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Symposium on decision making process regarding medical treatment in end of life situations

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Mayor of Antibes Juan-les-Pins
Deputy of Maritimes Alps
President of the Town Community of Sophia-Antipolis
First Vice-President of the UMP Group UMP at the National Assembly

Text read by the Coordinator

Ladies and gentlemen,

I regret that I am unable to personally participate in this Symposium. I would nevertheless like to share with you some thoughts concerning the French experience and in particular the process which brought about the adoption of the Act.

I would just like to say how much I welcome the holding of this symposium.

The subject of this meeting covers a wide range of ethical, medical, legal and social issues, which is why the multidisciplinary approach chosen, associating physicians specialising in palliative care, lawyers and ethicists, was highly appropriate.

The European dimension of this symposium is also a first, and should enable us to compare experiences and arrive at conclusions on medical practices which will ultimately be fairly similar.

The debate you will be holding will therefore be very useful for three reasons:

- it can help clarify such concepts as treatment withdrawal, terminal sedation, dual effect and withdrawal of artificial feeding;

- it can clarify the places of the patient, the physician, and family and relatives in decisions to withhold or withdraw treatment, since there is often major confusion about their respective roles;

- lastly, society needs precise rules on responsibilities for decisions to withdraw treatment, in order to distinguish between treatment withdrawal and what would provide an opening to a right to die, in the form either of a lethal injection administered by the physician or of assisted suicide. Our Spanish friends are well aware of this, since they seem to be heading towards legislation on treatment withdrawal, possibly to be enacted in March 2011.

However, the debate on euthanasia and assisted suicide is completely different, and is not the subject of this meeting

At this stage, as an introduction to our day-and-a-half of work, I think I can only put a number of questions which will hopefully fuel your discussions. I would like to mention the matter of the procedure for withholding and withdrawing treatment from three different angles, namely those of the patient, family and relatives and the physician.

Where the patient is concerned, you will have to differentiate between patients who are conscious and unconscious in end-of-life situations. The latter case would require particular attention. You will have to assess the criteria for the patients' autonomy, consider the requisite interpretation of their advance directives, their relationship with their condition, and the priority to be given to these directives in terms of the role played in this procedure by a surrogate appointed by the patient. Should we simply use general advance directives or, on the contrary, should we demand specific directives, as happens in Germany and the United Kingdom? Should they have binding force? How are we to overcome any contraction between these directives and the therapeutic option considered most appropri-

ate by the physician? Should there be an order of priority between the advance directive and the surrogate? Can we be sure that the opinion of the surrogate fully reflects that of the patient? Should the surrogate be different from the person to be notified?

The place of family and relatives is essential, but the latter are not always in full agreement. It can happen, as in the Terri Schiavo case in the United States, that not all the members of the same family agree on the advisability of withdrawing treatment. The physician must get to know the family, dialogue with them and establish relations based on trust. The choice of words and the approach to relatives, especially where the patient is unable to take decisions, are vitally important. This whole area requires time, and we should not forget that the palliative approach also involves the patients' relatives.

The place of the physician. The physician must analyse the therapeutic alternatives, comparing them with the choices of the patients and their families. He or she will consider the traditional ethical principles of beneficence and non maleficence. Which questions are most relevant to physician: should we prioritise survival with further chemotherapy, for example, or is it better to move on to palliative treatment? Is there any risk in treating the patient in an unreasonably obstinate manner? This is not always easy to assess. How are we to evaluate, for instance, unreasonable obstinacy in intensive care departments looking after patients with acute cerebral lesions? How is a physician to manage the ambivalence of the patient and his family, who waver between the survival instinct, a refusal to give up and treatment withdrawal? How are we to achieve a clinical evaluation of the patient and incorporate a pluridisciplinary dimension into this process? How are we to announce a fatal prognosis to a patient? What responsibility must the physician take for deciding to abstain from or withdraw therapy? Should the final decision go the physician, the surrogate or the close relatives when the patient is unconscious and in an end-of-life situation?

We in France considered these questions at great length when **preparing the 2005 legislation on the rights of patients in end-of-life situations** and once again in 2008, when the Prime Minister and the President of the National Assembly assigned me the task of evaluating this legislation.

I would just like to take this opportunity to describe the working method we chose and the content of this legislation. I am not trying to "sell" this law but would just like to outline it in order to fuel your upcoming debates.

The method consisted of a maturating process. Before tabling a bill, ie a parliamentary rather than a governmental proposal for legislation, in the National Assembly, which the National Assembly unanimously adopted, we held 81 hearings of philosophers, sociologists, representatives of the major monotheistic religions, health professionals, historians and lawyers. In connection with such a subject, which relates to each individual's innermost convictions and has not attracted much research, we were divided as a legislature, finally reaching consensus one-and-a-half years after the launch of the work. What help us reach agreement was the fact of this maturing process being fuelled by contributions from such a wide variety of sources.

And what was the aim of this 2005 legislation? It protects patients and health professionals by pursuing two complementary goals, namely proscribing unreasonable obstinacy and regulating good medical practices. We clearly affirmed that medical acts should not be conducted with unreasonable obstinacy, with reference to the two criteria of futility and disproportion.

In connection with patients in end-of-life situations, there are two possible scenarios:

If the patient is conscious, the physician must respect his will, having informed him of the consequences of his choice, and must provide palliative care.

If the patient is unconscious, the physician must take account of the opinion of the surrogate and the patient's advance directives. The decision to withdraw treatment is an exclusively medical decision to be taken collectively. This means that after considering any advance directives, the opinion of the surrogate (where one has been appointed) and the views of the family and relatives, and after consulting the whole medical team, a board of at least two physicians must meet to decide whether or not the current treatment is unreasonable.

Lastly, if the physician notes that the only way to relieve the end-of-life patient's suffering is to administer antalgics or sedatives liable to shorten his life, he is authorised to do so. This is the "double effect" theory set out in the Summa Theologica of St Thomas Aquinas. This approach was extended in 2010 by taking account of a very specific situation, namely the fact of keeping the patient alive by artificial means, or the advanced or terminal phase of a serious, incurable condition. The medical code of ethics allows physicians to resort to the appropriate antalgic and sedative treatments in such situations, where it is impossible to accurately assess the patient's suffering, as in the case of brain injuries. In such cases, extubation or withdrawal of artificial feeding must be accompanied by sedative therapies geared to ensuring end-of-life quality for the patient similar to that demanded for conscious patients capable of evaluating their pain. The mechanism adopted must guarantee relief tailored to the pain of each individual patient, and the physicians must accompany and support their families.

Alongside this regulation of good medical practices, we advocated extending the supply of palliative care. Under the 2008-2012 Palliative Care Development Strategy, palliative treatment must be further developed in units outside hospitals, and the decision was taken to quadruple the number of palliative care beds identified, now totalling just under 5 for every 100 000 inhabitants. We also decided that the legitimation and dissemination of such a medical field as palliative care necessitated a new university course on the subject. This is why we have decided to introduce ten new associate professorships of palliative medicine.

The lesson which I have learnt from this experience is that a resolutely educational approach is needed, because we are in a field where people often prefer binary reasoning on euthanasia and human dignity to any real ethical debate. In this field, the diversity and complexity of human situations are disregarded in favour of a fairly simplistic vision of end-of-life situations where the patients can easily be set in opposition to the medical profession. The fact is that this has nothing to do with day-to-day realties. First of all, the much-proclaimed human dignity is not a standard which decreases with the end of life but is a value intrinsic to the human being. Secondly, the requisite response to the suffering of an end-of-life patient is not euthanasia, even where such suffering is repetitive.

What patients nearing the end of their lives want is time, attention and provision tailored to their situation. **This points to the need to define good medical practices, transparent collective procedures. That is the purpose of this seminar, which must show that there are other responses to the demands of patients in end-of-life situation than an individualist view of this issue, a single answer to a complex question.**

This choice is not neutral. By providing a response based on the values of solidarity and openness and recognition of the central role of palliative care, society points to the place it wishes to give to the most vulnerable among us. **To adopt this approach is simultaneously to respect the aims of the Council of Europe, which for sixty years now has been striving to defend human rights and seek joint solutions to the problems of our societies.** This symposium is therefore fully in line with the goals of the Council of Europe, and I can only wish you every success in your discussions on behalf of the values defended by the 47 member States of this Organisation.

Biographical notes

Date of birth : 9 July 1948 in Marseille. Profession : cardiologist

Professional carrier

- 1965 : Faculty of Medicine
- 1971 : Senior Registrar at the Faculty
- From 1977 to 1997 : Head of Cardiology Department, Antibes Hospital Center
- From 1983 to 1995 : President of the Medical Commission of Antibes Hospital Center
- From 1981 to 1995 : lecturer at the Faculty of Medicine in Nice
- From 1983 to 1995 : Vice-President of the Board of Directors of Antibes Hospital Center
- Member of the Faculty Governing Board

Mandates and functions (other than elective)

- Member of the Social Affairs Committee
- 2003-2004 : President of the Parliamentary Mission on end of life support and care

Rapporteur for the Mission responsible for the Evaluation of the Act on Patients Rights and End of Life (22 April 2005)

- Rapporteur for the Mission of Information on the Revision of the Bioethics Laws
- Chairman of the Pilot Committee responsible for the States General on Bioethics
- Responsible for a Mission on the modernisation of the legislation on parental rights and rights of third parties.

- President of the French Hospital Federation
- President of the Regional Hospital Federation (Provence Alpes Cote d'Azur)
- President of the Health Conference of the Territory of East Maritime Alps

Author of four books :

- "Le principe de modération", Michalon Editors – 2003
- "Vivre ou laisser mourir", Michalon Editors - 2004
- « A la lumière du crépuscule » Michalon Editors – 2008
- « Quand la science transformera l'humain », Plon Editors– 2009

Prof. Eugenijus Gefenas (Lithuania) – Medical End-of-Life Decisions: Conceptual Clarifications and Ethical Implications

Lithuanian Bioethics Committee

Abstract

Medical end-of-life decisions: conceptual clarifications and ethical implications

The importance of medical end-of –life decisions (MELD) is understood in the context of demographic tendencies and progress in medicine that have been changing the patterns of morbidity, mortality and the mode of care provided to the dying people in the contemporary society. As many as two thirds of all dying people nowadays encounter a contact with health care professionals. Although there is a lack of empirical data about this area of medicine and the differences in terminology used make the international comparisons somewhat problematic, it is still possible to distinguish some major types of end-of-life decision making. The most common types of the MEDL reported in the literature are a) the intensified alleviation of pain and suffering and b) withholding and withdrawal of medical treatment. Administration, supply or prescription of drugs with the explicit intention of hastening the patient's death, which is the most controversial practice, occupies a very small portion of the MELD as reported in the studies available. This is one of the reasons why we concentrate on those MELD that are most common in practice and in respect to which a consensus could in principle be reached. However, even in these cases some sensitive questions can be raised. For example, what are the circumstances when the health care professionals consider withholding and withdrawal of medical treatment? Does the answer to this question depend on the type of treatment (e.g., medication, artificial nutrition or hydration) and what are the other factors that should be taken into account? Is the distinction between alleviation of pain with opioids and hastening of death always easily made? Another set of sensitive questions deals with the decision makers involved and the procedures on how the decisions are shared among them. For example, is it acceptable cultural variation that in some European countries the MELD concerning competent patients are neither discussed with them nor with their relatives, which is even more prevalent practice in case of incompetent patients? The location where the MELD is made, the age of people and the cause of their death - all these factors are also shaping a particular profile of the end-of-life care. The presentation will highlight the mentioned issues which are crucial to understand an encounter between the dying patient and his or her health care professional and to facilitate the decision making conducive to human dignity and human rights.

Full text

Introduction: the fundamental dilemma and culture of end of life care

The availability of modern technologies in the field of resuscitation and other areas of end of life medical treatment has made natural human dying much more complex than before. The problem is that in some cases these technologies can significantly extend what some commentators would call an unjustified prolongation of the dying process. On the other hand, the failure to apply the same end of life interventions in other cases could be called an unjustified shortening of human life. In other words, death in modern medicine is no longer a moment that in the past could hardly be postponed by those surrounding the dying. Nowadays it is rather a process in the hands of teams of health care professionals who may influence its timing, duration and what is no less important to choose the type of communication with the dying and his or her relatives. As a result, patients might be exposed to over-treatment decisions, which can be burdensome to them and costly to the society, as well as suffer from under-treatment scenarios that can be regarded as medical negligence and violation of fundamental human rights of the most vulnerable persons (7). In the circumstances where such sensitive issues are involved it is not a simple task to choose the means that are both respectful to the wishes of the patient/family as well as do not contradict the algorithms of medical decision making.

How to find the balance and to navigate between the two extremes mentioned above? Is the type of end of life care country specific or are there variations in the scope of interventions applied even in the same country and society? In other words, how and when could we talk about different "cultures" of end of life care? Some interesting insights to these questions has been provided by The Dartmouth Atlas of Health Care, which is the US government commissioned report to evaluate health care services provided within the framework of Medicare. Although the Report mainly deals with the financial aspects of health care, it also reveals rather striking differences in what is called the „culture of applying aggressive type of care in the last months of life". The results of the Reports published in the daily press sparked the debate about the differences in providing health care during the last months or years of human life in different hospitals. For example, it appeared that as much as 52,911 USD were spent in the U.C.L.A. Medical Centre as compared to 28,763 USD in Mayo hospital, St.Marys in the last six months of life of patients treated in the mentioned health care institutions. Both clinics claimed that the scope of health care provided to their patients was based on the accepted medical standards that should be applied in the circumstances. However, remarkable differences in the financial resources allotted to the apparently similar categories of patients raised a hot public debate about possible differences in perception of what is a proper medical care at the end of human life. The core of this debate is well captured in the question raised by the director of the Congressional Budget Office P.R.Orszag: „How can the best medical care in the world cost twice as much as the best medical care in the world?" (8). How should the health care professionals interact with their patients during the final stage of their life's? What are the situations when treatment can be considered "futile"? Who makes the "futility" decisions and are these decisions shared with the patients or their relatives. In other words, what are the most important features of the end of life treatment or medical end-of –life decisions and why does this problem continue to be in the centre of the ethical debate?

MELD and their importance

As has already been mentioned, the importance of medical end of life decisions in modern medicine has been raising in parallel with the advancement of biomedical technologies applied in the end of life situations. The need to analyse medical decision making in the end of human life is also understood in the context of demographic tendencies that have been changing the patterns of morbidity, mortality and the mode of care provided to the dying people in the contemporary society. The proportion of population whose death is influenced by MEDL significantly increased during the last century due to the change in the structure of mortality and the causes of death. The essence of this change has been the shift from acute deaths due to infectious diseases to dying from cancer and cardiovascular diseases. As a result only 1/3 of population nowadays dies suddenly and unexpectedly, while the 2/3 passes away as a result of not-sudden deaths. The patients who fall within the latter group usually have many contacts with health care professionals during the final period of their life's and are, therefore, subject to different of health care related decisions. It should be noted that the term MELD could be used in a broad sense as referring to all the interventions that a patient might be exposed during the final period of his or her life. However, it can also be used in a narrower sense as referring to only those decisions that could have an impact on the duration of the dying period of the person.

For example, a patient with an advanced cancer is hospitalized because of deteriorating condition and increasing pain that is not under control in the non-hospital setting. He undergoes all the necessary medical exams, which show a very poor prognosis with estimated life expectancy of approximately one month. The patient is prescribed necessary medication to control pain and improve his condition for the remaining weeks, however, dies in a few days because of cardiac arrest followed by unsuccessful resuscitation. In this case medical staff was making medical decisions with regard to the end of life treatment: it was decided to follow the strategy of palliative care to control pain and to make the last weeks of life the least distressful. It is important to note that in this case medical decisions made in relation to the end of life treatment did not intentionally shorten the duration of patient's life because all the measures were taken to extend it (including the resuscitation attempt). On the other hand, consider a few alternative scenarios about the same patient. First, it could have been the situation where the patient had himself left the do-not-resuscitate (DNR) order and therefore medical staff could have abstained from any interventions in the case of cardiac arrest. Second, in the absence of the DNR order the medical staff could have decided not to start the resuscitation considering it to be the "futile" intervention in the circumstances. Third, it could also be the case that due to the unsuccessful attempts to control pain and other distressful symptoms due to the advanced stage of the disease medical staff could have decided to significantly increase the dose of opioids even realizing that this could hasten death of the patient. In all three alternative scenarios the decisions of the medical staff could intention-

ally shorten the duration of patient's life. This type of MELD would therefore cover a narrower range of end of life treatment cases.

European international studies

Although the MELD is a very important part of health care, it seems that empirical data about this area of medicine is still rather scarce. First, in many European countries the data about the MELD is not available. Second, due to different terminology used as well as due to the attempts to investigate specific types of decisions, there is a lack of data that allows comparing the MELD between different countries. Most of the empirical studies referred to in this paper make a distinction between what we have called the broad and narrow interpretations of the term "medical end of life decisions". These studies are predominantly based on the narrower interpretation of the term applicable to those cases of non-sudden deaths where health care professionals believe that their decisions can have a life shortening effect. It is important to note that this type of MELD indicates the most sensitive cases of end of life treatment. The frequency of MELD cases corresponding to the narrow interpretation of the term within the general structure of non-sudden mortality varies among different countries, For example, it applies to only 23% out of 71% of non-sudden deaths in Italy, while in Switzerland their rate is remarkably higher - 51% out of 68% of deaths (6). The same figure is 47% out of 64,7% of non-sudden deaths in Belgium (1). Significant difference in the proportion of MELD within the structure of non-sudden mortality can be attributed to cultural differences between the countries. However, this could also be a result of a research bias as the end of life decisions is an area where the underreporting of socially unacceptable practices can take place (1).

In this paper we will refer to two types of studies. First, those studies that refer to the MELD in general population. Second, the studies that concentrate on the structure of mortality in a particular field of medicine, such as intensive care units. The EURELD is an example of the MELD studies in general population which brings important insights on the issues including the attempt to make some international comparative analysis. It covers the situation in 6 European countries - Belgium, Denmark, Italy, Netherlands, Sweden, and Switzerland and provides descriptive categories of the most important scenarios of MELD (1). It also provides, among other things, data on variations with regard to different types of MELD, their relationship to the cause and place of death, as well as analysis of communication and decision-making patterns between patients and health care staff.

Most frequent MELD

In this section we will concentrate on the most common types of MEDL. These are (a) the intensified alleviation of pain and suffering and b) withholding and withdrawal of medical treatment. Administering, supplying or prescribing drugs with the explicit intent to hastening death on patient's explicit request, which is the most controversial practice, appeared to be also one of the least frequent one. This type of MELD was predominantly applied to those younger than 80 y.o., suffering from cancer and outside the hospital setting. It occupied a very small portion of MELD as reported in the studies available, e.g. 1% of deaths or less in Denmark, Italy, Sweden and Switzerland (6). This is one of the reasons why this paper concentrates on those MELD that are most common in practice and in respect to which a consensus could in principle be reached.

As has been noted, the non-treatment decisions is one of the most common type of MELD, however, its range between different European countries is significant: 4% of all death cases in Italy as compared to 28% Switzerland. Within the structure of non-treatment decisions, those related to withdrawing or withholding medication happens most frequently (44% of all non-treatment decisions). The second most common non-treatment MELD is forgoing Hydration or Nutrition (22%). These two types of MELD are regarded to be the "low technology interventions", which could be contrasted with so-called "higher" technology interventions such as respiration (6%), oncotherapy (6%), surgery (6%), or hemodialysis (3%). Even though the "low" technology interventions are the most frequently forgone as compared to the higher technology interventions, such as dialysis, the life shortening effect of the latter is more significant. It is estimated to shorten the life of the patient by more than one month in 25% of cases as compared to the possible life shortening effect of the mentioned "low" technology interventions which do not usually shorten the life of a patient for more than one week. In addition, there has been a tendency to not discuss the "low" tech MELD with the patients or their relatives probably because medical staff thought these MELD were related with the attempt to avoid futile medical interven-

tions. The tendency not to initiate rather than then to stop an intervention is more common among older patients (> 80y.o.) and outside the hospitals (2).

Another most common type of MELD within the structure of general mortality is related to intensifying alleviation of pain or other symptoms with opioids, benzodiazepines or barbiturates that can hasten death as a possible side-effect. In contrast to the non-treatment decisions that are not specific to a particular cause of death, this type of MELD is typically seen in cancer patients. The variations between different countries are also seen in this case, although the differences are less expressed as compared to the non-treatment decisions. The lowest rate of this MELD among the countries was seen in Italy (19%), while the highest (26%) in Denmark (6).

MELD in other contexts

Continuous deep sedation (CDS) or coma until death is a particular situation which merits a separate discussion because its use in some countries has recently increased. For example, in the Netherlands it raised from 5,6% in 2001 to 7,1% in 2005. The CDS is used in terminally ill patients when medical treatment cannot relieve severe symptoms (pain and agitation) because it takes away perception of the symptoms. In most cases such a sedation continues for less than one week and just in 6% of cases it continues for more than one week (9). On the one hand, therefore, it is emphasized that CDS is only applied when life expectancy of the patient is relatively short. On the other hand, however, it could be combined with the administration of artificial food or fluids or, in contrast, artificial nutrition and hydration could be stopped when the CDS is started. The combination of these two elements, namely, deep sedation and forgoing artificial hydration/nutrition has made the moral status of this type of care the subject of fierce ethical debates (5).

It is also important to study not only the general trends of mortality and the corresponding MELD. No less important is to understand the patterns of end of life decision making in particular health care settings. Intensive care units are particularly relevant in this respect because of the high mortality rate of the patients that need this type of care as well as because decision making procedures in this type of setting is well-documented and therefore can help to distinguish between different patterns of human dying. For example, „The Ethicus study“ - an observational study that was conducted in 1999-2000 and took place in 17 European countries involving 37 ICUs has made a distinction between 5 mutually exclusive categories that led to the death of a patient at the ICU (10). The study distinguished and provided analysis of the following types of MELD: brain death which was diagnosed in 8% of all death cases at the ICU, death following unsuccessful cardiopulmonary resuscitation (CPR) which happened in 20% of cases. These two categories are not in fact related to any life shortening effect and therefore they would not fall within the scope of the narrow definition of MELD. On the other hand, other three categories: with-holding life-sustaining treatment – 38%, withdrawing life-sustaining treatment – 33%, and active shortening of the dying process – 2% were clearly in line with what falls within the remit of the narrow interpretation of MELD because all three types of decisions were linked with the life shortening consequences of the decision.

Parties involved in the decision making

One of the most important and sensitive issues that have been raised in the MELD discussion is related to the question on how and how often patients and their relatives are involved into the decision making process about the end of life treatment. For example, it has been claimed that the shared decision making and respect to autonomous choice of the patient is more prevalent in the US than in Europe. Similar comparison has been also made with respect to the Northern Europe as compared to the Southern Europe (11). However, according to the EURELD study more than in 50% of cases decisions were discussed neither with the patients nor with the relatives in Italy and Sweden, the countries representing different regions of Europe (6). Taking into account that Europe is represented by countries with different cultural traditions and attitudes to the end of life treatment, the following question can be raised: is it acceptable cultural variation that in some European countries MELD concerning competent patients are neither discussed with them nor with their relatives, which is even more prevalent practice in case of incompetent patients?

Concluding remarks

The analysis of existing practices and review of the relevant literature suggests that the end of life treatment and care needs more transparency and research. The number of cases where medical end of life decisions can affect the course of human dying as well as the quality of the final period of human life is remarkable. However, the details concerning these practices such as the internationally acceptable typology of MELD or the ratio between different types of MELD are not sufficiently clear.

Conceptual analysis of MELD is a prerequisite for empirical studies because of possible overlaps between some MELD as well as because the criteria of defining MELD can be ambiguous. It seems that the trend to define MELD as a decision which can hasten patient's death is a relevant tool for the analysis because it helps to distinguish the most controversial types of cases. It is also important to note that in the course of recent years new types of MELD (e.g., continuous deep sedation) are becoming more prominent in some countries. Normative analysis related to different MELD is a particularly sensitive issue even when we talk about the most common and widespread types of the end of life treatment. For example, what are the treatment options that can legitimately be stopped? Does the answer to this question depend on the type of treatment (e.g., medication, artificial nutrition or hydration) and what are the other factors that should be taken into account? Is the distinction between alleviation of pain with opioids and hastening of death always easily made?

One of the most problematic areas of end of life treatment is the quality of communication between health care practitioners and patients or their representatives. Such a communication can make difficult decisions easier for all the parties involved, however, empirical data suggest that in many cases it should be significantly improved. Development of policies (such as position papers opposing or allowing a specific MELD and proposing a detailed guidelines for caregivers on decision making procedure) could be a useful tool to facilitate communication between caregivers and patients. First of all, because this makes the MELD clear and transparent for all the parties involved. Second, because it makes it possible to covey all the information about a particular MELD taking place in the health care setting to the patients and/or their representatives. It should be noted, however, that the studies revealed that at present the reactive approach is prevalent in communicating information about MELD to the patients/relatives (4). It means that even in the countries were written policies on MELD are rather well developed the communication between caregivers and patients is limited to personal conversation when patients or relatives request information themselves.

Training of health care staff to implement existing policies and improve communication is another precondition to humanize the end of life decision making. There is no easy way to deal with the dying person in the medical setting. In addition to professional competence health care staff needs moral insight, psychological skills and cultural sensitivity to navigate between Scylla of prolonging dying and Charybdis of shortening life... (3).

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Biographical notes

Dr. Eugenijus Gefenas is an associate professor and director of the Department of Medical History and Ethics at the Medical Faculty of Vilnius University. He is also a chairman of the Lithuanian Bioethics Committee. Eugenijus Gefenas graduated from the Medical Faculty of Vilnius University in 1983. He obtained his Ph.D from the Institute of Philosophy, Sociology and Law in 1993. E. Gefenas teaches bioethics at the Medical Faculty of Vilnius University and together with the colleagues from the Center for Bioethics and Clinical leadership of the Graduate College of Union University (USA) co-directs the Advanced Certificate Program in Research Ethics in Central and Eastern Europe. His international activities also include the Vice-Chairmanship of the Steering Committee on Bioethics (CDBI) of the Council of Europe the membership in the European Committee for the Prevention of Torture (CPT) and the European Society for Philosophy of Medicine and Health Care. In 2007 he was elected to the Board of Directors of the International Association of Bioethics. The areas of his professional interest include ethical, philosophical and policy making issues related to human research, psychiatry and health care resource allocation.

Session 1 - Introduction
Evolution of the way patients in end-of-life situations are cared for (in time and between countries)

Prof. Stein Kaasa (Norway) - Shared historical evolution and international comparison

Professor, Dr. Med. Stein Kaasa, European Palliative Care Research Centre, Dept. of Cancer Research and Molecular Medicine, NTNU,Trondheim,Norway and Dept. of Oncology, Trondheim University Hospital,Trondheim,Norway

Abstract

Palliative care is the active, total care of patients whose disease is non-responsive to treatment (1). End of life care is a part of palliative care according to the WHO definition: it integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible until death and offers a support system to help the family cope during the patient's illness and their own bereavement.

In order to achieve optimal end of life care, some key elements have been identified by an EU ongoing project: culture, public priorities and clinical/research priorities (2,3).

A common cancer disease trajectory when it is not possible to cure the patient, is first to offer the patient life prolonging treatment, and thereafter symptomatic treatment. Palliative care emcompasses all of these phases as well as end of life care.

End of life care is not only an issue and a challenge for the health care system, but more so for the patient, the patient – family interaction and the society. It is expected that the health care system and the society offers a support system to help the family cope during the patient's illness and their own bereavement.

The health care system should primarily deal with symptom control and offer optimal care and facilitate (be a resource) to the family, to the patients and to the family – patient interaction.

Death in the modern society is by many researchers and clinicians identified to be less visible, which may also influence the care for the dying. According to several studies, the patients want to stay at home as much as possible, and to die at home – if possible. This wish is contrasted by empirical data identifying large cross-national differences between countries in Europe with regard to place of death, in that more patients are dying at home in some countries compared to others (4).

Modern medicine is expected to be evidence based. National and international guidelines are devloped based upon the best available evidence according to the medical literature. The European Palliative Care Research Collaborative (EPCRC) is in the process of developing European guidelines for the treatment and care of pain, cachexia and depression (5)(6).

The basis for cancer pain treatment for the last couple of decades has been the WHO pain ladder (7). As a follow-up on this ladder approach, the European Association for Palliative Care (EAPC) has developed guidelines based upon expert opinions (8). New guidelines are emerging from the EPCRC and EAPC.

The ultimate goal for end of life care nationally and internationally (as a European basis) should be to offer the patients optimal care, including symptom control and access to in-patient care when needed. However, the main place of death should be the patient's home and the health care system – independent of country – should be organised in order to reach this goal.

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(1) WHO: http://www.who.int/cancer/palliative/definition/en/

(2) Sigurdardottir KR, Haugen D, Van der Rijt C, Sjøgren P, Harding R, Higginson I, et al. Clinical priorities, barriers and solutions in end-of-life cancer care research across Europe. Report from a workshop. European Journal of Cancer 2010;46(10):1815-22.
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Full text

Shared historical evolution and international comparison

Palliative care is the active, total care of patients whose disease is non-responsive to treatment (1). End of life care is a part of palliative care, according to the WHO definition: it integrates the psychological and spiritual aspects of patient care, offers a support system to help patients live as actively as possible until death and offers a support system to help the family cope during the patient's illness and their own bereavement.

In order to achieve optimal end of life care, some key elements have been identified by an EU ongoing project, European priorities for research and measurement in end-of-life (PRISMA): culture, public priorities and clinical/research priorities (2, 3).

A common cancer disease trajectory when it is not possible to cure the patient, is first to offer the patient life prolonging treatment, and thereafter symptomatic treatment. Palliative care emcompasses all of the phases as well as end of life care.

End of life care is not only an issue and a challenge for the health care system, but more so for the patient, the patient – family interaction and the society. It is expected that the health care system and the society offers an extensive support system to help both the patient and his or her family.

The health care system should primarily deal with symptom control and offer optimal care and facilitate (be a resource) to the family, to the patients and to the family – patient interaction.

The culture of palliative care can be reflected upon from a societal point of view, from a health care point of view, and from a patient and family perspective. It is a challenge within the health care system to find enough space and place for death, both within the society and within the health care system. This is a sharp contrast to the major resources (economical as well as human) that are used during the last year of a patients' life. Accordingly, it seems important to widen the access to palliative care as well as to improve the quality of palliative care delivery. Within oncology care it has been discussed how palliative care and end of life care (which is considered to be a part of palliative care) should be incorporated into a normal disease trajectory. It is argued for the introduction of the concept of palliative care and symptom control already at a stage where patients are still receiving life prolonging treatment.

Death in the modern society is by many researchers and clinicians identified to be less visible, which may also influence the care for the dying. According to several studies, the patients want to stay at home as much as possible, and to die at home – if possible. This wish is contrasted by empirical data identifying large cross-national differences between countries in Europe with regard to place of death, in that more patients are dying at home in some countries compared to others (4). In the present study, the percentage of cancer deaths in 2003 varied substanially between countries: in the Netherlands 45 % of the cancer deaths occurred at home. 36 % died at home in Italy, 28 % in Belgium, 22 % in England and Wales and 13 % in Norway. These large cross-national differences point to organisa-

tional or cultural differences between different countries, that also demands self-awareness in clinical practice.

Modern medicine is expected to be evidence-based. National and international guidelines are developed based upon the best available evidence according to the medical literature. The European Palliative Care Research Collaboration (EPCRC) has developed European guidelines for the treatment and care of pain, cachexia and depression (5, 6).

The basis for cancer pain treatment for the last couple of decades has been the WHO pain ladder (7). As a follow-up on this ladder approach, the European Association for Palliative Care (EAPC) has developed guidelines based upon expert opinions (8). New guidelines are emerging from the EPCRC and EAPC.

Palliative care, including end of life care, has several limitations and challenges. First of all, death and dying is not a natural part of daily life, and the incorporation of this important part of a normal life trajectory needs to be given more place and emphasis in todays' and tomorrows' health care systems. Undoubtly, it is an issue of prioritising symptom control, and care for the dying gains the incorporation of new technology into the health care system, even though new technology only has a limited possibility to improve palliative and end of life care. A rapid increase in the elderly population as well as the cancer incidences, is well documented. Health care providers as well as politicians need to discuss and decide upon how to care for the elderly and dying population in the near future. What is the optimal place for care and death?

