopt a point of view similar to that of the families.

6.   Traceability within medical files, which is far from satisfactory, although the situation varies greatly between countries.

Reasons for the differences in Europe

The reasons mentioned (145; 146) are the cultural and religious diversity of the different European states, the personal history and clinical experience of practitioners, their age, sex, personal beliefs and the influence of legislation (codes of ethics and professional recommendations, but also legislation on health in the various health care systems.

Religious beliefs in Europe are extremely powerful in the field of ethical end-of-life decision-making. Within Europe itself, the southern countries have an even more powerful religious heritage than their neighbours in the north. In 1996, in response to a questionnaire on ethical issues sent to doctors, those declaring themselves practising Catholics engaged in treatment restriction or termination less frequently than those who declared themselves Protestants (144). In the ETHICUS study of 1999-2000, doctors declaring themselves Catholic, Protestant or without religion engaged in treatment restriction or termination more frequently than their Jewish, Greek Orthodox and Muslim colleagues (139).   A study conducted in the USA in 1998 (104) noted no such differences among the American states. Sprung suggests that this is due to the fact that the US states are more homogeneous than European countries (139).

The religious and cultural beliefs of the patient and his or her family are also a major factor in decisions relating to the end of life (145; 146). Some cultures are readier than others to regard as morally acceptable treatment restriction or termination. Some prefer decisions to be taken with the family rather than by the patient on an "autonomous" basis.   However, even if specialist literature splits the major cultural trends along north/south and east/west lines in Europe, no entire people can be "filed away" in a single cultural category. Travel and the media are promoting a shift towards a new "transcultural" and international culture and moving society towards a multicultural model.   Accordingly, a single model for recommendations and decision-making procedures will never respond to the real issues involved in decision-making in end-of-life situations (14).

Lastly, we should stress the major differences within Europe in legislation on end-of-life situations, codes of ethics (European and national texts) and the legislative and political aspects of each individual country. Fear of prosecution, it has to be said, plays an undeniable role in end-of-life decisions in intensive care units.

2.5.2 End-of-life decisions/Decisions in end-of-life situations in Europe, evidence from death certificates (EURELD)

The circumstances surrounding death changed in Europe during the 20th century, and are still changing. In this context, health care professionals are also seeing their practices evolve and are now having to take medical decisions liable to shorten patients' lives. Debate is currently proceeding in Europe on the rights of patients in the terminal phase and the conditions in which people die in European countries. The EURELD *(European End-of-Life Decisions)* survey took stock of medical end-of-life practices in six European countries, namely Italy, Sweden, Belgium, Denmark, the Netherlands and Switzerland. It was carried out simultaneously in these six countries in 2002. The survey took place on the following basis: each country colligated death certificates, from which a sample was selected. The doctor having issued the death certificate was identified and was sent a questionnaire to complete on the medical decisions taken prior to the death. A total of twenty thousand four hundred and eighty (20,480) deaths were inventoried in the six countries. The rates of replies from doctors varied: 44% in Italy, around 60% in Belgium, Denmark, Sweden and Switzerland and 75% in the Netherlands.

* Decision-making field

The terminology used for the decision-making options was clearly defined (12), and doctors were asked if they had ever:
(1) withheld and/or withdrawn treatment
a.   taking into account the probability or certainty that this would hasten the end of the patient's life, or
b.   with the explicit intention of hastening the patient's death?
        (= DECISION NOT TO TREAT: if answer is yes to at least one question)

(2) intensified the alleviation of pain and/or symptoms by using drugs
a.   taking into account the probability or certainty that this would hasten the end of the patient's life, or
b.   with the explicit intention of hastening the patient's death?
        (= RELIEF OF PAIN AND SYMPTOMS: if answer is yes to at least one question)

(3) administered, prescribed or supplied drugs with the explicit intention of hastening the end of life = PHYSICIAN-ASSISTED DEATH
a.   administration of drugs at the patient's explicit request
        = EUTHANASIA
b.   supply of drugs to the patient for self-administration
        = ASSISTED SUICIDE
c.   no patient request
        = TERMINATION OF LIFE WITHOUT PATIENT'S REQUEST.

In the great majority of countries, some 50% of the patients who had died were at least 80 years old. The percentage was highest in Italy and Sweden. In the other countries, the patients were over 65 years old on average. The causes of death were mainly cardiovascular pathologies and cancer. Deaths in hospital were more frequent in Belgium (49%) and Italy (50%).

- Decision-making processes

In all the countries, one-third of the deaths occurred suddenly and without warning, which served as a criterion for identifying the existence of decisions in end-of-life situations. From this angle, the proportion of decision-making procedures varies from 23% in Italy to 51% in Switzerland. Examples of "physician-assisted deaths" were noted in all the European countries surveyed. Decisions to restrict or discontinue treatment are more frequent than physician-assisted deaths, according to the authors, but they vary widely according to country: 4% of all the deaths in Italy, 14% in Belgium, Denmark and Sweden, 20% in the Netherlands and 28% in Switzerland.

* Patient typology

The main causes of death identified were cardiovascular, tumoral and respiratory diseases, damage to the nervous system and unknown causes (see tables in Appendix 2).

* Decision-making options

There were three options: a medical decision likely to hasten death; relief of pain or termination of treatment; or euthanasia (12).

- ***A medical decision hastened death in one or two cases out of three***

Between a quarter and half of the deaths covered by the EURELD survey were subject to a medical decision relating to the end-of-life situation: 23% in Italy and 51% in Switzerland. These medical decisions concerned:
–   the implementation of pain treatment, one of whose effects may be to shorten life: 19% of all the deaths in Italy and 26% in Denmark;
–   a decision to discontinue or not to implement treatment: 4% of the deaths in Italy, some 14% in Sweden and Denmark, 20% in Belgium, 20% in the Netherlands and 28% in Switzerland;
–   physician-assisted death, with the administration of a drug for the explicit purpose of hastening death: much less common, even if it occurs in all the countries; finding probably linked to bias in the survey and confusion in the definitions provided.

Physician-assisted death was common in patients under the age of eighty and in cancer patients in all European countries. The authors present a table of estimates of "shortened life spans" as a function of decisions made. For instance, the percentage of lives shortened by between one week and one month varies from 60 to 65% of deaths in Sweden, Italy, Denmark and Switzerland, with 50% for Belgium and the Netherlands. We might note that the period by which life was curtailed for patients undergoing pain relief treatment was shorter than for patients receiving "death assistance from the doctor", which was always more than a week.

In all the countries, end-of-life decisions were more common for "incompetent" patients than competent ones: Belgium 66%, Denmark 58%, Italy 59%, Netherlands 48%, Sweden 64% and Switzerland 58%. For a large number of patients in all the countries, but especially in Italy, Denmark and Sweden, there was no clear diagnosis of (in)competence. Moreover, the proportion of competent patients was higher in the countries with a high percentage of end-of-life decisions: 35% in the Netherlands and 32% in Switzerland. Where the patient was competent, end-of-life decisions were

discussed with him/her and the family, especially in the Netherlands and Switzerland, but much less frequently in Italy and Sweden. In the case of incompetent patients, participation by the patient in decision-making (advance directives or equivalent) was highest in the Netherlands (34%) and Switzerland. Decisions were most frequently discussed with the families in the Netherlands (85%) and Belgium (77%). In Italy and Sweden decisions were discussed with the (competent or incompetent) patient in only about 50% of cases. In all the countries surveyed, advance directives only existed in under 5% of cases. Colleagues were consulted about end-of-life decisions in 40% of cases in the Netherlands, Belgium and Switzerland, but far less (<20%) in the other countries. Nursing staff participated in Belgium (57%) and Switzerland (50%).

Decision-making options are therefore based on identifying a yes-or-no answer to the three questions, all of which are based on the hypothesis that death can only be delivered medically, and on the model of items, excluding resuscitation, which are not the only parameters involved in decisions taken in **end-of-life** situations. This model would suggest that there are different ways of interpreting the concept of "medical futility" in other European countries (87). This would necessitate envisaging different approaches to end-of-life situations in order to pinpoint more specific ethical problems.

. *Relieving pain or terminating treatment*

In a minority of cases covered by this survey, treatment to relieve pain was prescribed in order to hasten the patient's death as the only possible alternative for the patient: 0.4% of deaths in Sweden and 2.9% in Belgium. The analgesics administered are usually opioids (76% in Italy and 96% in the Netherlands). Western European medicine generally uses strong opioids, but the types of opioid and methods of administration vary widely from country to country. The doses administered also vary according to country.

The other end-of-life medical decisions covered by the survey consisted of terminating treatment likely to prolong survival or withholding such treatment. This type of decision is more common where the intention of shortening life is explicit (2% of cases in Italy, 21% in Switzerland) than where this consequence is only envisaged as a "side-effect" (Italy 2%, Switzerland 7%).

Among the cases where treatment was not provided, discontinuation of medication or hydration and feeding was the most common decision (62% of all non-treatment decisions in Belgium and 71% in Italy) (12). Non-treatment decisions were more often discussed with patients or their families in the Netherlands (95%), Belgium (85%) and Switzerland) than in Denmark (72%), Sweden (69%) or Italy (68%).

- *Euthanasia*

This subject is barely touched on in this study. We might wonder whether it is not covered by some of the other decision-making categories considered.

- *Deep sedation until death*

According to Bilsen, Cohen and Deliens (12), keeping the patient in deep sedation "or in a coma until death by means of such substances as barbiturates or benzodiazepines is practised in all countries, irrespective of any explicit intention of shortening survival". The percentages are highest in Italy (8.5% of deaths) and Belgium (8.2%), and lowest in

Denmark (2.5%) and Sweden (3.2%). In proportions varying from 1.6% of deaths (Denmark) to 3.2% (Belgium), deep sedation is accompanied by discontinuation of feeding and artificial hydration. According to the author, this is referred to as "terminal sedation" "because it leads to death in the short term", a claim far from having been proven. Men, cancer patients and young people dying in hospital are more likely than others to be placed in deep sedation. No selection criteria are specified. Bilsen complains that, "in connection with the substances possibly used to shorten life, pharmacological requirements vis-à-vis proper practice are not always satisfactory", concluding that "little is known about how carefully medical end-of-life decisions are taken. For instance, we might wonder whether the practice of deep sedation is not considered by some practitioners as an alternative to putting an end to life with lethal substances, without the legal complications, especially where feeding and hydration are discontinued".

* Factors influencing decision-making processes

Decisions not to provide treatment depend on many medical and cultural factors. Data comparable to those obtained by Cuttini (31), who studied end-of-life decisions in neonatal resuscitation services, confirmed in adults by the ETHICUS study (139), show the existence of a north/south cultural axis in decisions not to initiate or to discontinue treatment: in northern Europe, practices tend more than is the case in southern Europe towards withholding or withdrawing treatment (86% for northern Europe, 68% for central Europe and 57% for southern Europe). On the other hand, expediting the dying process is more common in central Europe (7%), but less common in the north (1%) and south (0%).

Analysis of the main European surveys of end-of-life decisions do not often address medical and ethical decision-making problems actually occurring in end-of-life situations. They highlight, thanks to their methodological rigour, an obvious necessity, viz the need for an interpretation in this field of " ethical medical decisions at the end of life" which differs from that of the hypothetico-deductive method. As the authors themselves have concluded, the studies have provided very little insight into the care with which end-of-life medical decisions/medical decisions in end-of-life situations are actually taken. This new approach, that of ethics, presupposes the drawing of a proper distinction between medicine, professional ethics and ethics in general, which was not covered by the studies.

2.5.3 Critical interpretation: medicine, professional ethics and ethics in general

The French language commonly refers to *moralis* to denote all aspects of the ethics of practice (professional ethics), and the Greek term *etikè* to describe ideas relating to this practice and the legitimacy of its ethical rules. The Greek terms *deon, deontos*, meaning "that which one must do", and *logos*, "discourse, word", refer the practitioner back to cognition of his duties and obligations (*déontologie* in French means professional ethics). Professional ethics in the medical world therefore span all of the doctor's professional duties, and these in turn require broader reflection on ethical practices, the scope of which covers all the legitimate rules of conduct "aiming at the good life" ("*visée de la bonne vie*") or at the ethical objective; in Ricoeur's words, the aim is "the good life, with and for others in just institutions" (121).

- **Medical ethics are not professional ethics**

In the current context of loss of reference points and media-hyped ethics, there is sometimes a strong temptation to confuse medical ethics with professional ethics. Even though the latter have been with us for a long time now[8], no professional code can match overall ethics, and the main danger today in medical decision-making processes is that the ethical debate is being omitted on the pretext that it is enough to follow the prescriptions and recommendations to fulfil all necessary ethical obligations. A review of European literature on this point is disturbing, because the current discourse tends toward such ethical models as "ethics of benefit", "ethics of non-harm", "ethics of autonomy", etc, not to mention "religious ethics". This means that medical decisions are confined to selecting and endorsing, by personal conviction, rather like an item of clothing, one "ethic" rather than another. The fact is that whatever the merit of these various moral codes, they cannot serve as a system of medical ethics, because ethics are broader than medicine and, where health issues are concerned, focus on a central aspect of human existence: "aiming at the good life", encompassing life, death and the whole meaning, or lack of meaning, of our existence.

- **Medical ethics are not a standard-setting system external to medicine**

The other mistake sometimes made is to link medical ethics to a system of ethics which lies outside medical practice and which is presented as "superior" because it is more comprehensive. But ethics in the field of decision-making in end-of-life situations relate to clinical practices and therefore cannot be treated as equivalent to a system of ethics that is constructed and systematised in and by a rational discourse. This does not prevent ethics from being analysed on the basis of a "rationalising" approach and discourse. However, ethics place reflection at a different level, that, one might say, of "reflection on reflection": "if reflection is not to be conducted on the slippery slope of the irrational and if history is to be meaningful, we must affirm the 'solidarity' of conscience and reason and the 'constant coinciding of existence and the rational'" (120). The new field of work for ethics in the medical sector involves a casuistic approach aimed at this "solidarity between conscience and reason" with a view to "constant coinciding of existence and the rational". The Hippocratic Oath bears the traces of just such a reflection on reflection, or of solidarity between conscience and reason, because this Oath is sworn by "Apollo the physician, Aesculapius, Hygeia and Panacea (his two daughters), and by all the gods and goddesses" (122). The prefatory invocation of the Oath is clear: the doctor refers to the divine powers, transcending all human institutions and their prescriptive systems.

- **Medical ethics are immanent in ethics *per se***

Medical action and moral action share one common field, viz that of "doing good". Two examples may be cited to illustrate this common field:
1.   Doctors aiding and abetting totalitarian and barbaric undertakings
        Taking the examples of experimentation in the Nazi camps, the psychiatric ill-treatment meted out to political opponents in the USSR, torture in Latin America, etc, the lack of moral sense is the same for all who took part in these actions. Ethics are challenged by the subordination of a people to such higher imperatives as improving the

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[8] First attested in Greece in the 5th century AD.

race, *raison d'Etat,* etc. Medical ethics, for their part, reflect on the fact that certain attitudes are alien or indeed contrary to medicine and medical practice. The criminal doctor is condemned on two counts: a moral one, as an ordinary criminal; and an ethical one as a doctor transgressing the ethical reflection imposed by his profession.

2. An anaesthetist raping an unconscious patient. This doctor is culpable both as a rapist and as a doctor having abused his professional situation to commit a crime.

- ### Medical ethics: taking medical action vis-à-vis a sick person

Nevertheless, moral action and medical action are distinguishable. Medical action is not only an "action" as a matter for morality, but it is also an "art", a specific medical mode of action which falls outside some of the fields of morality. What would one think of a doctor who confined his action to ensuring his patient's moral "welfare", while disregarding all the rest? This is a major risk in palliative medicine, which is why it is very important to link it up to health and health-oriented objectives (WHO). From the moral angle, when one ensures someone's "welfare" it means acting morally towards him or her, but nothing more. On the other hand "doing good", when one is a doctor, means taking medical action in respect of the person, specifying that such action must comply with professional ethics and the associated recommendations, but also with health ethics. This latter reference in the medical act is neither a gratuitous supplement nor a luxury, because, to the extent that the doctor's action targets a PERSON (not an animal or a machine), only ethics can orient the knowledge and powers of medical discipline towards the person's good/welfare.

- ### The role of ethics in medicine

This concern for the Other as a person differentiates the doctor from the torturer, who can use the same anatomical or physiological knowledge and the same instruments as the doctor. Ethics therefore act as a provider of meaning and regulator of acts in medicine, because, through the primordial act of "medical decision-making", they are intensely involved in discerning the objectives to be pursued in every clinical situation vis-à-vis situations of "life ending", and in choosing from the possible resources and the "either/or" options. Dismissing as a luxury medical ethics, together with the educational or training courses that they involve for doctors and health professionals, would mean exposing medicine to any passing ideology and talking about medical ethics shorn of their ontological foundations.

The approach taken to the various decision-making procedures has shown us that the Hippocratic and Aesculapian branches of medicine were basically ONE, as indicated by the etymology of the word "cure", which has given way to the term "medical treatment" in specialist literature. Furthermore, it has emerged that the nature of the supportive relationship is crucial to the special nature of end-of-life medicine. This implies openness to the humanities and familiarity with the hermeneutic method, the art of interpretation of thinking in the face of complex situations ("complex thought"). The very nature of this art means that it combines medicine and ethics. Analysis of the main European studies and surveys has highlighted the potential risks of ignoring this work, which has already begun in Europe but which now needs to be considered much more closely.

3. HOW TRADITIONAL EUROPEAN VALUES INFLUENCE DECISION-MAKING

European moral values have their origins in the various countries' histories of religious belief and observance. They can be deduced from Europeans' everyday values and attitudes towards the end of life: the concept of palliative care and practice.

3.1 The European cultural heritage: religious belief and observance in Europe

Religion had a vital role in the emergence of European civilisation. Although religion shaped Europe it also divided it, and the countries and regions of today's Europe still show the religious diversity that came into being with the successive schisms and divisions within the various religious cultures.

Christianity, which spread through the Roman Empire and ultimately covered all of it, laid the religious foundations of Europe. The empire subsequently split into an eastern part (the Byzantine Empire) and a western part, where Rome and the Catholic Church were to predominate. With the Reformation, the Catholic Church underwent a major separation, which took place along lines that very often corresponded to political borders and which gave birth to new cultural entities differing from Catholicism not only in their religious dogma, beliefs and organisation but also in their moral standards.

3.1.1 *The origins* (53; 54)

Europe's common religious matrix is ancient Christianity, which gradually distanced itself from its Judaic roots during the first few centuries AD. The benevolent, or sometimes less benevolent, neutrality of those in power enabled it to spread progressively throughout the Roman Empire, until Emperor Constantine I (312-337) enforced it as the dominant religion of the empire itself. The adoption of Christianity was a gradual process, but there is no country in Europe which did not convert at least a thousand years ago: "Europe is indeed the oldest Christian continent." (113). The Christian message constituted a genuine moral revolution, the key features of which are still very present in European culture today. These new moral principles, which were at variance with the standards of the ancient civilisations, can be grouped under four main heads:

- **Christianity had its basis in an individual morality, intended to attain world-wide currency.** In their day-to-day conduct Christians could not dissociate love of God from love for their neighbour. The cardinal virtues were patience, charity, humility and temperance, which were far from espoused in the pre-Christian world. They inspired a new concept of human relations. For instance, Christians no longer regarded marriage as a matter of free consent, a requirement for a marriage to be valid under ancient Roman law, but considered that it entailed a mutual conjugal morality, which prohibited dissolving a marriage, conceived as a sacrament, mirroring the community of love between God and the Church.

- **Christianity established the imperative of respect for human life,** which reflected and ensued from God's love for his creatures, whereas ancient Rome tolerated many departures from this principle: acceptance of abortion, the right of the paterfamilias freely to abandon an unwanted newborn baby, the scant consideration shown for those regarded as inferior - convicted offenders, slaves and Christians - in the games of the amphitheatre.