The population is expecting to receive care of high quality and ideally care that is based upon experience and data from research. European collaboration needs to be given place and resources within the area of clinical research, and clinical studies need to be conducted and funded at a pan-European level. Furthermore, priority needs to be given to clinical education within palliative and end of life care, taught at an undergraduate as well as at a post-graduate level within medical schools and other areas of health care education.

The ultimate goal for end of life care nationally and internationally (as a European basis) should be to offer the patients optimal care, including symptom control and access to in-patient care when needed. However, the main place of death should be the patients' home, and the health care system – independent of country – should be organised in order to reach this goal.

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1. WHO. Palliative Care Definition. Available from: http://www.who.int/cancer/palliative/definition/en/.
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Biographical notes

Stein Kaasa is Professor of Palliative Medicine at Faculty of Medicine, NTNU, Trondheim, leader of the European Palliative Care Research Centre, Faculty of medicine, NTNU, Trondheim, Director of the Cancer Department, Trondheim University Hospital and Cancer Director, Norwegian Directorate for Health, Oslo, Norway.

He also holds the position as chair of the European Association for Palliative Care Research Network (EAPC RN) and is a member of the Board of Directors of the International Association for Hospice & Palliative Care (IAHPC).

Since 2006 he has been the principal investigator and director of the "The European Palliative Care Research Collaborative (EPCRC)". A 6th Framework EU funded project under the call "Combating Major Disease – Combating Cancer" 2006-2010.

Professor Kaasa is also the leader of Workpackage (WP) 3 in "Reflecting the Positive diversities of European priorities for research and measurement in end of life care" (PRISMA); a 7th Framework EU funded project under the call "Optimising research on end of life care of cancer patients" 2008-2011.

In 2009, he established the "The European Palliative Care Research Centre (PRC)" through an initiative by the Palliative Care Research community and EAPC among others (www.ntnu.no/prc). The PRC will establish a formal collaboration with clinical and academic institutions and individual researchers across Europe and from other parts of the world. The EAPC RN will be an important contributor and facilitator of this work.

Professor Kaasa's main research interests are:
Basic research in assessment and classification of symptoms and subjective health
Intervention and prospective clinical studies in palliative medicine and cancer research
Symptom treatment including translational research on opioids and on cachexia
Professor Kaasa has published more than 350 articles and book chapters. He has authored the Nordic Textbook of Palliative Care, is co-author of the Oxford Textbook of Palliative Medicine and he is on the editorial board of Palliative Medicine, Psycho Oncology and Lancet Oncology. Professor Kaasa advises many international journals, either as an advisory board member or as a reviewer. He is also an expert reviewer in the EU's 7th Frame Work.

Session 1 - Introduction
What is at stake in the symposium in relation to the principles of the Convention on Human rights and biomedicine

Mrs Isabelle Erny (France) – What is at Stake in the Symposium in Relation to the Principles of the Convention on Human Rights and Biomedicine

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Abstract

End-of-life issues arise in two areas: the sphere of human rights, in that those rights safeguard the dignity of the human being, and the more specific area of bioethics, in that, in situations of high vulnerability, the necessary balance needs to be struck between scientific and medical progress and protection of human beings and their dignity. For this twofold reason, it is certainly a matter for a body like the Council of Europe to give thought to the decision-making process relating to medical treatment for patients nearing the end of their lives. The Council of Europe does provide the appropriate legal framework for detailed discussion of such a subject.

On the one hand are the fundamental rights protected by the European Convention on Human Rights, the scope of which is fleshed out by the case-law of the European Court of Human Rights (ECHR). The Court wishes recognition of a right to life (Article 2) which is absolute, but does not give rise to the diametrically opposite right to die, to be combined with a right to respect for private life (Article 8), understood to be a right to self-determination, particularly where decisions about one's own body are concerned. Furthermore, denying the right to assisted suicide to a person who is suffering cannot constitute an act of torture within the meaning of Article 3 of the Convention, and the right to autonomy needs to be tempered by a concern to avoid any shifts incompatible with the protection of vulnerable persons. At the same time, following the logic of these principles, the Parliamentary Assembly (PACE) takes a position in defence of palliative care, with care being organised in the manner most conducive to respect for the autonomy and dignity of the dying.

On the other hand, and more specifically, are the principles enshrined in the Convention on Human Rights and Biomedicine, the purpose of which is, as stated in Article 1, “to protect the dignity and identity of all human beings and guarantee everyone respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine”. The Convention sets down a number of general principles relating to patients' rights before it goes on to provisions relating more specifically to bioethics. Inter alia it recognises the principles of the primacy of the human being, of equitable access to health care and of consent.

One of the aims of this symposium is to demonstrate the relevance of the different rights and principles, including when applied to end-of-life situations, and to show that they really do, once they have been scrutinised in the light of all the situations that arise in practice, provide the core from which new lines of thought may be derived and, if need be, guidelines drawn up.

Full text

What is at stake in the symposium in relation to the principles of the Convention on Human Rights and Biomedicine

From a legal standpoint, and having regard to the mission and competencies of the Council of Europe, the issues covered by this symposium undoubtedly fall within the scope of the European Convention on Human Rights, and more specifically of the Biomedicine Convention.

INTRO
(Slide 1)

1. This deals with "human rights" problematic stemming from the principles laid down in the European Convention on Human Rights.

The **purpose** of the Council of Europe[1] is that of "*safeguarding and fostering the ideals and principles which are their common heritage - democracy, human rights and the rule of law".*

In this framework, the member states endeavor to find common, coordinated responses to the questions which arise in society, with the aim of **guaranteeing the protection of human dignity**. The European Convention on Human Rights is the reference text for this.

The anthropological and societal significance of the end of life and the questions it raises in terms of dignity of the person place these issues at the heart of current social concerns in all our member states; in this context the subject questions the principles laid down in the Human Rights Convention.

2. This deals with "bioethics" problematic stemming from the principles laid down in the Biomedicine Convention

Advances in medicine and developments in medical technology, enabling life to be prolonged and increasing prospects of survival, and even the possibility of excessive medical zeal, definitely give **renewed impetus to the end-of-life debate**.

That debate **illustrates the ambivalent nature of scientific and medical progress**, the awareness of which was the reason for setting up an ad hoc committee (later steering committee) to consider the protection of human rights and dignity of the human being in relation to the applications of biology and medicine.

The aim was, when confronted with **a feeling of loss of the universality of human rights principles in the field of medicine and medical science**, to identify and give formal effect to common principles based on the values manifested in the European Convention on Human Rights, while offering **more specific answers**.

Accordingly, the **CDBI** was instructed to draw up a convention and **find the necessary balance between medical and scientific progress and the protection of the human being and human dignity**: the *Convention for the protection of Human Rights and dignity of the human being with regard to the application of biology and medicine: Convention on Human Rights and Biomedicine* was adopted in 1997 in Oviedo.

***

Thus the Council of Europe institutions provide us with two sets of principles which will help in our deliberations:

- the European Convention on Human Rights

- the scope of which is clarified by the case-law of the European Court of Human Rights

- and which gives tangible form to a number of guidelines proposed by the PACE, the body in which the views of the national delegations are expressed (since its members are representatives of national parliaments); and

- the Convention on Human Rights and Biomedicine (Oviedo Convention), which lays down:

- principles relating to the specialist field of bioethics;
- and **general principles relating to the patients rights**. These last-mentioned principles deserve to be analysed in end-of-life situations where the implications for the individual's dignity take on essential, exemplary, importance.

***

I. The end of life and principles from the European Convention on Human Rights

[1] An institution for intergovernmental cooperation, with 47 member states including the 27 European Union states.

We shall take a brief look at the principles as laid down by the Court and affirmed by the PACE.

I.1 The case-law of the European Court of Human Rights:
(Slide 2)
The principles of the European Convention on Human Rights to be considered in the context of the symposium were identified and clarified by the case-law of the European Court of Human Rights on the occasion of **a landmark case, the PRETTY case in 2002.**[2]

Summary of the facts: Diane Pretty was a British patient suffering from a neuro-degenerative disease leading to death in the short term and condemning her to paralysis, thus making it impossible for her to end her own life. Diane Pretty wished her husband to help her commit suicide without the risk of criminal prosecution, assisted suicide being a criminal offence in her country. **The applicant's claim led the Court to reach a decision, not on the legitimacy of assisted suicide in relation to the principles of the European Convention on Human Rights but, conversely, on the legitimacy of legislation prohibiting assisted suicide.**

NB: It may be observed in this connection that the ECHR has never had to rule on whether euthanasia or assisted suicide are in conformity with the Convention, never having had such a question put to it, despite the fact that some European states have passed legislation of this kind since 2002. Nor does the Pretty case ask the Court the question in these terms.

The applicant cited several articles of the Convention in support of her application, and the Court clarified their combined scope. They are:

Article 2: **the right to life** versus the right to die (***Slide 3)***
Article 3: protection against **inhuman or degrading treatment *(Slide 4)***
Article 8: **the right to one's private life, including the right of self- determination *(Slide 5)***
Article 14: the principle of **non-discrimination.**

What does the ECHR say?

0 **Article 2 does not confer** a *"diametrically opposite right to the right to life"*, in the sense of a right to die which could be claimed.
1 Moreover, the fact that a state refuses, as in this case, to admit a right to assisted suicide, condemning a person who is unable to act alone to a death which he/she considers painful and undignified, does not in itself constitute inhuman or degrading treatment **within the meaning of Article 3**.
2 **The right to private life protected by Article 8 is violated where the principle of personal autonomy is infringed,** that is the right to make choices about one's own body, including choices about one's well-being.
3 The Court nevertheless states that **some infringements of Article 8 are justified** where they are **necessary and proportionate** to the protection of the rights of the person, **having regard to the risks of abuse** which legislation permitting assisted suicide would bring with it (the "slippery slope" argument), bearing in mind the **vulnerability** of the persons concerned.
4 Lastly, the Court does not recognise the ground for discrimination in violation of Article 14, such discrimination arising from the fact that the disabled person is not able to end her suffering herself, unlike an able-bodied person; the Court takes into account the difficulty of establishing such discrimination because of the need to protect vulnerable persons. However, the principle of non-discrimination ought to be mentioned here, in so far as it might be invoked in the context of non-accessibility to appropriate care, for example in an end-of-life situation.

- It is in **a coherent combination of all the principles laid down** that the ECHR offers interesting approaches.

Each state must strike a **balance**, in accordance with parameters peculiar to each society, **between**

[2] Judgment of 29 April 2002.

contradictory requirements, namely the absolute right to life and the right of self-determination:

- there is a **right of every person to refuse treatment** - whether therapeutic or to prolong life - even at the risk of his/her life, and **medical treatment imposed on a patient without his/her consent** also constitutes **an assault on his/her physical integrity;**

- the right of self-determination also includes the right to make **personal choices about quality of life;**

- these principles must be **weighted**, taking into account the degree of **vulnerability** of the person concerned.

I.2 The positions adopted by the PACE with regard to the rights of terminally ill patients *(Slide 6)*

The PACE reflects the attitudes of the parliamentary delegations of which it is comprised. It has express reservations on the question of euthanasia. In its view, therefore, **palliative care** is the only kind of procedure that is compatible with the principle of **respect for personal dignity.**[3]
However, over and above this mindset, since a resolution adopted in 1976 the Parliamentary Assembly has consistently defended a position based on this principle of respect for human dignity, which casts more light on our present subject, and which:

5 asserts the essential character of the **principle of autonomy**: the patient cannot be forced to submit to medical treatment against his/her will, and the **principle of consent** is the cornerstone of any arrangement; in this connection, **advance instructions** are to be encouraged;
6 underpins the **prohibition on ending life deliberately**, even where the sick person so requests: the*"person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.";*
7 **but** also makes it clear that **respect for human dignity means refusing excessive medical zeal** and **an obligation to relieve suffering.**

The PACE also takes care to **distinguish the concepts** of "refusal of excessive medical zeal" and euthanasia; the distinction lies in the **intention** to end life, while the prime intention is to relieve suffering, even if it that means a risk of shortening life.

Recommendation no. 1418(1999) on protection of the human rights and dignity of the terminally ill and the dying is the (non-binding) PACE reference text. Its position was again reasserted in Resolution no. 1649(2009) of January 2009.[4]

II. End-of-life situations and the Convention on Human Rights and Biomedicine *(Slide 7)*

The Oviedo Convention is now the only **binding** international legal instrument in the field of patients' rights and bioethics.

According to Article 1, the aim of that Convention is to ***"protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine."***

[3] On this basis, for the past 10 years it has opposed various proposals on euthanasia (report and draft resolution by Dick Marty in 2003 and 2005).

[4] In Resolution 1649(2009) of January 2009, the PACE reasserts its position in favour of palliative care, as the only way of dealing with end-of-life situations which respects the principle of personal dignity.

Apart from rights specifically arising in the bioethics field (research, transplantation, genetics etc.), the Convention contains two **introductory chapters:** one on "***General provisions"*** and the other on ***"Consent"***, a set of principles we may call **patients' rights.** These rights are meant to apply to all situations in which the individual confronts medicine, and it is quite appropriate for end-of-life situations to fall into this category. Indeed, it may be thought that it is at this time, when medical technology and therapy have done their utmost, that the patient returns to his/her rightful place and other players such as relatives enter the doctor/patient relationship, and this calls for some reflection on the scope of the rights and principles at issue.

What are those principles?

- Article 2: Primacy of the human being: the latter's interest must "prevail over the sole interest of society or science."
- Article 3: Equitable access to health care
- Article 4: Respect for **professional standards**
- Article 5: Free, informed **consent**
and its corollary, **Article 6: rules applicable to persons not able to consent**
- Article 9: taking previously expressed wishes into account (this last-mentioned clause is the one which makes the most direct reference to end-of-life situations by mentioning advance instructions)
Article 10: Private life and the right to information

The principle of primacy of the human being (Article 2)
(Slide 8)
"The interests and welfare of the human being shall prevail over the sole interest of society or science."

This provision lays down a **very general principle.** Its purpose is to **prevent any form of instrumentalisation** of the patient in the interest of:
- third parties (family, even carers)
- public health (prolongation of life and charges for health services; prioritisation of resources in view of their shortage)
- balancing of accounts (demographic weight of extreme old age and disability in economic terms).

From the standpoint of end-of-life decision-making, it follows from this principle that:
- the patient must be at the **centre** of health provision;
- the **wishes** of the patient, when expressed, must take precedence even if the patient refuses treatment;
- where the individual **is no longer able to take part** in the decision-making process, that process must then include factors which may **indicate his/her wishes** (advance instructions, information provided by the legal representative, close relatives etc.) and legal provisions must **arrange for his/her protection** (incapacities, system of representation);
- if no indication of the person's wishes can be determined, the interests of the patient implies that the decision take account of his/her **well-being and quality of life**, concerns, which may take precedence over treatment which has become futile or disproportionate;
- in other words, the interests of the individual imply setting limits which medicine must accept in order **not to entail unreasonably obstinate behaviours; the most appropriate care** in such circumstances is not necessarily the application of therapeutic treatment;

- **conversely**, the primacy of the human being also means that external considerations do not result in **abandonment** of the terminally ill: they must have access to **the care most appropriate** to their condition (**pain** treatment in particular, necessary nursing care, palliative care).

The principle of equitable access to health care of appropriate quality (Article 3)
(Slide 9)

> *"Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality."*

In end-of-life situations the objective is to organise **equitable** access to care and treatment **appropriate** to that situation and the follow up action taken to deal with it - pain relief, palliative care etc.).

Care must be **organised** but also **funded** (eg. by social insurance schemes).

This principle raises the question of **available** financial resources and **their possible prioritisation.**

Professional obligations (Article 4)
(Slide 10)

"Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards."

This clause refers to **the legal, but also deontological, obligations** of health professionals, and to the **good practice** they are required to observe. **These obligations may differ slightly** from one country to another, **but** the rules are generally based on the principles of personal autonomy, benefit, absence of harm, and justice,
They are reflected in:
- the duty to inform
- the duty to respect the person's wishes (requirement of consent, recognition of refusal)
- respect for the dignity of the patient, his/her private life and the duty to relieve suffering
- medical confidentiality.

More specifically in end-of-life situations, these obligations mean in particular that health professionals must:
- refuse all unreasonable obstinacy where treatment has become disproportionate or pointless;
- prevent pointless suffering for the patient and not abandon him/her, providing appropriate care and respecting his/her dignity, especially when the patient is no longer able to express his/her wishes.

Article 4 is a call to develop good practices in end-of-life situations.

The principle of consent before any intervention in the health field (Article 5)
(Slide 11)
"An intervention in the health field may only be carried out after the person concerned has given ***free and informed consent*** *to it.*

This person shall ***be given beforehand appropriate information*** *as to the purpose and nature of the intervention as well as on its consequences and risks.*

The person concerned may ***freely withdraw consent*** *at any time."*

Consent, the underlying principle in the sphere of patients' rights and bioethics, is the primary expression of the principle of autonomy.

In the end-of-life situation, this principle is paramount for as long as the patient is able to express his/her wishes. He/she must be **associated with the decision,** which determines his/her treatment, its adaptation, its limits and even its termination; no intervention, **no treatment may be administered against the patient's wishes**, even if absence of treatment is life-threatening.

The right to withdrawal of treatment, which is the corollary of consent, in other words **refusal of treatment** expressed by the patient, means that no further treatment may be administered.

However, questions arise about the limitations on this principle in the end-of-life situation. One needs to reflect on:

- **the concept of treatment which may be discontinued at the patient's request:** therapies, of course, but also life support treatments including artificial feeding and hydration.

- the reality of free, informed consent in the end-of-life situation: a terminally ill patient is vulnerable. In particular, how should one manage the decision-making process in intermediate situations where the

individual is considered legally capable of giving consent but is weakened by illness? What about neuro-degenerative or psychiatric illnesses which affect cognitive capacities?

Where the individual no longer has legal capacity to give consent, Article 6 supplements the principles with a series of additional provisions to compensate for the absence of consent but also preserve the principle of autonomy as much as possible.
(Slide 12)

*"...Where, according to law, **a minor** does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.*

*The opinion of the minor shall be taken into consideration as an increasingly determining factor **in proportion to his or her age and degree of maturity.***

*Where, according to law, **an adult** does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.*

*The person concerned shall **as far as possible take part in the authorisation procedure...."***

This article refers us to the **rules on legal incapacity** and **legal representation** applicable to protected minors and adults. Those rules may differ between national legal systems, hence the various possibilities envisaged by the authors.

In the medical decision-making field, these rules must as far as possible give way to the expression of the wishes of the person himself or herself, who must be listened to wherever possible.

The principle is of course valid in end-of-life situations, at the time when choices about well-being, or even vital choices, have to be made. Are these rules then sufficiently protective in view of the nature and consequences of the decisions to be taken?

Consent on behalf of another person is always a source of difficulty. The difficulty is even greater in the case of a decision to **limit or discontinue treatment** of a terminally ill patient. The procedures governing limitation or termination of treatment in the end-of-life situation should probably be clarified (who decides? in accordance with what principles? in accordance with what procedures?).

Lastly, there are **situations in which the individual is no longer able to take any part** in the decision because he/she is **unconscious** (coma, cerebral lesions). In such circumstances, what decision-making **processes** make it possible to safeguard the interests of the patient? How can one even **define the patient's interests?** Should there be **special procedures?** What is **the role of the different players** - doctors, nursing staff, family members and legal representatives, confidential advisers, persons with power of attorney, in the process? (or even of the person in question, where his/her wishes have been ascertained earlier).

Taking previously expressed wishes into account (Article 9)
(Slide 13)

"The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."

Article 9 is a solution put forward in the Biomedicine Convention, making it possible to preserve the principle of autonomy even after the individual has become incapable of expressing his/her wishes.

Article 9 covers situations in which the patient anticipates a deterioration in his/her condition which would prevent him/her from expressing his/her wishes at a later stage.
This provision is most directly relevant to end-of-life situations.

The Convention's authors did not wish to stipulate the binding nature of advance expression of wishes. They are merely *"taken into account"*, thus leaving carers a margin of discretion. The authors wished to introduce the idea of **advanced directives** into the Convention, but without going so far as to refer to "living wills". Thus, under the Convention, *"previously expressed wishes"* are **only an indication** for the doctor, who retains the possibility of assessing the situation and reconsidering the patient's wishes in relation to the actual situation and advances in medicine.

Nevertheless, the provisions of Article 9 are not a bar to states envisaging genuine living wills. From the legal perspective, however, the use of such instruments calls for some clarification.

Protection of private life and the right to information (Article 10)

The assertion of the right of privacy is an important issue where the patient is especially vulnerable, as in the end-of-life situation. It is essential at this time to guarantee him/her respect for private life, the sphere of which may be more and more restricted, if only because of the need for hospitalisation and the intervention of numerous health professionals. The same applies to the confidentiality of medical records.

The scope of this provision, in its twofold aspect relative to the different persons involved - the multidisciplinary medical team and also the terminally ill patient's relatives and carers - must be looked into.

Further, it is equally important to keep the patient informed, adapting the information to his/her degree of comprehension and listening capacity, having regard to his/her condition, so that he/she can go on playing a part in the decision-making process for as long as possible. However, that information must be adapted to the particular case, ascertaining what the patient wishes to hear or is able to hear without being made even more fragile.

***

Conclusion

Thus we have normative approaches, a **legal base** and a set of convergent principles and rules. However, while those principles do not cover all the questions that arise, they may where appropriate serve as a base and **starting-point for deliberation with a view to drawing up guidelines** for the decision-making process on medical treatments in end-of-life situations. Those principles must now be **seen against the reality of different situations** in order to be tailored to the specific, difficult problems of end-of-life situations. That is the true purpose of this symposium.

Biographical notes

Mrs Isabelle ERNY holds a Masters degree in civil law from the Faculty of Law of the Robert Schumann University of Strasbourg (France) and is a former student of the National School of Public Health (ENSP) in Rennes, where she began training in 1979 to be an Inspector of health and social affairs. When she left the ENSP, she was appointed to the Directorate of Social Security at the Ministry of Social Affairs.

As a principal administrative officer since 1994 at the Directorate General of Health (DGS), she is currently responsible for bioethics and patients' rights within the Rights, Ethics and Legal Support Division (DDEAJ) of the general secretariat of the DGS, where she is in charge of ethical and legal monitoring of activities and texts relating to bioethics, medical ethics and patients' rights.

She has participated in the work of the Council of Europe's Steering Committee on Bioethics (CDBI) as a member of the French interministerial delegation since 1994. She was a member of the Bureau of the CDBI from 2002 to 2008, being elected to serve as Vice-Chair of the Bureau from 2005 to 2006, and then as Chair from 2007 to 2008. She has now been asked by the CDBI to coordinate the symposium on decision making process regarding medical treatment in end of life situations to be held in Strasbourg at the end of November 2010.

Prof. Andreas Valentin (Austria) - Nature of possible decisions in end of life situations in intensive care

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Abstract

In highly developed societies a paradigm shift leading to an increasing proportion of patients dying while using hospital based services can be observed. As a consequence ICUs are increasingly faced with issues related to end-of-life decisions. The practice of intensive medical care takes place for the most part in borderline situations in which what is medically "doable" must be weighed against the real benefits to a patient. There is general consensus that the task and aim of intensive care medicine is to sustain life and not to prolong the course of death. Beyond that, however, in view of advances in intensive care medicine and also developments in other areas of medicine, the question arises of whether, in a concrete hopeless situation, it is justified to limit or discontinue treatment. In most cases ICU patients will not be capable of being involved in such decisions and surrogates might contribute in communicating patient's preferences or values. But based on the principle that any treatment needs a rationale, in many instances the obvious absence of a meaningful result of therapeutic interventions needs to be considered as determining factor. Decisions regarding intensive medical care should be based on the fundamental ethical principles of respect for the autonomy and dignity of the patient, interventions for the well-being of the patient, with avoidance of harm as the highest priority, and fair use of available means. When, according to the best medical knowledge available, it is not possible to bring about improvement of the condition - that is, there exists no possibility of instituting intensive medical therapy for the benefit of the patient – continuation of measures that will no longer achieve goals cannot be justified from the ethical or even legal point of view. Such decisions are intrinsically profound medical decisions that must be made in a responsible manner and cannot be delegated to others. As soon as the goals of care in an ICU patient are changed from curative treatment to primarily or entirely palliative care all efforts must be focused on maintaining the dignity of the patient and assuring freedom from anxiety, pain and dyspnoe. When critical care medicine reaches its limits, all available resources and experience must be concentrated on enabling a patient to die with dignity and peace.

Full text

Nature of possible decisions in end of life situations in intensive care

This text has the objective to reflect a presentation on the title above given at the symposium on decision making process regarding medical treatment in end of life situations, organized by the Steering Committee on Bioethics of the Council of Europe, which took place in Strasbourg from November 30 to December 1, 2010.

Introduction

Before addressing concepts related to end of life care from the perspective of an intensive care physician it might be worthwhile to remember article 6 from the recommendation 779 on the rights of the sick and dying, issued by the parliamentary assembly of the Council of Europe in 1976. The last part of article 6 reads as follows: "*the prolongation of life should not in itself constitute the exclusive aim of medical practice, which must be concerned equally with the relief of suffering*".

As a consequence of the very mission of intensive care medicine to treat patients in life-threatening conditions this discipline stands in the forefront when decisions about end of life care come into consideration. In fact, intensive care medicine allows a very focused view on end of life decisions because, i) life sustaining therapies constitute the fundament of intensive care medicine, ii) end of life decisions are frequent, iii) decisions are related to end of life situations in the short term. Intensive care medicine has contributed to a paradigm change in medicine where a natural death has become an illusion and medicine has learned to affect the process of dying. But in parallel with the rapid development of intensive care medicine, such as the progress from the use of iron lungs to the provision of a highly sophisticated artificial respiration, a change in perception has occurred. It turned out that not

everything possible benefits a patient. Consequently decisions to forgo life-sustaining treatments in intensive care unit patients are frequent as shown by a recent study in 282 intensive care units [1]. The authors reviewed data in 3050 deaths after 14,488 admissions to intensive care units. 45 % of all deaths in the participating intensive care units followed a decision to forgo life-sustaining therapies.

Basic principles and decision making

End of life decisions in intensive care patients are based on a general principle in medicine:

- Each treatment requires an indication.
- Without an indication there is no justification for any treatment.
- Any indication for a life sustaining treatment is based on a still existing prospect of recovery. That means on a (potential) positive effect for a patient.
- Because a treatment has an effect on the patient, it does not necessarily benefit the patient.

This principle of a mandatory required indication for a particular treatment serves as the very starting point for any care plans. It must be emphasised that in case of a missing indication the patient's will or the will of surrogate do no longer constitute the basis for decision making with respect to the treatment in discussion. The situation of a missing indication is also referred to as futile. The term medical futility describes the following circumstances:

- The absence of a useful purpose or useful result in a diagnostic or therapeutic intervention.
- The situation of a patient whose condition will not be improved by treatment
- Instances in which treatment preserves permanent unconsciousness or cannot end dependence on intensive medical care

In many circumstances the course of a disease will be the determining factor when the indication for a treatment is questionable. For example it might be indicated to intubate a patient with a small sized cerebral hematoma in an early stage but might be considered as futile to ventilate this patient if the cerebral hematoma shows massive progression in a later stage.

In a condensed view futility refers to a situation where no effective treatment exists or the outcome cannot be altered by treatment. There is broad agreement that futile care is inherently unethical and thus should not be provided (even if requested). Several quantitative and qualitative criteria have been described to assess futility. In intensive care patients physiologic criteria are commonly used. An example can be given by a severe hypotensive patient not responding to any intensive care treatment and developing multiple organ failure. Finally, concerns related to the concept of futility should be noted. In some cases it may be difficult to identify futility reliable and it is of uppermost importance to avoid self-fulfilling prophecies.

With the limitations mentioned above in mind it becomes clear that the level of prognostic certainty guides the medical approach. If treatment is considered as futile, it will not be started (withholding) or discontinued (withdrawing) when no further rationale exists. If the situation is less clear but a further deterioration would indicate a hopeless situation, a non-escalation strategy is commonly applied. This means that an existing treatment is not increased and no further treatment is added. But, in any of these situations a permanent therapeutic task will not be abandoned, namely to comfort the patient.

Withholding and withdrawing of treatment are based on the same reasoning and differ only by the point of time where sufficient information is gained to enable a decision. In this sense any reasons that justify withholding of treatment are also legitimate reasons for withdrawal of therapy.

A large study in 37 intensive care units in 17 European countries has confirmed that most end of life decisions are based on medical reasons. In 3086 patients where life-sustaining therapy was limited, withhold or withdrawn, the responsible physicians provided in more than 90% medical reasons for the decision [2].

The basic concept in end of life decisions in intensive care was described in a consensus statement of the Austrian societies of intensive care medicine a as follows: " *The task and aim of intensive care medicine is to sustain life, but not to prolong the process of dying*" [3]. A prolongation of the course of dying in a hopeless situation would contradict all fundamental ethical principles, such as avoidance of harm, interventions in the best interest of the patient, respect for the autonomy and dignity of the patient, and fair use of available resources.

Some typical clinical examples where such a concept applies are:

- Progressive multi-organ failure under maximal intensive care medical therapy with no prospect of successful treatment of the cause
- Terminal failure of vital organs with no prospect of transplantation or adequate long-lasting organ substitution
- Life-threatening intercurrent disease/complication or complete loss of autonomous vital functions after irreversible cerebral damage

- Terminal stage of chronic or malignant disease that no longer can be influenced by any therapy

Considerations on the given examples can be summarized as “according to the best medical knowledge available, there is no prospect of improving the patients’ condition”. However, it is important to note that decisions based on this criterion are immanent results of an individual physicians’ or medical point of view. Thus, on the principles of scientific theory, it is not possible to render these decision processes objective in a fashion that is both complete and beyond all doubts.
In conjunction with medical considerations the decision making process should involve relatives and surrogates, other care givers, the referring physician, and the intensive care team. Since most intensive care patients will be incapable of giving consent it will be necessary to determine the presumed will of a patient (in the absence of a patient directive). Advice from ethics committees and help from chaplains may be requested in particular circumstances. As far as possible the decision making should follow an established procedure and needs appropriate documentation. Any decision is potentially reversible if the condition of the concerned patient changes.

Implementation of end of life care

Before the implementation of a therapy limitation or discontinuation it is advisable and helpful to remember the basic principles in end of life care:

- Any treatment without a rationale is ethically unjustified.
- Continuation of measures that will no longer achieve goals cannot be justified from the ethical or the legal point of view (might represent a case of bodily injury).
- Any reasons that justify withholding of therapy are also legitimate reasons for withdrawal of therapy.
- As soon as it becomes evident that a patient with a life-threatening condition will not benefit from intensive care, the highest priority is to ensure that such a patient will die in dignity without further suffering.

Examples of therapies that will be withhold or withdrawn in end of life situations are:

- Non-initiation of invasive measures
    - Intubation
    - Reanimation
    - Artificial ventilation
    - Renal replacement therapy
- Discontinuation of
    - Antibiotics, blood products, catecholamines and vasopressors,…...
    - Fluids
    - Feeding
    - Ventilation: no artificial oxygen, disconnection from the respirator, extubation

Withholding or withdrawing of some measures needs particular consideration since it is commonly followed by a change in the patients’ condition in the short term. This refers particularly to the withdrawal of artificial ventilation. In a recent study the median time to death after withdrawal of ventilation was 0.9 hours with a range of 0 to 6.9 days [4]. To prevent a serious misinterpretation it is of uppermost importance to remember that the intention of withdrawing artificial ventilation is not to induce death. The intention is not to hinder or prolong the process of dying in a human being at the final stage of life. This intention is reflected by the meaning of the suggested term “*allow natural death*” [5].
As soon as the attempt to provide curative care has ended, the concern for the dying patient must be focused on dignity, freedom from pain, anxiety, and dyspnea, while providing comprehensive medical and nursing care. It includes the care for the patients’ relatives and requires adequate staffing as well as rooms and facilities. In an interesting study the views of intensive care patients and their relatives on important domains of palliative care were obtained. High-quality intensive care unit palliative care was described by the following characteristics: timely, clear, and compassionate communication by clinicians; clinical decision-making focused on patients' preferences, goals, and values; patient care maintaining comfort, dignity, and personhood; and care for families [6].
According to a definition of the World Health Organization palliative care aims to prevent and relieve suffering by early identification, assessment, and treatment of pain and other types of psychological, emotional, and spiritual distress. In reference to this definition palliative care is an integral part of intensive care medicine and is available to patients at all stages of illness [7]. Patients receive palliative care with respect to their needs concurrently with curative care beginning with the time of admission to the intensive care unit. After an end of life decision curative care will end, whereas palliative care peaks at that time. This emphasis on palliative care is illustrated by an example that shows a suggest-

ed approach to terminal withdrawal of ventilation with multiple assessments of the patients' comfort and potential measures to treat discomfort as necessary [8].
Measures to treat discomfort as necessary might include sedation. In other clinical settings the term "*palliative sedation*" has been proposed and defined as "the relief of otherwise intractable pain, dyspnea, delirium, cough, or existential distress by the use of medications that intentionally cause sedation in a patient who is otherwise close to death" [7]. Since intensive care physicians are used to provide sedation according to the patients' need it is not obvious to them why a particular term is necessary to describe such an approach.
When considering treatments in end of life situations frequently the doctrine of double effect is used to justify a palliative measure that has the potential to hasten death. According to the doctrine it is permissible to perform actions with foreseen consequences that would be wrong to intend, as long as the actual intentions are good. To adopt this perspective for end of life situations it would be necessary to discriminate good and bad effects of a treatment. But, what constitutes a bad effect in end of life care, other than the failure to relieve suffering? Assuming that another bad effect exists it would not be necessary to apply the doctrine of double effect but to balance this effect against the benefits as it is done with any other treatment. In other words, the doctrine of double effect might be irrelevant in this context. To illustrate this further it is worthwhile to address studies on the use of opioids and sedatives in end of life situations. Consistent with other studies Sykes and coauthors conclude from their data as follows: "*just as opioids are safe in the terminally ill when their doses are titrated against the symptom response, the same is true of sedatives*" [9].
Finally, another important issue refers to the question whether artificial nutrition and hydration is appropriate in palliative care. Again, a patient-centered approach must address the needs of dying patients. According to the testimony of hospice professionals the majority of patients in their terminal stage of life do not experience hunger or thirst. The predominant adverse symptom after forgoing artificial hydration is dry mouth, which is easily ameliorated with good mouth care. In most patients it is very likely that withdrawal of artificial hydration will result in symptom amelioration consisting of: relief from choking and drowning sensations; less coughing and congestion as pulmonary secretions are lessened; decreased urine output with less need for catheterization and fewer bedwetting episodes; decreased gastrointestinal fluid with fewer bouts of vomiting, bloating and diarrhea; decreased peripheral edema; no need for restraints to prevent patients from dislodging their tubes or intravenous catheters; and less pain [10]. This clinical view is supported by the results of a study in six European countries, where it was found that patients in whom artificial nutrition or hydration was forgone did not receive more potentially life-shortening drugs to relieve symptoms than other patients for whom other end-of-life decisions had been made [11].

Final remarks

In summary the points to consider in end of life situations in intensive care patients are:

- Any medical treatment must be justified by the prospect of a potential benefit for a patient.
- When curative treatment becomes futile, therapies referred to as life-sustaining may actually prolong the process of dying. Such a treatment is not to justify.
- Consequently the vast majority of EOL decisions are based on medical reasons.
- Palliative care is an essential part of EOL decisions.
- Any treatment in a palliative situation is guided by the aim to attenuate severe symptoms and suffering of a patient.

A peaceful hour of death can be seen as an ancient desire of human beings. A painting from Pablo Picasso's early years of training is titled "Science and Charity" and displays a sick woman lying in her bed surrounded by a visiting physician and a nurse carrying a child (Oil on canvas, Museo Picasso, Barcelona, Spain). The painting gives an impression of what is needed in the care of patients at their end of life. It can be summarized with the following statement: "*When critical care medicine reaches its limits, all available energies and experience must be concentrated on enabling the patients in our care to die with dignity and peace, in the company of their relatives*" [3].

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Recent selected publications

- Recommendations on therapy limitation and therapy discontinuation in intensive care units: Consensus Paper of the Austrian Associations of Intensive Care Medicine. Valentin A, Druml W, Steltzer H, Wiedermann CJ. Intensive Care Med 2008; 34:771 - 776
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Prof. Inez de Beaufort (The Netherlands) – Nature of Possible Decisions in End-of-Life Situations

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Abstract

In my presentation I will discuss different decisions at the end of life, and go into distinctions and definitions with regard to such decisions, and the issue of how do such decisions differ from other choices. Can we agree on what we are talking about when we talk about stopping or not starting or withholding treatments; or about increasing pain medication knowing that this might hasten death?

I will go into the guideline on terminal palliative sedation of the Dutch Royal Medical Society and the conditions they propose for the justification of these decisions. Finally I will discuss some of the arguments regarding autonomy, the theory of the double effect, and the need or duty to relieve suffering.

Full text

I thank the organizers for inviting me to this conference.

The structure of my talk is as follows:
The context
The notions
Some arguments

THE CONTEXT
My ideal death: I know I will die and have known for some weeks (not months rather, but weeks). I was not hit by unexpected death. I'm in my own house, in my own bed, the curtains gently fluttering through the wind and I look at my favorite paintings from my favorite painter that have always been in my bedroom. The family physician, with a good education in palliative care, comes regularly to provide pain relief medication. I'm surrounded by my loved ones. We look at important photographs, talk about important memories, I crack my last joke, and they laugh more because it may be my last joke, I wear my black silk nightgown, that my mother thought made me look like Ophelia - but then she is biased - from the kitchen comes a faint smell of vanilla and soup, the grandchildren preparing waffles for themselves and soup for me. Though not hungry anymore I will have some spoons and be grateful, I enjoy the smell of roses, I listen to Bach, either 'Ich have genug' or 'Wohin' from the Johannes Passion, say my goodbyes, kiss them, tell them to remember me but not be sad, I then die quietly, dignified and elegantly as I have tried to live. One cannot practice dying till one has mastered the art and has a 'black belt' in dying. One only dies once.
It is not likely I will die like this. I may die in a hospital, attached to machines that beep and flash, my neighbours in the crowded hospital room crying out in their drugged dreams, calling for dear ones long gone, or snoring or being surrounded by noisy family members. My loved ones trying to be close to me without hindering the nurses, the doctors disappointed that despite all their technologies they could not save me and discussing if there may be a new ruse to trick death. No grandchildren as they started crying when seeing me so vulnerable, so unlike the person they used to know, the dentures grinning at them from the glass on my nightstand, the merciless neon light exposing each and every wrinkle. I may be sedated and dressed in a hospital gown, my hair tangled, smelling of bodily odours one has so carefully tried to camouflage throughout one's life, in terrible pain, gasping for breath, and desperate to end the death bed that has lasted too long. Or I may be the subject of debates the doctors thinking it is enough, some loved ones wanting to keep trying, others arguing that this is not what I wanted. I may, despite my views now, desperately cling to life not ready to leave this world.
The way we die in many cases is not a matter of choice or of control, nor the disease that will prove to be the fatal one. Some die alone and in misery, some instantaneously, some are killed, some choose death as the only way out, some die after lengthy ethical discussions on what the right medical decision is, some in a hospice, some in a hospital, and some at home. For many to orchestrate their death is not a wish they have, or not an option they have. Some die scared of what is to come, sad because

they are too young to die, some don't realize, some continue fighting till the last minute and will not surrender to the inescapable.
Why do I start my talk like this? Because I want to stress that death and or deathbed have been medicalised as prof. Stein has elaborated upon. But dying does not occur in a social and cultural vacuum. In the words of Vincent " However, in general, rather than changing the law, we need to change the way in which people, both in the medical sphere and outside of it, think about these issues. All of us, if honest, would wish to die ate peace and with dignity; people should and will, given time, understand that increasing the dose of sedatives is morally acceptable, if this leads to a pain-free and dignified death. "i
Dying is a personal task and has to do with, or even reflects, who we are and how we lived. **It is not THE end of life decision, it is a decision or a chain of decisions regarding MY end of life, or yours or his.** I don't want to be romantic or nostalgic about dying in the past, people have died in the most atrocious ways, eaten by lions, or cancers, or cruel viruses. But it needs to be said, in the words of the famous philosopher Ronald Dworkin in his well-known book: "Doctors command technology that can keep people alive – sometime for weeks, sometimes for years – who are near death or horribly crippled, intubated, disfigured by experimental operations, in pain or sedated into near oblivion, connected to dozens of machines that do most of their living for them, explored by dozens of doctors none of who they would recognize, and for whom they are not so much patients as battlegrounds. We all dread that."ii

Or a conclusion of one of our well known Dutch researchers in the field of medical decisions regarding the end of life Agnes van der Heide: "Aggressive (and expensive) care until late in the terminal phase and negligence of the need to enable patients to prepare for dying were found to be common practice in hospitals."iii
According to the 2008 study of Veerbeek on Care and Quality of Life in the dying patient 'Several studies investigated what constitutes a good death and high-quality en-of-life care according to terminally ill patients and their relatives. "Next to physical comfort, many patients consider a sense of completion, and preparation to death important for a good death. They attach much value to their dignity, and the affirmation of the whole person. They often prefer to have a say in decisions about their treatment, about how they spend their time, and about the dying process. According to many of them, inappropriate prolongation of dying should be avoided." iv
In the recent end of life guidance of the UK General Medical Council it is explicitly mentioned that patients who may die within 12 months, have to be informed, and 'determination of preferences regarding life sustaining treatment including cardiopulmonary resuscitation' is necessary. ''A doctor has a duty to relieve suffering as well as pain, and the responsibility to tailor a good death, as defined by the patient, is the central principle of this guidance. "v
I appreciate the efforts and the successes that medical science and medical practice have given us. I would have been quite dead a while ago, had the miracles of modern medicine not been available. But these accomplishments come with a price and that is that decisions regarding the end of life have to be taken. The power to postpone death and fight disease come with a price and a responsibility. Both for the medical world as well as for those who die and for their loved ones. Difficult and sometimes decisions. In a dramatic novel the Portuguese Nobel Prize Winner Jose Saramango describes a country where death does not come anymore and people carry their dying loved ones to the neighbouring countries.vi We have tried to chase death away and sometimes we can. My father who died of a heart attack at the age of 54, had he become ill now, in all likelihood would have been diagnosed earlier and treated and might have had thirty years more.
The poet Szymborska on our ancestors short lives, when few made it to thirty.
"OUR ANCESTOR'S SHORT LIVES
Old age was the privilege of rocks and trees.
Childhood ended as fast as wolf cubs grow.
One had to hurry, to get on with life
before the sun went down,
before the first snow."

But our lives are longer and sometimes end of life decision making is inevitable.
The study by Löfmark e.a. (2008) showed that many are confronted with it "The experience of forgoing lifesustaining treatment ranged between 37% and 86%: intensifying the alleviation of pain or others symptoms while taking into account possible hastening of death between 57% and 95%, and experience with deep sedation until death between 12% and 46%. Receiving a request for hastening death

differed between 34% and 71% and intentionally hastening death on the explicit request of a patient between 1% and 56%."vii

MRS. JONES
Imagine Mrs. Jones. She is 60 years old. Six months ago she was diagnosed with pancreatic cancer in an advanced stage. She was always in good health, and suddenly struck by this devastating diagnosis and devastating disease, full of life and plans on what to do after she would retire, thinking of journeys to be made, friends to be visited, music to listen to. Then comes this diagnosis changing the perspective completely. The doctors proposed an operation, they were not very optimistic, but it offered a small chance of postponing death. Mrs. Jones chose to have the operation.

AN AUTONOMOUS PATIENT CONSENTS TO A TREATMENT AT THE END OF LIFE.
The decisions **to accept and undergo treatments** at the end of life are also decisions regarding the end of life. I want to stress that. Little attention because either the illusion it is NOT at the end of life, or hoping that this will at least POSTPONE the end of life. A lot of debate is going on on optimism of patients and doctors, denying the beginning of the end, and on the costs of such treatments. (I will not go into that now, but do wish to mention it.
Can we afford treatments that are very expensive and may prolong life only for a few weeks?) A treatment has to be medically sensible in that it – contributes to resolving the medical problem or the amelioration of the patient's situation, the means used are proportionate to the goal intended, and the patient should not be in a situation that can be considered as 'below a certain minimal threshold level'.
The first step is that the patient is informed about the prognosis and about the options (or the lack thereof). There are differences in different European countries (and Australia) when it comes to informing patients about their impending death. In the study of Voorhees e.a. "The percentage of physicians who indicated that they would actively inform competent patients of their prognosis varied between countries from 52 % in Italy to 99 % in Sweden. For informing relatives of incompetent patients, rates were higher, ranging from 86% in Denmark to 98% in Australia."viii
Not informing competent patients means that they have no voice in the decisions regarding their end of life. I would argue that one should have very, very good reasons to do so.
So Mrs. Jones underwent the operation, during the operation it was confirmed that the tumor was in an advanced stage and that she had metastases. Little could be done. She felt terrible, was nauseous, vomited, and suffered pain and itching. The doctors proposed a new experimental chemotherapeutic treatment that might provide a very small chance of postponing death but they were uncertain about it. They told her in all honesty.
She refused, thinking the chances that she would benefit from it were too small, and the doctors accepted her choice and respected her decision.

AN AUTONOMOUS PATIENT REFUSES TREATMENT AT THE END OF LIFE
This presupposes that again the patient is informed and able to balance the options. She left the hospital and went home where her partner and her adult children took care of her, helped by a professional caregiver. For a few weeks they managed, they talked, were very close, the grandchildren visited, but then the pains and thenausea became worse and worse.' I cannot take this anymore, enough is enough' she said to the family physician who had taken over the treatment after she was released from the hospital. He consulted the palliative team and suggested that the painkilling medication was to be increased. She was treated with morphine like products

AN AUTONOMOUS PATIENT ASKS FOR (MORE) PAINRELIEF
We can increase the doses but then we risk hastening death. 'Do so', said the patient 'It is a risk I certainly welcome.
INCREASING PAINMEDICATION FOR REASONS OF PAINRELIEF KNOWING THAT THIS MAY HASTEN DEATH.
NOT PASSIVE EUTHANASIA, NOR INDIRECT EUTHANASIA, NOR ANY OTHER FORM OF EUTHANASIA.
THE INTENTION and PURPOSE IS NOT TO HASTEN DEATH, BUT THE CHANCE THAT IT MIGHT, IS ACCEPTED, SOMETIMES EVEN WELCOMED.
It did not work well enough. Also she suffered from the side-effects of the morphine: Then the family physician suggested **TERMINAL OR CONTINUOUS PALLIATIVE SEDATION.**
The patient herself was very drowsy, agitated and anxious , she could not decide, so her partner and children gave permission for the terminal palliative sedation
TERMINAL PALLIATIVE SEDATION: BRINGING THE PATIENT INTO A DEEP COMA, STOPPING

ARTIFICAL NUTRITION AND HYDRATION IN ORDER TO SEDATE THE PATIENT TILL DEATH COMES .
THIS IS NOT PASSIVE EUTHANASIA OR INDIRECT EUTHANASIA . THE PATIENT DIES FROM HIS OR HER DISEASE.
She was brought into a deep coma with benzodiapines and died after 22 hours, surrounded by her loved ones.
What does the case of Mrs. Jones show us?
In her case there was no decision about FUTILE TREATMENT.

FUTILE TREATMENT IS A TREATMENT FROM WHICH THE PATIENT CANNOT BENEFIT.
To withdraw or withhold futile treatment is a MEDICAL DECISION.

She decided to have the operation. Had she refused it, that would have been a patients decision to refuse a treatment that in her eyes was disproportional compared to the possible beneficial effects. It implies a balancing decision of the patient (or his or her proxies, I will come back to that).

Increasing doses of painkilling drugs knowing that this may hasten death is a decision that is relatively often taken. The problem of course is the matter of intention.
Again I stress this is not passive or indirect euthanasia.
Terminal or continuous palliative sedation is an ultimum remedium. In the Netherlands it is carried out in 7.1 of the deaths. (9700 persons, data of 2005) The Dutch guidelines of the Royal Dutch Society state that it can only be done:

When the life expectancy of the patient is smaller than two weeks,
There are one or more refractory symptoms that cannot be alleviated in another way.ix
There is of course a:
Debate on Palliative sedation:
How certain can one be of the life-expectancy?
- **Apparently this often can be said with accuracy.**
Is it not very similar to euthanasia?
- **It is not active ending of life at the request of the patient.-**
- **It may according to some even lengthen life**
- **If there are similarities, what are the consequences? (same legal provisions?)**
Why restrict to the patients with a short life-expectancy? If someone has a longer life-expectancy and the suffering is equally bad, should it not be acceptable?

How about stopping or withholding artificial nutrition and artificial hydration?
There is a debate going on specifically regarding the withholding or withdrawing of artificial nutrition and artificial hydration, some argue that this should be continued as part of care, but others argue that such is odd, absurd or contradictory given the idea that the reason for terminal palliative sedation is to relieve the suffering and **allow the patient to die** from the disease he or she is suffering from. Accepting the inevitable death means stopping all treatments and or care that might lengthen life.
The argument that such artificial hydration and nutrition is not a medical treatment but care and therefore should never be withheld is at odds in the sense that the idea to sedate someone as the only way to end the suffering.
Stopping some forms of care does not mean one is stopping to care.
Then there is the complicated case of someone who is **not** in terminal stage of a disease and stops eating and drinking, and then finds himself in a situation in which the end of life is indeed to be expected within two weeks. A decision to stop living, also called 'auto-euthanasia' by some. It is a decision to bring about death, and in a way making sure that one fits the criteria for terminal palliative sedation.

Mrs. Hansen
The second case I want to discuss is that of Mrs. Hansen. She is a widow of 85 years old. She has a son and a daughter. The daughter has been taking care of her since 8 years ago it was discovered she has Alzheimer's disease.
She is brought to the hospital because she has probably had a stroke and was found lying in the bathroom where she fell. She is very confused and in pain.
In the words of Shakespeare:
"Last scene of all,

That ends this strange eventful history,
Is second childishness and mere oblivion
Sans teeth, sans eyes, sans taste, sans everything."
(W. Shakespeare, As you like it.)

The daughter insists that she be put in intensive care and that everything is done to save her. The doctors think the chances of therapeutic benefit are too small, virtually non-existent, and suggest to do everything to increase her comfort. They are convinced that intensive care is not in her best interest and would be a futile treatment.

THE DOCTORS REFUSE TO START WHAT THEY THINK IS A FUTILE MEDICAL TREATMENT. THIS IS NOT PASSIVE EUTHANASIA. NOTHING TO DO WITH INTENDING DEATH …. IT IS A MEDICAL JUDGEMENT ABOUT THE FUTILITY OF MEDICAL TREATMENT.
PATIENTS OR THEIR PROXIES CANNOT DEMAND FUTILE TREATMENTS TO BE PROVIDED.
Mrs. Hansen is very restless, moans, tries to get up but cannot. She is then heavily sedated. She develops a high fever. 'Can you not at least give her antibiotics?' Asks the daughter. The doctors hesitate but given the strong plea of the daughter they do. The fever goes down. She still seems to be in pain so they again give her stronger painkilling medication.
Her heart is very strong. The situation lasts for two weeks. The fever comes back. Then Mrs. Hansen's, son who is living abroad, arrives at the scene. He tells that his mother was very upset with the death bed of their father who has suffered a prolonged deathbed of cancer. She would, so he argues, not have wanted this. The son feels very guilty because his sister has been the one who has taken care of their mother. He visited them occasionally, but did not actually take care. He stresses that continuation does not make sense. Let her die in peace, she has suffered enough. Prolonging her life is not in her interest anymore. Let her go. The daughter realizes that there is nothing that can be done for her mother.

THE PROXIES ACCEPT THE PROPOSAL OF THE DOCTORS TO STOP ALL TREATMENTS, THE ANTIBIOTICS, ARTIFICIAL FEEDING AND HYDRATION, AND TO MAKE SURE SHE IS NOT IN PAIN.
She dies within two days.
These two stories illustrate different problems:

DIFFERENT PROBLEMS
- **THE PROBLEM OF INTENTION**
- **THE PROBLEM OF DECIDING ON WHEN TREATMENT IS FUTILE**
- **THE PROBLEM OF DECIDING WHEN TREATMENT IS DISPROPORTIONAL**
- **THE PROBLEM OF THE BOUNDARY BETWEEN FUTILITY AND DISPROPORTIONALITY**
- **THE PROBLEM OF THE CONDITIONS FOR PALLIATIVE TERMINAL SEDATION**
- **THE PROBLEM OF SUFFERING AND WHAT COUNTS AS SUFFERING**
- **THE PROBLEM OF THE DOUBLE EFFECT**
- **THE PROBLEM OF THE SLIPPERY SLOPE**

THE PROBLEM OF INTENTION
I already mentioned this problem. One may not intend a certain consequence but openly or secretly welcome it and hope for it. In the case of euthanasia, the intention is to end the life of the patient at his or her request. In letting a patient go, or allowing death to come, the intention is not to prolong the life by medical means but to alleviate suffering.
If euthanasia is not a legal option, one may have situations in which there is some juggling with intentions.

THE PROBLEM OF DECIDING ON WHEN TREATMENT IS FUTILE
In some cases this is not a morally difficult decision (though it may be a very hard personal decision) as all medical options have been exhausted. But in some cases there may be debate among doctors. It cannot be a decision on medication that aims at palliation of pain or other symptoms, such treatment is **never** futile. **It is always about therapeutic or life-prolonging treatments. Futility is always a judgment about a certain treatment, NEVER about the life of a patient.**

THE PROBLEM OF DECIDING WHEN TREATMENT IS DISPROPORTIONAL

People differ. They differ in their view on what the future holds, they differ in their view on suffering on pain, on dignity, on what a certain condition means for them. Some 'rage and rage until the dying of the light' to quote Dylan Thomas, others decide earlier that enough is enough. To account for these highly personal and existential differences is possible and in my view morally imperative, when and if the person him or herself is able to express what she thinks and wants. When proxies have to decide. They have to take into account morally in my view the narrative of the life of the person, what does fit and what does not fit? In the case of Mrs. Hansen this is what the son tries to do.

THE PROBLEM OF THE BOUNDARY BETWEEN FUTILITY AND DISPROPORTIONALITY
In some cases there is no problem. In some cases, however, there may be a grey area. The antibiotics for Mrs. Hansen were an example. Doctors and proxies may reasonably disagree.

THE PROBLEM OF THE CONDITIONS FOR PALLIATIVE TERMINAL SEDATION
I have already mentioned some of these.
It is actually euthanasia in a new disguise as has been suggested? I do not think so, as the goal is to stop the suffering in a drastic, ultimum remedium, manner, and to allow death to come because of the utter hopelessness of the situation. There is no alternative in the sense that the disease can be cured or there are life prolonging treatments.

THE PROBLEM OF SUFFERING AND WHAT COUNTS AS SUFFERING
In the case of Mrs. Jones we can all imagine what it is like to feel such nausea, pain, itching etc, in some cases it may be harder to understand deeply what it means for someone. Particularly when it comes to more difficult notions such as dignity and loss of it, dependence and of utter senselessness. Or if we have to, as in the case of Mrs. Hansen, interpret what she has said in the past when competent, in the context of the story of her life.

THE PROBLEM OF THE DOUBLE EFFECT
The theory of the double effect that holds that an act is justified even if it has consequences one does not want because the other purpose makes the act necessary and morally justified, has a long and complicated history.
Hastening death is not the intention of increasing painkilling drugs. Increasing of painkilling medication is chosen because of the need to kill pain, not the patient.
The theory of the double effect can be **abused** to disguise intentions that actually are there : 'I was just waving the ax' said the man and chopped of the head of his enemy (an example of my ethics teacher). It requires we trust the person who acts and his intentions. On the other hand it is common experience to have to accept consequences we do not want because of the other consequences we do seek and think morally justified, sideeffects of medical treatments for example.

THE PROBLEM OF THE SLIPPERY SLOPE
The problem of the slippery slope is an all too familiar one in the debate on decisions regarding the end of life. It is used on both sides of the debate when it comes to euthanasia, terminal palliative sedation and increasing pain killing drugs. Those in favour of allowing patients to decide to die, warn for the slope of having doctors prolong your suffering, those on the other side of the debate warn for disguised intentions, abuse, and 'getting rid' of people who want to live.
I think it is a dangerous argument and would like to warn against **the slippery slope of the slippery slope**: that is to attack and blacken each other's views, taking away the attention from where it ought to be: to receive the kind of treatment that allows people to die a good death, ending their suffering with medical means, not prolonging their suffering through medical means.

DIGNITY AND AUTHENTICITY AND A GOOD DEATH
Few moral notions are so much debated and disagreed upon as dignity. We all support it but may have very different views on what we mean by it, and whom is included in the circle of beings that the subjects of dignity. I will always remember the parents of a ten year old girl dying from a brain tumor who came to me and said: 'Why,why, she is going to die, we want to hold her and caress her and let her die with dignity, but we cannot as she attached to machines, the liquids from her brain literally seeping out…why ?'
The Austrian Recommendations of the Austrian Associations of Intensive Care Medicine, on therapy limitation and therapy discontinuation in intensive care units states:

"When critical care medicine reaches its limits, all available energies and experience must be concentrated on enabling the patients in our care to die with dignity and peace, in the company of their relatives."x

Again I want to stress that dignity has to do with authenticity, with who you are and what you want at the deepest level of living your life. And people are so different. Should we not allow these differences in the sense that putting people in a situation in which they die in a way that they consider, or would have considered, against their individual dignity, is morally wrong. To quote Dworkin once more: "A person's right to be treated with dignity, I now suggest, is the right that others acknowledge his genuine critical interests: that they acknowledge that he is the kind of creature, and has the moral standing such that it is intrinsically, objectively important how his life goes.

Dignity is a central aspect of the value we have been examining throughout this book: the intrinsic importance of human life."xi

I want to end my talk with the last pages of a Childrens book xii:

"Softly the snowdrops fell down. Something had changed. Death looked at the duck. She didn't breathe anymore.
She lay there quietly."
"He stroked a few feathers that stood upright, and carried her to the big river."
"There carefully he lay her down into the water and gave her a gentle push."
"Long he looked. When he could not see her anymore death had to swallow.
But such was life."

And Szymborska again
"Life, however long, will always be short.
Too short for anything to be added."

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Prof. Dr. Dr. Jochen Vollmann (Germany) – The Person, Even Though Sick, is in Full Capacity to Participate in the Decision Process

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Abstract

The assessment of patients' capacity in end of life situations

The decision making process regarding medical treatment in end of life situations in modern medicine undergo a process of change. Empirical data from several European countries show that the vast majority of patients' deaths are expected by the treating physicians. At least 50% of the expected deaths occurred with an end of life decision, in intensive care units in more than 70%. Limitation of treatment is most frequent end of life practices in clinical practice. However, data suggest that even in cases of limitation of treatment 45% of the physicians report an intention to hasten death.

Therefore a „natural" death has become seldom in modern medicine, medical expected and intended dying in frequent. In every day practice physician make ethical decisions at the end of life. Beside the ethical principles of nonmaleficence and beneficence doctors must respect the autonomous wish of their patient. In this context a professional evaluation of patient's mental capacity to make decisions regarding their treatment at the end of life plays a crucial role.

However, mental capacity can be limited by several factors e.g. depression. Empirical data suggest that patients suffering from depression show impairments of their capacity to make treatment decisions in 20-24%. Since about 50% of patients with a wish to hasten death in oncology suffer from clinical depression one must question the capacity of patients at the end of life who want to hasten death in about 10. Problems of the assessment of patients' capacity within the process of end of life decision making and their ethical implications for the clinical practice will be discussed.

Full text

Introduction

In medical ethics the principle of a patient's self-determination obliges the physician to obtain the patient's consent prior to medical treatment (Beauchamp & Childress 1994). In clinical practice, the physician generally presumes competence on the patient's part. But if a situation causes him to examine competence, in most cases he will proceed using his own subjective judgment and clinical experience and has difficulty applying standards suggested in the literature (McKinnon *et al.* 1989; Markson *et al.* 1994). In a given case, physicians also often evaluate competence differently (Marson *et al.* 1997). Considering the ethical and legal significance of competence and the desire for physicians' evaluations to be transparent and reliable, various objective testing procedures have been developed and applied in clinical trials in recent years (Janofsky *et al.* 1992; Bean *et al.* 1994; Marson *et al.* 1995; Kitamura *et al.* 1998).

The "MacArthur Treatment Competence Study" (Grisso & Appelbaum 1995), the current gold standard in the field is using instruments relating to the following four legal standards: to understand information relevant to the decision about treatment; to manipulate the information rationally (or reason about it) in a manner that allows one to make comparisons and weigh options; to appreciate the significance for one's own situation of the information disclosed about the illness and possible treatments; and to express a choice. Patients with scores below defined limits were categorized as impaired in that standard. A hierarchical order of the standards was not detected. Since depression is frequent in patient with somatic diseases, e.g. cancer, who ask to hasten death at the end of life, the reader should focus on the group of depressed patients within the following data.

Methods

As an instrument to measure competence to consent to medical treatment, we used the "MacArthur Competence Assessment Tool-Treatment" (MacCAT-T), a semi-structured interview which requires approximately 30 minutes for assessing the following patients' abilities related to competence: understanding the disorder and treatment; reasoning; appreciation, divided into appreciation of the disorder and appreciation of treatment benefit; and expressing a choice (Grisso *et al.* 1997; Grisso & Appelbaum 1998). Two research physicians have been trained to perform the MacCAT-T interview in German. The MacCAT-T is individualized for each patient's own specific treatment. Patients are given individual information on their disorder, including symptoms and diagnosis; they are also informed about the nature, benefits, and risks of the recommended drug therapy, as well as alternatives to it. To examine understanding, patients are given the task of retelling the information in their own words. The interviewer evaluated the accuracy of patients' statements. Reasoning is assessed using questions that examine whether patients can grasp the consequences of their decision for or against drug treatment for their personal lives, what effects the various decision options can have for their daily lives, and whether they draw comparisons between the options. To examine appreciation, patients are asked whether they can relate the medical information to themselves and acknowledge that they have the specified psychopathologic symptoms (appreciation of disorder), and whether they can see a benefit for themselves in the proposed treatment (appreciation of treatment benefit). The subjects also receive full credit for appreciation of disorder or appreciation of treatment benefit, if they can offer a reasonable explanation for an attitude differing from their physician's, for instance if they decline to take a recommended neuroleptic treatment, recalling strong side effects from an earlier treatment with the same medication. At the end of the interview, patients are asked for their decision for or against the treatment. If patients are able to formulate such a decision, they fulfil the requirements in the standard "expressing a choice." The logical consistency of the choice with their previous arguments is included in evaluation of the reasoning standard.

Patient responses were rated using the following scale: 2 points for adequate, 1 point for partially sufficient, and 0 points for insufficient. The following score totals could be achieved in the individual standards: understanding 0-6, reasoning 0-8, appreciation 0-4, which we evaluated separately according to appreciation of disorder (0-2) and appreciation of treatment benefit (0-2), and expressing a choice (0-2).

To allow group comparisons the results were dichotomised in the categories "impaired"/"unimpaired" and the following cut-offs defined for the "impaired" category: for understanding, 4 or less; for reasoning, 3 or less; for appreciation of disorder and treatment benefit, 0 for each. Following individual presentation of the standards, they were combined and the proportion of impaired patients calculated, with patients being considered impaired if they were impaired in at least one of the combined standards.

All attending physicians were asked to assess the competence to make treatment decisions of their patient on the day of the formal testing. The attending physician did not know the results of the MacCAT-T and was asked to make his judgement freely on the basis of his or her own clinical experience.

Results

The score distribution in the standards of understanding, reasoning, and appreciation of disorder and appreciation of treatment benefit shows substantial differences among the diagnostic groups (Table 1). The slightest impairments were found in the group of depressed patients: more than three out of four patients were in the upper score range in the standards of understanding and appreciation of disorder and appreciation of treatment benefit. The proportion of patients with impairments varied from 17.1 percent in understanding to 0.0 percent in appreciation of disorder, which is the lowest among all diagnostic groups. Patients are more severely impaired in the standards of understanding and reasoning than in appreciation of disorder and treatment benefit. With regard to the socio-demographic data of age, sex, and education, no statistically significant differences were detected between patients with or without impairment in all diagnostic groups.