- **Christianity espoused the principle of spiritual equality for all,** since it regarded everyone as a child of God. This principle challenged the very basis of a key Roman institution: slavery.

- **Christianity introduced the concept of equity**, which was mentioned in the Roman code of law as early as the 4th century AD. This mirrored the justice of a God filled with indulgence for his people. The law, which had its basis and justification in religion, had to be marked by clemency, humanity and moderation.

All these principles began to transform moral standards from the 4th century on, as can be seen from the changes in private law: denunciation of cohabitation by unmarried couples, recognition that an engagement to be married constituted a form of contract, arrangements for liberating slaves, the focus on respect for and recognition of the human person, concern to guarantee the family's moral unity.

From the standpoint of medical decisions, it is interesting to note how these historical concepts have imbued what, in the modern western world, constitute the cardinal ethical principles of the decision-making process, to which professional ethics are often confined: doing good, not doing harm, respect for autonomy, distributive equity or justice. This is because Christianity helped to make the consequences of God's love part of the European mindset: (1) an individual morality based on transcendence, intended to attain worldwide currency; (2) the imperative of respect for human life, regarded as a gift of God, from which it follows that all living beings are deserving of respect; (3) the spiritual equality of all human beings, every one of whom is a child of God, making slavery "immoral" and conveying the idea of what might be termed distributive justice for all; (4) the notion of equity for all of God's children, founded on the Christian duties of clemency, humanity and moderation.

3.1.2 *The religious mosaic*

Today, Europe can still be described as having three religious universes, to which certain countries with a mix of religions must be added. The fifteen member states of the European Union pre-enlargement can be divided up as follows:
(1) Catholic Europe: Austria, Belgium, France, Italy, Ireland, Luxembourg, Portugal, Spain
(2) Protestant Europe: Denmark, Finland, Sweden
(3) The "mixed countries" where there are large proportions of both Catholics and Protestants: Germany, the Netherlands, the United Kingdom
(4) Lastly, a single country belonging to Europe is Orthodox (Greece).

If account is taken of the countries that have recently joined the European Union, "Catholic Europe" gains Malta, Poland, Croatia, Slovakia, Lithuania and Slovenia; the "mixed countries" include Latvia (Catholic, Protestant and Orthodox), Hungary and the Czech Republic (Catholic and Protestant), Estonia (Protestant and Orthodox) and Romania, Bulgaria and Cyprus (19). Mention must also be made of the past and present links between Europe and Islam, since Islam's contribution to the religious and cultural history of Europe from the Middle Ages to the present is so often disregarded (129).

In most of the countries of western Europe (the pre-enlargement "EU fifteen"), membership of a religion remains relatively frequent, although it is declining, sometimes significantly as in the Netherlands, where a majority of the population now say they have no religion, but also in France (where nearly 5% state they have no religion) and Belgium. The more recently established countries show greater diversity regarding their population's "religiousness", defined as the "degree of active religious involvement and of identification with a belief" (82). At the same time, an opposite trend can be noted in other countries. It is therefore very difficult to assess the religious situation in Europe, and it can be noted, for example, that in Ireland, although attendance at religious services is shrinking, the number of professed believers remains high. The author therefore considers that three main tendencies can be identified on the basis of an analysis of three criteria: membership, Church attendance and belief in God. The results show that:

- religion is on the decline among young people
o countries scoring three positive indicators: Spain, Belgium, the Netherlands, the United Kingdom
o countries scoring two positive indicators: Ireland, France, Germany
- a religious revival is taking place in other countries: Italy, Austria, Denmark, Portugal
- a general Christian belief is being reaffirmed in other countries, which might be described as "religiously non-aligned"
- the situation is stable in eastern Europe, which remains very religious.

Through the changing patterns of this religious mosaic, which show that in Europe people are more of a religious frame of mind than actively involved in traditional religions, a reintegration of the immanent within the transcendent is to be observed. As a result of this integration process strong references to traditional Christian European values co-exist with an opening up of western thinking to the eastern worldview.

3.1.3 *The return of religion*?

A historical institutional process caused European societies gradually to distance themselves from the concept of a religious state. It led to a separation of civil society and the religious communities, allowing the latter to regain their independence from the public authorities (113). This general trend assumed different forms and took place at very different speeds in the different countries of Europe. Its corollary was a loss of religious influence over the policing of social behaviour, with the assertion of autonomy and of freedom to choose one's way of life. An example is sexuality, an area in which the moral code of the Church was demolished by the arrival of north European standards of behaviour. This trend is typified inter alia by the French concept of secularity.

Does religion's loss of influence over moral behaviour however mean the end of all religious influence, the evacuation of religion from modern life? Some writers (20; 151) subscribe to this theory, while others maintain that religion is not disappearing from modern societies, or even that, instead, a number of adaptations are taking place, as can be seen inter alia from the fact that consumers of religion now have direct access to everything that the different religions have to offer (88).

Accordingly, although moral standards are no longer directly linked to religious dogma, they are not breaking up. Reference to "tradition", that is the past's legacy of values,

remains a key factor in the shaping of European values (53; 54). It is true that values linked to individuation, with emphasis on autonomy, are spreading, but they have not erased the tendency to refer to traditional values. The latter still have a very direct correlation with religiousness (that is the religious frame of mind), which seems to be gaining ground even among Europeans who say they belong to no established religion.

3.2 Values of everyday life: family values in Europe

According to a survey performed in 1999 in the "EU fifteen" countries[9], the areas of life regarded as most important by the Europeans who responded were family (86%), work (57%) and friends and relations (47%). These outcomes are consistent with the fact that they are the values that define both the familial and the occupational role, that is to say which measure integration in a society. They nonetheless cannot be used to infer that the systems of relationships are the same from one European country to another.

Historically, the extended family model inherited from Ancient Greece and Rome survived for a very long time as a result of the Islamic invasions, particularly in southern Europe. However, over the centuries the whole of Europe gradually moved towards the nuclear family model, built around the couple. Glick sums up these two models as follows: "Islam provided a framework which legitimized tribal values and gave them religious significance; Christianity tended to work in the opposite direction, toward the development of inter-personal, rather than inter-group bonds." (58; 60).

The western model which emerged at the end of the Roman Empire was based on the family unit and exogamous marriage. It spread throughout Christian Europe, but not in a uniform way. In the north it blended with Germanic traditions based on the importance, firstly, of the tribe and, secondly, of the individual, and also based on women's visible position in society. In the south it intermingled with the eastern model, revived by the Berber invasions, to produce a focus on kin ties and the sense of solidarity that binds extended families. Subsequently, the Reformation helped to deepen and entrench the differences between the north and south European family models[10].

However, a number of writers (53; 54; 84) maintain that there are few signs of a complete standardisation of family models in Europe, and they attribute this to the different roles of women in the labour market. In northern Europe and the United Kingdom women are very prevalent in the workplace, but far less so in more central countries, such as Belgium, the Netherlands and Germany, and even less in the Mediterranean countries. The greater or lesser independence enjoyed by women is linked to the speed of children's emancipation, since the northern countries set less store by children's presence in the home. Respect for one's parents and the sense of filial responsibility, in particular for ageing parents, are stronger in southern than in northern Europe (53; 54).

3.3 European moral values in relation to serious illness and the end of life

From March 1998 to March 2001, a European project[11] was conducted to analyse the ethical aspects of the concept of palliative care in seven European countries: Belgium,

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[9] European Value Survey (Enquête européenne sur les valeurs), 1999, in: Futuribles 2002.
[10] The thinkers of the Reformation considered that marriage was no longer a sacrament.
[11] PALLIUM: European Commission BIOMED II Research Framework, Biomedical Ethics, 2002.

Germany, Italy, the Netherlands, Spain, Sweden and the United Kingdom. Two approaches were adopted in order to analyse the concept's moral implications:

(1)   Use of models to assess the foundations of palliative care as opposed to traditional medicine. Doctors were sent a questionnaire asking about the moral distinctions they drew between palliative care and other forms of medicine, and whether they perceived a greater moral dimension to palliative care.

(2)   Analysis of medical and ethical publications on the debate about palliative care versus other forms of medicine.

The results clearly showed that there is a very close link between palliative care and moral values. For 62% of the respondents, palliative practices should be initiated as soon as a serious medical problem is diagnosed. Over 90% of them considered that the chief focuses of the "palliative approach" itself should be quality of life, human dignity, acceptance of human mortality and an integrated approach. This is consistent with the WHO definition of palliative care. Professionals in the seven countries concerned are well familiar with the concepts of autonomy, beneficence (doing good), non-maleficence (not doing harm) and justice, but did not regard them as useful standards for the purposes of practice. The majority of respondents moreover considered that there was no additional moral dimension to palliative care as compared with other forms of medicine (109). The concepts deemed least important to palliative practice were emotions, feelings, empathy and the sacredness of life. Lastly, the respondents assigned very different degrees of importance to human dignity, hope or hopefulness and prudence (66).

However, confusion continues to surround the application of these concepts in palliative practice on the ground. For example, although 95% of the respondents stated that euthanasia could not be included in the range of palliative medical acts, 15.4% consider that increasing opioid dosage with the aim of shortening a patient's life was a palliative practice, and 36.5% that stopping a treatment with the same aim was a "good" palliative care measure (73). At the same time, only 10% of respondents thought there was a difference between the three concepts of euthanasia, increasing opioid dosage with the intention of hastening death (shortening life) and stopping treatment with the intention of hastening death (shortening life). This raises the question on what ethical basis can a medical decision intentionally to shorten life be included in a palliative approach, whereas euthanasia is excluded?

The dominant medical reasoning in current palliative practice offers a good illustration of the impact of this confusion, as can be seen from two examples: use of sedation and withdrawal of hydration and/or nutrition.

Where pain is intractable, it appears easy to justify the need for "sedation" rather than simply leaving the patient to die. However, in practice, there is an ambiguity between "**palliative sedation**", which involves periodically bringing the patient out of the state of unconsciousness in order to perform a new overall clinical assessment, and "**terminal sedation**", which consists of rendering the patient unconscious until death occurs. This also applies to "terminal sedation" proposed as a "treatment" for moral (or existential) suffering. Although such moral suffering is difficult to measure and alleviate, Billong, Monut and Portenoy contend that terminal sedation is not justifiable in such cases, firstly, because it is not suited to the symptom (whereas a form of "induced sleeping cure", consisting of periods of "palliative" sedation followed by periods of consciousness, is), and, secondly, because it is a disproportionate response (11; 94; 103). Moreover the

"double effect" argument sometimes advanced in this context is not defensible here, either (see below).

In some European countries withdrawing or withholding artificial hydration and/or nutrition has become a common practice. This was a topic of ethical debate throughout the 1990s (5; 30). In the Janssens survey (73), 28.8 % of the respondents considered that, even in extreme circumstances, allowing a sedated end-of-life patient to become dehydrated was not a recommendable "palliative" practice, as it could be suspected of constituting a disguised form of euthanasia.

In this context, palliative care professionals today have differing opinions about stopping or limiting treatment of any kind, although it is a standard practice. For 20% of the respondents to the survey, stopping or limiting ventilation or reducing nutrition or hydration are not part of the palliative care approach. It can be asked whether, in forming this moral judgment, the respondents do not regard stopping such treatment as causing an inhumane death, although western European writers are silent on this matter (3; 18). Another interpretation is that hydration and nutrition are part of the basic care to be provided to any patient, not medical treatments, and, accordingly, that stopping or reducing them should be considered tantamount to euthanasia. There must therefore be no withdrawal of them. No matter how burning these issues are for palliative care teams in western Europe, it is important to note that this debate is strongly linked to the terminology used, the implications of which remain confused: euthanasia, stopping treatment whether or not preceded by gradual withdrawal, stopping treatment with the intention of shortening a patient's life, and so on.

One of the criteria used in determining the morality of decisions to limit or stop treatment is the doctor's attitude to the informed consent of the patient (where competent) and/or the family. The results of the survey conducted in the seven European countries are in this respect consistent with the information to be found in the literature; palliative care professionals attach far more importance to the family's consent than to that given by patients themselves (45; 96; 133). Is this linked to the fact that patients are considered often scarcely "competent" to participate in decisions about their own lives? Or should another interpretation be given to this response? It is indeed surprising to see that the importance the PALLIUM respondents attach to the patient's consent is not in correlation with the significance they attach to the concept of patient autonomy. It is true that they regard the concept of autonomy as of scant assistance to them. Differing understandings of this concept are doubtless due to the cultural heritage of the individuals concerned.

Etymologically, the word "**autonomy"** comes from the Greek (*auto- nomos*) and means "living by one's own laws". Biologically, it is used to designate the capacity of any living being (whether a single cell or a complex organism) to preserve its unity and constancy in the face of environmental changes (15). Politically, Rousseau (126) considered that the concept of autonomy was implicit in the notion of submission to the general will. This entails that individuals disregard their own will (pursuit of their individual desires and interests) so as to express their will solely as citizens, that is to say as rational beings seeking to promote the general interest. From a moral standpoint, autonomous individuals are not those who live without rules, or according to rules imposed on them, but those who live solely by the laws they have prescribed for themselves in the interests of others and in the general interest. The Kantian definition of autonomy, drawing inspiration from Rousseau's notion of the general will, is the character of a will that is

self-determined of its own essence, that is to say that solely obeys the commands of practical reason, regardless of any affective motive. Autonomy is therefore the freedom of a reasonable being. It follows that, if autonomy is freedom, it is so in a very precise way: according to its etymology, autonomy means establishing laws for oneself. In contrast with the new paradigm arising from prevailing individualistic values, it is not at all a question of saying "this is what I want, this is my law", as the law is not relative to each individual, but is in essence universalisable. In moral terms, the converse of autonomy is not dependence, but heteronomy, that is subjection to an external authority, maintenance in a position of inferiority or submission, deprivation of liberty (78; 79; 126). As Ricoeur explained with reference to the "pact of trust" that forms the basis for any medical intervention, the autonomy the patient asserts vis-à-vis the practitioner results not in a "confrontation of two wills, as in a pact of 'distrust', but in a search by the patient himself for a rational and therefore universalisable form of conduct." (122). J. Ricot further expounds Ricoeur's theories: "The encounter between the (benevolent) health care practitioner and the (autonomous) health care recipient then finds a common ground, allowing all the adaptations required by the singular situation. This concept of autonomy naturally has nothing in common with freedom, as confused with the unlimited expansion of desires. If that were the case, if the patient could surrender to the spontaneity of his urges and his decisions, instead of attaining autonomy, the doctor-patient relationship would be finished: the former would become a mere provider of services subject to the latter's absolute power. Through a strange reversal, the excesses of the paternalistic model would then be replaced by the counter-excesses of a model exploiting the care-giver. The doctor's prescription would have been replaced by the patient's orders." (124).

The light which the PALLIUM survey sheds on the European cultural heritage makes it clear that, on account of cultural diversity, there is no real ethical consensus among the countries of western Europe, and even less so with the new European Union member states. Looking ahead to the opening of a debate on these questions, the terminology used in discussions between European states, as regards notions of relieving suffering with the risk of side effects, limiting or stopping treatment and the underlying intents, continues to pose a major problem. It is easy to imagine the consequences that concepts so dependent on each state's own culture could have for any attempt to clarify the approach to medical decisions in the end-of-life context. How is it possible to disclose the reasoning, the intentions or the intuitions that come into play in decision-making practice when so many diverse underlying cultures are involved? For example, what weight can be attached to intent in determining the morality of these acts? What meaning can be given to the still current expressions "active euthanasia" and "passive euthanasia"? What does this constant ambiguity of concepts signify? What are its ethical implications in practice? A real debate on the ethical foundations of medical decisions in end-of-life situations would be necessary, to add clarity to many of the decisions taken. For example, autonomy continues to be much referred to in medical circles today, although palliative care professionals consider it of little relevance. However, is it relevant and necessary to use this concept as a decision-making element in everyday practice? And in which practices - those relating to the end of life? When and how does one decide to disclose the situation to the patient with a view to obtaining his/her "informed" consent? Should consideration not be given to a pedagogic approach for training medical staff in imparting certain kinds of bad news? Must patients be informed that their treatment is "palliative" in nature? Is it necessary to deprive a patient undergoing palliative care of all hope? Is there a "duty" of awareness and a "duty" of support? These are just a few examples of the questions that arise.

3.4   Ethics and palliative care in Europe

European societies have a common cultural background, which has not erased the historical, anthropological and religious heritages of each member state. This accounts for the significant differences between European societies. Religion can be seen to play a key role in the most distinctive cultural traits. For instance, the antithesis between Catholic and Protestant societies is reflected in their ethical values (19 + Janssens 2001). The north/south axis also seems to be a constant in the geography of European values. It is possible to describe the contrasts between the community-based values of the south and the individualistic values of the north following the Reformation. However, alongside this north/south axis, a different east/west divide must not be overlooked, concerning which there is not enough information at present. Overall, the European cultural heritage is therefore a picture of cultural contrasts and "there is no reason today to say that these differences will fade in the near future." (54).

The history of the global, and hence European, palliative care movement reveals that people are unquestionably concerned about moral values. At its beginnings this movement was fed by popular rejection of the ethical attitudes of traditional, so-called "curative" medicine. The situation has undoubtedly been changing for some thirty years now: curative medicine pays greater heed to the end of life, the World Health Organization has recognised palliative care as an integral part of medicine, the proponents of palliative practices are becoming more conciliatory in their relations with curative medicine. A phase of integration of curative and palliative medicine, aspired to by the WHO, is emerging. However, in practice the boundaries and implications of "healing" and "caring" are sometimes so hazy that the term "medical treatment" is frequently used instead.   The objective of curative medicine is to make a diagnosis of a disease and deduce from it the therapeutic measures best suited to healing the patient. The objective of modern palliative medicine is, when confronted with an incurable illness, to promote the patient's quality of life until the end, to provide pain and symptom control, to support the patient and his/her family and friends via the use of specific relational skills (supportive care) and to incorporate medical decisions in an ethical approach. This false dichotomy of "healing" between two branches of medicine raises questions. Through the ages societies have always relied on "curative" practices that combined experience, individuals' natural resources, scientific knowledge of diseases and beliefs about life, illness and death.

Ethical research into end of life issues now has considerable implications not only in terms of health care, but also for education, the economy and politics. In the European context palliative care is of vital importance both for health care professionals and for the challenges that European health system themselves have to confront. For patients in Europe, and indeed all European citizens, which end-of-life ethics can emerge that take into account the many cultural differences? Ethics belong to everyone. They correspond to a demand of modern society, but not an unambiguous one. As the philosopher Ricot points out (124), "... it is often as a means of imposing the adaptation of moral standards to new scientific or technical data, to scientific or technical advances, that philosophers are asked to address social questions, rather than with a view to reiterating the fundamental requirements of respect for the human person. Lawyers experience the same ambiguous demands when, despite the legal traditions of all human societies, they are asked to bring their approaches into line with scientific and

technical progress and with the irresistible groundswell of opinion spread by the media and by contemporary individualism." (13).

When they are closely involved in caring for patients, particularly those in an end-of-life state, the professionals concerned say that they very much wish to be able to call upon additional scientific, technological, psychological and spiritual skills and to utilise thinking aids that are of a philosophical nature, if philosophy is construed as a "way of life", which is how it was defined in ancient Rome or Greece (65). Such aspirations were scarcely conceivable only a few decades ago, when the ethical questions arising from the Christian history of European values could be posed only in either theological or psychological terms.