- Table 1 -

Certain combinations of individual standards resulted in a clear increase in patients with impairment (Table 2). The greatest increase was in the proportion of patients with impairment in the combination of understanding and reasoning: 20.0 percent in patients with depression. Additional combination with appreciation of disorder and treatment benefit did not produce a further increase.

- Table 2 -

By comparison, the proportions of patients categorized as impaired in at least one standard in the MacCAT-T were significantly greater than in the clinical judgement (depression 20.0 vs. 2.9 percent).

Discussion

In the evaluation as "impaired" or "not impaired", there were high agreements between understanding and reasoning and also between appreciation of disorder and appreciation of treatment benefit. The agreements were less in other combinations, the lowest being between understanding and appreciation of disorder. Similar observations have also been made in other studies (Grisso & Appelbaum 1995; Appelbaum *et al.* 1999). Accordingly, the standards sometimes categorize different patients as impaired, so that we cannot deduce a lack of impairment in other standards from lack of impairment in one standard. For a thorough examination of competence in practice, all standards should be examined since deficits in just one standard can call overall competence into question. However, the more thoroughly competence is examined, i.e. the more standards are used in assessing it, the more patients will be evaluated as not competent. The selection and combination of standards depend on previous value judgments. This influences both the content requirements as well as the threshold for defining incompetence to consent.

Compared to the patients categorized as unable to consent by clinical assessment, the proportions of patients impaired in at least one standard of the MacCAT-T was significantly higher. The discrepancy between objective testing methods and clinical assessment in evaluating competence was already described.(Rutman & Silberfeld 1997) Considering the ethical demand to both respect patients' self-determination and also to protect patients with impaired competence for their well-being (and against serious and dangerous consequences of incompetent decisions), the question arises of whether clinical assessment or objective testing methods are more suitable for satisfying this demand. In light of the discrepancy found between clinical assessment and objective testing, we must decide whether the risks of decision substitution for possibly competent patients (objective testing) are greater than the risks of possibly non-competent patients making their own decision (clinical assessment).

In our study, the MacCAT-T showed good applicability in clinical practice. Most patients in the study evaluated the interview as positive since it gave them the opportunity to discuss their illness and possible forms of therapy at length with a physician. In our experience patients have great communication needs in this regard. The patient's statement illustrates the practical significance of informed consent within the meaning of an "educational process" (Roth 1983) and evaluation of competence within the meaning of an "evolving process influenced by therapeutic interventions" (Mahler & Perry 1988). More intensive education strategies tailored for the individual patients are of major importance in this regard.

It is open to discussion if the criteria for objective testing methods are too strictly or too one-sidedly oriented towards cognitive functions while ignoring evaluation of major emotional factors, as critics remark (Elliot 1997; Charland 1998; Welie 2001). Identification of such criteria, which people with cognitive impairments base their decisions on (such as emotional, social-context-specific, and biographical), and their integration into evaluation of competence may be starting points for further research. Considering demographic developments with an increasing proportion of older people in the population such research approaches gain sizable practical significance.

Controversy surrounds the question of whether objective testing methods can replace clinical assessment of competence. A major problem lies in setting the cut-offs in the tests. In many studies, these are set on the basis of statistical considerations. Studies comparing the objective testing methods with other evaluation methods (clinical assessment, forensic-psychiatric study) range from complete agreement (Janofsky *et al.* 1992) to significant discrepancies (Rutman & Silberfeld 1997). In our study, as well, the cut-offs have the primary purpose of allowing statistical comparison of groups and illuminating deficits in examined standards; a categorical decision as to whether competence is present or absent cannot be made solely on the basis of the test results. We take the MacCAT-T to be a suitable

instrument for detecting deficits in patients' decision making abilities in a concrete case, which should be followed by a thorough clinical evaluation that also includes non-cognitive aspects.

Mental capacity can be limited by several factors e.g. depression. Empirical data suggest that patients suffering from depression show impairments of their capacity to make treatment decisions in 20-24%. Since about 50% of patients with a wish to hasten death in oncology suffer from clinical depression one must question the capacity of patients at the end of life who want to hasten death in about 10%. This is a great challenge in the assessment of patients' capacity within the process of end of life decision making and for the process of ethical decision making at the end of life.

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Table 1: Score distribution in MacCAT-T

	Patients with					
	Dementia N=31		Depression N=35		Schizophrenia N=43	
standards and score ranges	N	%	N	%	N	%
Understanding						
0.0-2.0	11	35.5	0	0.0	1	2.3
2.1-4.0	9	29.0	6	17.1	11	25.6
4.1-6.0	11	35.5	29	82.9	31	72.1
Reasoning						
0-3	16	51.6	3	8.6	20	46.5
4-5	9	29.0	12	34.3	15	34.9
6-8	6	19.4	20	57.1	8	18.6
Appreciation of disorder						
0	7	22.6	0	0.0	7	16.3
1	5	16.1	8	22.9	23	53.5
2	19	61.3	27	77.1	13	30.2
Appreciation of treatment benefit						
0	10	32.3	1	2.9	3	7.0
1	10	32.3	5	14.3	6	14.0
2	11	35.5	29	82.9	34	79.1

The following cutoffs apply for “impaired”: 4 or less for understanding, 3 or less for reasoning, 0 for appreciation of disorder, 0 for appreciation of treatment benefit.

Significance of group differences in score ranges (df=4): understanding: χ^2=30.92, p<0.001; reasoning: χ^2=22.14, p<0.001; appreciation of disorder: χ^2=26.66, p<0.001, appreciation of treatment benefit: χ^2=23.51, p<0.001.

Significance of group differences in “impaired” category (df=2): understanding: χ^2=17.76, p<0.001; reasoning: χ^2=16.81, p<0.001; appreciation of disorder: χ^2=8.24, p<0.05, appreciation of treatment benefit: χ^2=14.88, p<0.01.

Table 2: Patients with impairment (combined standards)

	Patients with					
	Dementia (N = 31)		Depression (N = 35)		Schizophrenia (N = 43)	
Standards	N	%	N	%	N	%
U and/or R	21	67.7	7	20.0	21	53.5
U and/or A1	20	64.5	6	17.1	14	32.6
U and/or A2	20	64.5	6	17.1	13	30.2
R and/or A1	17	54.8	3	8.6	20	46.5
R and/or A2	16	51.6	3	8.6	20	46.5
A1 and/or A2	11	35.5	1	2.9	7	16.3
U, R and/or A1	21	67.7	7	20.0	23	53.5
U, R and/or A2	21	67.7	7	20.0	23	53.5
U, A1 and/or A2	20	64.5	6	17.1	14	32.6
R, A1 and/or A2	17	54.8	3	8.6	20	46.5
U, R, A1 and/or A2	21	67.7	7	20.0	23	53.5

U=Understanding, R=Reasoning, A1=Appreciation of disorder, A2=Appreciation of treatment benefit

Biographical notes

Jochen Vollmann, M.D., Ph.D. is Professor and Director of the Institute for Medical Ethics and History of Medicine and Chair of the Centre for Medical Ethics, Ruhr-University Bochum, Germany. He serves as member of the Academic Senate and of the Scientific Executive Board of the Ruhr-University Research School.

He completed a clinical training in psychiatry and psychotherapy at the University Hospitals in Gießen, Munich and Freiburg and wrote his habilitation thesis on ethical problems of informed consent in psychiatry at the Free University of Berlin. Prof. Vollmann was Visiting Fellow at the Kennedy Institute of Ethics, Georgetown University Washington, DC (1994/1995), Visiting Professor at the University of California at San Francisco School of Medicine and at the Mount Sinai School of Medicine, New York (1999/2000), at the Institute for the Medical Humanities UTMB (2001) and at the Centre for Values, Ethics and the Law in Medicine at the University of Sydney (2004, 2008, 2009 and 2010).
Professor Vollmann was honoured with the Prize for Brain Research in Geriatrics by the University of Witten/Herdecke in 1999, the Stehr-Boldt-Prize for Medical Ethics of the University of Zürich in 2001, the Ruhr-University Teaching Award 2009 and the „Gaudium docendi"-Teaching Prize 2010.
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Session 3 - The person can participate in the decision
The person is in a situation that affect or limit his/her capacity to express will

Prof. Thérèse St Laurent Gagnon (Canada) – End-of-Life Decisions in the Case of Children

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Abstract

End-of-life decisions in the case of children with severe disabilities

Children with severe disabilities often have complex medical conditions: difficult-to-control convulsions, medically assisted feeding and hydration, repeated episodes of pneumonia, multiple surgical interventions, etc. Because of their poor clinical condition, their life expectancy is often limited and they are at risk of dying before the age of 18. It is difficult, however, to determine exactly when the end-of-life, which may last from a few months to several years, begins.
Many of these children, therefore, are eligible for paediatric palliative care to relieve their symptoms and discomfort, and ensure they experience the best possible quality of life. Various treatment protocols for children receiving palliative care have been developed in recent years (respiratory distress protocol, convulsion protocol).
In this clinical context, the Canadian Paediatric Society recommends discussing with parents early on about advance care planning. When is the best time to initiate this such discussion? Who should do it and how? What is the most appropriate care for the child with severe disabilities we are treating? When should the child receive more aggressive treatment for respiratory distress or pain? Some of these questions will be addressed during the presentation.

Full text

End-of-life decisions in the case of children

Decisions regarding medical treatment in end-of-life situations are often difficult to take not only for patients and their family but also for the medical staff concerned. The difficulty seems much greater in cases involving children, for example children with severe disabilities, who do not and probably never will have the opportunity to express their preferences in the matter. The following text is confined to my clinical and ethical experience with children suffering from severe disabilities and/ or in palliative care. To begin with I present some groups of children in respect of whom it may be necessary to take end-of-life decisions. There then follows a brief examination of the Canadian clinical and ethical context. Finally, a set of guidelines are given for solving the most difficult problems.
Children in respect of whom it may be necessary to take end-of-life decisions.
Children with severe disabilities often have complex medical conditions: difficult-to-control convulsions, medically assisted feeding and hydration, repeated episodes of pneumonia, multiple surgical interventions, etc. Because of their poor clinical condition, their life expectancy is often limited and they are at risk of dying before the age of 18. Many of these children are therefore eligible for paediatric palliative care.
The Royal College of Paediatrics and Child Health in Great Britain (RCPCH 2007) proposed four groups of children who might require palliative care. The first group includes children with certain pathologies, for example muscular dystrophy, who may require intensive treatment to maintain their quality of life and are at a risk of dying at an early age. The second group comprises illnesses which directly threaten the child's chances of survival but for which curative treatment does exist but may not be successful (eg: cancer, transplantation or severe congenital heart disease). Some degenerative illnesses, such as trisomy 13 or the San Filipo syndrome, the treatment of which is exclusively palliative and can last several years, belong to the third group. Finally, quite a large number of our patients suffer from cerebral paralysis or other conditions which require intensive care and make the patients particularly vulnerable (group 4). Three children with severe disabilities have died in our palliative care unit over the last two years.
Compared to adults, children seem to suffer from a wider range of pathologies that may require end-of-life decisions. It is also much more difficult to give a prognosis for children than for adults. It is not uncommon to see very ill children recovering from a serious illness and a long stay in palliative care. In this situation, it becomes apparent that it is not simple to determine exactly when the end-of-life

begins for many of these children. The terminal care which is offered to adults in the final weeks of their lives - dealing with end-of-life symptoms (pain, respiratory distress) – is often required much earlier in the development of these children's situation. What is the best moment to start a respiratory distress protocol? The pain suffered by these children is often difficult to evaluate and therefore difficult to relieve. How can we make sure that children do not suffer pointlessly?

Ethical and clinical context in Canada

The parents of children with disabilities are often faced with complex decisions that are difficult to take over a number of years. In Canada, the parents' right to decide takes precedence over the doctor's paternalism. In the case of children with severe disabilities, who cannot take part in the decision-making process, "the best interests of the child shall be the paramount consideration'' (UN, 2006). It can, however, sometimes be difficult to distinguish clearly between the interests of the child and those of the family and of the child's brothers and sisters, as they are often inseparable. Ethical discussion of the situation is recommended (Zawacki, 1995). The healthcare team works in partnership with the parents, who should as far as possible be included as "collaborative" members of the team.

In this clinical context, the Canadian Paediatric Society (CPS) recommends discussing with parents early on about advance care planning. The doctor should discuss with the parents the objectives of various types of treatment, the benefits expected for the child and the drawbacks.

The Canadian Paediatric Society believes that:

"Advance care planning is part of the standard of care for paediatricians and other health care practitioners involved in the care of paediatric patients with chronic life-threatening conditions'' (CPS 2008).

We have therefore proposed a model list of treatments to be discussed with parents.

From the clinical standpoint, Canadian doctors try to offer their patients healthcare based on the best possible scientific evidence (evidence based medicine). Several protocols have therefore been drawn up with the help of specialists in pain management and pharmacists: respiratory distress protocol, convulsions protocol, etc. These different protocols can be adjusted to meet the needs of the individual patients and facilitate communication between the different persons and doctors involved in looking after the child.

The following questions are particularly difficult: Are some of the treatments we routinely offer appropriate for all patients? When should we start talking about limiting treatment? Who is best placed to initiate such a discussion with the family when we are working in a multi-disciplinary team?

End-of-life decisions and help with making such decisions

During discussion of the care planning, one of the main decisions to be made is whether or not to provide life-sustaining treatment. This includes intubation and mechanical ventilation, the use of inotrope therapy, artificial feeding and hydration, as well as the use of anti-biotics. One of the subjects most frequently discussed by our clinical ethics team over the past year was whether to stop 'artificial' (medically assisted) feeding. Several consultations on this subject were requested. The Bioethics Committee is now considering the ethical aspects of requests to stop medically assisted feeding.

In our working environment, most decisions are taken together with the parents and the multidisciplinary team. The team includes doctors, nurses, social worker, ergotherapist, physiotherapist and respiratory therapist. The multidisciplinary team holds frequent meetings to review the child's situation, the medical grounds for treatment, and the short- and long-term objectives of the treatment. Subsequently, the key staff involved meet the parents to ensure that they fully understand their child's medical condition and the corresponding prognosis. A specific care plan is drawn up for the child, including the new care objectives. Advance care planning is included in this process.

In the event that the parents and the team cannot agree, we hold a clinical ethics consultation. The consultation is aimed at achieving closer agreement between all those concerted: the team and the parents. The fact that patients and their parents are entitled to have their own opinions acknowledged in this consultation (Doucet, 2004). Special attention is paid to the family's values. In general, all those concerned , parents and staff, are consulted individually and are equally entitled to be listened to and to give their opinion (Doucet, 2004). The different possibilities with regard to the decision are identified. (We try to propose at least three for each of the options, the following points are assessed (Doucet, 2004)):

- Define the overall objective of the treatment
- Define its clinical justification
- Policy criteria (means, consequences, guidelines for assessing the situation)
- Arguments for or against the action (medical, deontological, legal, ethical body)
- Identification of the consequences for each of the persons concerned (patient, family and friends, carers, society, mankind?)

The ultimate aim of these meetings is to reach the best possible decision in respect of each individual child, by fostering an ethical dialogue between the staff involved and the parents. Some more complex situations raise questions which continue to stimulate debate, in particular everything relating to stopping, or deciding not to start, artificial feeding and hydration.

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Biographical notes

Dr St-Laurent-Gagnon is currently an Associate Professor of Pediatrics and Ethics at Montreal University, a general paediatrician at the Centre de réadaptation Marie-Enfant. Dr St-Laurent-Gagnon is also a member of the ethics committee at the Hospital Sainte-Justine (Montreal) and at the Canadian Pediatric Society. Having done her pediatric training at the Montreal University, Dr St-Laurent-Gagnon also completed a master's degree in clinical epidemiology at Mc Master University (Hamilton) and a doctorate thesis in bioethics at Montreal University. Dr St-Laurent-Gagnon was director of the home palliative care program for more than ten years at the Hospital Ste-Justine. Her doctorate thesis was: Research in children in palliative care: Norms and ethical dilemma. Her research interests include: Pain in children, pediatric palliative care, and research involving children in palliative care.

Session 3 - The person can participate in the decision
The person is in a situation that affect or limit his/her capacity to express will

Prof. Ergun Özsunay (Turkey) – Participation in the Decision by the Person who is in a Situation that Affects or Limits His/Her Capacity to Express Will

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Abstract

End of life care is the treatment of a seriously ill patient in cases where curative treatment has been abandoned and the progression of the illness can no longer be influenced. *End of life care decision* is a medical decision made by the physician in full consultation with the patient or patient's representatives. This presentation deals with the issues related to *participation of persons who are in a situation that affects or limits their capacity to express will in decision making process regarding medical treatment in the end of life situations.* This issue has been examined in the light of Oviedo Convention, some State laws in the US and some national jurisdictions on the Continental law (eg German, Austrian, Swiss and Turkish laws).

Regarding the end of life decision it should be emphasized that every patient has the *right of self determination.* The patient has the right to demand the treatment be discontinued as well as the right to decline all treatment. This right belongs to the *"rights strictly bound to person"* (höchstpersönliche Rechte). The patient's right to self-determination in this matter should be respected.

Persons who are not able to consent are *"incapacitated persons"* (ie mentally ill, feeble minded) and *"minors who do not have the capacity to consent"* (ie "power of discernment). Incapacitated persons are normally under *guardianship* or *custodianship.* Minors are normally under *parental care*, exceptionally under the *care of a guardian*. Parents and guardian or custodian are *legal representatives*.

Regarding the *decision of end of life care* the *guardian's consent* as the *legal representative* of an incapacitated person does not suffice. An *order from the Guardianship Court* or *Custodianship Court* should be provided. In making such a decision the *advance directives of the patient* (ie patient's instruction; Patientenverfügung) should be taken into account. *Patient's previously expressed wishes* should be respected. The *incapacitated patient* should as far as possible take part in the decision of the end of life care.

Regarding the *minors* a distinction can be made: (a) If a *minor is under the parental care* only his/her parents' consent is not sufficient for making a decision for the end of life care. A *curator* (Beistand, curateur) should be appointed by *Guardianship Court* in order to assist the minor's parents with regard to the decision of end of life care. The presenter thinks that it would not be a *realistic approach* to request the *child's opinion in decision making for end of life care*. (b) If *a minor is under the guardianship,* his guardian should obtain an *order from Guardianship Court* relating to the decision for the end of life care.

The self determination is essential in respecting the human rights and dignity of each person as human being. Therefore regarding the decision of end of life care *advanced directives* and *durable powers of attorney* play an important role. For this purpose these measures should be promoted in near future in order to cope with the serious difficulties related to decision of end of life care.

Full text

Participation in the Decision by the Person who is in a Situation that Affects or Limits His/Her Capacity to Express Will

A. "End of life care" and "end of life care decision"

End of life care is the treatment of a seriously ill patient in cases where curative treatment has been abandoned and the progression of the illness can no longer be influenced. The aim of the end of life care is the alleviation of suffering. End of life care refers to the active care of a patient who is close to death. It is treatment and support in the final stages of illness and during the process of death[5].

End of life care, **terminal care** and **palliative care** are partly overlapping concepts. All of them are often used to refer to symptomatic treatment[6].

End of life care decision is a **medical decision** made by the physician in full consultation with the patient or the patient representative[7].

This paper deals with the issues related to **participation of persons who are in a situation that affects or limits their capacity to express will in decision making process regarding medical treatment in the end of life situations**.

B. Categories of persons not able to consent

Persons not able to consent can be distinguished into two categories:

First category comprises the **"incapacitated adults"**: These are the **"adults who do not have the capacity to consent to an intervention because of a mental disability, feeble mindedness, disease or for similar reasons"** (Cf Article 6, No. 3, Oviedo Convention)[8].
The incapacitated adults are normally under the protection of a **"guardian"** (Vormund) (eg. Article 369 et seq. Swiss Civil Code [ZGB]) ; Article 404 et seq. Turkish Civil Code 2001 [TCC]) or a **"custodian"** (Betreuer) (§ 1896 German Civil Code [BGB]).

Second category covers the **"minors who do not have the capacity to consent"** (Cf Article 6 No. 2, Oviedo Convention). **Minors** are normally under the **parental care** (eg Article 296 ZGB; Article 335 TCC 2001; § 1896 BGB)[9].

A guardian is appointed for every minor who is not under the parental care (eg Article 368 ZGB; Article 404 TCC 2001)[10].

C. Legal representation of persons without capacity or with limited capacity under "Oviedo Convention"

I. Under the **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine** (The Oviedo Convention) of 4 April 1997 (ETS No. 164), "an **intervention** in the health field may only be carried out after the person concerned has given **free and informed consent** to it" (Article 5 para.1)[11].

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[5] See *The National Advisory Board on Health Care Ethics* (ETENE), End-of-Life Care- Memorandum of the National Advisory Board on Health Care Ethics, Report of the Working Group, Helsinki, 17 September 2003, pp. 5-6.
[6] *Terminal care* is end of life care that directly precedes death. *Palliative care* is the comprehensive care of the patient whose illness cannot be cured and where prolonging the patient's life is not the only aim of treatment. It is not bound to the closeness of death and can last up several years depending on the illness. See *The National Advisory Board on Health Care Ethics* (ETENE), End-of-Life Care- Memorandum of the National Advisory Board on Health Care Ethics, Report of the Working Group, p. 6.
[7] It can be a single decision concerning the line of treatment or the final result of a long process during which it has become clear that the patient's illness cannot be cured. See *The National Advisory Board on Health Care Ethics* (ETENE), End-of-Life Care- Memorandum of the National Advisory Board on Health Care Ethics, Report of the Working Group, p. 5.
[8] An "adult" is a person who has reached the age of 18 years. See "The *Hague Convention on International Protection of Adults"* (concluded on 13 January 2000), Article 2.1.
[9] *Their parents* are their *legal representatives*. Parental responsibilities cover legal representation as well as care and protection. See the Commission on European Family Law, *Principles of European Family Law Regarding Parental Responsibilities*, Principle 3:1; Committee of Experts on Family Law, *Draft Instrument on the rights and legal status of children and parental responsibilities*, Article 28 (CJ-GT3 (2010)2).
[10] A person other than a parent (third person) may exercise some or all parental responsibilities in addition to or instead of the parents Commission on European Family Law, *Principles of European Family Law Regarding Parental Responsibilities*, Principle 3:17. Cf Committee of Experts on Family Law, *Draft Instrument on the rights and legal status of children and parental responsibilities*, Article 31 (CJ-GT3 (2010)2)
[11] This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any tine (Article 5 paras. 2 and 3)

II. Article 6 of the Convention deals with the **"protection of persons not able to consent"**. "An intervention may only be carried out on a person who does not have the capacity to consent, for **his or her direct benefit**" (Article 6 No. 1)[12].

1. Incapacitated persons: An intervention may only be carried out on an **"adult who does not have the capacity to consent to an intervention because of a mental disability, disease or for similar reasons"** with the **authorization of his/her representative** or an **authority** or a **person** or **body** provided by law (Article 6 No. 3, Oviedo Convention)[13]

Nevertheless, the incapacitated person shall as far as possible take part in the authorization process (Article 6 No. 3, Oviedo Convention)[14].

Moreover, the **previously expressed wishes** relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account (Article 9).

2. Minors who do not have the capacity to consent: "Where a **minor does not have the capacity to consent** to an intervention, the intervention may only be carried out with the authorization of **his or her representative** or an **authority** of a **person** or **body** provided by law" (Article 6 No. 2)[15].

The **opinion of the minor** shall be taken into consideration as an increasingly determined factor **in proportion to his/her age and degree of maturity** (Article 6 No. 2)[16].

D. National Jurisdictions

I. U.S.

1. In general

"Capacity" is the ability to understand relevant information and make decisions to meet one's essential needs. Adults are presumed by law to have capacity, unless a court rules otherwise. Adults with capacity have the right to make decisions affecting their person (i.e. living arrangements, health care etc.) or property[17].

Under the **Uniform Guardianship and Protective Proceedings Act of 1982** (UGPPA) a **person is incapacitated** when the person is "impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication or other cause (except minority) to the extent that he lacks sufficient understanding or capacity to make or communicate responsible decisions concerning their persons"[18].

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[12] Regarding *"scientific research"*, the Convention provides additional requirements for the *"protection of persons not able to consent to research"* (Article 17). Likewise, a specific provision of the Convention protects the *"persons not able to consent to organ removal"* (Article 20).

[13] The representative, the authority, the person or the body shall be given the *appropriate information* (Article 6 No.4 in connection with Article 5). The authorization may be withdrawn at any time in the *best interests of the person concerned* (Article 6 No. 5).

[14] The Oviedo Convention provides also s*pecific protection of persons who have a mental disorder* of a serious nature. Under Article 7 "subject to protective conditions prescribed by law, including supervisory, control and appeal procedures, a person who has a mental disorder of a serious nature may be subjected, without his/her consent, to an intervention aimed at *treating his/her mental disorder* only where, without such treatment, serious harm is likely to result to his/her health"

[15] The representative, the authority, the person or the body shall be given the *appropriate information* (Article 6 No.4 in connection with Article 5). The authorization may be withdrawn at any time in the *best interests of the child* concerned (Article 6 No. 5).

[16] This provision complies with the *Convention on the Rights of the Child* (adopted by General assembly resolution 44/25 of 20 November 1989). According to this Convention, a child who is capable of forming his/her views has the right to express those views freely in all matters affecting the child. The views of the child shall be "due weight in accordance with the *age and maturity of the child*" (Article 12 No. 1).

[17] States have different tests for deciding whether someone has capacity to make decisions. Some are based on whether a person has a particular condition (such as mental illness, mental retardation or dementia). Some are based on whether a person is able to make or communicate decisions. Others are based on the person's ability to do certain things such as manage money or make health care decisions. And some combine some or all of these factors. See *ABA (American Bar Association)*, Facts About Law and the Elderly, A professional Guide to Capacity and Guardianship, (Division for Media Relations and Public Affairs), 1996, p. 9.

[18] According to the revised UGPPA of 1997, a person is incapacitated when, such a person is unable to receive and evaluate information or make or communicate decisions to such an extent that he lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technical assistance. See *Am.Jur. 2nd*, Guardian and Ward: § 30,

Incapacitated persons are under the protection of a guardian.

Guardianship is a relationship created by state law in which a court gives one person (the guardian) the duty and power to make personal and/or property decisions for the ward or legally incapacitated person[19].
The **guardian** owes the incapacitated person a special duty of care regarding his health[20].

If the patient has given a **durable power of attorney** (DPA) which allows a capable person to grant another person authority to act for him if incapacity occurs or if there is an **advanced directive**, medical providers should take them into account[21].

The guardian need only use good judgment concerning routine medical care (ie. regular checkups or treatments). As regards the life threatening or terminal condition, special attention and quite often, court intervention is required. Therefore, the guardian should be prepared to review any **existing health-care directives in advance**, and have them ready for consideration by the **doctors** and **judges[22]**.

Medical providers cannot treat an individual against his wishes, including wishes contained in an **advanced directive** (AD) or contrary to the decision of the **patient's authorized proxy[23]**.

2. State laws

a) Washington State

West Group, 2000. The same definition can be found in Colorado law. See CRS § 15-14-1001(1)). In Iowa law, "incapacitated person" is the person who is unable to make or carry out important decisions by reason of mental, physical or other incapacity". See *Pat M. Keith/Robbyn R. Wacker*, Older Wards and Their Guardians, Praeger, 1994, p. 156.

[19] Guardianship historically has been a matter of state, as opposed to federal, jurisdiction. Every state has enacted statutes that empower the courts to appoint guardians for incapacitated persons. See Am.jur.2nd., Guardian and Ward, § 21. Most state guardianship statutes are similar in the content. See *Georg H. Zimny/George T. Grossberg*, Guardianship of the Elderly, Springer Publishing Company, 1998, p. 16 et seq. Further see *ABA*, p. 9. For *state laws* see New York: Mental Hygiene Law (§§ 81.01 through 81.43); Minnesota: Minn. Stat. Ann. § 524.5-5-101 through 524.5-502; California: California Prob. Code §§ 1400 to 3803; New Jersey: New Jersey Stat. Ann. §§ 3B:1-1 to 4:83-12; Connecticut: Gen. Stat. Ann. §§ 45-70 to 77; Colorado: Rev. Stat. §. 15-14-301 to 402. For a list of state statutes see Table 2.1 in *Zimny/Grossberg*, p. 19. Further for State Public Guardianship Statutory Charts see *Pamela B. Teaster/Winsor C. Schmidt Jr/Erika F. Wood/Susan A. Lawrance/Marta S. Mendiondo*, Public Guardianship, In the Best Interests of Incapacitated People ?, Praeger, 2010, pp. 173-182). Almost every sate in the U.S. revised their guardianship laws between 1980 and 2000. See *Mary Joy Quinn*, Guardianships of Adults, Achieving Justice, Autonomy, and Safety, Springer Publishing Company, 2005, p. 236.

[20] See *ABA*, p.9. The guardian of an *infant* is ordinarily entitled to the infant's custody, and is under a duty to care for the ward. See *Corpus Juris Secundum*, Volume 39, Thomson-West, 2003, § 51. The guardian has the authority and the duty to make appropriate decisions regarding the ward's health. Thus, the court appointed guardian of an *incapacitated person* has the legal right to choose the physician to treat and care for the medical needs of the ward. In the jurisdictions that have adopted the UGPPA, the guardian also is specifically authorized to consent to medical or other care, treatment, or service for his ward. *Am.Jur. 2nd*: Mentally Impaired Persons, § 93.

[21] A *durable power of attorney for health care* (DPA) is a *proxy of advance directive*. It identifies and designates a named person or persons (the agent) to make decisions about the patient's care if and when the patient is incapable of doing so. A key concept underlying the DPA for health care is that the agent will exercise "substituted judgment", that is, the agent will make decisions that are consistent with what the patient would have decided for himself under the circumstances. See *W. Eugene Bosanta/Dale H. Cowan,* The Rights of the Terminally Ill - Withdrawal of Supportive Care and Physician-Assisted Suicide, Paper submitted to the Congress of International Association of Medical Law, Toulouse, 7-11 August 2006, p.13. Every state has a health care proxy law. Michigan and New York have also a "living will" statute. See *ABA*, p. 12. *Advanced directive* is a written instruction, such as a living will or durable power of attorney for health care under state statutory or case law, relating to the provision of health care when the individual is incapacitated. See *Am. Jur. 2nd*: Social Security and Medicare, § 2045.Advance directive refers to a written statement executed by a competent adult designed to medical personnel, family members, and others, information as to the person's wishes regarding the nature and extent of medical care to be provided in the future should he lose decision-making capacity. As such, an advance directive can apply to any medical care decisions. However, they are generally associated with life-sustaining treatment and end-of-life care. See *W. Eugene Bosanta/Dale H. Cowan,* p. 9.

[22] See *Scott K. Summers*, Guardianship and Conservatorship, ABA Senior Lawyers Division, 1996, pp. 116-117.

[23] The physician or health care facility must know about the AD in order to implement it. It is up to the patient and those close to the patient to ensure that everyone who might need a copy of the directive has a copy. Sometimes, vague language in a directive does not give much guidance, and even giving a proxy broad authority to interpret one's wishes does not help much if the proxy is not sure what the patient would want done. Most states permit a physician or facility to refuse to honor an advance directive based on reasons of conscience, but the facility must notify the patient of its policies regarding advance directives at the time of admission, and should provide assistance in transferring the patient to a provider who will comply with the directive. It should be noted that emergency medical personnel are required in most states to resuscitate and stabilize patients. See *ABA*, p. 19.

In Washington State, there are two mechanisms for effectuating an incompetent individual's right to make health care decisions: **advance directives** and **surrogate decision-making**. In the absence of an advance directive; state law allows surrogates to make medical decisions for incompetent individuals. In Washington, the persons authorized to make medical decisions (surrogate decision-makers) on behalf of an incompetent individual are as follows, in order of priority: (i) the appointed guardian of the patient, if any; (ii) the individual, if any, to whom the patient has given a durable power of attorney that encompasses the authority to make health care decisions; (iii) the patient's spouse or date registered domestic partner; (iv) children of the patient who are at least eighteen years of age; and (v) adult brothers and sisters of the patient[24].

b) Minnesota

Under Minnesota law regarding the end-of-life care decision the guardian should consider the **ward's currently expressed wishes**, as well as all available information about the **ward's past religious beliefs, values, and expressed wishes**. The guardian should also seek input from **involved family members[25]**.

In some cases, the guardian may need to request a **hearing** to obtain a **probate court's decision** on whether the treatment should be authorized or withheld. Depending on the circumstances, **decisions to authorize termination of life-support** may also require a **court order[26]**.

Consent for orders of DNR (Do Not Recussitate), withholding or withdrawing ventilators for assisted breathing, withholding or withdrawing artificially administered nutrition and hydration, or therapies such as kidney dialysis, chemotherapy or radiations need additional consideration. In such cases **all interested parties** should be involved so that all viewpoints are represented. **All family members who are involved with the ward's care** should be included and any other family members who reasonably wish to be included should also be notified[27].

c) New York

Guardianship of mentally retarded and disabled persons is governed by the provisions of the **Surrogate's Court Procedure Act**. Guardianship courts are of the opinion that the authority of a **"personal needs guardian"** to make major medical decisions does not include the **right to make decisions regarding the use or withdrawal of life sustaining treatment**.

Despite legislative direction to the contrary, in actual practice, many courts ignore the **Mental Hygiene Law** and apply their own **"best interests"** analysis as to whether to authorize the continued use of advanced directives, such as powers of attorney and health care proxies, that were purportedly executed at the time when the incapacitated person had capacity[28].

II. Continental European jurisdictions

1. German law

a) Adults who cannot carry out his/her business

aa- Appointment of a "custodian" (Betreuer)

[24] See *Washington Health Law Manual*. While the statute dictates a rather rigid hierarchy for surrogate decision-making, in practice, health care providers naturally to turn to family members and loved ones to make medical decisions for incompetent patients. See at http://www.wsha.org/page.cfm?ID=EOL-SurrogateDecisions. Further see *Karna Halverson*, Voluntary Admission and Treatment of Incompetent Persons with a Mental Illness, William Mitchell Law Review, Vol. 32:1, pp 173 -175.
[25] See *Minnesota Conference of Chief Judges Pending*, Guardianship and conservatorship in Minnesota, 2003 Amended 2009, 2010, p. 35. The procedures for admission and treatment of a person with a mental illness in Minnesota are contained in the Minnesota Commitment and Treatment Act. See *Karna Halverson*, p. 176. On "Third Party Decision Makers" see pp. 180-183.
[26] Pyschosurgery, electro-convulsive therapy (ECT), sterilization, experimental treatment of any kind, or treatment which violates the known religious, conscientious, or moral beliefs of the ward requires *court approval after a special court hearing*. See *Minnesota Conference of Chief Judges Pending*, Guardianship and conservatorship in Minnesota, 2003 Amended 2009, 2010, p. 35.
[27] *Ibid*.
[28] See *Guardianship Practice in New York State*, Volume Two, S 10-2.

Under German law if an **adult cannot carry out his/her business because of a disease or a physical or psychological or mental disorder**, a **"custodian"** (supervisor, Betreuer) is appointed for him by the **"Custodianship Court"** (Betreuungsgericht) (§ 1896 German Civil Code)[29].

Normally, a **"custodian"** is appointed upon the request of the **person who cannot carry out its business** provided that he cannot declare his intention[30].

A request for appointment of a "custodian" made by the **person who has not the capacity to act** (Geschaeftsunfaehigkeit) is taken into account by the court (§ 1896 Al. 1 s.1).

A **"custodian"** can only be appointed for the "sphere of duties" to which the care is necessitated. **Custodianship** (Betreuung) is not necessary as long as the business of an adult (major) can be carried out by a **"representative"** (Bevollmaechtigte) or through the assistance of other persons (§ 1896 Al. 2)[31].

§ 1901a German Civil Code deals with **"patient's instruction"** (Patientenverfügung, patient's will). If an adult (major) who has capacity to consent had determined in written the medical intervention or treatment should be carried out or ceased when he becomes **incapacitated** (Einwilligungsunfaehigkeit), the **"custodian"** examines whether this determination is true in the light of the current living and treatment situation. If the custodian determines that the patient's instruction is true, then he has to make this will valid (§ 1901a No. 1)[32].

If there is no patient's instruction or the custodian's examination shows that the patient's instruction does not seem true regarding the current living and treatment situation (of the patient), the custodian should try to detect the **"wish of the patient for treatment"** or his **"presumed will"** (mutmasslicher Wille) of the person under custodianship. Thereupon the "custodian" decides whether the patient's instruction is in favor of medical intervention or against it. The "presumed will" should be ascertained in the light of the concrete indications. In this process, the **oral or written statements made previously by the patient, his ethical or religious convictions** and **other personal value judgments** should be taken into account by the "custodian" (§ 1901a No. 2)[33].

bb - Approval of "Custodianship Court" (Betreuungsgericht) with regard to "medical measures"

Under § 1904 No. 1 BGB "any consent by the custodian to the examination of the health of the person under custodianship, to therapeutic treatment or to operations requires the **approval of the Custodianship Court** if there is justified cause to assume that the person under custodianship risks dying as a result of the measure, or may suffer serious and long term damage to his health. Failing such approval, the measure may be performed only if postponing it would entail danger". The approval is granted if the consent or refusal to consent, or revocation of consent corresponds to the **will of the person under custodianship**" (§ 1904 No. 3 BGB)[34].

The provisions of § 1904 Nos. 1 - 4 apply to the *"representative"* (der Bevollmaechtigte) of the patient (§ 1904, No. 5).

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[29] For the concept of *"Betreuung"* in German law see *Anne Röthel*, Betreuung (rechtliche Fürsorge) für Erwachsene, in "Handwörterbuch des Europaeischen Privatrechts", (Hrsg.: Jürgen Basedow/Klaus J. Hopt/Reinhard Zimmermann), Band I, Mohr Siebeck, 2009, p. 200 et seq. In this study we prefer to use the words *"custodianship"* in return for "Betreuung", *"custodian"* in return for "Betreuer", *"person under custodianship"* for "Betreuter", and *"Custodianship Court"* in return for "Betreuungsgericht".

[30] Against the *free consent of an adult* (full capacitated person) a custodian cannot be appointed (§ 1896 Al. 1a).

[31] The *representative* (Bevollmaechtigte) does not belong to the group of persons defined in § 1897 Al. 3 German Civil Code.

[32] Nobody is enforced to make a *patient's instruction*. Further, making a patient's instruction cannot be stipulated as a *condition* for conclusion of a contract (§ 1901a No. 4).The patient's instruction can be revoked at any time without any formality (§ 1901a No. 1). For detail see *Diederichsen,* in Palandt, Kommentar zum Bürgerlichen Gesetzbuch mit Nebengesetzen, 69. Auflage, München, 2010, § 1901a Rn. 10, 26 et seq.

[33] See *Diederichsen,* in Palandt, BGB § 1901a Rn. 26 et seq.

[34] See *Diederichsen,* in Palandt, BGB § 1904 Rn. 16 et seq. For further details see *Erwin Deutsch/Andreas Spickhoff*, Medizinrecht - Arztrecht, Arzneimittelsrecht, Medizinproduktrecht und Transfusionsrecht, 6. Auflage, Berlin, 2008, Rn. 691 See also *Christian Berger*, in Jauernig, Bürgerliches Gesetzbuch-Kommentar, 13. Auflage, München, 2009, §§ 1896-1908a, Anm.§ 21. "The *approval* provided for in paragraphs 1 and 2 shall not be required if the *custodian* and the *physician treating the patient* concur in that the consent, the refusal to consent or the revocation of consent correspond to the *will of the person under custodianship* determined in accordance with § 1901a" (§ 1904 No. 4).

b) Minors: A minor's parents have the duty and right for the **care of the minor** (parentel care, elterliche Sorge). The parental care covers the **care for the person** (Personensorge) and property of the minor (§ 1626)[35].

Parents having parental responsibilities have an equal right and duty to exercise these responsibilities. Parental responsibilities encompass normally the authorization of the medical treatment on the minor. **Decision on cessation of the treatment at the end of life** cases is a part of the parental care or responsibilities[36].

2. Austrian law

a) In Austrian law **minors** (Minderjaehrige) are under the care (Pflegeschaft) of their parents § 144 (ABGB, Austrian Civil Code). **Parents** have the duty to take care of their children. Duty of duty includes to take care of the welfare and development of physical and moral powers of the child (§ 146.1). In the exercising of the duty of care, the opinion and wish of the child should be taken into account (§ 146.4). The **foster parents** (Pflegeeltern) should exercise also the same duty of care (§ 186)[37].

Regarding medical treatment of a **"minor without power of discernment"** the consent of his parents is required (§146c.1). If the minor has the **"power of discernment"** his opinion should be taken into account (§ 146c.1)[38].

b) **Mentally impaired adults** and **other mentally handicapped persons** (behinderte Personen) are protected by appointment of a **"curator"** (Sachwalter) (§§ 268, 273 ABGB)[39].

c) End-of-life care decision

Regarding end-of-life care decision curator's consent (Sachwalter) is rather important. Handicapped persons to whom a curator has not been appointed can be represented by their **next of kin** (close relatives, naechste Angehörige) (§ 284b ABGB). **"Close relatives"** are the parents, children of full age, married spouse or the person living together in the same house for at least three years (§ 284c ABGB).

Regarding the end-of-life care decision the **"patient's instructions"** (Patientenvefügung) and **"power of attorney for health care"** (Vorsorgevollmacht) are taken into account (§ 273 ABGB)[40].

3. Swiss law

In Swiss law ,**"persons without the power of discernment"** (incapacitated persons, die Personen, die nicht urteilsfaehig sind) or **"minors"** (Unmündigen) or **"persons under guardianship"** (Entmündigten) do not have the **"capacity to act"** (handlungsunfaehig, Article 17 ZGB). **"Minors having the power of capacity"** (Urteilsfaehige unmündige) or **"persons under guardianship"** can bind themselves only with the consent of their "legal representatives" (Article 19.1 ZGB). Nevertheless they do

[35] See *Rakete-Dombek*, in Nomos Kommentar, Bürgerlichesgesetzbuch-Familienrecht, (Hrsg.: Kaiser, Dagmar/Schnitzler, Klaus/Friedrich, Peter, Band 4: §§ 1297-1921, 2. Auflage, Baden-Baden, 2010, § 1926, Rn. 10 et seq. See also *Anne Röthel*, Vormundschaft (rechtliche Fürsorge) für Minderjaehrige, in "Handwörterbuch des Europaeischen Privatrechts", (Hrsg. Jürgen Basedow/Klaus J. Hopt/Reinhard Zimmermann), Band II, Mohr Siebeck, 2009, p.

[36] See Oberlandesgericht Brandenburg, NJW 2000, p. 2361 et seq.; Oberlandesgericht Hamm, NJW 2007, p. 2704 et seq. For further details see *Balloff,* in Zivilrechtliche Regelungen zur Absicherung der Patientenautonomie am Ende des Lebens – Eine internationale Dakumentation/Regulations of Civil Law to Safeguard the Autonomy of Parties at the Ende of Their Life – An International Documentation, (Hrsg.: Jochen Taupitz), Berlin-Heidelberg, 2000, Rn. D 106.

[37] On *"duty of care"* (Obsorgepflicht) and *"joint care"* (gemeinsame Obsorge) see *Fenyves/Kerschner/Vonkilch*, ABGB, 3. Auflage des von Heinrich Klang begründeten Kommentars, §§ 137-267, Wien, 2008, § 144, Nr 12. On the content of *"duty of care"* see *Schwimann*, ABGB Praxis Kommentar, 3., neubearbeitete Auflage, Band 1, §§ 1-284 ABGB, (herausgegeben von Michael Schwimann/Bea Verschraegen), Wien 2005, ,§ Nr. 144 Nr. 3 and § 145 Nr. 7.

[38] In case of doubt a "minor" is assumed to have the "power of discernment and comprehension" (§ 146c. 1). See *Schwimann*, ABGB Praxis Kommentar, § 146c Nr. 11. Further see *Fenyves/Kerschner/Vonkilch*, ABGB, 3, § 146c Nr.2. On *medical measures which are not aimed at health treatment* see § 146c Nr. 55-73. On *medical experiments* see § 146 Nr. 55-56.

[39] On the concept of *"curator"* (Sachwalter) see *Koziol-Welser,* Bürgerliches Recht, Band I: Allgemeiner Teil, Sachenrecht, Familienrecht (bearbeitet von Andreas Kletečka), 13. Auflage, Wien, Manz, 2006, p. 565 et seq. Further see *Müller/Prinz*, Sachwalterschaft und Alternativen, Ein Wegweiser, nv Verlag; *Kozial/Bydlinski/Bollenberger*, ABGB, Kommentar, 2., überarbeitete und erweiterte Auflage, Springer Wien.New York.

[40] See also *Bundesgesetz über Patientenverfügungen* (Patientenverfügungs-Gesetz-PatVG) of 8 May 2006 in BGBl.I, Nr. 55.

not need the consent of the representative when they exercise the **"rights bound strictly to the person"** (höchstpersönliche Rechte) (Article 19.2 ZGB)[41].
Under Swiss law **"incapacitated persons"** (ie "minors who do not have the power of discernment under parental care" and "mentally ill or feeble minded persons under guardianship") are represented by their **"legal representatives"** (ie by their "parents" of "guardians").

a) Minors

aa- **"Minors"** (unmündig) are under the **"parental care"** (elterliche Sorge) (Article 296 ZGB). If the child is entrusted to **"foster parents"** (Pflegeeltern), they carry out the parental care (Article 300 ZGB). The parents or foster parents are "ipso iure" the "legal representatives" of the minor. Minors are represented by their "legal representatives" (Article 304.1 ZGB)[42].

Minors under parental care have **"limited capacity to act"** like **"persons under guardianship"** (Article 305.1 ZGB). If the welfare of the child is endangered and his parents do not take the necessary measures, the **"guardianship authorities"** (Vormundschaftsbehörde) take the appropriate measures for the protection of the minor (Article 307.1). The "guardianship authorities" are entitled to warn and instruct the parents or foster parents (Article 307.2). Moreover, if the circumstances necessitate, the "guardianship authorities" may appoint a **"curator"** (Beistand) to the minor. "Curator" is authorized to support the parents for fulfillment of the parental duty of care[43].

bb- In case of decision related to medical treatment following aspects can be distinguished:

If the **minor under parental authority has the power of discernment**, regarding the decision of the medical treatment not only his parents consent (or his guardian's consent), but also the minor's consent should be provided. The minor's consent is a **"right strictly bound to the person"** (höchstpersönliches Recht).

If the **minor does not have the power of discernment** the decisions belongs to his parents. Nevertheless, regarding the end-of-life care decision the **approval of the "guardianship authorities"** is required.

b) Persons under guardianship

aa- Under Swiss law, **every person of full age** who, by reason of mental illness or mental weakness**, is incapable** to manage his business is put under **"guardianship"** (Article 369)[44].

Likewise, a guardian is appointed to **a minor who is not of age and not under parental care** (Article 368 ZGB)[45].

Guardian (Vormund, tutelle) is the "representative" of the "minor" and the "ward" (der Bevormundete, la pupille). He should try to protect their all personal and property interests (Article 367.1).

Where a person of full age by reason of illness, absence or other similar cause cannot in some urgent matter act personally or appoint another to act for him a **"curator"** (Beistand, curatelle) is appointed[46].

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[41] Two categories of *"rights bound strictly to the person"* are distinguished: the *rights bound strictly to the person absolutely* (absolute höchstpersönliche Rechte) and the *rights bound strictly to the person relatively* (relative höchstpersönliche Rechte). *Consent to medical interventions* belongs to the second category. See *Kommentar zum Schweizerischen Privatrecht*, Schweizerisches Zivilgesetzbuch I, Art. 1-39 ZGB (Herausgeber: H. Honsell/N.P. Vogt/T. Geiger), Helbing & Lichtenhahn, 1996, Art. 19, Nr. 33 and 401-41.

[42] *Every minor who is not under the parental care* is under *"guardianship"* (Vormundschaft , Article 368 ZGB). In such a case the *legal representative* is the *"guardian".* The *parental care* is fulfilled by the guardian (Article 405 ZGB).

[43] Thus the "parental care" can be restricted. See Article 308 ZGB.

[44] An expert report is required for the guardianship on the ground of mental illness or weakness (Article 374.2 ZGB).

[45] For other situations which necessitate the "guardianship" see Articles 370-372 ZGB. Guardianship organs are *"guardianship authorities"* (vormundschaftliche Behörde, l'autorité tutélaire), *"guardian"* (Vormund, le tuteur) and *"curator"* (Beistand, le curateur). Regarding the procedure of appointment of guardian see Article 379 et seq. ZGB.

[46] Likewise, where the legal representative of a person under guardianship has interests in some transaction which are in conflict with those of the person for whom he is acting (ie a minor or ward), a *curator* is appointed (Article 392 ZGB).

bb- Regarding the **decision related to the medical treatment at the end of life** the following situations can be distinguished:

If the **person under guardianship** (the ward) **has the power of discernment**, for the decision of the medical treatment at the end of life the consent of his guardian is not enough. His consent should also be provided as the patient's consent for medical treatment is a **"right strictly bound to the person"** (höchstpersönliches Recht).

If the **guardianship is based on mental illness or weakness** and **the person under guardianship does not have the power of discernment**, the decision related to medical treatment will be based on the consent of the guardian as his legal representative. Nevertheless, the **approval of the "guardianship authorities"** is requested.

4. Turkish law

Regarding the legal status of **incapacitated** or **limited capacitated persons**, the solutions of the Turkish law are not much different from the Swiss law as the **former Turkish Civil Code** of 1926 and the **new Turkish Civil Code** of 2001 are modeled on the Swiss Civil Code[47].

1. **Incapacitated persons** impaired by reason of mental illness or physical disability are under the protection of guardianship (Article 405 TCC). Guardians are their **legal representatives** (Article 448 TCC 2001). **Regarding the end of life care decision** only the guardian's consent does not suffice. A **court order by the Guardianship Court** (ie Court of Peace) should be provided (Article 397 para. 1 TCC 2001)[48].

Regarding the decision of end of life care the **opinion of the person who does not have the capacity to** consent should be taken into account[49].

2. Under Turkish law **minors** (under the age of majority) ***having the power of discernment*** or **without it** are normally under the parental care (Article 335 para. 1 TCC 2001)[50].

The parents of minors are their *legal representatives* (Article 342). Parents' consent is required for medical treatment. As regards the **decision of end of life care** only the parents' consent does not suffice. A **curator** (Beistand, curatelle) should be appointed by the guardianship authorities (ie Court of Peace and Court of First Instance) (Article 426 TCC 2001). Curator should act for the best interests of the minor and assist his parents and family regarding the end of life decision.

E. Concluding remarks: Some Recommendations

The outcome of this study can be summarized as follows.

I. End of life care is the treatment of a seriously ill patient in cases where curative treatment has been abandoned and the progression of the illness can no longer be influenced. The aim of the end of life care is the alleviation of suffering.

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[47] For several types of *"reception of foreign law "* and particularly *"total reception of foreign codes"* during the Ottoman Empire and after the foundation of the Republic of Turkey see *Ergun Özsunay*, Legal Science During the Last Century in Turkey, Inchieste di diritto comparator, "La Science du droit au cours du dernier siècle", Padova, 1976, pp. 695 et seq.; *Ergun Özsunay*, The Total Adoption of Foreign Codes in Turkey and Ist Effect, in "Le Nuove Frontiere del Diritto e Il Problema Dell'Unificazione", Università degli Studie di Bari, Milano, 1979, Vol. II, pp. 803 et seq.; *Ergun Özsunay*, Some Remarks on the Amendments Proposed by the Preliminary Draft of the Turkish Civil Code, "Liber Memorialis François Laurent 1810-1887", (Editors: J. Erauw/B. Bouckkaert/H. Bocken/H. Gaus/M. Storme), E. Strory-Scientia, Bruxelles, 1989, pp. 605 et seq.; *Ergun Özsunay*, Religious Fundamentalism: Turkish Experience, Universidade da Coruna, Nacionalismo en Europa-Nacionalismo en Galicia, La religion como elemento impulsar de la ideologia nacionalista, Simposio internacional celebrado en: Pazo de Marinan A Coruna, 4-6 Septiembre 1997, NINO Centro de Impresion Digital, 1997, pp. 116 et seq.; *Ergun Özsunay*, Karşılaştırmalı Hukuka Giriş (Introduction to Comparative Law), Istanbul, 1978, pp. 269 et seq.; *Ergun Özsunay*, Türkiye'de Yabancı Hukukun Benimsenmesi Hareketi İçinde Türk Medeni Kanunu'nun Anlamı ve Önemi (The Meaning and Importance of the Turkish Civil Code within the Movement of Adoption of Foreign Law in Turkey), Istanbul Üniversitesi, Mukayeseli Hukuk Enstitüsü, TMK'nun 50. Yıl Sempozyumu (Symposium for the 50th Anniversary of the TCC), Istanbul, 1976, pp. 399 et seq.

[48] Guardianship Authorities are *Court of Peace and Court of First Instance. Court of Peace* is the Guardianship Court. *Court of First Instance* is a *supervisory authority*. (Article 397 para. 2 TCC 2001).

[49] Cf *Oviedo Convention*, Article 6 No. 3. *Turkey* has ratified the Oviedo Convention by the Law No. 5013 of 3 December 2003.

[50] A *guardian* is appointed for *every minor who is not under the parental care* (Article 404 TCC 2001).

End of life care decision is a medical decision made by the physician in full consultation with the patient or patient's representatives.

II. 1. Everyone has the right to **good and humane treatment** even if no curative treatment exists. All dying patients are entitled to **good end of life care** regardless of the diagnosis of their illness.

2. Every patient has the **right of self determination**. The patient's right to self-determination means the patient's consent is required for treatment. The patient's right to self-determination regarding the decision of end of life care should be respected. The patient has the right to demand the treatment be discontinued as well as the right to decline all treatment. This right belongs to the **"rights strictly bound to person"** (höchstpersönliche Rechte).

3. The patient has the **right to die at home** or in a place where he can be with his family and friends if he so wishes.

4. Special attention should be given to **persons who have restricted capacity to consent** and are not competent to decide about their treatment, if they are end of life care patients.

III. Persons who are not able to consent are **"incapacitated persons"** (ie mentally ill, feeble minded or physically handicapped persons) and **"minors who do not have the capacity to consent"** (ie "power of discernment). Incapacitated persons are normally under guardianship or custodianship. Minors are normally under parental care, exceptionally under the care of a guardian.

1. Regarding the **decision of end of life care** the **guardian's consent** as the **legal representative** of an incapacitated person does not suffice. An **order from the Guardianship Court** or **Custodianship Court** should be provided.

In making such a decision the **advance directives of the patient** (ie patient's instruction; Patientenverfügung) should be taken into account. His **previously expressed wishes** should be respected (Cf Oviedo Convention, Article 9).

Further, the **incapacitated patient** should as far as possible take part in the decision of the end of life care (Cf Oviedo Convention, Article 6 No. 3). As stated above the patient has the right to decline all treatment or to request the cessation of the treatment.

2. Regarding the **minors** a distinction can be made:

a) If a **minor is under the parental care** (eg Article 296 ZGB; Article 335 TCC 2001), only his parents' consent is not sufficient for making a decision for the end of life care. A **curator** (Beistand, curateur) should be appointed by the Guardianship Court in order to assist the minor's parents with regard to the decision of end of life care.

In medical interventions the opinion of the minor is taken into account in proportion of his age and maturity[51]

I think that it would not be a **realistic approach** to request the child's opinion in decision making for end of life care. Special attention should be given to children receiving end of life care[52].

b) If **a minor is under the guardianship** (eg Article 368 ZGB; Article 404 TCC 2001), his guardian should obtain an **order from the Court of Guardianship** relating to the decision for the end of life care.

[51] Cf *Oviedo Convention*, Article 6, No. 2 and *Convention on the Rights of the Child*, Article 12 No. 1.

[52] The serious illness of a child and the associated treatment put great strain on the child. Accepting the fact that illness cannot be cured may extremely stressful to the child's family. A child receiving end of life care should be allowed to lead as normal life as possible right up to the end. Treatment procedures should not restrict the child's normal life too much. See *The National Advisory Board on Health Care Ethics* (ETENE), End-of-Life Care- Memorandum of the National Advisory Board on Health Care Ethics, Report of the Working Group, p. 14.

IV. The self determination is an essential in respecting the human rights and dignity of each person as human being. At present it is observed that there is a strong tendency to protect persons with incapacity. Another tendency is the promotion of self-determination and autonomy.

Regarding decision of end of life care **advanced directives** and **durable powers of attorney** play an important role. For this purpose these measures should be promoted. In this respect **Council of Europe Committee of Experts on Family Law** (CJ-FA) **Working Party No. 2 on Incapable Adults** (CJ-FA-GT2) has prepared a **"Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity"[53].**

Advance directive is a written instruction for health care. It is issued by a capable adult with the purpose of giving binding instructions, or expressing wishes, concerning situations that may arise in the event of the author's incapacity[54].

Continuing power of attorney is a mandate given by a capable adult with the purpose that it shall remain in force, or enter into force, in the event of the **granter's incapacity**. The **attorney** is a person mandated to act on behalf of the granter[55].

The attorney is obliged to act in accordance with the power of attorney and in the **interests of the granter**. The attorney should, as far as possible, inform and consult the granter on an ongoing basis. He has to ascertain and take into account of the past and present wishes and feelings of the granter and give them due respect[56].

It should be noted that despite a durable power of attorney was granted the **legal capacity of the granter** is not restricted[57].

I am of the opinion that these measures should be developed in near future in order to cope with the difficulties related to decision of end of life care. "States should promote self-determination for capable adults about their lives for periods when they are not capable of making decisions by means of continuing powers of attorney and advance directives"[58]

ABBREVIATIONS

ABA: American Bar Association; **ABGB**: Allgemeines Bürgerliches Gesetzbuch (Austrian Civil Code as amended); **AD**: Advance Directive; **BGB**: Bürgerliches Gesetzbuch (German Civil Code as amended); **BGBl.** : Bundesgesetzblatt für die Republik Österreich (Official Gazette for the Austrian Republic); **Cf** : Compare; **DNR**: Do Not Recussitate; **Hrsg.**: Herausgeber (Editors); **NJW**: Neue Juristische Wochenschrift; **No.**: Number; **Nr.**: Nummer (Number); **Rn.**: Randnote (Margin Note); **p.**: page; **para.**: paragraph; **TCC**: New Turkish Civil Code, No. 4721 of 22 November 2001; **ZGB**: Schweizerisches Zivilgesetzbuch (Swiss Civil Code of 10 December 1907 as amended)

[53] See CJ-FA-GT2 (2008) 10 rev.
[54] See *Draft Recommendation*, Principle 2 and 14 et seq.
[55] See *Draft Recommendation*, Principle 2 et seq.
[56] See *Draft Recommendation*, Principle 10 Nos.1 and 2.
[57] See *Draft Recommendation*, Principle 9.
[58] See *Draft Recommendation*, Principle 1 No. 1.

Biographical notes

Prof. Dr. Ergun Özsunay graduated from the *Istanbul University School of Law*. Then he attended graduate studies at *Harvard Law School* (LL:M.), and *Faculté Internationale pour l'Enseignement de Droit Comparé* in Strasbourg. He studied also in *Max-Plack Institut für auslaendisches-und internationales Privatrecht* in Hamburg (1964-1965).

Prof. Özsunay was appointed associate professor of law in 1965; he became a full professor in 1973. He served as the Director of the *Institute of Comparative Law of Istanbul University* from 1978-1985.

Professor Özsunay is the author of several books, including the *Introduction to Civil Law, Legal Status of Persons, Legal Entities, Introduction to Comparative Law.* He has written more than seventy articles in various fields of law. He made also several researches on medical law.

Prof. Özsunay is at present President of the *International Association of Legal Science* (I.A.L.S./A.I.S.J) (Paris) and Chairman of the Middle East and African Law Group at the *International Academy of Comparative Law* (Paris), member of the *International Association of Procedural Law* (Ghent), corresponding member of *Deutsche Gesellschaft für Rechtsvergleichung* (Freiburg/Br.) and collaborating member of *UNIDROIT* (Rome).

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Prof. Özsunay has been teaching at present Comparative Law and EU Private Law at the Istanbul Kültür University.

Session 4 - The person cannot participate in the decision
Previously expressed wishes: advanced directives/living will/continuing power of attorney

Dr. Irma Pahlman (Finland) – Previously Expressed Wishes: Advanced Directives/Living Will/Continuing Power of Attorney

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Abstract

Previously expressed wishes: advanced directives/living will/continuing power of attorney; the person cannot take part in the decision

Legal Basis and Ethics: The instrument of previously expressed wishes has the legal basis on the Convention on Human Rights and Biomedicine and national legislation as well as the European Convention on Human Rights.[i]
Self-determination: The decision-maker is always, ultimately, the patient.[ii]
Previously expressed wishes; patients´ active role[iii] **: Living Will** states that he or she would WISH or would not want certain types of care under certain conditions. Living Will is the only direct expression to the physician making the decision. **Appointment of a Surrogate** to speak and make decisions on his or her behalf in named situations. By issuing a **Continuing Power of Attorney** one can make sure that his or her affairs will be taken care of even if, for instance, illness or deteriorating health later makes lose his or her capacity.
The expression of living will can be made by a competent person or patient. The patient expresses his or her will in writing a living will or direct to a doctor verbally during his or her healthcare process. The patient can express his or her will to a surrogate decision maker, too.
Advance directives are instruments which have no power while the patient still has the capacity to speak for him- or herself. The patient is able to revoke or amend his or her document. This kind of document tells to a physician what the patient wish to do or not want to be done.

[i] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine.
Oviedo, 4.IV.1997 and the Explanatory Report.
The Constitution of Finland (731/1999)
The Act on the Status and Rights of Patients (785/1992)
The Act on Continuing Powers of Attorney (648/2007)

[ii] i and iii

[iii] Beauchamp, T L and Childress, J F. Principles of Biomedical Ethics, 4th edn. Oxford University Press 2001.
Brazier, M. and Cave, E. Medicine, Patients and the Law. 4th ed. Clays Ltd, St Ives plc, 2007.
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Full Text

The objective of advanced directive is to get a good death, a death with dignity as personally defined by the declarant. The concept of advance directive is rooted in respect for self-determination and autonomy. Advanced directives are instruments which have no power while the patient still has the capacity to speak for him- or herself.

The instrument of previously expressed wishes has the legal basis on the Convention on Human Rights and Biomedicine, the European Convention on Human Rights and National Legislation.

According to the article 9 of the Convention on Human Rights and Biomedicine the previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.Important explanation of the article 9 can be found from the explanatory report. This article is designed to cover cases where persons capable of understanding have previously expressed their consent (that is either assent or refusal) with regard to foreseeable situations where they would not be in a position to express an opinion about the intervention. The article covers not only the emergencies but also situations where individuals have foreseen that they might be unable to give their valid consent, for example in the event of a progressive disease such as senile dementia. According to the explanatory report the article lays down that when persons have previously expressed their wishes, these shall be taken into account. Taking previously expressed wishes into account does not mean that they should necessarily be followed. For example, when the wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding the patient's opinion. The practitioner should thus, as far as possible, be satisfied that the wishes of the patient apply to the present situation and are still valid, taking account in particular of technical progress in medicine.

The Definition of Advance Decision

Advance decision means a decision made by a person, after he/she has reached X age and/or when he/she has capacity (competence) to do so, that if

1) at a later time and in such circumstances as he/she may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him/her, and

2) at that time he/she lacks capasity to consent to the carrying out or continuation of the treatment,

the specified treatment is not to be carried out or continued.

An advance decision is only effective if the patient is over x age and/or competent when he/she made it.

An advance decision is only to be relevant if the patient lacks capacity to consent to the treatment.

The definition of advance decisions only allows negative decisions it cannot be used to compel a medical professional to provide treatment.

Forms of advanced directives

Living Will states that he/she would wish or would not want certain types of care under certain conditions. Living Will is the only direct expression to the physician making the decision. The will can be very specific or very general. Reflect a moment in time, and may therefore need regular updating to ensure that the correct course of action can be chosen. The patient is able to revoke or amend his or her document.

Power of attorney or health care proxy means that someone is appointed by the individual to make decisions on their behalf when they are incapacitated. These are documents, where an individual appoint someone to make health care decisions in their behalf if they should ever be rendered incapable of making their wishes known. Limitations to power of attorney: the person specify and/or the restrictions imposed by law.

Patients usually want their family-member or family-members to make decisions for them if they are not capable to make their own decisions. Patient can chose the person because for instance he or she is closest or felt closest or the person understands the patient or the person is geographically the closest.