An overview of the shared Christian European origins of the EU member states therefore shows that the ethical standards applied to decision-making in end-of-life situations are changing: the legacy of theological values continues to provide a framework for a European system of values; at the same time, the cultural differences bring to light two major dividing lines, one north/south and the other east/west, in terms of both ethical principles and dominant religions, which shape people's attitudes towards the elderly and the meanings people give to the end of their own lives or those of their family or friends. Confronted with the end of life, people increasingly refer to the concept of autonomy, still along these same dividing lines. Today, however, it is linked with the concepts of quality of life, human dignity and acceptance of human mortality, and no longer with religious dogma, as it was in the past.

The European ethical approach to the end of life is accordingly being absorbed into medical practice and, as a result, first and foremost into medical decisions. This process corresponds to a demand of modern society, which is not devoid of ambiguity, and it would be highly desirable for a European seminar on the subject to be organised.

4 THE ETHICAL IMPLICATIONS OF DECISION-MAKING PROCESSES IN WESTERN MEDICINE

As we have seen, the Hippocratic tradition (*chapter 2*) and the European ethical approach (*chapter 3*), shaped by its theological origins, are coming together with the consumerism prevalent in modern society and successfully taking over the sphere of palliative medicine (Fiona Randall Downie).

4.1 The ambiguous nature of palliative care and the ethical issues: the paradoxes inherent in the definition of palliative care

4.1.1 Quantifying a patient-focused medicine

As can be seen from the history of palliative care, it is a form of medicine that is patient-focused (26). In their palliative practice the professionals concerned rely on "evaluation tools" involving systematic use of questionnaires. This has caused some people to become seriously disillusioned about palliative medicine, as they see it as an aberration of the palliative approach, consisting of setting aside the essence of the relationship between two individuals. It is true that automatically, systematically completing a questionnaire has nothing in common with the committed, attentive role of the health care practitioner, which first and foremost entails enquiring into and heeding the needs

identified by patients themselves. But how can the practitioner know a patient's needs, fears and wishes without asking about them? And how can practitioners react to the phenomena described by patients with a benevolent, non-judgmental neutrality?

4.1.2 Autonomy and entitlement to interfere in people's private lives

Whereas palliative medicine focuses on the patient's autonomy and respect for the patient as an individual, as reflected in the importance attached to patient consent, the palliative approach does involve a considerable degree of paternalism. For example, the approach stresses the need for an evaluation of the patient's psychosocial and spiritual needs, whether the patient wants it or not. This very often leads to care initiatives being taken on the basis of practitioners' cultural and professional standards, again frequently without any real consent by the patient, who is under no personal obligation to correspond to the model of the "good patient" as conceived by palliative care practitioners.   Does palliative care give the professionals concerned a form of entitlement to interfere in people's private lives, with the excuse that they are weak and vulnerable? Is this not inconsistent with one of the fundamental facets of the definition of palliative care - respect for the patient's autonomy - and with the professional duty to give the patient access to the best possible care, regardless of his or her physical and mental condition?

4.1.3 Where does the care priority lie: with the patient or with the patient's family?

As we have just mentioned, under a palliative approach the care focus is on the patient and on considering the patient's wishes when taking decisions. However, in everyday decision-making practice it can be seen that sometimes families' needs are regarded as equal to, and even given priority over, the needs of patients themselves. When a patient makes it clear that he or she wishes to die at home, in a house that he/she owns at least a share of, the patient's wish is often refused, without even discussing it with him or her, because it runs counter to the family's wishes. This is indeed no simple ethical issue: the patient has his or her rights, and the family accepting the patient's presence in the place where it lives also has rights. The more far-reaching ethical question posed for each of the participants in this ethical debate concerns one-to-one supportive relationships: each person is "autonomous" ("establishes his/her own laws"), but does this autonomy allow for the additional third partner in the relationship, which is the disease itself, for the health care system and its limitations, which are not the same in rural and urban areas, for family members' own state of health or problems, etc? A similar situation arises, for example, where a family requests that the patient's life should not be prolonged because they themselves suffer when they see the patient in such a state, and where this request is not consistent with the interests or the wishes of the patient.   Not infrequently, on the basis of various arguments, confined to mere justifications of their attitude, the family imposes its wishes, which override the patient's own interests. Families moreover tend to take decisions which are influenced by their own experiences of end-of-life situations. However, the WHO definition of palliative care clearly states that such care is not intended "to hasten or postpone death"!

4.1.4 What status for medicine?

The three paradoxes cited above to underline the ambiguities in the definition of palliative care (or palliative medicine, sometimes also called the medicine of incurable diseases) lead to the question of the status of medicine: What makes medicine medicine

(25; 149)? This is a narrow, radical and decisive question. It concerns the essence of medicine, not its nature: if medicine does not have its own essence, which determines what it is, it is merely an empty shell, a collection of simple historical facts, in which the most disparate elements can be grouped together. The outcome will be an incapacity to theorise medicine, that is to say to "give it the means to express its theories and its practices, to enlighten its self-awareness and to preserve the meaning of its role despite all the frictions that surround it." (48) The current discussions about defining palliative medicine as an art, but only curative medicine as a science, are symptomatic of a dangerously slippery slope. Is a doctor who knows how to cure a sore throat more of a doctor than his fellow practitioner who treats AIDS patients but does not yet know how to heal them? Can it not be said that palliative medicine is emerging from its past when, since it dealt only with the most vulnerable, incurable patients, its sole "status" was as provider of support for the dying?

To avoid becoming bogged down in these internal disputes, it is important to look at the very foundations of the medical profession. Medicine can then be seen to be an "art", a term which needs some clarifying to prevent a number of contemporary misinterpretations.   The term "art" comes from the Greek "*tekhne*" and is not the opposite of "science" - "*episteme*" - or wisdom - "*sophia"* (philo *sophia* = philosophy = love of wisdom or the science of first causes and principles, designated metaphysics). As Aristotle explained (4), "*tekhne*" (art) is the intermediate stage between "experience" and "wisdom". It is precisely in this middle ground between experience and wisdom that medical decisions are taken. No art would be possible if human beings did not have access to the knowledge (*logos*) which allows them to distinguish between what is them and what is not them (standing back from reality, from the truth), to set objectives and to devise the means to achieve and implement those objectives. It is the entire decision-making process, which constitutes the medical act itself, that Aristotle designates as "art". As an example he cites the art of "determining that a given remedy has relieved all people of the same temperament, belonging to the same kind, suffering from the same disease, such as phlegmatic, bilious or feverish people." According to Aristotle's conception, art must nonetheless remain firmly grounded in individual experience, the level at which the reasons and causes are sought, failing which one runs the risk of choosing the wrong treatment. "Medicine in fact deals with Callias, Socrates or 'so-and-so', never with patients in general: 'what needs healing is the individual'. Experience therefore contributes the individual dimension, without which there is no medicine worthy of the name." (48).

This medical art is neither "*episteme*" (science or knowledge) nor "*sophia*" (wisdom). *Episteme* refers to any methodical knowledge in the broad sense, as opposed to both ignorance and art. For Aristotle (4), having scientific knowledge (*episteme,* although the etymological root of "science" is the Latin "*scio"* - I know) about something means knowing the cause which makes it what it is. The object of the science is what is necessary, that is to say what cannot be other than it is. The field of science is therefore "*phusis*", or nature, which is not itself a thing or a number of things, but a principle or cause that explains how things happen or come into being. *Sophia*, which is both knowledge and reasoning, focuses on first causes and principles, which constitute the "*metaphusis*" (metaphysics), as opposed to the "*phusis*" (nature - observation of phenomena). One English term for a doctor - physician - has retained the Greek root. Medicine is concerned with the nature (phenomena) of humankind, whereas philosophy is concerned with metaphysics.

In his treatise on "Ancient Medicine" Hippocrates said that medicine is not and must not be based on any hypothesis concerning the nature of non-apparent realities. He thus ruled out, as a matter of principle, any kind of preliminary metaphysical approach and all the theories explaining the origins of things that happen or come into existence. However, in its decision-making approach, the art of medicine is based on both **scientific and philosophical methods** moving from the individual (a finding) to the general, before coming back to the singular in the act itself. The **traditional diagnostic approach,** on which all medical decisions are based, comprises a number of stages: gathering of data, which are always singular in nature, choosing among these data those which can serve as diagnostic indications, grouping these indications in nosologic form,[12] which function as diagnostic hypotheses by reference to general principles, and, lastly, comparing these diagnostic hypotheses with the singularity of the patient's clinical situation so as to make a choice (decision) as to what seems most consistent with the irreplaceable, unique reality of the case. This art of diagnosis simply involves forming a judgment that is directly linked to the practitioner's culture and experience and therefore depends on his/her commitment, since it is conditioned by his/her culture, the inevitable limitations of his/her knowledge, his/her biases and his/her motivation. Since the 19th century this traditional diagnostic approach has been combined with a probabilistic approach, taking into account the context of uncertainty surrounding a clinical decision: uncertainty of the data obtained from questioning the patient; uncertainty of the information diagnostic investigations are expected to provide; uncertainty about the expected benefits of the therapeutic prescriptions. The fact is that any medical decision can but be probabilistic, which leads to an awareness that medical decision-making inevitably entails a degree of error. This is not without implications for ethical choices. The context of uncertainty raises the key question in the decision-making process of how to manage de facto uncertainty in situations where one is faced with contradictory demands and needs and obliged to take a decision that will always have a negative aspect. Can ethics be viewed in terms of open searching, in contrast with a closed set of moral principles? Or rather, can medical ethics constitute a new form of regulation reflecting a cultural distrust of the moral, personal, private conscience of the health care practitioner or researcher? Where would medicine be today if our current ethical rules had existed earlier? Are medicine and uncertainty a question of culture (the history of care) or a question of nature? According to Canguilhem, any medical intervention (and accordingly any medical decision) is intrinsically an experiment: "However, as neither Claude Bernard nor anyone else, for that matter, is able to say in advance where the boundary lies between the harmful, the neutral and the beneficial, as this boundary can vary from one patient to another, all doctors must tell themselves and make it known that in medicine one experiments, that is to say one treats patients, only in a state of trepidation. This might be better expressed by saying that a medicine concerned with the human person as a unique living being can only be a medicine that experiments." (22). This is why Hippocratic medicine and Aesculapian medicine constitute the same art.

4.1.5 *Where does medicine stand today?*

In its definition of palliative care, published in 2002, the WHO says palliative care can "enhance quality of life and may also positively influence course of illness. [It] is applicable early in the course of illness, in conjunction with other therapies that are

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[12] Nosology: 1) study of the characteristics that can be used to define diseases; 2) the science of the classification of diseases.

intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications;" (153). This manner of defining the objectives of palliative care reflects the WHO's unifying view of "curative" and "palliative" medicine. From both these standpoints is the patient not in fact always unique? Is it not true that, whether seen from the curative or the palliative angle, medicine is always experimentation, since it is an art and not a pure scientific theoretical approach? Is the interface between the palliative and curative medicine models, which people sometimes attempt to contrast, an either/or one, as might sometimes be imagined in practice, or a both/and one, linked to the non-interchangeable clinical situation itself?

From the point of view of the outcome, or the usefulness of initiating a treatment, the goal is the same for curative medicine and for palliative medicine: the best treatment suited to the stage reached by a disease present in a unique individual at a given time and in a given place (availability of certain treatments, cultural aspects of perception of the disease or the treatment, and so on). In both kinds of medicine, from the standpoint of the genesis of the medical decision, the choice of medical treatment is based on both the hypothetico-deductive method of reasoning used in the natural sciences and the hermeneutic method[13] applied to the human sciences. Foucault defines hermeneutics as "the totality of the learning and skills that enable one to make the signs speak and to discover their meaning" (50). It is a comprehensive method specific to the human sciences. Unlike the explanatory methods of the exact sciences, it uses expression as a way of understanding people's inner lives. The teaching of medicine today relies on a rationalistic, too exclusive pedagogic approach. The result is that two forms of medicine have emerged - one curative and the other palliative - and curative medicine regards itself as a pure scientific discipline, whereas palliative medicine is attempting to become one. The two attitudes clash when ethical decisions have to be taken concerning end-of-life patients: the recommended approach for practitioners of curative medicine is prolonging life until death occurs. In a curative medicine context, treatments aimed at "**prolonging life**", such as intravenous hydration in a patient with an irreversible intestinal obstruction, will be administered to end-of-life patients. In a palliative care unit, the same patient would probably not receive hydration, as it would be seen as a treatment aimed at "**prolonging death**". Along these lines, we are currently at the top of a slippery slope as we move towards increased recognition of patients' rights and public rejection of what is sometimes termed excessive medical zeal, that is the relentless use of futile treatments. Is it not possible that, since curative medicine's objective of prolonging life may be obstructed by the legal risk that patients, their families or care teams will see it as "excess zeal", a paradigm shift could occur in the opposite direction, that of "**hastening death**"?

The existence of such paradoxical situations calls for a change in the pedagogic approach to the teaching of medicine. Canguilhem has already voiced his surprise at the situation: "Is it not strange that the teaching of medicine covers everything but the essence of medical activity and that it is possible to become a doctor without knowing what doctors are and what is required of them? It is a known fact that doctors are not unconcerned about these matters, but their interest is expressed more through medical

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[13] Hermeneutics: "the totality of the learning and skills that enable one to make the signs speak and to discover their meaning" (Foucault, "The order of things"). It is a comprehensive method specific to the human sciences. Unlike the explanatory methods of the exact sciences, it uses expression as a way of understanding people's inner lives.

literature than in the form of medical pedagogy. We must be clear about our thoughts on this subject and admit that, in our opinion, since nowadays acceptance of the health care practitioner's role increasingly entails a willingness to experiment, this also involves acceptance of a strictly disciplined professional liability" (22).

This list of examples of paradoxes inherent in the definition of palliative care, highlighting certain ethical issues relating to medical decisions in an end-of-life context, naturally brings us to an analysis of the main ethical concepts involved in medical decisions centring on the end of life.

4.2 The main ethical concepts involved in medical decisions in end-of-life situations

This is an area that cannot be dealt with exhaustively. With a view to addressing them in greater depth, we shall discuss the main ethical issues referred to above. **In which contexts, and how,** do the questions of quality of life, autonomy, dignity, respect for the individual, a patient-focused integrated approach, the role of the family and health policy and society arise in medical-decision making? And what **conclusions can be drawn** at present about how these concepts are applied in medical decisions in Europe relating to the end of life?

4.2.1 *The concept of quality of life in medical decisions*

From 1961 to 1965, before Cicely Saunders opened St Christopher's Hospice in London, (131) the term "quality of life" was not indexed in the Medline data base. Conversely, between 1966 and 2000 the number of articles containing the key words "quality of life" stored in Medline reached 12,749. This concept can therefore be seen to be a pure medical product, used to designate the state of complete wellbeing referred to in the WHO's definition of health.

Historically, the term was coined in the context of the socio-economic development of western Europe and the idea of leading the "good life", which went hand in hand with a denial of death. When individuals realise that they have little time to live, they tend to seek to live what remains of their lives as well as they can and with the greatest possible intensity and commitment. Quality of life therefore corresponds to this idea of the best quality of life for the time one has left to live following the dawning of an awareness of human mortality.

Although the term's general meaning from an existential point of view is easy to comprehend, it is nonetheless still difficult to pin down precisely from the standpoint of professional practice. It is a complex term, and this complexity even makes it indefinable in the medical sphere. It is indeed difficult to see how the score obtained from the replies to a questionnaire is linked to the problems raised by practitioners on the basis of their professional experience, or even by patients themselves and their families (100). The field of experience of the person behind the decision-making criterion "quality" is not of the same order as that of Hippocratic medicine and its explanatory method. Like Aesculapian medicine, this exercise requires a comprehensive approach, that of the human sciences (a hermeneutical method). The transition from one to the other is not a question of competition and rivalry, but has to do with the way **the decision-making act itself interlinks the decision-maker and the target situation or event**, the origin and the place of the decision. **It is the interaction**

that permits the conjunction of the act's aim or purpose (teleology), which has its basis in practical reasoning (and hence in the decision-making process itself), **and the event,** which has to do with the causal explanation (professional ethics). **The transition from Hippocratic to Aesculapian medicine describes the alchemy of the integrated medical decision-making process[14],** taking as its basis the historical condition of all human beings, that of being pulled between a past received as a legacy, or "space of experience", and a future open to initiative, the "space of promise" or horizon of expectation[15]. The dialectical "qualitative" link, forming a bridge between the "space of experience" and the "space of promise", corresponds to "work on thinking well", to borrow Pascal's expression. Its qualitative nature, brought into play by the dialectic, then makes it possible to move outside the sphere of quantitatively-based accepted wisdom, the role of which is to deal separately with phenomena (the Cartesian approach) so as to explain them in a causal manner. This dialectical link itself makes it possible to understand the phenomena in motion: the functional or physiological aspects and not just the anatomical ones.

Many of the questionnaires utilised by health care practitioners may adopt a moralising tone, to which patients respond with mutism. It is not infrequent for patients to feel no need to discuss their private personal experiences with health care professionals. However, they do need the professionals' skills so as to obtain relief from their symptoms. Sometimes, mobile palliative care teams regard it as abnormal, or even pathological, for a patient not to talk about his/her death with them, since they know that death is close and even foreseeable. This observation of course goes hand in hand with a recognition of the powerlessness of medicine and with the risk that relentless technical zeal will be replaced by a form of relentless relational zeal surrounding the impending death, or even by attempts to hasten it as a "logical" conclusion: "since it cannot be avoided at least let it be as quick as possible". These situations, frequently encountered in the field, raise a number of questions: (1) On the basis of which criteria, and how, do professionals decide the time of a patient's death? Biological test or scanner results? Is it not true that, through the ages, the philosophers and common sense have told us that death is certain, but its time uncertain, even with modern medical imaging techniques? (2) Is there a truly "phenomenological"[16] approach to death, and what influence do emotional and existential factors have in this end-of-life context? (3) What is a good choice for the person as a whole? (4) Is it possible to envisage ethical decision-making criteria suited to end-of-life situations, and if so in what terms?

The use of questionnaires concerning the "end of life" with a view to providing an integrated care approach therefore requires a **complete reinterpretation of the purpose of the medical act. What could be an operational definition of the concept of integrated care,** since the concept of "quality of life" measured by the quality-based questionnaires is not the answer? A qualitative understanding indeed requires a method different from the quantitative approach.

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[14] An expression re-used later in the report.

[15] Paul Ricoeur, *Du texte à l'action* (From Text to Action), pp.269 and 271; *Soi-même comme un autre* (Oneself as Another), p.107

[16] "Phenomenological" is here used in Husserl's sense of a return to the origins of the perceptions we have of objects. This is a non-psychological science of the immanent forms of consciousness.

4.2.2 Autonomy, dignity, respect for the individual, an integrated patient-focused approach

The doctor-patient relationship is lacking in symmetry from the outset: the former receives the patient and attempts to alleviate his/her problem or suffering through a process of "working with language". The medical decision, the founding act of medicine, indeed consists of studying signs (semiology) in order to assign predicates[17], or symptoms, paving the way for the semantic innovations that diagnoses constitute. The diagnostic decision-making process of the medical act has to do with the "living metaphor" process, described by Ricoeur as the "process whereby discourse liberates the power of certain fictions to reformulate reality" (118; 119). In "Time and Narrative" he wrote, "Although it is true that every use of language is based on a gap between signs and things, it also entails the possibility of putting oneself at the service of things that must be said and thus attempting to offset the initial gap through an increased obedience to the demand for discourse, which arises from experience in all its forms." (120).

This is how the doctor cares for a patient. The patient reveals himself in the vulnerability of his historical condition, which is both a space of experience and a horizon of expectation. The human encounter between doctor and patient takes shape as the pact of trust unfolds: one party, with its weakness, does not simply deliver itself up to the other's all-powerfulness, as is the case in a paternalistic relationship. As Ricot points out "the health care practitioner must no longer substitute his will for that of the patient, and the limit on his skill and benevolence lies in the autonomy of the patient, wishing to control his fate and to determine the criteria of his own dignity." (124). This means that between the **principle of benevolence,** which guides the health care practitioner's conduct, and the patient's freedom, there is a latent conflict of an ethical nature. Does the benevolent party, that is to say the person who is seeking what is good for me, really know where that good lies? Which criteria does he apply to decide it? Is the good in question of a moral or a medico-technical nature, or again, as the term benevolence implies, merely a kind of solicitude, filled with respect, in the encounter of two consciousnesses? The paternalism of the doctor-patient relationship is today being replaced by a patient-focused care approach showing respect for the patient's will (rights) and citizenship (the encounter between two citizens or two consciousnesses). What then will constitute a "good decision"?

The **pact of trust** at work in the principle of benevolence simultaneously requires that recourse be had to the principle of the patient's autonomy, so as to safeguard both parties from the harmful consequences of a pact of distrust that can come into being at any time not only between a patient and a doctor, but also between the clinical and the procedural. The health care practitioner's benevolence and the patient's autonomy come together at the heart of the intersection created by the decision-making act. Here the doctor's aim (the purpose of the act) intersects with the patient's horizon of expectation, setting the seal on a space of promise, as evidenced by the pact of trust. This dialectical link, which opens up the space of promise, has its basis in Pascal's "work on thinking well". For both partners, striving to "think well" means taking the risk of

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[17] From the Latin *praedicare*: to proclaim or assert. It means what is affirmed or denied about a subject (Aristotle, Organon).

active, responsible[18] participation in a dialogue. The doctor-patient relationship then naturally evolves into a supportive relationship - its ultimate phase, concerning which both parties could echo the sentiment Montaigne expressed in his "Essays" for his friend La Béotie "because he was he, and I was I". This supportive relationship that comes to resemble a relationship of friendship, as Ricoeur says, drawing on Aristotelian ideas, is possible only if autonomy is not reduced to self-sufficiency and self-determination, erroneously giving the impression of the subject's independence, but is construed in the etymological sense of the Greek "*auto*" - oneself - and "*nomos*" - the law. Autonomy is then subjection to a rational, universalisable law on which it is possible to base a coherent dialogue, no longer reduced to "Me ... this is my choice, this is my law". Autonomy understood as obedience to the law one has prescribed for oneself entails a rational behaviour, which is therefore universalisable, lending itself to sharing and exchanges with the other. It is then possible to arrive at a common ground in a context of dignified dialogue, allowing of all the adaptations required by the particularities of the situation.

A doctor-patient relationship founded on this kind of pact of trust constitutes a "course of recognition"[19] for both the health care practitioner and the patient. It is made up of ongoing adaptations in the dual exercise of self-recognition and mutual recognition. Recognising oneself, with the verb in the active voice, entails participation by asking questions such as "What do I want?", "What can I do?", and the development of a self with a coherent set of wishes, which is no easy matter. Without the constant effort on each side to "think well" or think rationally, communication remains muddled: asking without knowing what one wants, asking for something impossible, asking to change reality…. Self-recognition (the pronominal voice) then becomes possible, which then enables recognition of the other, like oneself, and paves the way for a friendly relationship.

This "therapeutic alliance" between the health care practitioner and the patient, drawing on Ricoeur's philosophy, is not that which prevails under the model of the English-speaking world, which is more widespread today. Under this model the doctor-patient relationship is that of a service provider subject to the absolute power of the patient/customer. It is a model that "exploits medicine, as if the doctor's prescription was replaced by the patient's orders" (124). Will this commercial type of relationship based on "what I want", not on autonomy in the sense of true freedom, lead to such extremes that the sale of organs, paid surrogate motherhood ("wombs for rent"), doping, drug abuse, voluntary mutilation, prostitution, suicide, euthanasia, and so on become ethically and legally acceptable? Even if, in some European Union member states, **society decides** that one or the other of these acts shall no longer be a criminal offence, each state's freedom in this area does not result in a constitutionally protected right to sell one's organs, to rent out one's womb, etc. From an ethical, legal and political viewpoint there are higher values more deserving of protection than a state's or an individual's own freedom. First and foremost among these superior values, mention can be made of the protection of the most vulnerable members of society, who can be manipulated in many ways, as numerous investigations have shown. Would it therefore be possible for a democracy to lay down a first principle restricting individual freedom, notably in decision-making relating to the end of life - the principle of protection of the most vulnerable? And

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[18] "Responsible" is here used in the sense of its etymological root "*respondere*" that is to say responding and being answerable for.
[19] Paul Ricoeur's last work was entitled "The course of recognition" (123).

in the context of this attempt to draw distinctions between the terms "autonomy", "individualism" and "singular preference", could a second principle not be envisaged in connection with medical decision-making in end-of-life situations - that of protecting the moral integrity of health care professionals?

These questions show that, to avoid muddling the concepts, it is important in this field to draw a clear distinction between an individual act and an act of universal value.   This distinction, which has already been highlighted with regard to the term "autonomy", is also necessary in the case of the term "dignity", which is linked to the concept of autonomy in day-to-day language and in the field of medicine. In day-to-day language (the individual dimension), dignity is synonymous with the respectability, or decency[20], of the image one projects to oneself and others. In Kantian and legal terminology based on universal human values (the universal dimension), it has a completely different meaning. Kant defines **dignity** in terms of the following principle: "Act in such a way that you treat humanity, whether in your own person or in the person of another, always at the same time as an end and never simply as a means" (79). According to this principle, the life of every being with rational faculties, and hence "autonomous" (in the Kantian sense), constitutes an end in itself with an absolute, objective value. This status of an "end in itself" conferred on the autonomous reasoning human being is what Kant calls dignity. From this standpoint, dignity is therefore an "unconditional, incomparable" value attributed to humanity as a whole, which each rational being has the duty of bringing to tangible realisation in his words and deeds. Dignity accordingly designates the link of humanity between the absolute and the relative, or between the universal and the individual.   Only persons have "dignity", whereas things have a "value", which is comparable, quantifiable and exchangeable. Conversely, dignity, which is specific to human beings, admits of no comparison or degrees. One human being's dignity cannot be sacrificed in favour of another's. This is how dignity is construed in Kantian thinking.

In the modern context of self-sufficient freedom, the term "dignity" takes on an entirely different meaning, fraught with risks and pitfalls, since it is no longer linked to the universal dimension and is reduced to the relative dimension of self.   It becomes synonymous with mere individual propriety, a result of each person's freedom of choice, with no reference to the irreducible human subject seeking "the good life, with and for others in just institutions", as Ricoeur defines the ethical perspective. However, the Kantian concept of dignity is still given precedence in the wording of the Universal Declaration of Human Rights[21]: far from being a matter of personal propriety, dignity is the affirmation that human beings are recognised as having a universal, absolute value. At the end of the Second World War, the legal term "crime against humanity" was coined in order to make a distinction between such crimes and homicide. The classification of "crime against humanity" applies to crimes committed, not against human life (homicide), but against **human humanity**, that is to say **human dignity.** The term "dignity" is hence meaningless without an ontological link, and accordingly poses questions for medicine relating to its primary purposes or objectives.

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[20] The etymological origin of "decent" is the Latin "*decet*", meaning it is fitting.
[21]   "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world, ... The General Assembly proclaims ... Article 1. All human brings are born free and equal in dignity and rights."

The doctor-patient relationship is but one aspect of the issues relating to human autonomy and dignity that underlie the founding pact on which this relationship is based. Autonomy here becomes the way of forging an authentic creative relationship between persons subject to the same rational law. Dignity becomes the mutual recognition or relationship of common humanity founded on human mortality, which tells each of us in our heart of hearts "You do not know the date or time of your death, just as you did not choose to be born." This effort of reasoning, in the humility brought by the mortality inherent in our human condition, is what Pascal terms "work on thinking well". This work helps us avoid becoming imprisoned in a mental illusion of complete mastery of the situation, into which both autonomy and dignity could fall "when they elude the work of reasoning" (124).

Nonetheless, with the modern tendency for the pact of trust to become blurred, the "customers" of medicine are shifting and amplifying the demands they make of it, while at the same time asking why they should have greater confidence in a doctor than in an Internet site. They expect a doctor to dispense medical care with certainty and with an obligation as to the result. They also expect to always have immediate access to flawless medical care. They wish to be informed in a "transparent" manner and will verify what their doctors tell them by looking their condition up on the Internet. They expect doctors to communicate with them in a climate of openness to ethical considerations, requiring them not to conceal the "truth" from their patients, who should be able to participate actively in decisions concerning them and whose consent should be sought. In this new consumerist context of medical practice, making reference to reason, autonomy and dignity, construed as described above, is a way of underlining firstly the practical importance of the principles of truth and patient consent, and secondly the need to be aware that respecting a patient's dignity does not solely mean "supplying" a treatment (service) simply because the person concerned has asked for it. Medical reality ("medicality") is a more complex matter, and its **alchemy can be based only on the doctor-patient relationship in its expression of a mutual recognition between patient and doctor, both confronted with each other's capacities and human fallibility.** This is because, in mutual recognition, the capable individual is nonetheless fallible. According to Ricoeur (116), a person who is "capable" is someone who both acts and suffers, that is to say a person torn between responsibility and vulnerability. "Fallibility" indicates that the possibility of wrongdoing is part of the human constitution, making people capable of doing both good and bad.

The initial asymmetry in the doctor-patient relationship has shown that it is indeed the **relationship itself,** the location of a "living metaphor", that lays the basis for an ethical debate and approach. This relationship has abandoned the paternalistic aspects it had in the past so as to become more of an encounter, an alliance, a pact of trust, on which the relationship is founded. It has assumed various characteristics: autonomy, dignity, respect for the individual, a patient-focused integrated approach. This opens up a new field of ethics: that of decisions taken in a hermeneutic context by a capable person, no longer concerned with the binary objective of a "closed" accepted wisdom of "good" and "bad", situated on a transcendental level, but aiming to identify what constitutes the "lesser evil".

4.2.3 The place and role of the family in end-of-life medical decisions

In its definition of palliative care, the WHO says that the aim of such care is the "quality of life of patients and their families". Assessing the family's quality of life poses the same

methodological problems as just described with regard to patients: the need for specific methods appropriate to the qualitative sphere which are part of a hermeneutic methodology based on a comprehensive approach, and no longer an explanatory approach as in Hippocratic medicine. However, including families in the care dimension raises new ethical questions.

- **The boundaries within which care is taken of the family's needs**

Indeed, in the context of a health care system and its clinical activities, what does taking care of the "physical, psychological and existential" wellbeing of a patient's family mean? The term "taking care" is also debatable. At which generation should one stop? The practice recommendations of modern codes of medical ethics are solely concerned with the patient's "wellbeing". How can one link together, within this dual objective (patient and family), the disclosure of bad news, the ethical issues surrounding consent to a resumption of chemotherapy, or to stopping such treatment, the beginning of artificial nutrition when the patient is against it but the family asks for it, and so on? Will ethics have to progress towards a duty of "care"[22] of both the patient and the family with the same degree of priority? What will be the consequences for medical confidentiality, consent to treatment and participation in decision-making by the most vulnerable patients, who have been declared "incompetent" or "incapable"? Ethical questions about the respective roles of the patient and the family generally arise in the context of serious conflicts of interest between the two. Some writers on palliative medicine have called for a clarification of health care priorities, with an attendant risk of marginalising the patient. One article published in "Palliative Medicine" states that palliative care services must in fact provide relief for the physical and psychological symptoms of the patient and the family with the same perspicacity (51). A statement of this kind raises the question: what types of conflicts of interest between a patient and his/her family arise at the end of life? They more often than not concern quite understandable requests for information and the patient's need for respect of medical confidentiality, the place of death, often a source of disagreement, with much remaining unsaid vis-à-vis the patient himself or herself, or the time of death and the usefulness of treatments regarded as futile from a utilitarian standpoint, "since death is in any case inevitable", the potential benefits of bereavement support for relatives and the accompanying difficulties owing to the fact that this kind of care is not reimbursed by health insurance schemes, the cost of taking care of the family's needs while caring for the patient. In all of these situations how can the patient's best interests be determined in the context of taking care of the "patient in his family environment"? How can the specific sphere of this patient/family system be defined, and what are its ethical limits? Must medicine also become involved in taking care of the bereaved, whereas bereavement, although it sometimes has medical consequences, is nonetheless a social problem?

- **What benefits for the family?**

The "family's needs", to use the term accepted in palliative care circles, are considered to be assessable with the same kinds of tools as are used to measure the patient's. The same model is applied. The aim is to facilitate decision-making by professionals with the aim of doing good to the family, and perhaps also to the patient. The difficulty that often arises is that the only ones not informed about this are patients themselves, whose

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[22] "Taking care" is here used in the sense of dealing with, caring for.

consent is seldom sought by doctors. Discussions with families are often held in secret, which is scarcely conducive to the quality of the ethical debate.

What needs do the family have, and what action must be taken as a consequence? According to writers on the subject, families have specific needs. For Ilora Finlay, each family member needs information so as to be able to take decisions about the future and co-operate better on the basis of their own experience of loss (47). Sometimes patients' rights conflict with those of the family, particularly with regard to confidentiality, but Finlay does not deal with the question of how health care professionals can take the "right" decision in such circumstances. How should palliative care teams react when the family requests information that has not been given to the patient, or which the patient did not wish to hear, or again which it is not "useful" for the patient to know? (An example is multiple cerebral metastases necessitating palliative encephalic radiotherapy, whereas the patient has no neurological symptoms and has simply been told he or she has a metastasis in order to explain the therapeutic measure.)

Are the benefits of family support by health care professionals so obvious that they themselves justify incurring health care expenditure? And if so, on the basis of which indicators? The current scientific data cannot be used to answer this question since they are considerably biased: for instance, they do not properly take into account the time team members spend with families and do not calculate how many additional patients could have been cared for during this time. The difficulty in conducting this kind of study lies in the fact that family support is mostly privately financed, and the charitable institutions concerned are free to use their funds as they wish. Pending the availability of reliable data, and in the present context of cutbacks in professional health care staff, it seems reasonable to suggest that preference be given to partnership with teams of voluntary carers specialising in family support. This would make it possible to divert the care time spent with the family to general caring for the patient, a solution which would avoid "loss of patient time". This is an important question as, whatever the decision, there will be a loser on one side or the other!

- **When the place or time of death is in question**

Can health care professionals remain "neutral" and "impartial" when the family is involved in decisions concerning the place and time of a patient's death, and much remains unsaid to the patient himself or herself? One of the prime objectives of palliative care is to focus care on the patients' needs, which means satisfying the patient's wishes in the area of private life as far as possible. However, how can coherent decisions be taken that meet the needs of two parties with their own responsibility, autonomy and dignity: the patient and the family? The exercise of "thinking well" has to be learned, as can be seen from the lack of both analysis criteria and a methodological approach that can provide guidance and allow an improvement in the quality of decision-making. Must the patient be given sole priority simply because he or she is "a nice person"? Or should precedence be given to the patient's likeable family? In decision-making, what importance should be attached to the family of an end-of-life patient who has unrealistic wishes, even if the members of the family are exhausting themselves trying to meet those wishes? Does the family not have a "right" to decent living conditions at home?

As the end of life approaches, therapeutic measures may have the effect of either prolonging life or hastening death. Here too, regarding the family as a "secondary

patient" is not devoid of implications. During the terminal stage the patient's interests may diverge widely from those of the family. They may even be completely disregarded for the family's benefit, particularly where a patient is unable to communicate (mouth and/or throat cancer, for example). If palliative care did not entail an obligation to take care of the family's needs, the professionals concerned would provide care aimed solely at the patient's benefit. This argument advanced by some commentators can be countered with the assertion that taking care of families' needs has a knock-on effect in terms of supporting patients themselves. This justification is sometimes relied on even where a decision goes against the patient's wishes or is not consistent with the patient's interests. Such situations again underline the need for an integrated approach to the teaching of ethics.

Lastly, in the register of individual experience of human life, it is impossible to say nothing about the existential suffering of families confronted with the imminence of a loved one's death, preceded by what they live through as an interminable period when nothing happens. This is particularly difficult for families with a loved one in a chronic vegetative state.

- **The risk of excess relational zeal**

If the family is regarded as a "secondary patient", to borrow Finlay's expression, it can be asked whether taking this palliative ideology to extremes does not also involve risks: the risk of doing more bad than good and of generating a form of "relational zeal" outside the health care field. Behind this ideology, with its paternalistic overtones, is there not a presumption that approaching death can only be dehumanising, justifying the medicalisation of end-of-life situations? According to which criteria does one provide family support or not? The criteria most often cited are the family's participation in the provision of home care, or clinical situations involving particularly fragile patients or families. However, these criteria are not well-developed and decisions are often guided more by feeling than by a reasoned approach.

Systematic support for families, without reasoned decision-making, entails a risk of treating the persons concerned like children, on the assumption that they will not be "capable" of dealing with the phases of a family member's death. However, in such cases hardship is consubstantial with loss and needs to be experienced. Something which is hard to experience is not impossible to live through. At such times many families talk about the serenity they subsequently feel and say this trial they thought they could not face has helped them to achieve peace of mind and to grow. Some even say that they have "experienced true human dignity".

- **The risk of invasions of privacy for evaluation purposes**

As with those covering patients, it can be asked whether questionnaires which ask about family members' private sentiments and reactions when their loved one is in the final stages of life are consistent with respect for personal privacy? Indeed, what conclusion can be drawn when a family confronted with the loss of a loved one is required to complete a seven-stage evaluation questionnaire, in which each question is of an extremely private nature? Is this not tantamount to theft of the family members' experience of the stages of their loved one's death?

- **The roles of palliative care professionals vis-à-vis family members of patients in end-of-life situations**

How can the legal and moral obligations of health care professionals vis-à-vis family members of patients in end-of-life situations be conceived today? This issue is linked to that of the potential - in technologically advanced, consumerist societies - for the existence of a **humane relationship**, whereby everyone owes others a "duty of humanity" with regard to death. In other words, the question posed by our technological society is: does human solidarity exist and, if so, for what purpose?

Historically, the spread of humanism[23] went hand in hand with the emergence of Europe, although the term was used for the first time within Europe only in the 19th century, with the meaning - quickly abandoned - of general love for humankind. It underlies the values Europe has espoused over time *(chapter 2)*, which underlie respect for human dignity and individuals' right to autonomy and to be personally regarded as ends in themselves. Bearing in mind this historical context, one of the key features of the history of European moral standards, a number of observations can be made concerning European attitudes to the theme of the end of life and the duty of humanity from the psychological, moral and political angles:

(1)   The individual's psychological dimension is universally considered to be of considerable importance: saying "no" to someone does not constitute a denial of their wishes, contrary to what might be assumed from certain aberrations of the carer-patient relationship. It is true that nowadays one sometimes hears people say that the patient must be given everything he or she asks for, which implies that patients must even be enabled to die, if that is their wish. But where does that leave the carers with their own ethical beliefs?

(2)   In political and moral terms, in a democratic society it is indeed possible to refuse a request, while showing great respect for the principles of equality before the law, freedom and fraternity. It is not denying others' rights as citizens to tell them that they are perhaps not entitled to demand euthanasia for themselves.
In political terms, it is important to build a society in which NO human being can be in a situation where they believe that the final act of love they will ask of someone else is to help them kill themselves or even to perform the act of putting them to death. Otherwise, this introduces into democracy the possibility of a homicidal relationship between two citizens.
In moral terms, we must ask ourselves why it is that some of our fellow citizens believe that the last service another man or woman can do for them may be to bring about their death.