A Surrogate can speak and make decisions on his or her behalf in named situations. If a person is unable to make decisions about personal health care, some other person or persons must provide direction in decision making. If there is a durable power of attorney for health care, the agent appointed by that document is authorized to make health care decisions within the scope of authority granted by the document. If the person is court-appointed with authority to make health care decisions, the person is the authorized surrogate.

A surrogate can make his or her decisions on two bases, which are substituted judgment or best interest. The first means that she or he makes the decision he or she believes or knows the patient would have made. The second means that the surrogate makes the decision using the best interest standard. The decision should be the best knowing the medical limits.

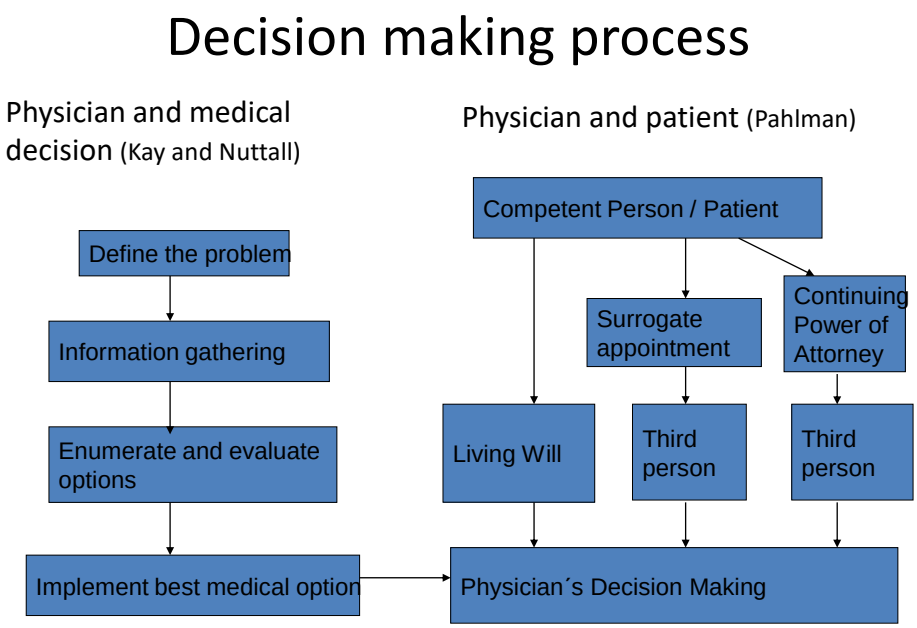
Some Questions
Who is competent enough to express his/her will?

According to the Convention on Human Rights and Biomedicine patient has a right to self-determination. Articles 5 and 6 mean that competent patient can be a minor, too. The evaluation of the competence has to be made by health care professional, mainly a physician. The main principle is that the patient has to be cared in mutual understanding with him or her. If the patient refuses a certain treatment or measure, he or she has to be cared, as far as possible, in other medically acceptable way in mutual understanding with him or her. The logical decision should be that if a minor patient owing to his/her age and level of development can decide on the treatment given to him or her, he or she has to be cared in mutual understanding with him or her.

Does the decision need to be in writing?
The logic of self-determination and autonomy should respect person's opinion weather it is written or not. That should be the main principle. A verbal wish and will must be documented immediately after expression.
If the advance decision does reject life-saving treatment, must it be in writing and signed by the patient and witnessed by a third party? Should a person, who has power of attorney have the same rights to request or refuse treatment that the individual would have if still capable of making and communicating health care decisions? A surrogate, guardian or other legal representative should not have the right to forbid any care which may be required to avert a threat to the patient's life or health. Only a competent patient him- or herself actually or by written living will, is the only person who can forbid any and all care.
Duration of verbal or written wish of will is important. Without paternalism there should be no expiration, but person's wish or will can be revised or revoked at any time.
If a patient or person writes his or her will, who can or cannot be a witness? There are various possibilities as a living will requires no witness, or a living will requires one or two witnesses or a notary. The good legal practice dictates that an unrelated third party should witness the document. Unrelated and objective witnesses provide best solution.

Some aspects
All surrogates have an obligation to follow the expressed wishes of the person and to act in the person's best interests, taking into account the person's values if known.
Health care professionals are responsible for honoring these wishes as well. Health care practitioners and other health care professionals should not provide treatments that are medically inappropriate, such as those that are against generally accepted health care standards.

Decision-making process regarding medical treatment in end -of -life situations with previously expressed wishes
Figure adapted from Kay, E and Nuttall N. Clinical Decision Making – An Art or a Science. British Dental Association, London 1997, p. 56, and accomplished by Pahlman I, 2010.



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Biographical notes

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Publications: Books and articles. The latest article in English: Pahlman**,** I. et al. (2010), Pandemic influenza: human rights, ethics and duty to treat**.** Acta Anaesth. Scand., vol 54, pp. 9-15.

Session 4 - The person cannot participate in the decision
Previously expressed wishes: advanced directives/living will/continuing power of attorney

Prof. Pablo Simón Lorda (Spain) - Advance Directives in Europe and Spain: Situation and Challenges

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Abstract

Advance directives in Europe: situation and challenges

1) The Article 9 of the Oviedo Convention was a milestone that opened the subsequent development of Advance Directives regulation in many European countries, but not in others. The result is that legal regulation in European countries is quite diverse, from strict and broad regulation in some countries to no regulation in others.
2) More recently, on 9 December 2009, the Council of Europe's Committee of Ministers adopted the Recommendation (2009)11 on "continuing powers of attorney and advance directives for incapacity". This document represents an important step forward in the promotion of patients' self-determination regarding medical treatments to be implemented in the event that the individual becomes incapacitated. The Recommendation (2009)11 consists of a preamble and seventeen principles. Most of the 17 principles of this Recommendation (9/17) concern continuing powers of attorneys and only (4/17) deal with Advance Directives. The effect that this Recommendation will have in the regulation about advance directives in Europe is something that already has to be seen.
3) The number of European people that has filled out any form of Advance Directive is quite unknown. Most of the countries lack any type of Registry where the citizens can deposit a copy of his or her Advance Directive and that could be accessed by the healthcare professionals for consultation if needed.
4) There is no clear relationship between the level of legal regulation of Ads and the number of people that has filled out one AD. For example, Spain has one of the most complete regulations in Europe, but the number of citizens with Ads is very low, on the contrary in Germany, where many citizens have ADs although the regulation is scarce.
5) The way in which European healthcare professionals are using ADs in clinical decision making is also badly known. In many countries, especially in Mediterranean countries, the role of the family continues to be more important than ADs.
6) The main challenge for ADs in Europe is to be considered by patients and healthcare professionals as clinical tools that can increase the quality of decisions and not as merely administrative or bureaucratic documents disconnected of clinical decisions. In this sense should be important that any effort to increase its use were included as a part of what is known as Advance Care Planning (ACP). Clinical evidence is telling us that the best way to stimulate patients to fill out ADs is to have the opportunity of discussing this topic with healthcare professionals and that just give people leaflets or information in the websites is not effective.

Full text

Advance directives in Europe and Spain: situation and challenges

1) Advance directives in Europe: a short overview

The situation of Advance Directives (ADs) in Europe is characterized by its disparity between the different countries of the Region. A good example of this disparity is the different attitudes of the two main European institutions in relation with ADs: The European Union and the Council of Europe.

The Charter of Fundamental Rights of the European Union does not content any reference to ADs. Article 3.2 just expresses that "in the fields of medicine and biology", "the free and informed consent of the person concerned, according to the procedures laid down by law must be respected". Furthermore, the European Group on Ethics in Science and New Technologies (EGE) has never issued any recommendation or report about this topic.

On the contrary, the Council of Europe has a long tradition defending the need of including these tools, ADs, in the regulations of the States as well in the clinical practice. In fact, the Article 9 of the

Oviedo Convention (1997), about "previously expressed wishes" was a milestone that opened the subsequent development of Advance Directives regulation in many European countries –for example, this was the case of Spain.

In 1999, the Parliamentary Assembly of the Council passed the "Recommendation 1418: Protection of the human rights and dignity of the terminally ill and the dying". This Recommendation encouraged the State Members "to ensure that a currently incapacitated terminally ill or dying person's advance directive or living will refusing specific medical treatments is observed".

More recently, on 9 December 2009, the Council of Europe's Committee of Ministers adopted the Recommendation (2009)11 on "continuing powers of attorney and advance directives for incapacity". This document represents an important step forward in the promotion of patients' self-determination regarding medical treatments to be implemented in the event that the individual becomes incapacitated. The Recommendation (2009)11 consists of a preamble and seventeen principles. Most of the 17 principles of this Recommendation (9/17) concern continuing powers of attorneys and only (4/17) deal with Advance Directives.

The Principle 14 of this Recommendation establishes that Advance Directives may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed.

Principle 15 points that States should decide to what extent these documents should have binding effect. This is a very important point and a lack of consensus exists between the different European countries. In my opinion is difficult to accept a broad not-binding approach, at least in relation with the refusal of treatments (withholding or withdrawal), when the clinical situation of the patient is the same described in the AD and the decisions and desires expressed by the patient in the document are clear, unambiguous . If even in this condition we do not give any binding effect to the ADs and we leave to the doctors the last word about if they will follow or not the patient's desires, then we can be lying to the citizens. We are telling to people, "¡OK, we want to respect your autonomy so you have the legal right to decide in advance!", but the real thing we should be telling to them is "OK, you can write what you want, but in the end we will decide your *best interest* because we do know what to do in such situations".

Anyway, the Principle states that if ADs do not have binding effect, then they should be treated as statements of wishes. The regulations should also address the issue of situations that arise in the event of a substantial change in circumstances that can limit the valid use of these documents.

In Principle 16 the Recommendation says that Advance Directives should be made or recorded in writing and that regulations should include other provisions and mechanisms to ensure validity and effectiveness of these documents. This is important: desires and preferences expressed verbally are not "Advance Directives". Advance Directives are written documents. Another different question is the value that regulations give to these verbal expressions in the surrogate decision-making process.

Finally, Principle 17 indicates that Advance Directives shall be revocable at any time and without any formalities.

The effect that this Recommendation will have in the legal regulation of Advance Directives in Europe is something that already has to be seen. Nowadays the situation is that legal regulation in European countries is quite diverse, from strict and broad regulation in some countries to no regulation in others [59]. In 2008, a report prepared by Prof. Roberto Andorno, from the Institute of Biomedical Ethics of the University of Zurich was clear about this. This Report was presented to the 35th meeting of the Steering Committee on Bioethics (CDBI) of the Council (2-5 December 2008). The title of this Report was "The previously expressed wishes relating to health care: common principles and differing rules in national legal systems". It was the result of a "Exploratory Workshop on Advance Directives" organized by the Institute of Biomedical Ethics of the University of Zurich with the support of the European Science Foundation (ESF), held on the 18-22 June 2008 [60]. The summary of the situation outlined by the Report is as follows.

"At present, the legal status of advance directives in the national legislation of European states is very disparate. However, as it will be indicated below, several countries show a clear trend towards a greater recognition of the value of patients' previously expressed wishes. Currently, four groups of countries can be distinguished*:*

a) Countries where specific laws on the issue have been adopted assigning binding force to previously expressed wishes (UK, Austria, Spain, Hungary, Belgium, The Netherlands, Finland);

[59] More information on ADs all over the World can be found at www.advancedirectives.eu. Accessed December 5th 2010.

[60] Steering Committee on Bioethics . Council of Europe. The previously expressed wishes relating to health care. Common principles and differing rules in national legal Systems. Report prepared by Prof. Roberto Andorno. Available at http://bit.ly/fBz3OF . Accesed December 5th 2010.

b) Countries where specific laws on the issue have been adopted in recent years, but without assigning binding force to such documents (France);
c) Countries where there is no specific legislation yet, but which are planning to introduce it in the next few years in order to attach to AD a binding effect (Germany, Switzerland);
d) Countries where there is no specific legislation yet and which do not have any concrete plans to introduce it in the coming years (Norway, Italy, Portugal, Greece, Turkey, Serbia, Slovakia, Bulgaria, Lithuania)."
Obviously this situation can change very fast. For example, Portugal is nowadays in the beginning of a process of regulation of Advance Directives, and probably many other countries will initiate it very soon as well.
The number of European people that has filled out any form of Advance Directive is quite unknown. Most of the countries lack any type of Registry where the citizens can deposit a copy of his or her Advance Directive and that could be accessed by the healthcare professionals for consultation if needed. Should be of great interest if would exist some European project to research about this point.
Anyway, there is no clear relationship between the level of legal regulation of ADs and the number of people that has filled out one AD. For example, Spain has one of the most complete regulations in Europe, but the number of citizens with ADs is very low, on the contrary in Germany, where seems that many citizens have ADs although the regulation is scarce.
The way in which European healthcare professionals are using ADs in clinical decision making is also badly known. In many countries, especially in Mediterranean countries, the role of the family continues to be more important even than ADs. As Roberto Andorno points in his Report to the CDBI:
"What is the real use of advance health care documents in current medical practice? Interestingly, while they are legally accepted and widely recognized in the clinical practice of the United Sates, in most European countries it is still unusual to base clinical decisions on patient's previously expressed wishes. This explains why, from a legal point of view, the validity of advance directives still remains unclear in many European states, which are just beginning to recognize"
We do need to do more research about this topic if we want to understand better how European doctors and patients are using ADs and to know what we can do to ameliorate it. In fact only if the approach of "Advance Care Planning" is used as the main guide, we will be able to increase the use of ADs by patients and clinicians. The evidence is telling us that speaking with patients and their proxies is the best way to increase the use of ADs, and that passive informative material, such as posters, leaflets, information in websites or videos, in isolation does not significantly increase AD completion rates[61]. Interactive communication is the most important tool for this task This is the approach of Advance Care Planning.

2) Advance directives in Spain: a shorter overview

The first clear step towards the legal regulation of ADs in Spain was a product of the European framework. Spain signed the Oviedo Convention in 1997, which became law in Spain on the 1st of January 2000. The Article 9 established a basis for the subsequent development of the legal regulation of decision-making involving incompetent patients and ADs. Surprisingly, Regional Governments, rather than Central Government, were the first to legally regulate these areas. Catalonia passed the first law of this type in Spain in 2000. Subsequently, the remaining 16 Autonomous Regions also began to produce legislation relating ADs regulation. Nowadays, all the Regions have their own regulation on ADs. The danger of excessive diffusion of the regulations led the Spanish Parliament to draw up a general regulation that establishes basic requisites in this area. Basic L*aw 41/2002, of November 14th, for the Regulation of Patient Autonomy, Rights and Obligations with Regards to Medical Information and Documentation* was passed with significant parliamentary consensus. This law has been in effect since the 16th of May 2003 and today represents a fundamental piece of legislation. Article 11 of this law regulates "Healthcare Directives" (Table 1). Therefore, Acts passed by the various Regional Governments, both before or after the enactment of this State law, must abide by its stipulations. In this case, State law takes priority over the regulations of the Autonomous Regions.

Nevertheless, the different legal regulations do share a number of common features[62]:

[61] Tamayo-Velázquez MI, Simón-Lorda P, Villegas-Portero R, Higueras-Callejón C, García-Gutiérrez JF, Martínez-Pecino F, Barrio-Cantalejo IM. Interventions to promote the use of advance directives: An overview of systematic reviews. Patient Educ Couns. 2010 Jul;80(1):10-20. Epub 2009 Oct 29. PMID: 19879090.
[62] Simón-Lorda P, Tamayo-Velázquez MI, Barrio-Cantalejo IM. Advance directives in Spain. Perspectives from a medical bioethicist approach. Bioethics. 2008 Jul;22(6):346-54. Epub 2008 May 12. PMID: 18479491

- ADs allow patients to express their opinions and wishes in three areas:
    - ✓ Their values, wishes and preferences with regards to treatment or care that they wish, or do not wish to receive when they are unable to make this decision on the grounds of being incapable.
    - ✓ Their preferences with regards to organ donation.
    - ✓ The appointment of a "proxy" who will act as an interlocutor with health professionals when an AD must be applied. In general, the proxy must provide his or her written consent in order to be appointed.

  Laws do not make reference to other questions, such as advanced consent in relation to research.
- ADs are, in general terms, legally biding. Healthcare professionals are, in principle, obliged to respect them, except in the case that the clinical circumstance does not adequately suit to the situation described in the AD.
- Most of the Acts make reference to a prohibition on actions that are "contrary to good clinical practice" and/or "contrary to the legal system". "Contrary to the legal system" is an indirect reference to euthanasia, which is a criminal offence in Spain that is classified in the Penal Code. Therefore, whilst no restrictions are placed on a patient´s potential to request euthanasia, healthcare professionals are forbidden from complying with this petition.
- With the exception of Andalusia, other Regions do not possess a legally established, obligatory model for ADs. Certain Autonomous regions (Catalonia, Valencia, Castilla La Mancha, etc) have developed model forms, although these are of a voluntary nature. Usually all these forms are available through the websites of the institutions.
- In order to be valid, the AD must be filled out in accordance with one or more of the following procedures, depending on the legislation in each Autonomous Region:
    - ✓ Before notary. In this case, witnesses are not required.
    - ✓ Before three witnesses who are of legal age and competent, at least two of whom must not have a relationship with the testator based on kinship or estate. This is a problematic procedure, because it can not assure the correct evaluation of the capacity of the person that is filling the AD.
    - ✓ Before a government civil servant, who is normally an employee of the Living Will Registry of the Autonomous Region.

  Therefore, the direct participation of health professionals is not required when completing an AD. This fact must be considered a problem of the Spanish model, because places the process of filling and AD completely outside of the healthcare system.
- In general, only competent individuals of legal age may draw up an AD.
- Each Autonomous Region possesses an official Registry where citizens may lodge their ADs. Lodging the AD in the Registry is voluntary but recommended. It is compulsory in 3 Regions: Andalucia, Baleares and Extremadura Registries are computerised and provide health professionals with the possibility of accessing the content of ADs via computers or, in some Regions, directly by phone.
- The creation of the National Registry is underway, in accordance with article 11 of Law 41/2002. The National Registry will be charged with linking up all the Registries in each Autonomous Regions via telematic means. Spain does not possess private telematic Registries such as those that exist in the United States.
- Citizens may revoke or modify an AD at any time via an established procedure. However, Spain possesses no laws that place an automatic date of expiry on ADs.

The existence of the Registries allows to Know quite exactly the number of Spanish citizens that have filled an AD. On the 1st of January 2010, it was estimated that 78,806 individuals had filled in an AD in Spain, which represents scarcely 2 people per 1000 inhabitants. More than 60% of this group were women.

So, in spite of the broad development of the legal framework, the use of ADs by Spanish citizens remains to be very low. On the 1st of January 2010, it was estimated that 78,806 individuals had filled in an AD in Spain, which represents scarcely 2 people per 1000 inhabitants. More than 60% of this group were women.

Many factors must have influenced these results, but they have not been analysed with due attention. We are probably dealing with a very short timescale: only eight years have passed since the legal

framework began to take shape in 2003. It is likely that cultural factors within the Mediterranean tradition give rise to certain moral views that condition people's attitude toward ADs. These factors could explain tendencies such as the widespread reticence within the Spanish population to openly discuss about death with anyone. This subject is still a taboo. Other possible factors may include the influence of traditional catholic morality, with its stress on the salvific nature of pain and the notion that life belongs to God and therefore should not be limited in any way. These views remain embedded in the collective subconscious, despite the growing and marked secularisation of modern Spanish society and despite the fact that the official doctrine of the Catholic Church is against futile life support. Ironically, it was the first institution in Spain to distribute living wills.

All of these factors may encourage patients to maintain passive attitudes that reinforce traditional medical paternalism. Decision-making seems to be left to doctors and other family members, who undoubtedly base their decisions on what they think is best for the patient at all times. In this context, ADs are unnecessary. This is the great paradox of the Spanish situation, demonstrating that legal recognition does not always lag behind the demands of modern society, as is often claimed. At times, exactly the opposite occurs. Spanish laws appear to recognise more patient rights than the patients themselves are currently willing to exercise, or health professionals are willing to respect in daily practice.

However, Spanish society is undergoing rapid change. Younger generations place more importance on the need to respect their autonomy, which will undoubtedly provoke substantial changes in AD use over the course of the next few years.

Table 1: Article 11 of Law 41/2002, which regulates ADs in Spain at state level

Article 11. Healthcare Directives

1. Via the healthcare directives document, a competent person of legal age may freely state his or her wishes in advance with regards to healthcare and treatment, with the aim of having these wishes carried out in situations wherein they are incapable of expressing these wishes for themselves. Healthcare directives also allow individuals to express their wishes in relation to the use to which their body and organs are put after death. Moreover, the individual executing the document may appoint a proxy who, where necessary, will act as an interlocutor with the doctor or medical team to endeavour to ensure that the healthcare directives are carried out.

2. Each health department will regulate an appropriate procedure to ensure, where appropriate, that the healthcare directives of each person are observed. Healthcare directives must be presented in written form.

3. Healthcare directives that are contrary to the legal system or to the "lex artis" will not be applied, as is the case with healthcare directives under circumstances other than the circumstances envisaged by the interested party when the directives were issued. The patient's medical history will include a detailed record of the notes relating to the directives.

4. The healthcare directives may be freely revoked at any time and a written record will be made to this effect.

5. In order to ensure nationwide efficacy of healthcare directives issued by patients and formalised in accordance with the legislation in each Autonomous Region, a national Registry of Healthcare Directives will be created within the Ministry of Health and Consumer Affairs, which will be governed by the regulations determined by law, subsequent the consensus of the Inter-territorial Council of the National Health System.

Biographical notes

Born in Zaragoza (Spain) in 1965

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Alzheimer Europe (Patient organisation) – The Use of Advance Directives by People with Dementia – the Views of Alzheimer Europe

Ms Dianne Gove, Information Officer, Luxembourg

Abstract

The use of advance directives by people with dementia – The views of Alzheimer Europe

As new forms of treatment for Alzheimer's disease and other forms of dementia are developed and as patients start to be diagnosed at a much earlier stage, people with dementia increasingly have the opportunity to influence their own current and future medical care and treatment. This is one of the reasons why we believe it is important to inform people with dementia of their diagnosis.
Alzheimer Europe further recognises that a right to be informed about one's diagnosis and the possibility of writing advance directives are effective tools to ensure that people with dementia take a more active part in decisions affecting their lives.
For that reason, Alzheimer Europe started work on a project in January 2004 which involved carrying out an overview of the legal status of advance directives throughout Europe, as well as an extensive literature search on the use of advance directives by people with dementia.
In his presentation, Dianne Gove will present some of the key findings of this work and the organisation's position on the use of advance directives by people with dementia.

Full text

Good afternoon ladies and gentlemen. I would like to thank the Council of Europe for inviting Alzheimer Europe to take part in this very important meeting and to apologize for the fact that Jean Georges was unable to attend. I will therefore try on his behalf to present some of our thoughts on the issue of dementia and advance directives.

Topics to be covered

In the next fifteen minutes, I would like to address the following issues:

1. People with dementia at the end of their lives
2. The capacity to consent and the ability to participate in decision making
3. Making an advance directive in the case of dementia (and other possibilities)
4. Using advance directives

The views I am expressing reflect those in our position paper on the use of advance directives by people with dementia and to some extent our work on good end-of-life care of people with dementia.

People dying with/from dementia includes:

The first point I would like to make is that having dementia does not mean that a person cannot participate in end-of-life decision making.

The main groups of people with dementia who might need end-of-life care are :

1. People who reach the end of life but die from some other identifiable condition, such as cancer, before reaching the final stage of dementia.
2. People who reach the end of life with a complex mix of mental and physical problems but where the effect on brain functioning is not as advanced
3. People who reach the end of life and die of the complications of dementia, such as end-stage dementia

This means that we cannot presume that people with dementia who are dying have very severe cognitive decline, extremely limited decision-making capacity and severe communication difficulties. They might be in an earlier stage of dementia. This is why in our work on palliative care we refer to people dying with or from dementia.

Whilst a lot of people with dementia do unfortunately die in hospital, we feel that advance directives should not be restricted to hospital care but should cover medical treatment irrespective of where it is provided (such as in nursing homes, in hospices and at home). Moreover, we encourage the development of mobile palliative care teams specialized in the care of people with dementia as hospitals are in most cases not the ideal place for people with dementia.

Capacity and decision making

1-2. Depending on the stage at which a person is diagnosed, they may live with the disease from that point on for anything from about 5 to 20 years. During this time, the mental capacity of people with Alzheimer's disease and some other forms of dementia will gradually and progressively deteriorate and this will affect their ability to make decisions. In the early stages, people with dementia can still make some decisions but not others. As the disease progresses, the ability to make decisions will deteriorate although people may still be able to participate in the decision-making process to some extent. Eventually, there may come a time when they will no longer be able to make any decisions. At various times during the illness, situations will most probably arise when healthcare decisions must be made.

3. Capacity is not an all-or-none phenomenon. We believe that it should always be considered and assessed in relation to specific decisions or categories of decision (the person is deemed capable or incapable *of* decision A or decision B, etc.). In addition, capacity can be partial. In dementia a person does not usually *suddenly* lose the capacity to decide about something, but *gradually* loses it. In many forms of dementia, furthermore, a person's capacity to make certain decisions may fluctuate with time. For all these reasons, capacity should be assessed on a case by case basis, in relation to specific areas of decision-making, and taking into account the overall condition of the person.

One might presume that in the very last stage of dementia, participation in decision making is impossible, but it is important to differentiate between the capacity to consent and the ability to participate in some way in decisions affecting one's life. Some form of participation may be possible even if the person lacks the capacity to consent to the proposed treatment.

Respecting autonomy and dignity

Alzheimer Europe feels that it is important that people with dementia are given the opportunity to exercise their right to self-determination and is of the opinion that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity.

However, we would like to put the writing of advance directives in the context of advance care planning in general. For people with dementia, this can be seen as a global approach to future health care and welfare involving reflection, discussion and communication of treatment and care preferences throughout the course of the disease and also at the end of life.

Advance care planning may or may not lead to the writing of an advance directive. We would like to stress that no one should be forced or put under any pressure to write an advance directive. If somebody does not want to address such issues and prefers to let others decide on their behalf, their choice should be respected.

However, for people to be in the position to make such decisions, they need to be considering such issues when they have sufficient capacity to do so which is one reason why early diagnosis is important.

Advance planning is not just about people refusing treatment that they don't want. On the contrary, it can be about ensuring that personal preferences are taken into account, on the place of care, on what

makes life meaningful, about spiritual issues etc. These are all important issues when considering quality of life and personal wellbeing.

Practicalities

Alzheimer Europe favours the use of a form which specifically refers to dementia, as decisions concerning future care in the case of dementia are likely to differ from those made by people with other conditions. As dementia may exist alongside other medical conditions, it may be useful to choose a form which allows for treatment choices in relation to different scenarios e.g. dementia, dementia with co-existing terminal illness, dementia and coma etc.

Alzheimer Europe accepts that some people might want to focus on outcomes (e.g. resulting quality of life, burden of the treatment, likelihood of a positive or negative prognosis) rather than on specific forms of treatment. This puts the onus on medical staff to decide which treatment corresponds best to the patient's wishes and to ensure that they have the necessary information, and have consulted with significant others (such as close relatives, a partner or close friend), to enable them to judge, if necessary, what constitutes quality of life for the person concerned. For this reason, we recommend that people who prefer to focus on outcomes consider the possible advantage of writing a "statement of values"

We believe that it is essential to consult with doctors (or other relevant healthcare professionals) in order to ensure that the correct terminology is used (not too vague to be meaningless and not too precise or detailed that it is unlikely to correspond exactly to any particular future situation). Also, studies have shown that people do not always understand the treatment that they are refusing or are unaware of the different ways in which it is actually used.

In some countries, advance directives must be renewed or confirmed every few years or so but in the case of dementia, a person may make a advance directive which in the specific case of end-of-life decision making will only be used some ten to fifteen years later and in the years prior to its use, they may have lacked the necessary capacity to update or confirm it. Moreover, the disease trajectory of dementia differs from many other conditions and may involve several near death experiences with the person often pulling through.

As dementia is a condition which can last for a number of years, during which time a person's mental capacity gradually declines, Alzheimer Europe is not in favour of setting a limit on the duration of validity of advance directives. On the other hand, as long as the person has sufficient capacity, we would recommend updating or confirming an advance directive every 5 years.

Healthcare proxies, continuing powers of attorney in healthcare issues and trusted persons

We feel that it should be possible to use an advance directive to appoint a health care proxy with the power to make decisions on behalf of the person with dementia when the latter is no longer able to do so. People should also have the possibility of appointing a trusted person which is someone whom doctors must consult about end-of-life issues when the patient is no longer able to express his/her own will.

Whilst it is customary to express one's wishes with regard to treatment possibilities in an advance directive, when combined with the appointment of a healthcare proxy or trusted person, we feel that this should be optional as the person's intention may be to transfer responsibility to another person who is willing to take on that responsibility. We would nevertheless encourage people with dementia to discuss their values, preferences and wishes with the proxy or trusted person.

One of the advantages to having a healthcare proxy or trusted person in the case of dementia is that there may times when the advance directive does not cover or correspond exactly to the current situation due to recent medical advances, unforeseen health complications or ambiguity in the way that a wish is phrased.

A few points to consider

Doctors should only follow the instructions/wishes contained in an advance directive if the person who wrote it lacks the capacity to give or refuse consent to a particular treatment at the time the treatment is needed. The existence of an advance directive should not prevent doctors from trying to assess the current views of a person with dementia.

Alzheimer Europe believes that the wishes contained in advance directives should generally be respected. There are, however, two exceptions:

1. Current competently expressed wishes cannot be overridden, and

1. Nobody should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is obvious that they are currently displaying clear and unambiguous signs of wishes to the contrary.

In such cases, staff should be able to act humanely in accordance with current professional standards and taking into consideration the context**,** and the doctor-patient relationship and on the basis of a good communication between all concerned, including the person with dementia. The advance directive should also be regarded as part of this communication.

Alzheimer Europe believes that existing legislation on advance directives which limits their validity or binding nature to cases where a person is suffering from a terminal illness or facing unavoidable death should be amended to specifically include people suffering from dementia who lack the capacity to make health care decisions, for example by including incurable and progressive conditions within the scope of the legislation.

Perceptions of dementia and risks of influencing end-of-life decisions

Some people may be influenced in their choices regarding life-sustaining and life-saving treatment by their perception of the message from society that some lives are less worthy of being saved or prolonged than others. In the case of dementia, with might be linked to messages about insufficient funds to cover healthcare, by negative stereotypes, discrimination, loss of status and in the last stages even of personhood.

Alzheimer Europe recognises its role in increasing awareness of dementia as a disease, reducing the stigma attached to it, protecting the dignity of people with dementia of all ages and presenting a positive image of people with dementia.

Biographical notes

Dianne Gove is the Information Officer of Alzheimer Europe where she has been working since 1996. She has been in charge of a number of projects including the drafting of care manuals, an inventory of social support in Europe, an exploration of gender differences in attitudes towards caring and the compiling of an overview of legislation relating to the rights and protection of people with dementia in each member state of the European Union.

More recently, she has worked on issues related to the end of life of people with dementia. This started with the elaboration of Alzheimer Europe's position on the use of advance directives by people with dementia. Together with a group of legal experts, a representative from the Council of Europe, a person with dementia, a psycho-geriatrician and representatives from Alzheimer associations, the practical, legal, medical and ethical issues linked to the use of advance directives by people with dementia were debated. This was combined with a summary of the legal situation regarding advance directives in each country, which was updated last year with the assistance of a legal expert from each country. This was followed in 2008 with a project on the end-of-life care of people with dementia which again was carried out in collaboration with a group of experts and involved examining ethical, practical and medical aspects of end-of-life care. Attention was paid throughout to the need to take into consideration the current and previously expressed wishes of people with dementia.

Session 4 - The person cannot participate in the decision
Decision process

Prof. Emmanuel Agius (Malta) – Safeguarding the Unconscious Patients' Overall Benefit: Towards a "Consensus Building' Approach"

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Member of the European Group of Ethics in Science and New Technologies (EU)

Abstract

Safeguarding the Unconscious Patients' Overall Benefit:
Towards a 'Consensus Building' Approach

The classical medical-ethical question: 'What should we do in relation to what we can do?' assumes a novel dimension in today's development of knowledge and biotechnology which offer new possibilities to prolong the process of dying.