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[23] Humanism: a sociocultural movement that came into being in Renaissance Italy with a revival of the study of ancient Greek and Roman texts and a rejection of the scholasticism of the Middle Ages. The humanist scholars were philologians keen to see a return to the values of the Greek and Roman philosophers. The movement took the form of philosophy's parting of ways with theology and the embracing of a new form of anthropology founded on promotion of the individual and the autonomy of reasoning individuals. The term "humanism" came into use only in the 19th century, although it had already been used in 1765 with the meaning, quickly abandoned, of "general love for humankind." (J.C. Margolin, 90).
In the modern ethical sense, it designates a movement whose members believe in respect for human dignity and individuals' right to be treated as ends in themselves, rejecting all forms of alienation and oppression (Kant, Levi-Strauss, Heidegger).

The stages of dying cannot always be reduced to a gentle twilight of life, culminating in the final breath. Death is sometimes a violent confrontation between the natural and the worldly, between self and others. It is for this reason that support for the dying has existed since the origins of humankind. Practising the **supportive relationship** involves a discovery of another dimension (knowing how to be) and lifts one above the level of the treatments dispensed to a failing body (Hippocratic medicine, know-how) so as to penetrate the register of being, beyond the various ways of being (Aesculapian medicine, knowing how to be).

At the level of being, what is of the greatest importance is expressed in words, but also and above all in silence, listening and presence. This relational skill, which can be learned, breaks the prison of solitude, the solipsism of all individuals that comes to the fore with the awareness of an impending death. It is here that the alchemy of the relationship's transformation takes place. Taking care of another person with the aid of one's professional skills evolves into an "encounter", based on knowing how to be, or rather into the friendly relationship which, as we saw above, is the basis of any medical act. At this level the purpose is no longer to obtain a response or a result, but rather to lose oneself, as a river loses itself in the ocean of life made up of births and deaths. By supporting both the failing body, through Hippocratic medicine (know-how), and the individual in his or her last journey, through Aesculapian medicine (knowing how to be), the doctor reaches the culmination of the medical art, and also the final limits of all possible forms of medicalisation and the ultimate link of solidarity among human beings united by their common mortality.

4.2.4 Health care interventions: considerations of effectiveness and cost in end-of-life medical decisions

4.2.4.1 **Treatments that may prolong life**

* *"Prolonging death" or prolonging life?*

** Questions of terminology or of philosophy?

According to the WHO definition, palliative care has three kinds of objectives:
partial or total functional support (quality of life: mobility, relational and spiritual cognitive faculties, and so on), prolonging of life and acceptance of death when it becomes inevitable. **This is what is at stake in any decision. The whole set of ethical issues raised by the end of life can be summed up in the diagnostic and therapeutic dialectic: palliative phase or terminal phase?**

This is because, in all the other phases of illness - the curative phase and the palliative symptom control phase, the fundamental objective of medicine is to "**prolong a person's life**". However, once a patient enters the stages of the dying process, the first medical decision concerns his/her diagnosis, which will determine the therapeutic attitude. This is a very difficult stage, because death remains taboo for scientists and public alike. This unspoken question "palliative phase or terminal phase?" is a difficult one for the patient, who is informed, if he or she is capable of communicating, that certain treatments are not possible, because what he or she then understands that "this is the end, they can no longer do anything for me", and it is difficult for the family, which also perceives a form of "therapeutic abandonment". It is also hard for the care team

members, who have to deal with the same distress while being in the position of "decision-maker", reaching the conclusion that the patient's situation has changed (153). Because it is difficult to arrive at a clear-cut diagnosis, the conclusion that the patient is at the "end of life" is often not clearly stated, with the result that patients undergo aggressive treatments unsuited to their state and inconsistent with their wishes. The outcome is naturally unsatisfactory for both the patient and his/her family and for the care teams (inadequate relief of symptoms, lack of appropriate relational support …) (35; 39). Few professional recommendations exist at this level (9, 16; 30; 38; 46; 52; 59; 94) and, generally speaking, members of the health care professions are uncertain how to behave toward someone who is dying. In this decision-making context, the expression used in the WHO definition, to the effect that palliative care should not "hasten or postpone death", should be given more thorough consideration from a critical, hermeneutic standpoint, since this debate, which is both medical and philosophical in nature, is one of the fundamental aspects of the palliative care approach. It is indeed surprising that, at international level, writers on this subject lay more emphasis on the possibility of "prolonging death" than on that of prolonging life, and say little about the question of intent. Retaining the current terminology utilised in the health field regarding this "no man's land" of the end of life, the main ethical issues at stake will be addressed by drawing a distinction between "treatments that may prolong life" and "treatments that may prolong death".

**The difficult "terminal phase" diagnosis and its consequences: a "no man's land"

From a terminological standpoint the expression "prolonging death" is inappropriate as, in this terminal phase, the agonal process is already under way, and death can be prolonged only in terms of an afterlife. Etymologically speaking, "agony" comes from the Greek word for a "contest", mental suffering, but also a mental struggle for victory. Collins Dictionary defines agony as "the struggle or suffering preceding death". The palliative care philosophy according to the WHO definition would then become "neither to hasten death nor to prolong the process of agony or the terminal phase". One of the great problems encountered in attaining this philosophical objective is that diagnosing this phase is very difficult. In addition, it is not always easy to distinguish treatments that may prolong life from those that may prolong the agony. Not enough research has been done in this specific field. In this "no man's land" of the terminal phase, the lack of sufficiently precise criteria on which to base a diagnosis result in a failure to identify this developmental stage of a disease, and in the continuation of palliative, and even curative, therapeutic measures: transfusions, various kinds of invasive measures, restraint of patients who themselves attempt to pull out drips or tubes, scans, transfers of patients for further examinations. In the early days of palliative care such measures could not have been envisaged, as they were regarded as incompatible with the end-of-life stage for three reasons:

   (1) such measures are more or less futile once agony is under way
   (2) the technological solutions involved fail to respect the dying person's dignity
(3) these "active" measures prevent patients from realising that they are dying, which is damaging to the patient and to the family.

This dual approach continues to exist in the field, increasing the confusion surrounding these practices: in traditional medical/surgical departments, standard techniques are applied to patients in the terminal phase, whereas in departments pursuing palliative methods, the patient can be given forms of care better suited to his/her state. It can be

seen that a huge amount of training is needed, in technical aspects, in communication in end-of-life situations and in the ethical approach.

** The development of a palliative culture

At European level the current growth in palliative care is resulting in both the establishment of specific palliative care institutions and the emergence of a "palliative culture" within those not specifically offering palliative care. A decision with ethical implications taken in an end-of-life situation would be considerably different with regard to the same patient, in identical circumstances, according to whether the practitioner had been trained in palliative care and ethics or not, since different medical philosophies dictate different attitudes. What decision-making approach might be capable of combining the two standpoints in a manner that makes them complementary, rather than mutually exclusive? Yet again, the importance of training for all concerned is abundantly obvious, as is the need for an in-depth debate on the objectives of modern medicine and of palliative care within medicine, in particular at the end of life.

**The consequences of the terms used in the WHO definition of palliative care

In the modern context of growth in palliative care, the idea of "not postponing death", according to the WHO definition, is often interpreted by professionals as an "injunction not to prolong the natural process of dying", or even "not to prolong life in a terminal situation". This would then make it justifiable and a "good practice" to "speed up the stages of dying", as nowadays "death is no longer perceived as a necessary part of life" (74). The shifts in meaning inherent in these assertions have three main implications:

(1)   Firstly, medical decisions may be taken primarily on the basis of the doctor's tacit philosophical reference framework, and no longer according to the patient's best interests as a matter of priority. The patient would then be at risk of not receiving certain beneficial therapeutic measures. For example, patients with amyotrophic lateral sclerosis who have trouble swallowing or choke when eating may not be fitted with a feeding tube, and a patient with incurable pelvic cancer may not be fitted with a urethral catheter to treat stenosis causing renal insufficiency. However, evidence-based medicine has shown that these treatments are of real benefit and offer a not-insignificant prolongation of life while promoting patient comfort.

(2)   Secondly, since professionals find the expression "not postponing death" confusing, they may interpret it as a professional injunction not to prolong life (the goal of all medicine) and to "hasten death".

(3)   Thirdly, the idea of "prolonging death" is logically unbearable for care-givers, whose fundamental role is to prolong the patient's life in "a state of complete physical, mental and social wellbeing" (WHO).

When a patient is in the final stages of life a precise diagnosis based on characteristic signs and symptoms is therefore absolutely essential. It is essential for health care professionals to learn to identify and recognise this developmental phase in a disease. This diagnosis is the first stage of any decision-making process in an end-of-life situation: "What are we talking about? Is the patient in a state of impending death or not?" The second stage entails situating the medical decisions in a genuine ethical approach based on the very foundations of medicine: at this stage too decisions must be

taken in consultation with the patient (if his/her state permits) and, if that is not possible, "for" the patient.

A far-reaching ethical debate is necessary: the question is that of the very purpose of medicine and of palliative care at all stages of illness: the curative stage, the palliative stage and the terminal stage. What are the professionals' real "intentions" in these clinical situations? And what are their professional duties?

Maintaining or withdrawing life-sustaining treatments

The question of decision-making in end-of-life situations arises in two contexts: that of a disease which has run its developmental course and that of a patient who has reached the end of life. This field of decision-making, like all other medical decisions taken at patients' bedsides, involves two necessarily conjoined aspects: the disease and the patient, both living things in a state of constant change. It is the complexity which requires the development of a form of reasoning suited to this kind of situation: a method capable of meeting the challenge of the complexity. "It will not be a matter of espousing the aim of the simple thinking process, which was to control and master reality. It is a question of training oneself in a form of thinking capable of dealing with reality, of dialoguing and bargaining with it." (92). This is the field of hermeneutics, or interpretational dialogue.

** Ethical guidelines for medical decision-making

In this field various academic societies in Europe and elsewhere have established ethical guidance to aid the decision-making process in such matters (United Kingdom, Canada, France…)[24]. One example is the recommendations published in the United Kingdom in 1999 (17), which state: "The primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm. If treatment fails, or ceases, to give a net benefit to the patient (or if the patient has competently refused the treatment) the primary goal of medical treatment cannot be realised and the justification for providing the treatment is removed.".

All documents relating to medical decision-making should draw attention to this guidance. Roy has published a document specifically concerned with palliative care (128). In it he discusses the thorny problem posed by nutrition and hydration of a patient in a chronic vegetative state, stating that the real ethical question is not whether we have the **right to stop** this treatment, but rather **what right we would have to discontinue** this treatment. The emphasis here is on the need for an effort properly to think through ("thinking well") the issues, teaching us to reason in terms of benefits, futility, the patient's interests, the development of the disease, and so on. Accordingly, when faced with a patient whose impending death has been the subject of a precise, well-documented diagnosis, before deciding that the patient will receive the terminal-phase treatments suited to his/her state, all health care professionals must ask themselves: what are the reasons for deciding and declaring that there is no possible other treatment for this patient? This is because medical goals change, with "quality of life" taking priority over "quantity of life".

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[24] A comparative analysis of the published guidelines is necessary.

The emerging ethical issues are all the more fraught with difficulties since, in reality, these are always complex, sensitive decisions requiring a specific methodological approach. This is because the measures making it possible to prolong or sustain a human life do not have the sole effect of making the patient live longer. They may also at the same time alter the stages of dying and increase the discomfort involved. Here too research into alternative therapeutic treatments capable of providing more comfort depending on the symptoms observed is necessary. For example, in a patient with amyotrophic lateral sclerosis, placing a gastrotomy feeding tube will result in a not inconsiderable extension of life. Instead of dying of serious denutrition, serious dehydration or pneumonia caused by inhaling fluids into the lungs, the patient will live longer and more comfortably, even if the disease continues to run its course, eventually leading to complete paralysis and a state of total dependence. At the very end of his/her life, the patient will have difficulty breathing on his/her own. Even at this stage of the disease, non-invasive ventilation can still be offered and further prolong survival. However, the scientific data show that the disease is then often associated with frontotemporal dementia, accompanied by personality disorders and behavioural symptoms.

This example clearly shows how medical decisions must be taken in the light of the disease itself and its natural course, the various risks run by the patient of developing one or another complication and the prognostic factors making it possible to anticipate the various symptoms that may develop at the different stages of the dying process.

** The dawn of a practical wisdom

When decisions have to be made, **a major role is played by the experience** of health care professionals used to dealing with certain kinds of patients and their clinical problems. Generally speaking, they can see that the therapeutic measures aimed at sustaining life (such as a feeding tube) are not always of benefit. As they acquire more experience, they are therefore inclined not to provide such treatment.

The ethical issue of when to initiate treatment and when to withhold it is always a difficult one, and, whether that particular treatment is provided or not, neither attitude will avoid the patient having to accept the therapeutic limits imposed by his/her illness. A real supportive relationship assumes its full meaning when the dialogue is pursued to the end while respecting the patient's speed of thinking, which is not always the same as the speed of progress of the disease and the resulting emergencies. Medicine therefore cannot be summed up as Hippocratic practice alone, but must combine the two dimensions of medicine viewed as a single discipline whose sole goal is to be of benefit to the patient.

How can the interfaces between these two medical approaches be managed? It can be seen, for example, how the terminal phases of disease require health care professionals to pay particular attention to, and be at ease with, the different registers (Hippocratic and Aesculapian) where medicine and wisdom combine. As D. Roy says, in the terminal phase, the medical act is highly specific, since the attention paid to the patient concerns not only biological or imaging data, but also the clinical state of a singular individual with his or her unique, non-interchangeable history, needs, desires, projects, hopes and experience, suffering, strengths, weaknesses and limits (127).

The complexity of these situations highlights the need for experience and hence to make experience itself the starting point for addressing the ethical issues on the ground. This means taking different viewpoints into account and not deciding on a solution before having analysed the situation as a team. This is the collegial approach called for in the Leonetti law on patients' rights and the end of life[25]. Each participant then properly plays his or her role, and this ethical approach requires that we learn to work together in an interdisciplinary context.

4.3.4.2 Treatments that may "prolong death"

There can be no constructive debate until an effort has been made to give in-depth thought to the vocabulary used when we shift from the logic of "prolonging life" to that of "prolonging death", as we strive to take a phenomenological approach. The WHO definition of palliative care states that it is not intended either "to hasten or postpone death"; this provides food for thought and needs clarification. Does it mean that an act which hastened death, without any intention of causing death, would be lawful and ethically legitimate, and could therefore be recommended as a good practice? In terms of the causality of the act implicating the person committing the act, the person benefiting from it and the act itself of neither hastening nor delaying death? Is it a matter of not directly or indirectly bringing death about? Or is the act one of killing, but not identified as such? What respective limits apply now that we so frequently refer to "shortening the time taken to die", making death come sooner (which we justify by speaking of "making death more comfortable")? More comfortable for whom? This question often arises in practical contexts.

This confusion in terms of both practices and current vocabulary draws our attention to two fundamental ethical questions:

1. Can it be regarded as ethically "acceptable" for a health professional to take a decision in "expectation" of death (in the sense that death would occur earlier than it would have done naturally, insofar as the time of natural death can actually be known), without having the intention of causing death or of so doing?

2. Does the idea of "hastening death" necessarily imply that the health professional concerned has "brought about" the death of the patient?

*   Not hastening death or not having the intention of hastening it?*

In most European countries, other than in the Netherlands and Belgium, which have made euthanasia (the act of intentionally causing the death of another person) lawful, the act of euthanasia is legally defined as murder, and thus as a crime. This legislative position provides no clear answer to the questions which actually arise in everyday practice: does the WHO definition of palliative care – a fundamental text for members of the medical profession – mean that it is acceptable to hasten a person's death without having the intention of causing his or her death? There are two main reasons for devoting time to this question: one is the prohibition throughout the history of human society of the causing or facilitating of death, on the ground that human beings are vulnerable and need to survive in society, and the other is that the intrinsic purpose of health care is to "prolong life", implying that it would be professional misconduct to

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[25] Cf. the Leonetti law of 24 April 2005, legifrance.org

induce death before its natural time. It may be concluded from this interpretation that palliative care, by definition, must never involve the hastening of death by the professionals concerned, even if death is not the true intention of their act. This slight shift in meaning observed in certain teams sometimes prevents the administration of the doses of medicines needed to ease patients' symptoms. Yet it has been clearly shown that leaving a patient to suffer intense pain may make death come more quickly. Confusion about practices emerges as a result of slight shifts of meaning, resulting in the following possible courses of action:

1. a decision not to provide beneficial treatment intended to prolong the patient's life (provide appropriate relief);

2. a decision to take action with a view to bringing about death: death that is desired, wished for or expected, or brought about intentionally, i.e. euthanasia;

3. altering the time of death to some extent, in view of the uncertainty of the time at which death would have come naturally.

The absence of clear thinking nowadays about the precise meaning of these terms leaves professionals very uncomfortable in the face of what feel like unachievable professional objectives. In practice, virtually every treatment has side-effects and is potentially fatal. So what medicine to choose for the patient? The ethical approach requires the cautious attitude to be taken of causing the least harm, described by Paul Ricoeur as lying in a grey area, or where evil meets a greater evil. This shows how difficult it is in practice to produce a sound argument about the terms "intentional death" and "expected death", which call into question the person committing the act and require some out-of-the-box thinking placing the emphasis on the intentional dimension of both theory and practice. This "course of recognition" (recognition of the identity of the act, mutual recognition of the supportive relationship and recognition in the form of gratitude for an accepted mortality) (123) will lead us to some critical hermeneutic work on these clinical situations. In practical terms, it would be interesting to discuss proposed ways of clarifying the definition of palliative care and of the objectives for medicine that are implicit in that definition.[26]

* Causing death or letting a person die?

The idea of "not hastening death", as we have already seen, remains ambivalent, since it encompasses both the concept of "causing death" (euthanasia) and that of "letting the dying process go through its various stages", if necessary taking the risk that, as with any prescribed medicine, there might be side-effects. These terminological niceties have the benefit of making a clear distinction between two attitudes:

- "Letting a person die" means constantly assessing the balance of treatment as the patient goes through the stages leading up to death, and in the light of relative risks and benefits; the objective, as in all medical acts, is to serve the patient's interests;

- "Causing death" clearly entails murderous intent, taking us out of the health field, as this is an issue for society itself, reflecting the decisions that it takes.

While it is helpful to be able to use these precise terms, they only refer to the legislative aspect, and further thought needs to be given to the purely ethical dimension. When decisions have to be taken, the situations are not so clear-cut. When it is decided not to

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[26] Proposed subject for discussion: "Palliative care professionals have a duty to avoid intentionally hastening the death of a patient, but an earlier death may be a possible consequence of such treatment".

treat a patient to keep him or her alive, the logical, and scientifically proven, consequence is that "death is hastened, without any intention of causing it". This ambiguous idea of "hastening" death muddies the waters as further technological advances are made, making it feel as if the context in which decisions have to be taken is one where death seems "never natural, but always induced". A patient once described death as coming "when the doctors bring it". This idea that death is never natural, but always induced, is one that passes through the minds of all children.

Unless, when we refer to "hastening death", we specify "without the intention of causing it", we have to consider all decisions to limit or cease the intensive care of a patient in a chronic vegetative state to be forms of "hidden euthanasia". If we think about such situations, we realise that, assuming that certain clinical time limits and certain criteria have been complied with, the true "cause" of the death of a patient "in a vegetative state" is the disease itself, and not the cessation of treatment. Treatment had been started in order to keep the patient alive pending the natural resumption of temporarily inactive vital functions. If resumption does not occur, the situation is different: the disease is progressing in a manner unfavourable to the patient. Quite logically, if the measures taken to keep a patient alive are halted, the patient's death can be expected, since the disease would, had nature been left to take its course, already have proved fatal: without the measures taken, he or she could not survive alone. This kind of argument is current among, for example, the staff who provide intensive care, both for newborn babies and adults, and many studies have been written. Several European and other states have already issued methodological recommendations (including the United Kingdom, Canada and France).

Intention or expectation that death will result?