The quality of decision-making process in end-of-life issues in clinical settings when patients are unconscious depends on taking seriously into consideration the following issues: which fundamental ethical values should be considered; what is meant by the 'patient's overall benefit' or the 'patient's best interest'; what is medically meaningful treatment and by whom is this determined; who is the decision-maker; what are the criteria for selecting the decision-maker; if a patient is mentally incapacitated or brain-damaged, what value does an advance directive (an oral or written statement of end-of-life preferences) have; if there is no advance directive, who is the legally valid surrogate responsible for the decision-making; what happens when the legally valid surrogate does not have the best interest of the patient at heart; how should conflicts, such as regarding futile or inappropriate treatment, be resolved, and how could such conflicts be prevented?

End-of-life decisions, particularly in case where patients do not have the capacity to decide on life-sustaining treatment for themselves, is an inclusive process which aims to determine what is the best treatment of the individual, at that time and in that place. It is a negotiating process among all parties involved which should ultimately lead to consensus building.

At the end-of-life decision process the issue of deep and continuous palliative sedation often crops up. The thorny issue is whether it is ethically and legally permissible to withhold or withdraw nutrition or hydration when deep and continuous palliative sedation is administered. No ethical problems arise if palliative sedation is administered to a patient in cases when there is a strong objective medical indication for such administration. However, when deep palliative sedation, together with the withdrawing or withholding of artificial nutrition and hydration, is administered without any objective medical indication, simply because it is requested by the patient, serious contentious ethical and legal issues arise.

The 1999 Recommendation 1418 of the Parliamentary Assembly of the Council of Europe on the *Protection of the human rights and dignity of the terminally ill and the dying* explicitly upholds in article 9.c the prohibition against the intentional killing of the life of terminally ill or dying persons. It recognizes the fundamental right to life and declares that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.

Full text

Clinical decision-making is a fundamental aspect in medical practice. Healthcare professionals, patients and their relatives are routinely involved in reviewing options for diagnostic studies and treatment. Though healthcare professionals get familiar and comfortable with the decision-making process, patients approaching the end of life as well as their relatives are usually unprepared to face the thorny ethical issues involved in such a complex process.

With today's advancement in the field of biomedicine, biotechnology and pharmacology, patients approaching the end of their lives are offered high-quality treatment and care. However, such advancement in end-of-life treatment raises ethical issues that are clinically complex and emotionally distressing.[63] The classical medical-ethical question: 'what should we do in relation to what we can do?' assumes a novel dimension in today's development of knowledge and biotechnology which offer new possibilities to prolong the process of dying. These clinical advancements raise the issue concerning the ethical permissibility to withhold and withdraw life-sustaining treatment when the evidence of the benefits, burdens and risks of this treatment are not always clear-cut, and when there may be uncertainty about the clinical effects of a treatment.

Ideally, patients themselves take decisions on their own end-of-life care. Often, however, patients lose their decision-making capacity before their wishes for the use of life-sustaining treatment have been determined. In these complex and controversial situations, when no advanced directive was made by the patient, the treating healthcare team and family together need to plan care for the patient. Such treatment must reflect the patient's wishes and values as much as possible and should avoid inappropriate over- and under-treatment.

Various authors have recommended different approaches in end-of-lives care on how to reach good clinical decisions which respect and safeguard the patient's rights.[64] Some defend the 'substituted judgment' model, others 'the patient's best interest' model. The 'substituted judgement' approach attempts to make a treatment decision that the patient would have made if he/she were conscious on the basis of his/her values, religious beliefs and attitudes towards medical care.[65] One should keep in mind that substituted judgments are inherently speculative and for this reason there is the danger that surrogates confound their own assessment of the situation with the patient's hypothetical choice.[66] To resolve this danger, Rebecca Dresser pleads that the 'substituted judgment' should be replaced by the best interest standard based on community values.[67]

In practice, the 'patient's best interest' or 'patient's overall benefit' approach in decision-making involves the weighing of benefits, burdens and risks associated with treatment that are not always limited to clinical considerations. To reach a balanced view about the patient's overall benefit, one must weigh the benefits of a treatment that may prolong life, improve a patient's condition or manage their symptoms against the burdens and risks for that patient. Ethical fidelity demand all those involved to seek genuinely the patient's best overall interest.

Though these two models of end-of-life decision-making process are beneficial in some ways and inappropriate in other aspects, a third model of decision-making process shall be discussed which gives high priority to consensus-building. This approach incorporates both the previous two models and at the same time offers a much inclusive and broader perspective.

The quality of decision-making process in end-of-life care depends on taking seriously into account the following moral issues: which fundamental ethical values should be taken as a guidance; what is medically meaningful treatment and by whom is this determined; what is the role of healthcare professionals and family members in the decision-making process; who is the decision-maker; what are the criteria for selecting the decision-maker; if a patient is mentally incapacitated or brain-damaged, what value does an advance directive (an oral or written statement of end-of-life preferences) have; if there is no advance directive, who is the legally valid surrogate responsible for the decision-making; what happens when the legally valid surrogate does not have the best interest of the patient at heart; how can consensus among all parties involved be reached; how should conflicts, such as regarding futile or inappropriate treatment, be resolved, and how could such conflicts be prevented; when is deep and continuous palliative sedation, together with the withdrawal or withholding of artificial hydration and nutrition, ethically permissible?

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[63] General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, May 2010, p. 8.
[64] David E. Weissman, "Decision Making at a Time of Crisis Near the End of Life", in :*Journal of American Medical Association*, vol 292, no 14, Oct 2004.
[65] Dresser R., "Treatment Decisions for Dementia Patients: The Search for Normative Boundaries", in http://bioethics.georgetown.edu/pcbe/background/dresser.html. p.1.
[66] O'Brien, "What is Palliative Care?" in *Ethical Eye: Euthanasia*, vol. 1, Council of Europe, 2003 p. 91.
[67] Dresser Rebecca, "Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making", in *Journal of General Internal Medicine* 2008 September 23(9): 1514-1517.

In what follows I shall discuss these ethical issues within the context of consensus-building approach in end-of-life decision-making process, focusing primarily on patients who cannot participate due to their unconsciousness or brain-damage. According to my considered judgment, this approach does justice to the dignity of the dying patient who remains a subject of rights until death.

1. Overarching Fundamental Ethical Principles

i) Human Dignity and Fundamental Rights

Human dignity is the leading fundamental value in Europe. Article One of the *European Charter of Fundamental Rights* endorses this important value which is reflected also in the 1999 Recommendation 1418 of the Council of Europe on the *Protection of the human rights and dignity of the terminally ill and the dying.* The explanatory memorandum of the 1999 Recommendation affirms that dignity is bestowed equally upon all human beings, regardless of age, race, sex, particularities or abilities, of condition or situation, which secures the equality and universality of human rights. Thus, a human being possesses dignity throughout the course of life. Pain, suffering or weakness does not deprive a human being of his/her dignity.[68] To believe that human dignity may be divided or limited only to certain stages or conditions of life is a form of disregard for human dignity.[69] Terminally ill or dying patients are vulnerable and for this reason they are in danger of being exposed to individual, social and societal pressure and discrimination.

If human dignity applies to anyone, it applies also to people who experience serious illness and suffering. What constitutes dignified treatment for unconscious and brain-damaged patients? Do patients who are unconscious or brain-damaged have dignity? Do patients who are unable to participate in decision-making, bedridden, incontinent, tube-fed and completely dependent lose their dignity? Does a patient who is surrounded by strangers, who lose their privacy and communication skills, who is frail and who need complex interventions, who suffer hair loss, severe weight loss, and other unwelcome changes become undignified? Ruth Macklin[70] and Rebecca Dresser[71] give different answers to these pertinent questions.

ii) Equity and Justice

It is in accordance with the principle of equality that patients approaching the end of their life must the given the same quality of care as other patients. Dying patients should not be discriminated against because of their poor quality of life or other conditions. A dying patient has a right to live with dignity and respect while dying. For this reason, they must be treated with dignity, respect and compassion. Moreover, patient's rights must be respected, irrespective of their physical condition, age or disability.

Article 3 of the *Convention for the Protection of Human Rights and the Dignity of Human Beings with Regard to the Application of Biology and Medicine* states that, taking into account health needs and available resources, appropriate measures should be taken to provide equitable access to health care of appropriate quality. The explanatory report to the Convention states, however, that "equitable means first and foremost the absence of unjustified discrimination" and is "not synonymous with absolute equality" but "implies effectively obtaining a satisfactory degree of care". Moreover, article 13 of the *European Social Charter* also foresees equal access to health care services of appropriate quality. To guarantee this principle for the terminally ill or dying is a pressing need. Discrimination against dying patients because of their physical condition is an offense against justice. On the other hand, wastage of resources on medical treatment which is contra-indicated and disproportionate in the context of a terminal treatment is also against justice since such resources could be used for the benefit of other patients.

iii) Respect for Human life

[68] Council of Europe, Recommendation 1418 (1999), *Protection of the human rights and dignity of the terminally ill.* Explanatory Memorandum, par. 3.
[69] Ibid. 6.
[70] Macklin Ruth, "Human Dignity is a Useless Concept" in BMJ 2003;327:1419-1420 (20 December).
[71] Dresser Rebecca, " Human Dignity and the Seriously Ill Patients", in *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics,* Washington 2008, (Chapter 19).

The primary goal of medical care is preservation of life. Decisions concerning potentially life-prolonging treatment must not be motivated by any prejudice or desire to bring about the patient's death. The decision-making process must start from a presumption in favour of prolonging life. In practice, this means that the healthcare professionals must take all reasonable steps to prolong a patient's life.[72]

However, one must keep in mind that there is no absolute obligation to prolong human life irrespective of the consequences for the patient, and irrespective of the patient's' views if they are known. Life is a fundamental value and not an absolute value and for this reason there are clinical situations which permit the withholding or withdrawing of medical treatment which is judged to be disproportionate or futile.[73] For this reason, when human life cannot be preserved, the task is to provide comfort and dignity to the dying person.

iv) Solidarity

Dying patients face the danger of finding themselves isolated from human warmth and compassion in institutions, cut off from access to human presence by technology which dominates the institutional setting. Staff members may prefer the efficiency of technology, but human contact may be diminished in the process. By providing a supportive and nurturing environment for those who are dying, healthcare professionals aid them in powerful ways to overcome their sense of isolation. Fostering a humanly enriching environment for those facing death often means giving explicit attention to human presence and human contact, even in the midst of a plethora of technology that may surround a patient. Solidarity should also be shown towards the dying patient's family members who might be feeling helpless in such situations and who might be experiencing stress and fatigue.

v) Subsidiarity and Participation

One objective of the EU policy is the creation of a health system in Europe that ensures the best health care possible for all citizens and to shift responsibility as close as possible to the individual citizen, based on the principle of subsidiarity. The EU is committed to the politics of subsidiarity. Patient's right to participate in medical decision-process is justified not only in terms of patient's autonomy but also in view of the principle of subsidiarity. When patients lose their capacity to take decisions, the legal proxy has the right to be consulted and to participate in the decision-making process. If this is not available, then family members should be consulted and actively involved in the decision-making process. However, the final decision should not be entrusted solely in the hands of the patient's next-of-kin.

vi) Beneficence and Non-maleficence

Since Hippocratic times, beneficence has been considered as one of the core values of medical care. It is the duty of every health care provider to be of benefit to the patient, as well as to take positive steps to prevent and to remove harm from the patient. Medicinal interventions should always serve the patient's rights and best interest. No harm should be inflicted on the patient. Just as under-treatment could be harmful to the patient, so also over-treatment when judged to be useless.

Medical care should avoid two extremes, namely 'medical utopia' and 'medical pessimism'. Just as refraining from taking action to treat medically the patient because he/she is going to die anyway may be harmful, so also offering medical treatment beyond reasonableness could be detrimental. It may be of no overall benefit to provide potentially life prolonging but burdensome treatment in the last days of a patient's life when there are strong objective medical indications that the focus of care needs to change from active treatment to managing the patient's symptoms and keeping them comfortable.[74]

2. 'Consensus Building' Approach

End-of-life decisions, particularly in case where patients do not have the capacity to decide on life-sustaining treatment for themselves, is an inclusive process which aims to determine what is the best treatment or non-treatment for the individual, at that time and in that place. It is a negotiating process

[72] General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, May 2010, pp.5-6.
[73] Ibid., p. 12.
[74] Ibid. p. 28.

among all parties involved which should ultimately lead to consensus building. The underlying values of the consensus-building approach are the following:

a) *The right to know and to choose*: When a patient lacks decision-making capacities, the first thing the consultant should do is to check the patient's medical records for information about whether the patient has made a potentially legally binding advance decision or directive refusing treatment. Advanced directives can be binding or non-binding. The doctor must make a judgement about its validity and its applicability to the current circumstances. If an attorney or other legal proxy has been appointed to make healthcare decisions for the patient, the doctor explains the options to the legal proxy, setting out the benefits, burdens or risks of each option. In cases where no legal proxy is appointed by the patient, the doctor must consult the patient's next-of-kin who have the right to be informed and to participate actively in the decision-making process.

b) *Beneficence as appropriate withholding and withdrawing of life-sustaining treatment*: Appropriate end-of-life care should intend to provide the best possible treatment for an individual at that time. If the goals of care shift primarily to accommodate comfort and dignity due to medical treatment which becomes disproportionate, then withholding or withdrawing of life-sustaining medical intervention may be permissible in the best interest of the dying patient. The danger of hastening the decision to discontinue treatment should be safeguarded by the ethical fidelity of physicians and families to the patient's welfare.

c) *Proper assessment of Clinical Futility*: Futility is that state in the history of a patient's disease when he/she is beyond medical rescue, i.e. beyond the powers of medical technology to help. Clinical futility is present when any medical intervention is: i) *ineffective*, i.e. unable to change the natural history of a disease or its trajectory towards death; ii) *non-beneficial*, i.e. unable to satisfy any good or value perceived by the patient or his/her surrogate; (iii) *disproportionately burdensome* to the patient, physically, psychologically, or financially. Balancing the relationship among these three criteria is at the heart of prudent, precautionary, and proportionate action.[75]

d) *A collaborative approach to care*: Healthcare professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking into account of previously expressed patient wishes where known, and the patient's believes and values when there is no expressed will. [76] End-of life decision making is most effective when all members of the healthcare team work together in assisting patients and patients' families. Trust between team members is crucial in this process. Collaboration between healthcare professionals and family members when dealing with end-of life issues may decrease the moral distress experienced by each group.[77] Studies show that the quality of healthcare professionals' relationship affects the outcomes of care.

e) *Transparency and accountability*: The decision-making process and its outcome should be clear to the participants and accurately recorded in order to preserve trust of those receiving health care, and to ensure that decisions are fairly made. It is the senior treating clinician who is accountable, as leader of the treating team, to the patient, the family, and the institution and ultimate to courts for the process of consensus building about end-of-life decision.

f) *Non-discriminatory care*: Treatment must be dependent only on factors that are relevant to the patient's medical condition, values and wishes.[78]

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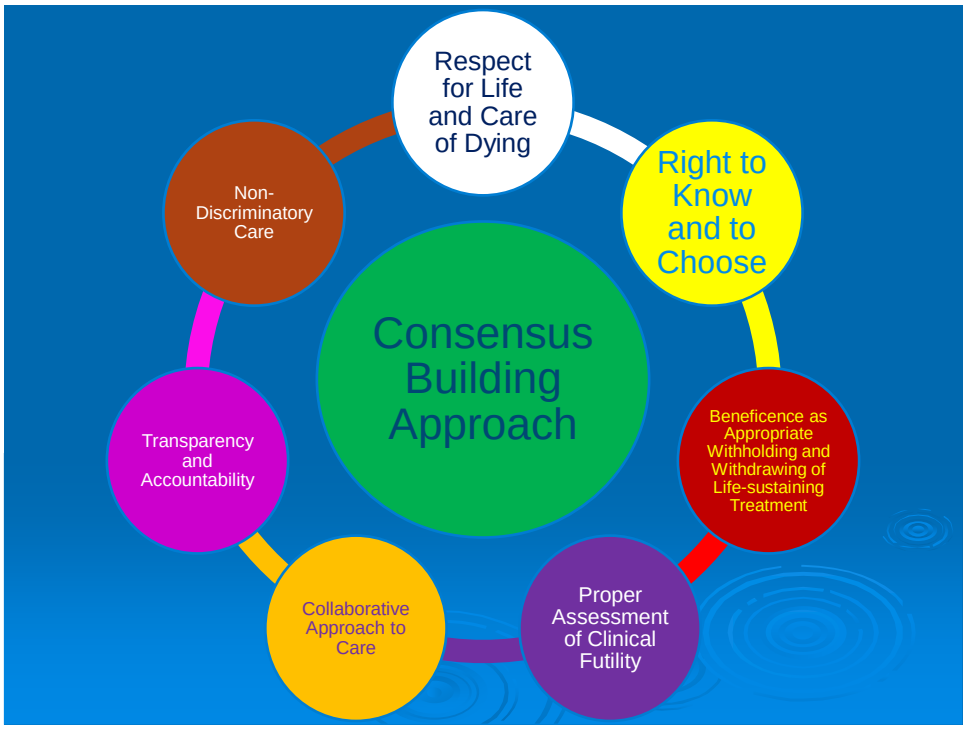
[75] Pellegrino, E., "Controversies in the Determination of Death, Personal Statement", 2009 (http://bioethics.georgetown.edu/pcbe/reports/death/pellegrino_statement.html)
[76] Swedish National Council on Medical Ethics, *Patient autonomy in end-of-life decisions*, 2008, p. 14
[77] Thelen, Mary, "End of life Decisions Making in Intensive Care", in *Critical Care Nurse*, 2005, 25, p.33.
[78] NSW Department of Health, *Guidelines for end-of-life care and decision-making*, Sydney, 2005 (http://www.cena.org.au/nsw/end_of_life_guidelines.pdf), p.2.



Moreover, a sound consensus-building decision-making process for end-of-life decision-making in cases of patients without decision-making capacity includes the following fours elements:

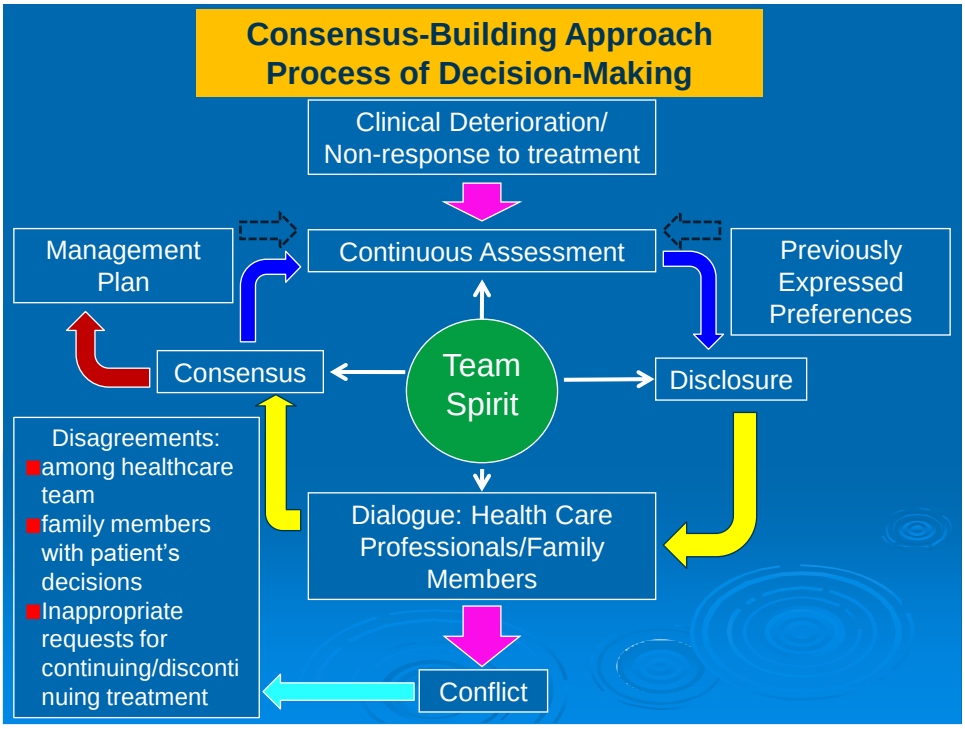
a) *Management plan of treatment:* The aim of a shared decision-making approach aims to reach a consensus within the treating team, and between the treating team and family about a plan of care that is as consistent with the patient's wishes and values as possible. When a patient has an advanced directive, his/her wishes must be respected in the management plan of care. Planning end-of-life care is an iterative process based on assessment, disclosure, dialogue and consensus building with the patient's proxy and/or their family and the treatment team. This process can take place over a short period, such as hours, where the patient suddenly or unexpectedly deteriorates, but it can also extend over weeks or months.[79]

b) Continuous assessment of the clinical situation. Since planning for end-of-life care usually takes place in the context of ever-changing circumstances, it is important to assess continuously the plan of treatment in view of clinical deterioration or non responsiveness to treatment. Obviously, it is difficult to predict an individual's response to a particular treatment. If a clinical situations improves or deteriorates, all available information has to be collected in order to review with the treating healthcare team and the patients/or their family the appropriateness of continuing the treatment. Thus, all decision-making must be individualised and tailored to the unique set of circumstances affecting a unique individual at a specific point in time.[80]

c) Spirit of collaboration among the treating team. The treating team involves various health professionals such as medical specialists, surgeons, general practitioners, clinical pharmacists, nurses and allied health workers such as social workers, chaplains or pastoral workers and patient advocates. Each members of the treating team may bring valuable perspectives and information to the process of planning care. Ideally, all members of the treating team collaborate with each other to reach an agreement. This is an important initial step, particularly in clinical cases where patients no longer have decision-making capacity. Such a collaborative approach helps to reduce subjectivity or bias, particularly in cases of uncertainty. The healthcare professional must be careful not to rely only on his/her personal views about a patient's quality of life and to avoid making judgements based on poorly informed or unfounded assumption. For this reason continuous consultation with other members of the team is crucial.

[79] Ibid., 7.
[80] O'Brien, "What is Palliative Care?" in *Ethical Eye: Euthanasia*, vol. 1, Council of Europe, 2003 p. 80.

d) Participation of Family members: A collaborative process of management plan of treatment aims to draw on the family and treating team's knowledge and understanding of the patient's personal values and medical condition. The participation of family members is important since it avoids placing a senior treating clinician in a position of guessing at a patient's wishes concerning end-of-life treatment without the participation of others. It is also consistent with a desire of many patients for their family to be involved in end-of-life decisions when they are not able to participate. Moreover, it reduces arbitrariness in determining the best interest of the patient and avoids imposing additional stress on a family to carry the burden of decision-making alone.



3. Resolving Disagreements

In most situations in end-of-life care, the family and the treating team readily come to an agreement on appropriate medical management. However, in same cases disagreement may arise between the treating team and the family. This can be avoided by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient's values and wishes. One may argue that is the negative aspect of the consensus-building approach. However, the following solutions are recommended to resolve the different levels of disagreement:

i) Disagreement in the healthcare team: when one or more of the health care team are in disagreement with the others, the team as a whole should consider the basis for disagreement and seek the opinions of health professionals from the same discipline as the disagreeing member/s. In the event that support for the dissenting position cannot be found, it may be appropriate that the dissenting member/s not to continue being involved in the treating team. Situations may arise where a health professional may exercise conscientious objection. One has the right to withdraw from providing care if the decision about life-supporting treatment is against one's religious, moral or other personal beliefs.[81] However, arrangements must be made by the healthcare professional who has conscientious objection for healthcare professional to take over his/her role.

[81] NSW Department of Health, *Guidelines for end-of-life care and decision-making*, Sydney, 2005 (http://www.cena.org.au/nsw/end_of_life_guidelines.pdf) p. 9, and General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, May 2010, pp.47-9.

ii) Disagreement of patient's family with a patient's decision: The wishes of the adult patient with decision-making capacity are paramount. If the patient's expressed wishes in an advanced directive regarding active treatment or refusal of treatment prior to loss of decision-making capacity are known, then these wishes prevail over the wishes of the family.

iii) Inappropriate requests for continuing or discontinuing treatment: When a patient prior to the loss of the decision-making capacity or the family requests an intervention that appears to be unreasonable or inappropriate to the treating team, such a request should not be accepted. When a patient's condition continues to deteriorate even with optimal therapeutic intervention, when treatment fails to serve important patient's goals such as independence from life-support devices, or when fails to produce a successful clinical effect for which it is ordinary used, then such intervention would be extraordinary or disproportionate. When family members of a patient without decision-making capacity demands continued treatment which has unrealistic expectations about what can be achieved, then such request cannot be respected. Likewise, when family members demand the withholding or withdrawing of treatment from the unconscious patient which in the considered judgement of the healthcare team is beneficial to the patient, such request should not be honoured. Family members do not have the right to the ultimate say in the decision since their wish could be overridden by the consultant when it is clinical evident that the decision is taken not in the patient's best interest.

As in the case of the 'substituted judgement' model, healthcare professionals do not comply with the next-of-kin recommendations when they realise that relatives are advancing their own values and concerns in the guise of a decision that purports to be what the patient would want. Incompetent patients retain a core set of interests that should never be compromised. To protect these interests, there must be an inquiry into the patient's current situation and the benefits and burdens that would accompany various treatment decisions. This requires observers to apply the so-called objective approach to treatment decisions for incompetent patients.[82]

4. Deep and Continuous Palliative Sedation

High-quality treatment and care towards the end of life includes palliative care that focuses on managing pain and other distressing symptoms; providing psychological, social and spiritual support to patients; and support those close to the patient.

The provision of palliative care for patients should continue throughout all phases of terminal illness, and especially during the dying process. This care should encompass controlling pain, relieving other systems of disease and providing emotional and psychological support in preparation for death. Other issues such as relief of psychological suffering and spiritual care may be raised during discussions about end-of-life care.

At the end-of-life decision process the issue of deep and continuous palliative sedation often crops up. The indications for palliative sedation are relief of intractable pain when specific pain-relieving protocols or interventions are ineffective for the relief of intractable physical, emotional or spiritual anguish. The depth and intensity of palliative sedation both can be controlled in accordance with the medical needs of the patient. The intent of temporary sedation is to provide a reversible deep sedation, as opposed to permanent sedation, in which the intent is to provide deep sedation until death occurs and without concern for reversibility. The thorny issue is whether it is ethically and legally permissible to withhold or withdraw nutrition or hydration when deep and continuous palliative sedation is administered.

The Swedish National Council on Medical Ethics set up in 2008 a Working Group on end-of-life issues. In its memorandum, the Group concluded that when a physician, together with the other health care staff concerned and in accordance with good clinical practice, finds that curative treatment is no longer meaningful, this treatment is to end and be replaced by palliative care. The report goes on to suggest that when medical efforts do not have the desired effects, the supply of nutrition and hydration is seldom meaningful in a medical sense at this stage and can even aggravate the symptoms of the patient. Thus they conclude that this treatment could also be terminated when starting palliative seda-

[82] Dresser R., "Treatment Decisions for Dementia Patients: The Search for Normative Boundaries", in http://bioethics.georgetown.edu/pcbe/background/dresser.html, p. 2.

tion, after due consideration of the individual care situation, culture and religion. Continued good nursing care goes without saying.[83]

Moreover, the Swedish report also defends the patient's right to self-determination. According to this report, the patient has the right to deep palliative sedation, including the termination of hydration and nutrition, even when death is not imminent. The group also defends the same position in cases of incurable deceases. The majority of the Council members agreed with the memorandum of the working group. However, some members questioned whether the expression of the patient's wishes in such situations could always be considered to be authentic and autonomous. Patients can be subjected to pressure from relatives and convince themselves that they are a burden to their family.

The recommendations made by the Swedish National Council on Medical Ethics raise serious ethical and legal issue. No ethical problems arise if palliative sedation is administered to a patient in cases when there is a strong objective medical indication for such administration. However, when deep palliative sedation together with the withdrawing or withholding of artificial nutrition and hydration is administered without any objective medical indication, simply because it is requested by the patient, serious contentious ethical and legal issues arise.

The 1999 Recommendation 1418 of the Council of Europe on the *Protection of the human rights and dignity of the terminally ill and the dying* explicitly upholds in article c the prohibition against the intentional killing of the life of terminally ill or dying persons. It recognizes the fundamental right to life and declares that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death. The explanatory memorandum states that the ethics of the healing profession prohibits anyone healthcare provider to participate in the taking of the life of another human being. The withholding and withdrawing of nutrition and hydration without medical indications during the administration of deep and continuous palliative sedation is another form of euthanasia.

The withholding and withdrawing of hydration and nutrition is permissible in end of life decision depending on the clinical situation. Clinical cases involving PVS patient present particular ethical debate in end-of-life decision-making. The crucial issue is whether the administration of food and water, even when medically delivered by feeding tubes, is merely a medical act or a natural means of preserving life. In principle, artificial hydration and nutrition should be administered since it is basic healthcare. However, when artificial feeding and nutrition are no longer medically efficacious to achieve their proper goal to nourish the patient and alleviate suffering, then they are no longer morally obligatory. In their decision-making process, the healthcare team and family members could decide to withdraw or withhold artificial hydration and nutrition when: 1) it is medically futile (it does not provide effective nutritional support or prevent dehydration, or when the patient is unable to assimilate food and liquids, so that their provision becomes altogether useless, or when the body sometimes starts rejecting artificial feeding); 2) the patient would experience no real benefit, 3) the burdens for the patient outweigh the benefits (when artificial nourishment and hydration become excessively burdensome for the patient or may cause significant physical discomfort, for example resulting from complications in the use of the means employed and thus become medically contra-indicated), and 4) the patient is dying.

Conclusion

The consensus-building approach has a number of advantages when compared to the 'substituted judgement' and 'best interest' models. Among these advantages, one may refer to the following: it takes into account the opinions of all involved; the experience and knowledge of everyone involved is taken on board; the patient is safeguarded from rushed decisions or hidden agendas; family members do not have guilt feelings due to lack of participation or disagreement with the decisions taken as they were not informed and involved; the treating team and the patient's family learn to listen to each other and to understand and respect each other's views; and decisions and responsibility are shared. The leading disadvantage is that conflicts can never be completely eliminated. However, many options are available how to resolve them. All things considered, the consensus-building model of decision-making in end-of-life situations safeguards patient's overall best interest and rights.

[83] Swedish National Council on Medical Ethics, *Patient's autonomy in end-of-life decisions*, Stockholm, 2008, p.6.

Prof. Jane Seymour (United Kingdom) – The Person Cannot Take Part in the Decision

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Abstract

The person cannot take part in the decision (session 4: 2nd part)

In the UK, new guidance for clinicians on good practice in decision making in end of life care[1] draws attention to the importance of assessing the 'overall benefit' of any treatment for patients who lack the capacity to decide. This is consistent with the legal requirement to act in incapacitated patients' 'best interests' (Mental Capacity Act, 2005, England) or 'benefit' (Adults with Incapacity Act, 2000, Scotland). Any decisions relating to potentially life prolonging treatment must be underpinned by a 'presumption in favour of prolonging life'[1 para 10] although there is no 'absolute obligation' to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views (if these can be established). Under the Mental Capacity Act of 2005, there are minimum standard steps to work out someone's best interests. These include establishing which option is least restrictive of any future choices the patient may have and appropriate consultation with those close to the patient (this will include any relatives that the patient has, as well as members of the multi-disciplinary team). The Mental Capacity Act means that it is now possible for patients to make a legally binding advance decision to refuse treatment (ADRT), placing the onus on clinicians to establish whether such a decision exists and if so, whether it is valid and applicable in the circumstances at hand. Other non-binding advance statements of wishes and preferences should also be considered. In addition, enquires should be made to establish whether a patient has given power of decision making for particular health and welfare decisions to a nominated individual, under the device of 'lasting power of attorney'.

In practice, the process of establishing whether a particular type of treatment may benefit an incapacitated person at the end of life is complex and difficult, and associated with inconsistent and contradictory patterns of behaviour, as well as with poor understanding of ethical and legal frameworks amongst clinicians and 'users' (i.e. lay family members, public and patients). This leads to conflicts between members of the multidisciplinary teams (usually couched in terms of medicine vs nursing) and poor bereavement outcomes[2]. A number of interactional strategies may be used by clinical teams to help them cope with these issues, including diffusion of responsibility[3]. Codes of ethics and biomedical frameworks are not enough to provide clinicians with the resources they need to respond compassionately to situations involving human suffering.