What distinction should be made between the "intention" and the "expectation" that death will result? Some writers (61) take the view that, in switching off a ventilator, the doctor is scientifically certain (anticipates) that the patient's death will result; consequently, the conclusion has to be drawn that the doctor necessarily intended to "cause" the patient's death. Other authors (110) say that a doctor who turns off a ventilator which is bringing no benefit to the patient and thereby constitutes "ineffective" treatment is certainly expecting the patient to die (the consequence of the withdrawal of ventilation), but is not intentionally inducing death, as the intention remains that of serving the interests of the patient.

Two questions arise in relation to the doctor's intention:

1. Is death the doctor's desire or wish?

The question of intention arises in respect of the person committing the act: what does he or she know and want, what is he or she capable of? Does he or she desire the death of the patient? The answer to the question posed in such terms is that clearly no doctor seeks or wants a patient's death, but at the same time, no doctor wants or would wish to impose on a patient treatment that would bring no benefit and would have numerous side-effects.

2. Is the intention responsible for the patient's death?

Some doctors will say that it is, taking the view that withdrawal of a treatment, knowing the consequences, shows the intention to cause the patient's death. Others will say not, taking the view that death is part of the pattern of the disease, and that the withdrawal or limitation of a treatment providing an alternative to vital functions which are inactive does not induce the patient's death, as death was already present in the absence of the functioning of vital organs.

Anticipation of the result of an act may or may not have anything to do with the person committing it. When a farmer expects a poor harvest after bad weather, for instance, that has nothing to do with the human being concerned! When a surgeon operates on a patient (an intentional act), he or she expects the patient to suffer pain after the operation and therefore arranges for painkillers to be administered "in anticipation". This by no means indicates an intention that the patient should suffer. This would be the wrong conclusion to draw.

With a view to clarifying the practical implications, we may describe the **withdrawal or limitation of a treatment which brings more disadvantages than benefits <u>to the patient</u>** (in the interests of the patient) as having nothing to do with a medical intention to commit euthanasia. When **a doctor anticipates the logic and the consequences of the withdrawal of treatments which are keeping the patient alive**, a situation which we may compare to that of the farmer expecting a poor harvest after bad weather, it is not his wish that the patient should die.

* Double effect and sedation to reduce distress

In the end-of-life period, therapeutic risks are higher than in other clinical situations, because the stages of the dying process bring with them a slowing down of all metabolisms, and scientific data are lacking, their collation being difficult for obvious ethical reasons. In extreme end-of-life situations in which life is hanging by a thread, a modification of treatment intended to provide relief may concomitantly contribute to death. This is not a matter of "hastening death", but of taking the risk of bringing the time of death nearer, a risk taken whenever a course of treatment is prescribed.

People speak of the "double effect" rule, an ethical principle contrasting the prescription of treatment intended to provide relief with that of treatment intended to induce the patient's death. A single act may produce two effects, one desired, and the other undesired, but predictable. This is a pharmacological fact, and the medical profession considers it permissible to prescribe medicines to treat symptoms deemed unbearable for the patient, even if such treatment may well shorten his or her life, provided that certain conditions are met:
- no other medical or other action is available to provide relief to the person whose illness is in its terminal phase;
- the intended aim is therapeutic, and the expected effects and side-effects of the treatment are proportionate to the intensity of the symptoms (141).

This represents a professional rule which can be quoted in ethical discussions, but is not an answer to the questions which arise in certain grey areas of ethics, or where evil and greater evil come into conflict.

The question now is whether this doctrine of double effect is an instrument of relevance to ethical end-of-life decisions. It is a long-established theory, and Tom Beauchamp, in

his "Principles of biomedical ethics" (10), puts forward four specific conditions in which a "double effect" situation may be said to exist:

1. The nature of the act, which must be "good" or at least morally neutral (viewed in detachment from its consequences);
2. The intention of the person committing the act, which must be wholly "good". An ill effect may be anticipated, tolerated or allowed, but not intentional;
3. A distinction between means and effects: ill effects must not be used as a means of obtaining good effects. Were an ill effect to be directly caused by the means of obtaining a good effect, it would be the intention of the person committing the act for this ill effect to occur after the good effect;
4. Proportionality between the good effect and the ill effect: the good effect must outweigh the ill effect. Ill effect is permitted only if it is anticipated and offset by a proportionate good effect.

These arguments, by which professional practice could be guided, are in fact little known or poorly understood, and this may give rise to serious misunderstandings. The main one is the belief that the doctrine of double effect means that an act associated with a negative effect (the death of the patient) is justified or lawful if it was not the intention of the person who committed that act to hasten the patient's death, although this effect was predictable. It is this misinterpretation that now gives rise to some abuse. One example is the conviction of some professionals that the doctrine of double effect justifies euthanasia, or even makes it lawful, whereas this cannot be the case, because the word "euthanasia" by definition implies an intention to hasten another person's death. In the face of such abuse, we may wonder whether it is logical to apply this doctrine of double effect in palliative care, even if its non-deviant application would help to clarify some situations.

When patients are suffering intractable pain or are both agitated and confused, it is internationally recommended "good professional practice" to offer them sedation known as "palliative sedation", in order to distinguish it from the sedation procedure used in intensive care units, which does not follow the same methods. Palliative sedation draws on techniques already used for many years in psychiatry to relieve the intractable fears which come with certain mental pathologies.

In end-of-life care, sedation means "the use of pharmacological means of altering consciousness in order to relieve a patient suffering either from a very painful symptom resistant to suitable treatments or from a situation of uncontrolled distress" (114). On the subject of palliative care, more specifically in the terminal phase, the *Société Française d'Accompagnement et de Soins Palliatifs* states that "palliative sedation involves an effort to reduce vigilance, through medicinal means, which may take the patient right up to the point of loss of consciousness, with the aim of diminishing or eliminating the perception of a situation deemed unbearable by the patient, when all the available means which are suitable in this situation have already been offered and/or implemented, without enabling the relief expected by the patient to be achieved" (137).

The main problems which arise in practical terms and which have ethical implications for both the patient and society as a whole are ignorance of these definitions and increasingly frequent inappropriate practice as palliative culture spreads, necessitating much greater amounts of teaching and vocational training about these subjects, and at the same time a new process of ethical reflection. Various writers have indeed shown that 64% of health professionals working in patients' own homes and at health

establishments use only morphine when they prescribe <u>sedation with a view to "hastening the end of life"</u>. But morphine is not the appropriate choice: benzodiazepines are recommended.

This perverse use of morphine can certainly teach us something, again showing the importance of teaching and training, but also encouraging us to consider what the end of life means to health professionals, and the ethical implications of this.

* The questioning of prohibition

It is clear from the bibliography on end-of-life medical decisions in Europe that health practitioners are now calling for legalisation at European level, using the term "mercy killing" in this context. Those who argue in favour of euthanasia base their argument on the following reasoning:
●   the initial axiom: there is no difference between "mercy killing" and "letting a person die", the latter being deemed identical to the limitation or cessation of a patient's treatment;
● if there is no ethical difference between these two acts, that is because they are identical;
● since "letting a person die" is lawful, causing a person's death must ALSO be lawful.

There are several flaws in this reasoning. It regards as axiomatic, and therefore outside the scope of the argument, the identical nature of causing death and letting a person die. It confuses an act relating to a person (letting that person die) with an act relating to a treatment (causing that person's death). It confuses expectation with intention. It makes no reference to the responsibility and freedom of the patient, who may accept or refuse treatments offered by the doctor, either directly, within the context of the supportive relationship between doctor and patient, or indirectly through an "advance directive" and/or the opinion of the person of trust. According to this consequentialistic approach, if the consequence is the same, the act is of the same nature. Through the act of "causing a person's death", the doctor has the intention of causing the patient's death; the cause of that death is the medical act, and the object of the act is a human being who may or may not be capable of giving his or her opinion, which is in any case not always asked for!

As Ricot wrote when the Comité national consultatif d'éthique français suggested in an opinion that an exception be made for euthanasia, "Standard practice may 'move ahead of the law', and it may be necessary to change the law. But it may also be the case that there is a need for a law which, despite being frequently broken, protects fundamental values, to be clearly drawn to people's attention, so that it continues to prevent standard practice from going too far off the rails. By no means may it be <u>declared as a matter of principle</u> that the discrepancy between rules and reality should be rectified by an amendment of the rules. The general principle accepted by every society is that the law is not reducible to the level of the facts. If the facts are not in accordance with the law, they have no power over the law. This elementary and common-sense reminder needs to be clearly understood: it is human beings who create law, and who therefore have power to undo or to redo it, but the aim must always be to maintain fundamental values and prohibitions" (124).

On the ethical plane, it is important not to set reason against compassion, and the Stoics, like Spinoza, long ago warned against any abdication of reason in the face of

sentimentality. Thomas Aquinas, for his part, attached value to benevolence only where it was the outcome of the will, and not of passions. Kantian rationalism itself helps to consider the intersubjective dimension of morality, in so far as obligation, as its etymology suggests, shows the "link" with the other person to whom one becomes obliged. As Levinas and Ricoeur have written, this characteristic makes it possible to reconcile, within the moral sphere, the rational requirement for universalisation and concern for others. The resulting solicitude, on which the supportive relationship is based, provides protection from a morality founded solely on sensitivity, and makes otherness a transcendent condition of morality by placing the medical act in the service of the patient. As Ricot said, "the ruinous opposition between principles and compassion may be rejected, since it is reason itself which calls for the solicitude required by intersubjectivity" (124).

Consequently, once the law withdraws from the scope of the practical wisdom (Greek *phronesis*) of doctors and nurses the evaluation of the decisions to be taken, and gives this task to legal rules and regulations, transgressions are codified, and the rock of prohibition cracks. In contrast to prevailing opinions, autonomy, meaning "adopting one's own law", is not a matter of choosing purely individually and arbitrarily the rule by which one wishes to live and die, since the concept of "law" implies universality, and therefore a restriction on desires, so that our society can be one where it is good to live. What view does present-day Europe take of the human dimension and of ontological dignity? Is Europe involved in the unfurling of a freedom which no longer knows any bounds other than the indefinite extension of its desires, and which makes other people into instruments of its will? Western Europe has helped to develop a society based on a utilitarian vision of humankind: human beings no longer have their place in it because of what they ARE, but because of what they DO. This logic takes us to the point at which we no longer recognise as human beings persons who are dying, elderly or no longer productive (because of disability). In such a world, what scope will be left for relating to other people (relationship of recognition in its three forms[27])? Is there a hint that the relationship with other people consists of confirming to them the loss of self-esteem that they feel at a certain stage of life?

As we have seen throughout the preliminary consideration of the paradoxes surrounding both the concepts of protecting death and protecting life and the variants of "causing a person's death" and "letting a person die", and the highlighting (*chapter 3*) of the absence of rationality, or what Pascal calls "work on thinking well", all kinds of obstacles now restrict the vitality of the practical rationality proper to ethical reflection and action, for current thinking is drowning in prejudices and good sentiments, as Monique Canto-Sperber complains. The intellectual process that is currently lacking is that of "*understanding the reality, deliberating and justifying the decision*" (24).

This work, which is becoming essential in the face of extreme situations in human life, is based on each individual's moral anxiety. The "suffering of doctors and nurses" challenges us to produce an ethical interpretation: recognition of an emotional psychological starting point turning into moral anxiety through recognition of identity, opening the way to mutual recognition and then recognition in the form of gratitude. The ethical approach cannot dissolve into compassion alone; the medical profession cannot bypass consideration of the values and concepts of the human being in his or her "own"

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[27] Recognition of identity, mutual recognition, recognition in the form of gratitude, according to Ricoeur.

world and in "the" world. Hence, instead of basing prohibition on human dignity, as at the present time, would it not be better, on the basis of a deeper relationship between doctor and patient, to base prohibition on the value attained in this human exchange, based on **the need to protect the individual from interference by others**?

Generally speaking, medical decisions in end-of-life situations first take shape as the terminal stage of a disease is recognised/identified. In this respect, while the concepts can be clearly defined, it is nonetheless true that, in the context of medical practice and the relationship with a living person, decisions are not a matter of black and white, but of different shades of grey. As the patient is alive, he or she undergoes a constant process of change, his or her condition alternating between the palliative and the terminal stage, as it had at the start of the disease between the curative and palliative stage. Medical decisions and the doctor's art thus need **an ethical approach**, by definition implying discursive thinking, or what Pascal called "thinking well", with a casuistic methodology based on experience and moving gradually towards a "*practical wisdom*", meaning professional conduct which is subject to both reason and will.

With a view to such an ethical approach, the countless situations in which a practical impasse occurs can shift from an EITHER/OR approach to an BOTH/AND solution, like the one that we have already seen in our discussion of intention and expectation. Thus medicine will be able to consider setting objectives which are "achievable" by the members of the profession. Having been neglected for some time, the vocation of medicine may resurface with a new face, but still the same relevant and never-changing one of being in the service of the patient and those who are most vulnerable, whatever their social background, and participating with commitment in present-day society. Adapting to changes in Europe does not mean getting lost in a contextual maze. The instruments of professional ethics, as well as good practice recommendations, are very important parts of the ethical approach, but not the whole of it: they remain practical instruments.

5.   "WORK ON THINKING WELL"

As we consider how we might make an ethical approach central to medical decisions, we shall look at the following themes: what are "good decisions" in the context of the need for justification? What place should justification have in health care? How should we interpret the concept of healing in the doctor's art today? What are medicine's objectives in the 21st century? And, finally, how can we steer a course in our daily lives between uncertainty and responsibility?

5.1 "Good decisions" and the need for justification

In the 21st century, medical decisions in Europe, whether they relate to investigations or to treatment, are taken in a context exposed to the constraints of the global economic market. Thus the agreement between patient and doctor is an economic contract for the patient, the doctor and society. So "good decisions" at this level are those which are in conformity with all such contracts, or come closest to achieving this.

5.1.1 *Medical decisions within a commercial relationship*

This commercial environment alters the relations that practitioners have with their patients and with society as a whole. For it is no longer the relationship with suffering,

life and death which is to the fore. Indeed this relationship is often pushed well into the background, with some patients for whom the doctor is considering the possibility of a treatment with an effect that is not "certain" saying that they would "prefer not to cause the social security system too much expense", as they "will never be able to work again". This is some lesson in humanity. So the two-way relationship between doctor and patient has had a third component added, namely health care funding systems. The patient has become a "health consumer", playing an active part by demanding adequate information, a part in decision-making and scientific justification of proposed investigations or treatments, and checking information on the Internet. Thus doctor-patient discussions may well be reduced to exchanges of data, likely to be better dealt with by computers than doctors. But thinking in terms of "solutions", without taking account of the problems arising or of their context, derives from an illusion of control which reaches its peak in end-of-life situations. Each society is judged by the way in which it helps its frailest members to retain their self-esteem. While medicine of course has techniques to offer, once those reach their limits (as they inevitably do!), the only other service that it can offer the patient is humanity, without making any claim to have the key to the enigma of life and death.

The modest and resolute relationship between doctor and patient on which medical decisions are based reveals the ethical approach as it spans the whole infinite range of human attitudes: silent presence, discreet withdrawal, lending an attentive ear, speaking kind words, showing solicitude, etc. It involves an acceptance of the inevitability of death through refusal of disproportionate medical intervention; use of every possible means to ease pain, even if the patient's life is thereby shortened; continuing care appropriate to the patient's condition until life ends; support for the positive image of the end of life, especially when the patient has become dependent and is exposed to the atmosphere of approaching death, no longer perceived in its natural dimension, but as the enemy to be defeated. Professional efforts to restore the self-esteem of others underlie the service offered by medicine.

5.1.2 Requirements and justifications

Several kinds of justification are expected by patients: the sources of information used by the doctor when taking the decision; a risk-benefit analysis; the comparative costs of investigations and treatments. But increasingly, codes of medical ethics and recommendations emphasise the quality of the doctor-patient relationship, for trust is the best safeguard against improper procedures.

According to France's code of medical ethics, every medical decision should be based on "current scientific information". This is a praiseworthy, but to some extent fanciful, requirement: a global total of 20,000 scientific articles on medicine are published every month, and it is up to the practitioner who reads them to make sure that the information provided is scientifically credible and evidence-based. Depending on the rigorous nature of the methodological approach taken and on an analysis of the statistics, some scientific evidence is considered more reliable, and some less. It is up to the doctor reading each article to decide whether or not it is applicable to the specific cases that he or she has to deal with.

What is more, as rapid growth in the consumption of health care resources has coincided with a situation of inadequate funding, publicly-financed sickness insurance has faced the problem of introducing a policy of regulating or reducing expenditure

without jeopardising social equity, insofar as this was possible. This tricky exercise involves continuing to meet citizens' health care needs while keeping medical costs under control. That control relies on **sensibly prescribed and justifiable treatment**, or in other words on a rational efficiency drive. Viewed from the "practical wisdom" angle, we need to add another factor: human health needs are not invariable, but depend on several parameters, such as history, social structures, the availability of health care and the awareness of this in different communities. In western countries, this awareness is considerable, in a society of which much is expected, and which is well-provided with medical facilities. J de Kervasdoue writes: "It is surprising to see the extent to which the political class is deluded into trying to measure, or just to estimate, the population's 'health needs'. This is a semantic game which it can only ever lose, for it will always be possible to find an unmet 'need'" (80). As health care costs are very likely to continue to rise, the spectre on the horizon in the shorter or longer term is that of a rationing of care, unless more rational medical decisions start to be taken. But rationing for the sake of what? Individual egoism? Collective human dignity? What will be the basis for decisions? "On the answers that society gives to these major questions will depend the meaning, i.e. the philosophy, of not just medical decisions, but also the action of the community as a whole, a community which claims to show, or likes to think that it shows, solidarity. At stake is the meaning of a civilisation to which we are all historically and culturally attached" (62).

The requirement for medical decisions to be justified is one of the effects of a society based on contracts, the positive aspect of which is a concern for traceability of the information involved in the continuing provision of care. All medical decisions will have to be justifiable, even in the longer term, and it seems that the need for justification will be central to future medical practice. This development may be considered to show a growing maturity of the democratic conscience. It is important, however, for this maturity to benefit from an ethical approach, in order to keep on the path of "practical wisdom". The questions now arising in this field may be: What will have to be justified? To whom? For the sake of what? Clearly, these questions and the answers that will be given to them will bring changes in the ways in which medicine is exercised, in the taking of ethical decisions, and even in the ethical foundations and meaning of the profession within society… On what will tomorrow's medical ethics be based?

5.2 The concept of healing

Healing is **one of the basic aims of medicine**. The verb "to heal" is defined by Collins as meaning "to restore or be restored to health".

5.2.1 *The history of words*

"Heal" is a term derived from Old High German "heilen", which was also the origin of the words "hale" and "whole". Used transitively, the verb means restore to health, bring ill health to an end. Used intransitively, it means be restored to health or repaired, often by natural processes. There is even a reflexive verb, "heal oneself", meaning act on oneself in order to recover one's health. All three reflect a profound and existential desire to be healed, or a "will to live", evidenced both by animals which lick their own wounds and by vulnerable patients who, in the eyes of modern society, "take for ever to die".

Since the dawn of time, all human societies have introduced healing practices drawing on both their experience of natural resources (observations) and their beliefs about life, sickness and death (feelings). Part of the process of life, healing has a before and an after, as well as a prospect of mortality. The **before** is a danger (acute illness, fractures or other injuries, disease, disability), the **after** exists once the suffering becomes a thing of the past, but without a full recovery (chronic illness), and the **prospect of mortality** is an idea present throughout life. In the 19th century, being "healed" meant complete recovery, the restoration of normality, a concept which is still alive today. At that time, dictionaries contained two possible definitions of the word "cure". The first, based on the word's etymology, meant the care given to a patient irrespective of the outcome of the disease. The modern verb "care for" has the same sense, and "palliative care" also uses the word in the same way. The second meaning, the etymological sense, encompassed only the happy outcome of treatment which brought healing. The words "curable" and "incurable" share the same origin. Diderot (1713-1784) also included a figurative meaning in his Encyclopédie, indicating a continuity in this concept of the body and the mind. He described the verb "heal" (*guérir*) as relating both to the state of health and the state of illness, indicating the transition from the latter to the former, either with the assistance of medicine or thanks to the forces of nature. In his view, it could be taken both literally and metaphorically, and was used as much in relation to illness of the mind as to illness of the body. The word is now applicable, in various languages, both in the somatic and in the psychological and religious context, but has been little discussed with medical practitioners, being of greater interest to philosophers and psychoanalysts.

This focus on words shows up an aspect that had been forgotten, namely the first meaning of the word "cure", the idea of "looking after" someone, and this oversight has led to neglect of the ontological basis of medicine.

5.2.2 *The history of the idea of healing and the history of therapy*

The two histories are distinct, as therapy historians have focused on describing the procedures followed and methods used by doctors. Theirs has been a descriptive task, as they attempt to establish links between the causes of diseases and the remedies selected to counteract them. Foucault (49) considered the relations between the supply of, and demand for, medical care, which he regarded as a kind of quasi-contractual transaction. Neither surgeons nor people wounded in war or by terrorism choose the causes of their ill-health. But in many cases, is it not the supply which creates the demand?

The supply of medical care was long shored up by charity. In this context, the treatment and healing of the sick was based of recognition of an authority coupled with a relationship of trust, and with a sufficient level of evidence of efficacy, creating a debt of gratitude. This relationship of trust can be, and was, misused or abused, as Jules Romains (1885-1972) showed in his play, "Knock". The healing market used to be a modest one, compared to the current situation. And the potential is there for an even greater demand to arise, as the means of satisfying it already exist. How can "thinking well" lead to "good decisions" without reference to the ethical aspects of medicine? This is where ontological neglect of the first meaning of the word "cure" comes in.

So how can we "think well" in the European future? As we know:

- Medical assistance is not supplied to all who need it, and, following fears of a situation in which there is too much medicine, there is now a fear that social protection will decline as medical costs rise. As they take their decisions, can doctors ignore these facts?
- Present-day patients are told that there are therapies which can make them feel better. Narcissism has no limits. Diderot said that fever was cured by quinine, but that literary or other glory was cured … by reason. Is it not time, in countries where human rights prevail, to make an effort to "think well", with each of us applying our own share of "reason"?
- Finally, scientific medicine can make mistakes, and not everything that is technically feasible is necessarily in the patient's interest or "good" for humankind. The ethical approach cannot be ignored in current medical practice.

5.2.3 *The hostile intrusion and the power to expel suffering*

Disease has long been attributed to a hostile intrusion, an archetypical product of our imagination. So healing seems to be possible only through the exercise of **a power to expel suffering**. What form might this power of healing take? In Homer's Iliad, an epidemic was brought to an end by making a sacrifice to appease the wrath of the healing god (Apollo). In other words, it is the superior power which brings about disease, but it is the same power, through a reversal of the process, that can provide healing. **The relationship has the ambivalence of the sacred.** In mythology, the restoration of health arrives through a reversal of the superior power which caused the suffering: finding the remedy in the suffering, and healing suffering through suffering are formulae still at work in therapeutic methods such as vaccination, homoeopathy and neurostimulation for neuropathic pain.

The ancient Greeks had many sites at which healing gods were worshipped, and such sites still exist today[28]. Aesculapius was worshipped and praised as a "**saviour**" (soter) for his compassion and his gentleness. When medicine endeavours to prolong life whatever the cost, confusion results, although everyone knows that a doctor who "saves" a patient does so as a "rescuer" (saving someone from a certain situation), not as a "saviour" (saving someone's soul). Many ultimately overlook the difference, especially at a time when life is ending, and when the desire for strength is combined with dread.

Those who sought healing from Aesculapius **regarded healing as a personal event**. They travelled all the way to his temple, where they slept in cells prepared specially for them.   Healing came through various means: the god made his appearance, accompanied by a dog and a serpent. Sometimes he would place his hand on the patient, sometimes it was the dog's or the serpent's tongue that effected the miracle cure. Often the god ordered remedies, baths, physical and intellectual exercises (gymnasium) and theatricals, and he interpreted dreams the content of which imposed a certain therapy. Patients came to him because they had heard how he had "healed patients whom doctors had given up treating".

What is the position today in respect of the mythology and imagination surrounding the expectations of patients and their families who call on the assistance of the new "rescuers", namely the staff of intensive care units, when the end of life beckons. What influence does this imagination have on health care professionals and on medical

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[28] Cf healing gods in some French regions.

decisions? A patient whose illness makes him or her more vulnerable is exposed to all kinds of influences, that of the medicine which either promises healing or leaves him or her in dread of death, that of non-conventional medicine and that of sects which promise miracles…

5.2.4 *Health, sickness and healing are the effects of natural causes*

Aesculapius preceded Hippocrates, but the two did meet on Kos. The well-known Hippocratic oath invokes "Apollo physician", Aesculapius and his two daughters. But these divinities are not called on to play a part in Hippocratic medicine, but to guarantee the holiness of the doctor's action. The patronage requested thus relates only to **the way in which the doctor will exercise his or her own power, and does not call for healing by the divine powers**. According to the major texts in the Hippocratic collection, health, sickness and healing **are the effects of natural causes**, which are accessible, through patient activity and experience, **to reasoning, for medical action is possible only where the forces of nature are in play**.

Thus a quite new concept of healing prevails in the Hippocratic texts which have come down to the modern day (140). The treatise on the "sacred disease" (epilepsy) begins with a "hermeneutical critique", i.e. a critical reading of interpretations and magical practices, and it concludes by positing "**the principle of a possibility of healing through the application of natural agents no different from the agents which caused the disease**". Most diseases are curable using the very things that caused them (vaccination, homoeopathy, somatic and psychological desensitisation, etc). By bringing opposites into play, medicine proposed to restore the balance of humours and their correct temperatures. Thus the principle of treatment of the causes was established. The treatments applied were targeted on the symptoms, on the basis of a simplified version of the patient's perceptions (symptomatic medicine). The medical aim was not to heal (bring about complete recovery), but to protect and to prevent disease from occurring. It was hygiene measures that were taken, which **medical tradition continues to distinguish from treatment proper**. The particular characteristics of diseases and observation of their "constitutions" and the associated weather conditions provided a basis for "deciding" on the treatment indicated and its composition.

The development of the concept of healing under the influence of Hippocrates contains the seeds of a SINGLE medicine with two faces. Hippocrates observed the disease and the patient in order to decide which was the best treatment in the interest of the patient. But in doing so, he made a distinction between hygiene measures and treatment proper, and if the disease did not respond to treatment, he referred to practical wisdom and advised the patient to meet Aesculapius.

5.2.5 *Healing and salvation*

During the Middle Ages, a surgeon called Ambroise Pare (1509-1590) took up Hippocrates' formula again, but amended it to say that it was **not nature which healed, but God**. From the theological perspective of Jewish and Christian tradition, absolute power belongs to God, whose role is not limited to responsibility for nature. As the symbolic tale of Job shows, healing, but also disease (ambivalence of the sacred) come

straight from God. He is the sole supreme healer, or delegates healing tasks to others[29]. This dual theme of healing and salvation features more prominently in the New Testament, where the healing work of Jesus Christ and his raising of the dead are described. The Christian faith goes beyond the restoration of the physical and psychosocial body, with the raising of the dead presaging the healing of the mortal condition.

With the passage of time, the task of healing carried out in Hippocrates' days by nature has passed to God, through his son Jesus Christ, who was capable of raising the dead, and now finally to the human race itself. In the cultural imagination, the gods of medical technoscience are the staff of intensive care units: they have become "saviours", and no longer mere "rescuers". As a result too much effort is sometimes devoted to diagnosis and/or therapy, especially at the end of life.

5.2.6 *Failing to heal, but without denying hope*

Western medicine, thanks to the expansion of its means of action in the 20th century, is achieving results that are better to an incredible extent than any that had gone before. Should we say that it has healed more people and restored them to normal health? But it has cast aside the ontological view of illness, although an ontological concept was necessary in order to believe that (combating or) conquering illness meant eliminating the cause of suffering, repelling an intruder which had invaded the body, and returning to the previous state of health.

Very often, there is indeed an attack from without, but once a chronic disease has been triggered, run its course and reached the convalescence stage, irreversible changes will have occurred inside the body. Doctors have gradually come to realise that, even when an illness has been vanquished, biological processes have changed, and the patient has not been "healed", although his or her life has been prolonged by medical action.

Returning to health is not equivalent to returning to the same state as before ill-health struck; after all, as each new day comes, is it possible to return to the previous day? Health is the accumulation of new constants making possible well-ordered behaviour within an area of action that also changes. Canguilhem (23) denies, in the idea of healing, the classical principles of mechanics and cosmology, which implied the "reversibility of phenomena which, in succession, constituted illness". He supplements the second principle of thermodynamics[30] with the fact that the body is an open-ended system subject to deterioration at any time, and for which no healing implies a return.

However helpful new treatments may be, we avoid speaking of healing nowadays, a concept deemed to be vague and subjective, and refer instead to a set of objective parameters. These are linked to a probable timescale, emphasising the provisional nature of the result obtained. We prefer to speak of a period of remission, and the virtual certainty of the fatal outcome of the original disease is replaced by a series of morbid

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[29] Psalm 103 states that it is the Lord who "forgiveth all thine iniquities; who healeth all thy diseases".

[30] The first law of thermodynamics states that heat can be converted into mechanical work and vice versa. According to the second law, heat cannot be transferred by a continuing and independent process from a colder to a warmer body. And the third law says that absolute zero can never be reached.

manifestations, controllable in principle, but with a measurable effect on quality of life and probability of survival. There is an "extended cure" rate in terms of survival without ill-health after several stages of treatment. The concept of healing is thus governed by statistical parameters, and is consequently reduced to the language used by patients to express their perception of themselves. So while it is possible to repel illness, there can never be unrestricted healing without any changes in the pre-illness situation. Where human mortality is concerned, patients need the help of a philosopher more than that of a doctor: "Learning to heal means learning to grasp the contradiction between one day's hope and ultimate failure. Without denying hope" (23).

The following points have emerged from this examination of the concept of "healing", which, together with the concept of the preservation of health, defines the medical art:

● Over the course of time, the language has lost sight of the first meaning of the term "cure", which is "the care given to a patient, irrespective of the outcome of his or her illness". This loss is now causing confusion about the fundamental objectives of medicine.

● The comparative history of ideas about healing and therapy shows that, in order to take the "good decision", "thinking well" is necessary, requiring reference to be made to the ethical dimension of medicine.

● Lastly, mentalities have changed where the concept of healing is concerned, resulting in significant confusion, connected with the ambivalence of the sacred, between the role of the doctor as a rescuer and the role of the doctor as the saviour of humankind!

In the context of end-of-life medical decisions, the question which arises in this confused situation is that of the scope of the medical responsibility, at the end of life, of those whose "art" is that of preserving health and healing.

5.3 The preservation of health and the end of life

Sickness causes death. But is it possible for health to be another cause? We cannot speak of health without referring to sickness as well. But ill-health gives rise to a twofold approach of, on the one hand, recognising or identifying the illness, and, on the other, recognising ONESELF as being ill. The Indo-European languages encompass semantic differences taking the concept of sickness in many different directions: weakness, ugliness, malaise and pain (63). Physical and spiritual ills are linked, as today's neurosciences show (76). The English language distinguishes between three terms: "illness", used by the patient to describe his or her state; "disease", illness as objectivised by biomedicine; and "sickness", the sociocultural reality of ill-health. These distinctions emphasise the huge importance of anthropological representations as a component of the health field. Such representations are clearly part of the intellectual legacy of medical "decision-takers".

5.3.1 *Health is not an absence of illness*

According to Canguilhem (22), health is characterised by the capacity of the living body to tolerate and absorb variations, to deal with differences while remaining capable of maintaining all its adaptive functions. So a pathology is no longer judged by standards based on virtual or theoretical models, regarded as "essential", but refers to **a**

powerlessness or inability to absorb and compensate for variations. Latently, Canguilhem's vision underlies the current medical attitude dictated by neuroscience for dealing with patients following strokes. "The pathological is not the absence of a biological norm, but another norm in comparative terms rejected by life" (23). How should this other norm be imagined? A new area of work opens up, that of a critical hermeneutic approach. **In this context, sickness therefore needs to be subordinate to the patient, and the patient needs to be understood as an entire being (integrated approach), with a history, a person living in a world. And both health and sickness also have a history, excluding a reduction to a purely biological approach.** Do we not, nowadays, speak of "emerging pathologies" with an emphasis on climatic, environmental, social and moral factors? In end-of-life situations, could we not refer to a "pathology of vulnerability", of "incurables", of "chronically ill", of "palliative cases"… for all who are excluded from a "single way of thinking" which objectifies life?

Thus the ethical issue is how to think in appropriate terms about what is living, changing, shifting. What is the alternative to confining thought to the field of a unilateral and linear logic? **How are we to think about the complexity and interlinkages of all living creatures?** These questions suggest a need to **rethink medical education and training** to cover an objective medicine, not in isolation, but in the context of its environment (human sciences, etc).

As both an **art** and a **practical science**, medicine can but continue to be the subject of two conflicting tendencies, one applying an objectivising logic to sickness and pathologies, the other (a humanising tendency) subjectivising it in the light of several different approaches and several simultaneous and living logics, i.e. **through dialogue**. A SINGLE medicine is constrained by its practical nature to pursue two objectives at once, both to **explain diseases** (scientific approach) and to **understand patients** (hermeneutic approach). A focus solely on the patient might well result in reduced knowledge about his or her disease, while concentrating exclusively on the objective pathology could make the doctor take a tyrannical attitude, providing treatment in a manner a long way removed from "patients' rights".

5.3.2 *"Good doctors" look after all patients, whatever their condition*

Plato, in "The Laws", defines a "**good doctor**" as one who "carries his enquiries far back, and goes into the nature of the disorder; he enters into discourse with the patient and with his friends, and is at once getting information from the sick man, and also instructing
him as far as he is able, and he will not prescribe for him until he has first convinced him; at last, when he has brought the patient more and more under his persuasive influences and set him on the road to health, he attempts to effect a cure" (102). In the current context, the idea that professional ethics require doctors to use "persuasion" on patients, meaning that they themselves need to be sure, is often reduced to a predominantly psychological dimension involving accusations of "manipulation". The ethical dimension of persuasion is overlooked. When Plato's "good doctor" addresses his patient, **this does not exclude from the field of medical interest** all persons who do not meet the statistical criteria of standardised life in society: those most vulnerable, those incurably ill and those in great distress. Are people who are incurably ill now to be prevented from retaining their dignity and freedom, for the sake of the statistical norms of their "pathology"? Human dignity and freedom do not depend on health. But in order to

escape from the present undercurrent of opinion, dignity and freedom seem in need of a "course of recognition", which Ricoeur (123) described as comprising three levels:

1. *Recognition-identity* defines health as "a state of complete physical, mental and social well-being" (WHO); thus health is not an absence of pathology or of standardised norms;

2. *Mutual recognition* within the doctor-patient relationship: this keeps the patient among the living, among his or her fellow human beings, until life comes to an end, participating in the exchanges which underlie any society. In the doctor-patient relationship, the act of listening to any complaints is an comparable to that of asking, not for something **in return** (as in bartering or trade), but to give something **in one's turn**. This change from the commercial level to an openness to the other person is central to the supportive relationship, to mutual recognition. It is the latter which fosters human dignity and affords protection up to the time of death to the rights of human beings, of citizens.

3. *Recognition in the form of gratitude*, which sometimes complements mutual recognition, even in its fullest form.

5.3.3 *The end of life is more than just a matter of death*

Although the human imagination has sometimes defined death as the "final illness to be overcome", death is not the true objective of medicine, for when it comes, medicine is no longer in a position to do anything. Yet death in practice remains a constant medical concern, for every sick patient faces the possibility of death, and whenever a serious illness is diagnosed, both the patient and those close to him or her ask "how much time is left?". The field of medicine is that of service to the sick person, however little evidence of life that person may be showing. Thus medicine also has a part to play in the process of approaching death, when a person's health is in decline.

* The ages of human life

The end of life has no correlation with a specific age, and stillborn babies, young people taken in their teens, and people who die at an advanced old age after a life fulfilled are categories in respect of which different sets of problems arise. In substance, the ethical problems thrown up by death are the same, and it is the interpretation that people make in today's Europe that changes. The ages of life used to be inseparable from a natural cycle of birth, growth, decline and death. Today's objectivising and administrative approach leads to confusion between physiological criteria and social roles, giving rise to categories which are as artificial as they are uncertain. The great difficulty, in order to "think well", is that of detaching oneself from the vivid surrounding elements which may well interfere with an ethical vision. Old age and incurability are now experienced in a context of despondency, absurdity, vanity, futility of the treatment available. This ideology will continue until such time as it is realised that, notwithstanding huge amounts of scientific data, the human being's age is not the same as that of his or her arteries, but that of his or her life story, which does not fit in to any predetermined chronology. Whatever the age of a dying person, death is a crucial moment in an individual story. Medical thinking about the end of life should therefore be detached from any

consideration of age, or medicine will deny treatment on grounds of age to many patients, overlooking the key medical objective of providing a service to sick persons.

Every patient is a human being, his or her age is irrelevant, for each "person" travels through the various seasons of his or her life until the end is reached. Human dignity pays no attention to chronology. There can quite simply be no question of "old people" and people who are dying being considered to be useless, for the definition of a "human being" makes no reference to any kind of usefulness. Indeed, Kant draws a legal distinction between things and persons, writing: "whereas rational beings are called 'persons', because their nature already marks them out as ends in themselves (i.e. as not to be used merely as means) - which makes such a being an object of respect, and something that sets limits to what anyone can choose to do"[31]. And he concludes with a practical imperative: "Act in such a way as to treat humanity, whether in your own person or in that of anyone else, always as an end and never merely as a means"[32]. This definition now underlies the wording of the 1948 Universal Declaration of Human Rights. Of course, some 20th century anti-Kantian philosophical movements (Marxism, naturalism, etc) and the progress made by medical techniques disturb our own interpretation of the law, but it is interpretations that change, not the intrinsic value of the human being! Medical decisions are now often determined by such interpretations, which waver as social procedures exert their influence.

Where human beings are concerned, should the 1948 declaration be rewritten, or the value of the human rights enshrined therein reaffirmed? Is our society mature enough to find a new answer to the universal question of derivation, or to the universal question of the end of life? Doctors' and biologists' unease is highly legitimate: it is not their responsibility to provide the answers. If the word "democracy" is to retain a living sense, citizens with a clear understanding of what is at stake in these discussions should be asked to reach a decision, but on the basis of philosophical considerations drawing on history; a well-designed education should now be preparing them for the necessary thought process.

* Natural death, human death

Death, like birth, is common to all living creatures. Birth and death are the two extremities of human life. Thus death is a natural occurrence, but the human interpretation of it determines the meaning attributed to life.

In the ancient world, human life was regarded as part of the life of the cosmos, so death was considered to be an event which should be met with wisdom. In this context, the problem of death is not that of the good and bad ages of life, but that of the opposition between what is wise and what is pointless! In today's Europe, as we have already seen, the problem of old age is regarded as an economic issue. Whatever different interpretations may have been given of death over the course of history and in various civilisations, this shows that death in itself has no meaning. Whether or not it has a meaning depends on whether or not life is considered to have a meaning, and life has different aspects: biological, social, spiritual, etc. It is these different interpretations and thoughts surrounding death which, interwoven, give rise to the ethical problems

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[31] Groundwork for the Metaphysic of Morals (chapter 2), Immanuel Kant (1785), as translated by Jonathan F. Bennett (2005).
[32] Ibid.

associated with death in the world of medicine. Depending on the way in which death is approached, medical resources will be applied in different ways: if human life is regarded as part of the universal process of life, the person concerned will draw on wisdom of one kind or another; if the context is Christian, the person will look forward to the promised eternal life; if life is regarded as essentially a matter of keeping in control of one's own physical and psychological powers, the deterioration brought about by sickness will be experienced with the utmost dread.

Thus medicine, at the centre of this existential tension, can only exist between two extremes: the natural (matter) and the spiritual (mind), of which the dialectic is life itself. Medicine makes every effort to combat fatal illness, until the very end comes; it does not have to face death, but is confined to dealing with life. For the medical profession, every patient, even one who is dying, is a person and an authentic living being. How could doctors and nurses show so much humanity to patients in a coma and to very elderly people whose bodies, and sometimes mental faculties, are failing, if they could not see through the symptoms and perceive the human beings who are their patients? Thus medicine constantly faces a paradox: it is superfluous vis-à-vis the natural process of death, whereas Hippocratic medicine is inadequate and ineffective against the spiritual aspects of death, in respect of which what is needed is philosophy, wisdom or religion. Unless a recentring of medicine can, in cases of associated disease, cast a different light on the end of life in Europe today, and a new health dynamic emerge, based on joint efforts between health professionals and others, centred on ethical thinking for the sake of the sick person until such time as life ends.

Generally speaking, it is therefore impossible to speak of health without speaking of illness, and health does not mean an absence of illness. Hence illness must be regarded as subordinate to the SICK PERSON, regarded as a complete being requiring a comprehensive or holistic approach, which we might call "medicine of the person".

The holistic approach draws on a specific methodology derived from the way in which one should think about living beings, who are ever complex, because ever changing. Medical decisions change in the course of a single day for the same patient, as the patient's condition may differ from one moment to the next. The method taken by the holistic approach is based on the interplay of views from different angles, and therefore on a critical hermeneutic approach: the ethical approach.

According to Plato, a follower of the holistic medical approach that existed in his day, there is a SINGLE medicine for "good doctors", based on an ethical approach centred on the SICK PERSON. Application of this ethical approach means that all those who, statistically, are not leading standardised lives in society are not excluded from the purview of medicine. Medicine, by applying the holistic and ethical approach, plays its part in respect for the dignity and freedom of all European citizens, regardless of their culture, and abides by the Council of Europe's instruments, thereby ensuring that this holistic approach is not a luxury for the few, but is applied to all.

The end of life is more than just a matter of death. It is not correlated to the human being's physiological performance, so health at the end of life does not mean trying to achieve "health/physiological performance", but the state of health described by the WHO: "a state of complete physical, mental and social well-being". The aim is to serve the interests of the sick person, and in the end-of-life period, an ethically-based holistic approach is needed. This need is all the more urgent for the fact that technological and

scientific progress are throwing up ethical questions for doctors which they did not face in the course of their previous practices. Another illustration of the importance of the integration of an ethical approach into medical and palliative culture.

5.4 Uncertainty, which is inevitable, and responsibility

5.4.1 *While death is certain, the time of death is uncertain*

Death is certain, but its timing is unknown, giving death one of its characteristic ambivalent aspects: it is determinable, for it is a certainty, but it is also indeterminable, because its timing is uncertain. Jankelevitch described the advent of death as "an absolute certainty, if it is considered in terms of its metaphysical effectiveness or natural necessity, with only its date and its circumstances making it seem a <u>possibility</u>. It is a known fact that death will come, but as we do not really know *what* death is, we do not really know *what* will come; we know neither *when* it will come nor what it consists of, and we do not know what will happen, or whether what happens will "consist of" anything: thus an event that is both certain and apprehended is reduced to the simple and impalpable fact of its coming. But in this instance, the verb has no subject! For death is something that comes to us without anything actually coming, and since this coming does not bring with it a new form of existence, it is a coming which is more of a leaving" (71). In the face of death, gnawing uncertainty about its timing becomes unbearable, and all of us react either by feeling sorry for ourselves or by opening up the gates of hope, seeking indefinite deferral by calling an ambulance, as present-day statistics confirm. This ambivalent situation of an uncertain certainty often leads families to hope that a relative will die. They do not ask for euthanasia. They are experiencing an intense existential suffering which gives rise to a wish to put an end to painful ambivalence by destroying life itself. It is soothing to talk about it and to get to know one's own life instinct and death wish in the face of the troubling existential dimension. But there are questions which often have to be spoken: "What is the point of living? It is taking so long…" ask patients, families, nurses and doctors. The unbearable wait for the uncertain moment of death brings with it a hatred of life and even a rejection of that uncertainty through a request for "intentional" death, often interpreted in the current context as a request for euthanasia, although in fact it is in line with Seneca's view that: "So great is the folly, nay madness, of men, that some are driven to death by the fear of death"[33].

In end-of-life situations where life and death are blurred, what is the ethical dimension of medicine? In D Folscheid's words, "Medical ethics cannot be tacked on to, or adopted by, medicine, but can only be the ethics inherent to medicine, so inseparable from it that medicine without its ethical dimension would no longer truly be medicine" (48). End-of-life situations make it clear that the mainstay of medicine is the instinctive certainty that the doctor's experience and ethical consistency are at the service of the patient, whatever the doctor's own personal choices and commitments may be. Otherwise, there can be no true doctor-patient relationship and no therapeutic alliance. The fact remains that this situation is no longer as clear as it used to be, in a society uncertain of its way and full of muddled words, and some people may feel destabilised, or at least start to have doubts. "There is an urgent need for an ethical approach within medicine, not requiring innovation or invention, but mostly requiring explanations and reminders of what usually goes without saying" (48). For medical activity involves medical decisions,

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[33] Letters on Ethics 24, 22-23.

and the role of ethics is to guide towards the "good" of a person knowledge and skills which, viewed in isolation, may have opposite effects. In medicine, ethics bring meaning to, and regulate, action. Ethics help in the search for the end to be pursued, and help to choose one of the available means: they are the alchemy of the decision-making process. Failure to take an ethical approach to medical practice exposes the patient to receiving as a service acts carried out purely with a view to performance, prestige or experimentation. It is medical ethics which underlie the first Hippocratic principle of medicine: "Do no harm".

5.4.2 *The ethical dimension of medicine at the end of life: "either/ or"*

Thus the foundations of medical ethics can be found in the doctor-patient relationship, within which **the moral obligation to provide care** leads to the doctor looking after the patient, an asymmetric relationship of which Levinas and Ricoeur have already given a good description (86; 123). Were it not for this care obligation, the doctor's profession would be a job like any other, and the service provided would be like any other, lacking any ontological foundation (75). In other words, it is the experience of meeting the other person which offers an opening to the infinite, within the finiteness underlying the ethics, whereas reason might well bring enclosure within the "totality" (86). Levinas considers the most vital thing to be meeting the other person in the form of a face, which is not what one perceives of the other person, but that person's presence when called. "The face takes me hostage", wrote Levinas, reflecting his feeling that he was under an exclusively unilateral obligation to the other person, without reciprocity: this is the mutual recognition to which Ricoeur refers, based on "giving, not **in return**, but **in one's turn**" (123). The asymmetry of the relationship leads to a distinction between the moral and the legal register: the obligation to come when the other person calls does not imply any reciprocity, and my duty to the other person is absolute, without any corresponding right arising for myself in return. Ethical responsibility thus precedes liberty, and is not the consequence thereof. This finding is not without effect on medical decisions, for without liberty we would be subject to instinctive determinism, and our behaviour would simply stem from our fears. Ethical freedom specifically makes it possible for us to "choose", and not to be blown around from one extreme to another. As Kierkegaard wrote, ethical freedom is possible only through the "either/or" alternative, which commits us body and soul to an existence which ultimately consists solely of choices, with an absolute choice of ourselves by ourselves to be made at any moment (81).

5.4.3 *How to decide when faced with the "either/or" alternative: responsibility for a weakness which brings an obligation (of general and professional ethics)*

Palliative care, a form of medicine in the service of the patient, is a new and vital adjunct to the twofold approach of Hippocrates and Aesculapius. And the link between them can be made via "ethics", which is why palliative care is such a promising new medical discipline at a time when demographic and economic tensions are presenting Europe with a true historical challenge. It is indeed the case that curative medical treatment is not the only treatment applicable in every situation; the pseudo-rationality of a single way of thinking prevents diversification of (diagnostic and therapeutic) instruments and excludes some groups from the healing system, from full restoration of their previous state of health and eternal youth, with sundry insurance contracts requiring certain results. Palliative care offers a reminder that there is a SINGLE medicine from the ethical and from the PATIENT's viewpoint. So the decisions that need to be taken involve a constant effort to find the "best option" in a unique situation ("situational ethics",

or practical wisdom). **Incorporating the medical approach in an ethical approach** would prepare the way for testing innovative health and social policies. Based on a new understanding of healing, viewed through a critical hermeneutic reading, this testing process would enable account to be taken of current changes in Europe and worldwide.

It is clear how much priority should be given in education and training to ethics, in the form of practical wisdom integrated into clinical wisdom: it is through ethics that links can be made between the curative and the palliative, resulting in a SINGLE medicine, and offering a reminder, in troubled times, of the impossibility of making death one of the aims of medicine. Although there are certain expectations that death should determine the main purpose of medicine, with death being described as the "final illness to be overcome", death is only the outcome of an illness, it is not in itself an illness. It is not death which is the final test of human freedom, it is the suffering caused by the lack of proportion between the finiteness and infinity of fallible and vulnerable human beings. This existential test can be eased only through a relationship of mutual dignity.

The fact remains that, in practice, the doctor does face a constant paradox in his or her art: rejection of death, which always looms too soon, and an awareness of life, which reminds us of Goethe's advice **to think about death, but not to forget to live**. It is within this dialectic that the relationship with others changes dimension, as already mentioned with reference to the supportive relationship, and that the responsibility of a moral conscience arises. It is in fact in the ambivalence of "either/or" options, in a situation where death is certain, but its timing is not, that the doctor's art forges a therapeutic alliance. But ethics cannot apply in a vacuum. The medical profession is required to engage in "praxis", and it is **the actual taking of a medical decision** that commits the doctor (responsibility).

As European studies relating to end-of-life decisions show as clearly as does practice when medical decisions in "end-of-life" situations are made, doctors usually find themselves in a situation where they are afraid, making them angry with themselves. Conversations with people who are seriously ill, at their very lowest point, open the way to a different understanding: it is not always possible to separate things in terms of "either/or", although this dichotomy is fully valid in some fields (hypothetico-deductive method). At the same time, it is also necessary to work on "thinking well" and to apply the "both/and" principle. This requires an awareness in doctor-patient relations that no clear distinction can be made between the observed object and the observer. This distinction between the person carrying out the act and the other person, or the object of the act, is largely a product of conditioning. Each party needs to work to "think well", in other words to shake off this conditioning in order to forge a new and different relationship with the other. In this context, it becomes impossible to perceive personal interest as detached from the interest of others. It is in the therapeutic alliance that the knot of responsibility is tied (or untied), the knot of commitment to the other person as a "face".

The ethical aim of carrying out medical action in the service of others, the doctor's fellow human beings, requires each medical act, and therefore the art of decision-taking, to be regarded as part of an ongoing process. As Goethe wrote, it is not speaking that is important, but thought and action.

"Thought and action, action and thought are the sum of all wisdom… Both must always alternate in life, like breathing out and breathing in. Action must be tested by thought, and thought by action."[34]

This again shows the importance of education and training concerning the supportive relationship which underlies both the palliative and the ethical approach, as well as, more simply, the relationship of dignity and individual freedom within medical and ethical decisions. There is a Council of Europe recommendation dating from 2003[35] which states that "Palliative care policies should be based on values propounded by the Council of Europe: human rights and patients' rights, human dignity, social cohesion, democracy, equity, solidarity, equal gender opportunities, participation and freedom of choice".

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[34] *Wilhelm Meisters Wanderjahre*.
[35] Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care. Adopted by the Committee of Ministers on 12 November 2003 at the 860th meeting of the Ministers' Deputies.

CONCLUSION

The end of life is a societal issue. On the cusp of medicine and ethics, it relates to the most intimate feelings of the individual, each person's own as well as others', "aiming at the good life, with and for others in just institutions", according to the definition of ethics given by Ricoeur (121).

Medical decisions in end-of-life situations seem to play an important part in incorporation in the ethical approach. This approach means, in Pascal's words, "work on thinking well" within a SINGLE medicine, albeit one with several different faces which change with the seasons of human life and the stages of illness: curative, chronic/palliative, terminal.

Chapter 1: **Terminological issues** showed that ethics cannot be reduced to opinions and require a hermeneutic approach or a comparison of different views through dialogue, or the "therapeutic alliance" (supportive relationship), centring on the interests of the sick person.

Chapter 2: **The approach to decision-taking processes at work in medical decisions in end-of-life situations** showed, on the basis of the citation index, that there has, over the course of medical history, been a dual process at work in the decision-making procedure. It has played a part in every medical act carried out since Antiquity: **explain** (hypothetico-deductive method, or Hippocratic method) **and understand** (hermeneutic method, or Aesculapian method). Documentary research focusing on "end-of-life medical decisions in Europe" has revealed in existing comparative studies an exclusively explanatory and technical interpretation. Grammatical shifts are significant: the expressions "end-of-life decisions" and "decisions in end-of-life situations" provide food for thought. "End-of-life decisions" is an expression coined by the staff of intensive care units, relating to cases in which treatment administered to maintain life is reduced or halted, whereas "decisions in end-of-life situations" relate to all the problems arising in respect of the end of the patient's life.

This finding pointed research into decisions in end-of-life situations towards palliative practices and the ethical aspects of other medical disciplines.   The resulting documentation makes certain things clear: medical ethics are not the ethics of the medical profession and are not a system of norms external to medicine, but are "implicit in ethics themselves"; they require medical action to be taken when a person is ill. And a study of working methods as revealed by medical literature shows the extent to which there is a SINGLE medicine, and reveals that this is based on the doctor-patient relationship, or supportive relationship. This relationship requires the ethical approach to be learnt and incorporated into medical practices. European studies are all too often focused on "end-of-life decisions", so vigilance is needed in view of the risks inherent in any disinclination to incorporate ethics into contemporary medical practices.

Chapter 3: **The factors which influence medical decisions very much depend on moral and religious values.** Europe is characterised by a common Christian heritage, and the values which have come down from theology continue to help to structure European value systems. Cultural contrasts (major ethical principles, distribution of dominant religions, attitudes to the elderly, meaning attached to the end of life for oneself and one's loved ones) trace two main lines within Europe, with a huge influence on medical decisions.   The ethical approach dominated by rational hypothetico-

deductive thought follows a line from north to west, while that dominated by hermeneutic thinking runs from south to east.

Chapter 4: In order to obtain a better overview of **the ethical implications of end-of-life decision-taking processes**, we attempted a critical interpretation of palliative practices, on the basis of certain ethical paradoxes or conflicts inherent in the current palliative approach. This interpretation revealed that a major obstacle to end-of-life medical decisions was the **recognition and identification of the terminal phase of an illness**. But this is precisely where, the explanatory method alone being insufficient to provide a satisfactory response to the patient's situation, the comprehensive - or hermeneutic – method (thus including the ethical approach) becomes a relevant supplement to the explanatory method. Those who have to take medical decisions thus need to combine an ethical, or comprehensive, approach with the explanatory one. Today, the ethical approach continues to be too often confused with issues governed by the law or purely professional ethics. Yet health professionals say that training needs in this field are great, reflecting their quest to work on "thinking well".

Chapter 5: In the context of **efforts to incorporate the ethical approach into day-to-day medical decisions**, the main lines of thinking identified are the concept of "good" decisions and the need for justification, the question of "healing" in Europe today, the problem area of the end of life and the preservation of health, and the inevitable uncertainty which is the context in which medical responsibility exists.

With these issues needing to be resolved, Europe, which shares a common set of traditional moral values into which new aspects have been injected by all the cultures that now exist side by side, faces a new challenge, that of working on "thinking well" so that its population can live well together. Where health professionals are concerned, this means that the different professions must no longer be kept rigidly separate, divided by impenetrable expert knowledge, but should open up to other skills, without losing their own, learning to compare their views in an overarching approach within which each person has a place in and through ethical thinking.

In Europe's demographic situation, medical and ethical decisions can but be based on the Universal Declaration of Human Rights. Reference to the Declaration provides a basis for dialogue between different cultures. **"Medical decisions in end-of-life situations"** offer a day-to-day learning context which provide an opportunity to **explain**, where possible, but also to **understand**, not only the thinking of the various disciplines, professions and civilisations, but also the ways in which the various branches of science, art, spirituality, case-law, business and industry understand the problems, as well as the potential of new research in every field to point the way to the future.

Viewed again in the context of the Universal Declaration of Human Rights and of the various European and global legislative texts, medical decision-making offers each and every one of us an opportunity to take Goethe's advice and think about death, but not forget to live. For he considered that the important thing was not speech, but thought and action. "Thought and action, action and thought are the sum of all wisdom… Both must always alternate in life, like breathing out and breathing in. Action must be tested by thought, and thought by action."

APPENDIX 1

Citation index
Centre de Ressources National soins palliatifs François-Xavier-Bagnoud
Research carried out by Marina RENNESSON
Date of research: 26/09/08

The research field was the years 1966 to 2008. The tools used were:
- MEDLINE, the thesaurus of which is run by professional research specialists who select and give a weighting to the terms included in the thesaurus;
- the INDEX, the thesaurus of which has terms automatically fed into it when they occur in texts or titles.

The research carried out gave the following results:

1. The concept of "end of life" does not appear under the Medical Subject Headings (MeSH), but appears 6,383 times in the index over the same period (1966-2008).

Key word	MeSH	Index
END OF LIFE (EL)	-	5,910
EL CARE TREATMENT	-	3
EL DECISION	-	366
EL TREATMENT	-	104
TOTAL	*-*	*6,383*

2. The expression "*euthanasie active volontaire*" (voluntary active euthanasia) does not appear in the Index, but does appear under the MeSH.

Key word	MeSH	Index
EUTHANASIE (E)	11,878	21,130
E. ACTIVE	3,185	2,767
E. ACTIVE VOLONTAIRE	1,422	-
E. PASSIVE	5,632	5,636
TOTAL	**23,304**	**29,533**

The concept of euthanasia is a medical one much used in medical reasoning, but is based on highly imprecise terminology which needs clarification, in accordance with the adage: "it is necessary to think well to act well".

3. Terminological comparison of MeSH and Index occurrences

Key word	MeSH	Index
END OF LIFE	-	6,383
EUTHANASIA	23,304	29,523
PALLIATIVE CARE	28,907	32,095
TERMINAL CARE	31,922	16,137

WITHHOLDING	10,404	9,388

The current terminology is inconsistent, for the term "euthanasia" refers to an act, whereas the term "end of life" refers to a period of human life.

Terminal (palliative) care is picked out by the professionals (MeSH) more than by the automatic search (Index). For professionals, terminal care refers to a particular concept of care. Terminal care is thus clearly distinguishable from general palliative care, so palliative care is not just "end-of-life" care.

Withholding, meaning the reduction of, or failure to provide, treatment, is a common medical practice.

4. Decision-making/Decisions not to provide, or to reduce, treatment in some European countries

Key words	MeSH	Index
DENMARK	29,331	299,446
SPAIN	36,057	300,048
FRANCE	59,025	766,983
UNITED KINGDOM	233,866	146,302
TOTAL	358,279	1,512,779

The great variations between the figures in the MeSH thesaurus and the Index highlight the discrepancy between acts and words. The variations are very significant in respect of Denmark, Spain and France. The literature relating to these acts, however, is based solely on use of the term in the decision-taking process.