1.General Medical Council. Treatment and care towards the end of life: good practice in decision making. London, GMC. 2010
2. http://www.healthcarecommission.org.uk/_db/_documents/spotlight_on_complaints.pdf
3. Seymour, J.E. Negotiating natural death in intensive care. Social Science and Medicine, 2000, 51: 1241-1252

Full text

End-of-life decision-making for people who lack capacity to decide: perspectives from the UK

Introduction

I want to start with a case study about an elderly man who was a resident in a care home in England. Although he had advanced dementia and Parkinson's disease, when he was sent into hospital by his GP as an emergency with an apparent myocardial infarction and circulatory collapse, this vital information did not travel with him. Partly as a result of a lack of information, partly as a result of a lack of experience on the part of the treating doctor, the patient received invasive life prolonging treatment in intensive care which, once started, was difficult to stop because all the non-treatment decisions that should have been taken earlier in the course of the patient's disease became the sole responsibility of the ITU staff[1, 2]. Once treatment was eventually withdrawn, the patient died very quickly. His family were left feeling confused, questioning whether his death was some form of euthanasia.

The case demonstrates that decisions about end of life treatment are a property of health care systems, which are poorly prepared to provide a co-ordinated response to the needs of chronically ill older people who make up the majority of those with a loss of capacity prior to death; many of whom will experience a series of care transitions in the last year of life[3]. In the past, serious illness led to death quite quickly and there were clear expectations of what the journey towards death would be like. Now, with the rise of what has been called the 'indistinct zone' of chronic illness and the concentration of death in older age[4], it is possible to live for a long time with even very serious illness and death may occur relatively unexpectedly. As a result, appropriate plans for end-of-life care and transitions to palliative care for those who are likely to die may be either delayed or never completed, with the resultant outcome that quality of care and experience during dying falls far short of the ideal[5]. The 'protracted and negotiated death'[6] has taken the place of something which used to be short and unproblematic at least from an ethical, if not a personal, point of view.

Policy and practice standards in the UK: an overview

In the UK, new guidance for clinicians on good practice in decision making in end-of-life care[7] draws attention to the importance of assessing the 'overall benefit' of any treatment for patients who lack the capacity to decide. This is consistent with the legal requirement to act in incapacitated patients' 'best interests' (Mental Capacity Act, 2005, England) or 'benefit' (Adults with Incapacity Act, 2000, Scotland). Any decisions relating to potentially life prolonging treatment must be underpinned by a 'presumption in favour of prolonging life'[7 para 10] although there is no 'absolute obligation' to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views (if these can be established). The guidance draws attention to the importance of early identification of patients approaching the end of life, so that plans can begin to made for their care before they lose capacity to make their own decisions. This is also a key emphasis in National Strategies to improve end-of-life care published in 2008 in England[8] and Scotland[9].

Under the UK Mental Capacity Act of 2005, which was implemented in England and Wales 2007 and has an accompanying Code of Practice[10], there are minimum standard steps to work out 'best interests' that should be undertaken by the clinician who takes responsibility for the relevant aspect of the patient's treatment. These include carefully establishing which decision needs to made and appropriate consultation with those close to the patient, including their relatives as well as members of the multi-disciplinary team. The Code of Practice [10, para 5.13] has a non exhaustive checklist which must be considered in respect of trying to work out someone's best interests when a particular decision needs to be made:

- Determining what is in someone's best interests cannot be based merely on their age, appearance, condition or an aspect of their behaviour which may lead others to make unjustified assumptions about what is in their best interests;
- All relevant circumstances should be considered when determining someone's best interests;
- Every effort should be made to encourage and enable the person who lacks capacity to take part in the decision making process;
- If there is a chance that the person will regain capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent;
- Special considerations apply about life sustaining treatment;
- The person's past and present wishes and feelings, beliefs and values should be taken into account, where information about these is available;
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of any deputy or attorney.

The Mental Capacity Act means that it is now possible for patients to make a legally binding advance decision to refuse treatment (ADRT), placing the onus on clinicians to establish whether such a decision exists and if so, whether it is valid and applicable to the circumstances at hand. ADRT decisions only apply when that person lacks capacity to consent to, or refuse, the specified treatment under consideration. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment. An advance decision to refuse treatment:

- Can be made by someone over the age of 18 who has mental capacity
- Is a decision relating to refusal of specific treatment and may also include specific circumstances
- Can be a documented verbal statement. If an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk';
- Will only come into effect if the individual loses capacity;

- Only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision;
- Is legally binding if valid and applicable to the circumstances.

Other non-legally binding advance statements of wishes and preferences should also be considered. In addition, enquires should be made to establish whether a patient has given power of decision making for particular decisions to a nominated individual, under the device of 'lasting power of attorney'[10].

Realities of practice: evidence from the UK

In practice, there are a number of characteristic problems in achieving good practice in decision making for people who lack capacity at the end of life, which is clearly revealed by empirical evidence from the UK. One example of such evidence is a report released in the UK during 2007 which analysed complaints to the Healthcare Commission: the NHS watchdog in England. The report analysed 16,000 complaints made between July 2004 and July 2006, finding that more than half (54%) of complaints from bereaved family members about hospital treatment were about end-of-life care and, of these, most centred on failures perceived in relation to communication and degree of 'preparedness' for the death[11]. Over the last decade or so, research evidence suggests a similar picture has emerged from many other developed countries. Among the largest and most frequently cited is the US SUPPORT study [12], which found that among a large sample of seriously ill hospitalized patients recognised as at high risk of dying, 50% had a 'do not attempt resuscitation' order written in the last two days of life and more than one third spent their last days in an Intensive Care Unit.

More recently, a review of the care patients received who died within four days of admission to hospital provides a detailed insight into some of the 'systems' factors that lead to such outcomes[13]. The study was an audit of over 3000 deaths in hospitals in England, Wales and Northern Ireland to explore remediable factors in the process of care for patients who died within 96 hours of admission over a six month period in 2007. Most of the population examined in this study was elderly, with a majority of patients admitted aged 66 and over. Just over half, 56.6% (1772/3128) of the patients were admitted via the emergency department and 70% had 'severe or incapacitating' illness. One section of the report devotes itself to an analysis of end-of-life care and shows that in about half of cases, clinicians reported that they did not expect patients to survive. Most common in this group were patients were severe or incapacitating illness, many of whom would have lacked capacity due to their condition.

The report notes that '*With such a large number of patients who had a poor prognosis the importance of discussion of treatment limitations …would be considered of upmost importance' [13, p5; p100]* . However, in about 17% of cases where death was expected there was no evidence of discussions of this type either between health care teams, or with patients' families. Almost two thirds of patients who were expected to die had no clear care plan[84] for their terminal care, about one third did not have a 'do not attempt resuscitation' decision and less than half were referred to palliative care specialists. A comparison with the group whose prognosis was less certain or were expected to survive, shows larger numbers of patients with diseases other than cancer and patients who had had a delay in senior clinician review. In this group, less than 5% received any palliative care input and in about half of cases there was no discussion either between clinical teams or with patients' families about non treatment decisions.

The report concludes that in many cases clinicians lacked the ability to identify patients approaching the end of life, that there was inadequate implementation of end-of-life care and poor communication with patients, relatives and other health care professions. Instances of poor decision-making and lack of senior input, were particularly common in the evenings and night time.

Possible explanations for the 'gap' between guidance on end of life decision-making and clinical practice

There is a lack of research evidence in relation to factors influencing clinical decision making processes at the end of life, partly because of the difficulties of conducting such research, but the explanations for such behaviour are likely to be extremely complex. One important problem is a widespread reluctance to prognosticate about disease[14]. This means that opportunities to establish goals of care with patients[15], before they lose capacity, are commonly missed.

A second problem relates to the number of care settings through which many patients in the last year of life move. Patients who experience non sudden death have been observed to be transferred between settings in the last three months of life (when loss of capacity will be more common), with 10% moving three times or more [3]. There is a tendency for decision-making responsibility to be trans-

[84] The authors of the report were referring to the 'Liverpool Care Pathway for the Dying Patient' a tool to guide clinicians' practice in terminal care, see: http://www.mcpcil.org.uk/liverpool-care-pathway/

ferred at the same time as the patient, with resulting evidence of care fragmentation and decreased quality of care among people with complex care needs who move between care settings [16]. Inadequate education and training of clinicians, which is an international challenge, about clinical, ethical and legal issues in end-of-life care and decision-making and the importance of anticipatory care planning[17] probably reinforces the tendency to give responsibility about difficult end-of-life care decisions to others.

At a cultural level, there is an obvious tension between, on the one hand, the widespread reluctance among the public and professionals to engage with advance care planning and a lack of education about ethical and legal issues at the end of life, and on the other hand, an unrealistic emphasis on the autonomy focused rhetoric of 'choice' and 'control' as a 'solution' to complex problems of decision-making[18]. Feeding this tension is our highly ambivalent and often contradictory relationship with medicine and medical technology, described elegantly by the physician and sociologist, Frank: '…*high tech medicine offers real hopes, [but] resistance to 'dying on a machine' is itself resisted by wanting what that machine might offer*'[19].

Lastly, it has been demonstrated that effective interdisciplinary team working leads to effective and timely decision-making processes in end-of-life care[20]. Unfortunately, outmoded hierarchical relationships between nursing and medicine remain the norm in many environments. This mean that nurses' perspectives are often not properly incorporated in the decision making process in spite of the fact that they spend the most sustained periods of times with patients and patients' families[21, 22].

Recommendations to enable good practice in end-of- life decision-making for people who lack capacity

Good practice in end of life decision making can only be enabled by a systems based approach. Firstly, a strategic approach is required to identify points of transition when it is timely to assess patients' end-of-life care needs. Secondly, there is much work to be done to nurture genuine team work so that patients' best interests can be appropriately established and responsibility for decision making appropriately allocated and executed. However, focusing on the quality of clinical interactions within and between teams is not enough. We also need a major public and professional education initiative to enable a shift towards advance care planning[23], although we need to recognize that this requires a huge cultural shift in attitudes and will take many years.

As we move towards the middle of the 21st century, the incidence of dementia has been predicted to increase rapidly. In England an increase of 72% in the number of people estimated to have dementia has been predicted to occur over the next 20 years, purely due to demographic change[24]. Meeting the challenge of providing good care and decision making for people with dementia will, at the same time, improve the quality of care and decision-making received by all those who lack the capacity to act in their own best interests. It is urgent that we prepare to meet this challenge.

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Biographical notes

Jane Seymour is a nurse and social scientist who has worked in palliative care research and education since 1994. Before that she had a clinical career working mainly in acute and critical care settings. Her PhD was a study of end of life decision making in intensive care. She is currently the head of the Sue Ryder Care Centre for Palliative and End of Life Studies in the School of Nursing, Midwifery and Physiotherapy at the University of Nottingham. The Centre has a wide portfolio of funded research in palliative and end of life care, with a particular emphasis on policy implementation and evaluation, advance care planning and other aspects of end-of -life care decisions, older people's experiences and outcomes of end of life care and approaches to public and professional education in these areas. Jane is involved in palliative care education at Master's and doctoral levels, and seeks to support nurses and other clinicians from the UK and internationally to develop clinical, academic and policy leadership roles. She works closely with the National End of Life Care Programme to support their work in implementing the End of Life Strategy for England. She is currently revising, on behalf of a working party convened by the Department of Health, national guidance for health and social staff in decision making and advance care planning. Her publications span palliative care, nursing and social science. Selected publications include:

Clarke A and Seymour JE (in press) 'At the foot of a very long ladder': discussing the end of life with older people and informal caregivers. *Journal of Pain and Symptom Management.* doi:10.1016/j.jpainsymman.2010.02.027

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Session 4 - The person cannot participate in the decision
Decision process

Prof. Anatoly Zilber (Russian Federation) – Making Decision and Special Care in End-of-Life Patients

Chair of Critical and Respiratory Care Medicine, Republican Hospital of Karelia and Petrozavodsk State University

Abstract

Making decision and special care in end-of-life patients

This presentation is based on review of service for dying patients in five Intensive Care Units (ICUs) of the Republican Hospital of Karelia for patients of:
– General Surgery and Internal clinics,
– Cardiovascular Surgery,
– Respiratory Medicine,
– Neurology and Neurosurgery,
– Cardiology.
Total: 5 ICUs

We took into consideration the experience of our Republican Ethical Committee of Karelia: Dr. A.P. Zilber is the Chairman of the Committee for two dozen years.

The results of the analysis are founded on the critical evaluation of 46 end-of-life patients in 2007-2009.

We believe that **making decision of end-of-life patient must be based** on the evaluation of following real conditions:
1) main cause and pathogenesis of disease,
2) there are sufferings of patient or not,
3) is patient in consciousness or not,
4) can the patient to express his will now or he expressed it earlier;
5) neither age, nor patient's social status should influence the decision.

Alternative end-of-life decisions for our 46 patients are:
1) only comfort support care (16 patients);
2) palliative care (18);
3) withdrawing or withholding treatment (4).
According to our data withdrawing or withholding treatment is prohibited in Russian Federation by article 45 of «Legislation on Public Health service» (1993). At the same time at this «Legislation» there is the article 32, permitting for patient to refuse from any method of treatment. We believe withdrawing or withholding treatment can be used according to this article 32.
4) radical therapy to prolong (8 patients).

Who makes the end-of-life decision.
Among our 46 dying patients alternative end-of-life decision were made by patient (27), by relatives (14), by physician, social worker and priest (5)
We are sure: if a patient is in right mind his wishes and opinions have priority over opinions of relatives, physicians and social workers.

Biographical notes

Anatoly P. Zilber, MD, PhD, DSc, Professor & Chairman, Republican Hospital of Karelia and Petrozavodsk State University, Chair of Critical and Respiratory Care Medicine, Head Anesthesiologist and Intensivist, Karelian Public Health Ministry.

Born 13.02.1931
1948-1954 - Medical School – I Leningrad Medical Institute;
1954-1957 - Surgeon of the Republican Hospital of Karelia;
from 1957 - Anesthesiologist and intensivist at the same hospital;
1959 – Head, Department of Intensive Care, Anesthesia and Resuscitation, Head - at the same hospital;
1961 – associate-professor, Chair of Surgery and Anesthesiology, Petrozavodsk State University;
from 1961 - up to now - Professor& Chairman, Chair of Critical and Respiratory Care Medicine.

Proposed presentation for End of Life Seminar
"Bioethical, deontological and legal decision at the bed of moribund patient in the routine clinical practice".

Main directions of research
Clinical Physiology in Critical and Respiratory Medicine
Physiological and Medico-social problems of Pain syndromes
Humanitarian problems of medical practice and education.

Published works: 438, including 33 monographs edited in Russia and abroad.

Main publications on the subject
Treatise on Euthanasia: with reflection on painless serene death, made and written by the author in hours relieved of cares to prolong life. – Petrozavodsk: PetrGU, 1998. – 446 p.
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Session 4 - The person cannot participate in the decision process

Mrs Andrée Endinger (France) – The Person Cannot Participate in the Decision Process

Nurse specialised in palliative care, Clinique de la Toussaint, Strasbourg

Abstract

Brief reminder of the current legislative framework in France, particularly the *loi Léonetti* governing cases in which a person is incapable of communicating his or her wishes. This legislative framework is useful for our palliative care services.

In the event that a person cannot express his or her wishes and cannot play a part in the decision, we rely on two provisions:

- advance directives ;
- the surrogate ("*personne de confiance*").

In our department, this problem arises mainly for patients in a neurological coma or in a vegetative state, and very often concerns the starting or cessation of parenteral or enteral feeding (I shall give examples of cases dealt with in our department prior to the *loi Léonetti* and others dealt with after that law, which sets the current framework).

<u>The limits to the taking of decisions for others</u>

- The *loi Léonetti* is not sufficiently well-known to the public.
- Advance directives have not become standard practice.
- When advance directives exist, it is not always drawn up as required by the law.
- Experience in our department has shown that the concept of a "*personne de confiance* " is unclear in patients' and their families' minds (specific examples from the department).

<u>The respective roles of the persons concerned</u>

The concept of collegiate effort has always existed and been applied in palliative care, since long before the law highlighted it. A lot of consultation has always taken place within the team (I shall give some examples of this modus operandi).

The persons concerned are doctors, the care team in the broad sense (nurses, nursing auxiliaries, duty staff, physiotherapists, art therapists, chaplains), families, relatives, the "*personne de confiance*" (I shall give the example of an ethical framework for consultation used in the department).

Full text

By way of background to my address, let me tell you that I am a nurse and that I have been working for some ten years in the Palliative Care Department of the Clinique de la Toussaint in Strasbourg.

The Leonetti law of 22 August 2005

- The law has three aims:
  - to relieve our citizens' legitimate fear and anxiety about end of life;
  - to relieve the fears of health professionals seeking for legal safeguards in procedures where treatment is limited or discontinued;
  - to reconcile patients' demands concerning freedom of decision-making and transparency of procedures with carers' need for legal certainty.

- The law recognises the patient's right to object to unreasonable persistence and sets the framework for good medical practice.

▪ The legislative framework is obviously a great help to our palliative services, especially in the situations we are concerned with this morning, where the patient is unconscious or incapable of taking part in the decision.
In our department, the problem arises mainly with patients in a neurological coma or in neurological vegetative states and is very often concerned with starting or discontinuing enteral or parenteral nutrition.

The procedure for limiting or discontinuing treatment has to satisfy three requirements:

- respect for the patient's personal will
- joint decision-making
- medical collegiality.

Respect for the patient's personal will is ensured in two ways:

- If the patient has previously appointed a confidential counselor, the latter's opinion, except in emergencies or impossible cases, takes precedence over any other non-medical opinion in investigation, intervention or treatment decisions taken by the doctor.
- The patient may draft advance directives in case he/she is one day unable to express his/her wishes. These will state his/her wishes as to the end of life, can be revoked at any time and must have been drafted within the past three years.

Joint decision-making involves dialogue with the trusted adviser, the family or one of the close relatives of the patient and the nursing team.
The medical decision is based on a **collegial procedure**:

- There must be a team of doctors, the composition of which will vary depending on whether hospital doctors or non-hospital doctors are in charge.
- This medical decision must be the result of a consensus. It is a decision shared by several doctors, not a simple consultation.
- The decision is backed by reasons and noted in the medical file.

Let me give you an example of a situation which we experienced in the department a few years ago, before the Leonetti law was passed.

Mr O. lapsed into a coma following a cerebral haemorrhage. After several weeks' hospitalisation in the CHU, he arrived in the palliative care department. He is not strictly speaking at end of life, but until that point there had been no structure able to accommodate him. His wife is present every afternoon. She looks after him, talks to him, massages his legs and arms, and so on. His two children are also present when possible; his son lives in Strasbourg, and his daughter lives in the west of France. It is an attentive, loving family. Over the weeks we see that the wife is more and more exhausted. But at no time do we see her "abandon" her husband. Of course Mr O. no longer feeds himself and is drip-fed via a gastrostomy tube.

Then one day, in the course of a conversation with the duty doctor and with the agreement of her two children, Mrs O. asks the doctor to stop feeding her husband.

The doctor informs his colleague about this request; the team starts talking about it when taking over from each other, etc. It is a difficult decision to take, anyway not one that can be taken in a hurry.
And the senior members of the department held a meeting with all the team members, to which three members of the group's ethics committee were also invited in an advisory capacity. Mrs O.'s daughter came to explain the family's exact request and the reasons for it. Then, without the family being present, everyone regardless of his/her function was asked to give his/her opinion. We also listened to questions and clarifications by the members of the ethics committee; there was a gynaecologist, a lawyer and a historian, and I remember how interesting and helpful it was to have their views, which exposed new and original perspectives.

After hearing everyone's opinion, the doctors took their decision. Whatever the circumstances, the final decision is always a medical one.

At that point in time the decision taken was to continue feeding.

Without wanting to rewrite history, one might wonder whether the decision would have been the same after the 2005 law was passed. One certainty is that the framework set by the law is an aid factor in this kind of problem.

The limitations of the decision for other people

- The Leonetti law is not sufficiently familiar to the French public. Time is needed to get away from major news events, the often dramatic cases reported in the media which shape public opinion.
- Advance directives have not become a norm, and people who take the time to draft their wishes on what is to be done in an end-of-life situation are rare.
- Where they exist, advance directives do not always conform to legal requirements.
- As regards the confidential counselor, experience in our department shows that the concept is not clear in the minds of patients and their families. Normally, on admission, a card is supposed to be filled out stating the name of the confidential counselor, but the card is not always - I would say rarely - filled out.

Moreover, when a patient is asked to give the person's name, practically all hospitalised patients answer "My wife of course" or "My husband, naturally". But no, it is by no means evident that the spouse is best placed to perform that role, which requires objectivity, and not being too emotionally involved. But the majority of patients do not dare to search for a person who might be a confidential counselor, and especially do not wish to hurt their spouse.

The respective roles of the persons involved

The concepts of joint decision-making and collegiality have always been a reality and a *modus operandi* in palliative care, long before the law made them basic priorities. We listen a lot to patients and to their close relations, trying to understand who they were from these discussions with those close to them.

Joint decision-making as a team has always been a reality.
Recently, the question arose whether a feeding tube should be fitted to a patient; the family was very clear on the point and could not see the potential benefit of this surgical act. Complications such as congestion might be expected…

Another case that arises fairly often: should a blood transfusion be considered for a terminally ill person likely to die quite soon? Will it help? Will it boost their energy level? For what purpose?

All these ethical care issues are mentioned, talked over by the team, and always behind them there lies the question "**For what quality of life?"**

The doctor, although he relies a great deal on other doctors and on the department staff and the teams, who often cast a more subjective - but valuable - light on the matter, remains responsible for the decision. That decision is taken on a collegial basis with other doctors in the palliative care unit, sometimes with oncologists and the department staff.

To conclude, I should like to present to you an **ethical tool** that we have used on several occasions in the department. It is a decision-making aid which comes from Belgium and goes by the name of GIRAFE. It is not a decision-making tool in the strict sense, but rather an ethical research method which we use in difficult and complex cases, sometimes with severe emotional implications.
4 stages:

- listening to the account
- taking in emotions and spontaneous judgments
- standing back, seeking understanding and discernment
- sharing change.

1. **Listening to the account.** The session moderator explains the situation, giving an exact, documented account of the patient's situation. The patient is really the subject - a person in the fullest sense; his/her history and background must be taken into account.

2. **Taking in and sharing emotions.** When listening to an account is motivated by experience of a difficult situation, almost always linked to suffering and death, it immediately sparks many feelings in

carers. This stage is primarily an internal reflexion which everyone does at his/her own pace. Then everyone can share his/her emotions, in a mutually receptive atmosphere, non-judgmental and open to others.

3. **Standing back, seeking understanding and discernment.** This stage takes place in sub-groups of 3 to 4 participants. Each sub-group invents 3 possible scenarios taking account of:

- the quality of life of the patient, of his/her close relatives, the nursing staff and society;
- the values preferred, the values neglected, and the principal value by virtue of which this scenario might be adopted;
- the means to be deployed. Lastly, the sub-group selects the decision which it finds most appropriate.

This stage ends with the full group meeting to draw conclusions from the work.

4. **Sharing change.** This stage is one of reflection about the question “Between the start of this joint exercise and the conclusions drawn, what has changed in me?”

We have used this tool in the case of a person suffering from ALS who asked for everything to be stopped, in particular the respirator; for a difficult case of a patient suffering from ALS, and for a complicated case of unmanageable pain. It can be used in all cases where the situation is difficult and one does not know what decision to take. It really is a preparatory tool for clearing the ground.

Biographical notes

Following a standard school career, she obtained her Baccalaureate (in *série D*) in 1971 and entered the Faculty of Law in Strasbourg in 1971, hoping to become a juvenile court judge. She did not complete this course and ultimately, in 1975, entered the nursing college at the city's *Hospices civils*, qualifying as a nurse in 1978.

She then worked in the medical B clinic at Strasbourg's regional hospital centre, in a cardiac department with intensive care beds, then moved to the surgical A department, working in general surgery but specialising in operations on the digestive tract.

Life then took her to the Nice/Antibes area, where she worked as a night nurse for the hospital-at-home service in Nice.
While working as a nurse, she also acted as hostess at CIRFA (International Centre for Applied Research and Training) at Biot, in the Alpes-Maritimes department, a recognised private further education centre which prepares school leavers with the baccalaureate for their future life and work.
While in this post, she was responsible for arranging speakers' visits (catering, supplies, switchboard) and played her part in teaching students how to cope with day-to-day life.
As holder of a BAFD (certificate in voluntary holiday centre management), she managed and led several training courses leading to the BAFA qualification (certificate in voluntary youth activity leadership) and ran summer camps for between 120 and 300 teenagers for the Fondacio community between 1984 and 1992.

On her return to Alsace, she started work at the *Béthesda* clinic in 1993, first in the continuing care unit, then in the nephrology department.
Already very interested in palliative care, she went on to obtain a university diploma in the subject. Since 2000, she has been working for the Saint Vincent group of hospitals, in the palliative care department of the*Toussaint* clinic.
Her main interests are ethics and training. She regularly addresses auxiliary nursing students and trainees following the in-service training provided within the Saint Vincent group.

European Multiple Sclerosis Platform (patient organisation) – A Time to Reflect and a Time to Share… the Perspective of Patients

Dr Cynthia Benz, Person with MS and Volunteer within Palliative and End of Life Care, UK

Abstract

A Time to Reflect and a Time to Share . . . the Perspectives of Patients.

This presentation is something like a piece of theatre.
The parts are played by patients and carers, all levels of clinical staff, social workers, chaplains, ethicists and lawyers.
We will take a last lingering look at the roles we may find ourselves in, the realities we may struggle with, and what rights and responsibilities we try to maintain.
The dominant voices will be those of patients and carers. They explore some of the drama and paradoxes they have already experienced or foresee when the time comes for others to make critical decisions about their living and dying because they are unable to make their own preferences heard.

Full text

Outline
This presentation considers the centrality of the patient in end of life situations and the importance of communication, explores a simple way of rating end of life situations from the perspectives of patients, and tells two stories.

Introductory thoughts
Imagine a lone patient, wheeled into place in the centre of a stage. The patient is suspended between life and death. It could go either way. Here is a potential tragedy. Can anyone guarantee a positive outcome? Without the patient there is no drama. The patient is central.

Has anything much changed about death and dying over the last century or two? Would anyone want to go back to the good old days? Victorian society had a fascination about death and dying, which penetrated literature and the arts. Recently I noticed a picture on the wall of a doctor's surgery – a copy of an old painting. The painter used the play of light to focus on a sick child with a doctor at the bedside and placed the worried parents in the dimness of the background. There's a feeling of stillness about the portrayal, which marries hopefulness and acceptance while watching and waiting for nature to take its course. It reminds me of the fact that although today's patients would still prefer to pass away at home rather than in hospital, most of them actually die in hospital beds.

"Whose life is it anyway?"
This question is not simply a challenge made by today's patients and those close to patients – it is also intensely personal and poignant. Patients who engage in advance care planning and specify in advance how and where they want to be treated in end of life situations are clearly invested in owning not only their living but also their dying. It remains a matter of trust that stating personal preferences for future care will influence decision-making but cannot prescribe the outcome.

"Whose life is it anyway?" is also about success or failure, good or bad timing, the possibilities and impossibilities of postponing death, weighing the best interests of the patient and the cost to society in general. That cost may be more than monetary for there are also other costs like care and compassion.

Darren was adamant that he must always be treated and had an advance statement in place. 'I don't want to die', he would say. Again and again he would be rushed into hospital to be given antibiotics for one infection after another. In the end it seemed as if his body had no more strength left to fight. He died with MS aged 34.

Amanda has chronic obstructive pulmonary disease (COPD) and has needed resuscitation several times. She has great zest for life, already planning her 50th birthday party in 2012. However, she hates the emergency dashes into hospital and how she feels when receiving treatment. Recently she said she was thinking about refusing treatment in future.

Without capacity

It is obvious that patients without capacity cannot contribute to decisions that may tip the balance between their living and dying. They have no voice to ask, 'Am I dying?' They make no movements to indicate viable involvement and have no way to take control. The fact that they are centre of stage does not lessen their vulnerability. It may be true that within "the medical profession, every patient, even one who is dying, is an authentic living being,"[85] but it doesn't always seem like that in practice.

About fifty percent of patients who may be given medical treatment in end of life situations do not have capacity. It goes without saying that patients without capacity are unable to re-negotiate previously expressed wishes and if they haven't already made their wishes known, it's too late. That appears to leave patients in a precarious position. They will not realise it at the time but their families and friends are likely to feel that way.

Patients deserve reassurance that they will continue to receive full medical care until the end. They want to be kept comfortable. It matters that no treatment they receive will hasten death or delay it. They seek reassurance that what the medical team does or does not do for people without capacity will not infringe their basic rights and freedoms. They may wish to understand what it means to balance benefits and burdens and how doctors check that what appears be a beneficial treatment does no harm. Patients probably want their doctors to offer explanations about difficult decisions to any of their 'nearest and dearest' who want to know. Withdrawing or withholding 'treatment' seem counter-intuitive if family do not know that at end of life, for example, even a sip of water can cause distress to a patient. Patients, family and friends prioritise dying with dignity and in peace.

Defaults

Doctors are expected to know their 'default position'. 'Patients are central and relating to patients is their role.'[86] However, end of life situations 'by their very nature . . . are hard to predict'. When doctors explain how much 'care, time, skill, and energy go into decision-making', could it help patients to know 'how difficult it is to do it really well'?[87] Perhaps patients need to appreciate that doctors have a breadth of competency: the practical science of health care together with input from ethics and law as well as relational and communication skills. Patients expect the primary responsibility of doctors is about building up a trusting therapeutic relationship with them, and, where appropriate, with those closest to them - and can be refreshing realistic about it. 'I trust my doctor but I don't always agree with him!'[88] As Dame Cicely Saunders, founder of the modern hospice movement and champion of palliative care, famously said, 'Patients matter to the very end.'

Patients already have an option to choose a default position for their own care and support via advance statements and directives to accept or refuse medical treatments. That implies a willingness to think about death and dying.

Communication

Yet death and dying are taboo topics of conversation, even for people with serious health problems, and also for some medical professionals. Patients deserve to understand how potentially serious some of their apparently commonplace medical problems are - like urinary and respiratory tract infections and sepsis. Are patients without capacity even more at risk? Perhaps they are, unless medical professionals communicate such significant information to their supporters – family, friends, neighbours, and carers.

Patients who have not expressed their wishes in advance, those whose documentation gets lost, or who are without capacity, hope that their doctors will take time to talk to and involve people close to

[85] Prof. Lucie Hacpille. 14
[86] Dr Rachel Burman – personal communication.
[87] Dr Felicity Murtagh – personal correspondence.
[88] A patient with cancer shared this with me recently.

them. They deserve to have explanations so they can understand what's happening, what decisions need to be made and why, the implications of those decisions and their timing. They do not deserve to be given pronouncements. Nor do they deserve to be left without communication. Who knows what snippets of information may prove significant? Involvement is when a family member suddenly says, 'Oh yes, he'd never have wanted to go on like this!' or 'I remember she always said she'd like …'

Quality communication is about taking sufficient time to share sensitive information with care and compassion. To do it well means using non-technical language, bridging gaps in understanding, interpreting and rephrasing information until it becomes clear. It takes time for people to be ready and able to absorb it. Information needs to be repeated, consistent and updated as necessary not only for the family and friends already there but also for later arrivals as well as for staff across shift changes. It must be interactive, and inclusive of patients, supporters and colleagues.

Communication goes beyond words. Silence and presence - simply being there with another person as witness - score over facts and contribute deeply and powerfully towards fair decision-making. There's so much to absorb in the unfamiliar territory of end of life situations. Palliative care specialists are practised in this sort of encounter as are other people, whose neutrality and availability are significant. They include chaplains, counsellors or trained volunteer visitors who are skilled in knowing how to listen and wait, have the time to do so, and are not afraid of strong emotional responses.

Ongoing communication between members of medical care teams is also vital across all disciplines. Nothing informs better than dialogue, sharing experiences, respecting expertise gained and tested in real life situations, and building on that good practice. Without it, patients may be written off as hopeless cases.

Inevitably end of life scenarios vary from person to person and so different decisions will be taken. Open discussion allows for sharing across disciplines and gives time to acknowledge the relevance of guidelines and laws. Decision-making is not prescriptive. Rather it is rather a fine-tuning of profession practice, compassionate support and responsiveness in the best interests of the patient and with consultation with all who are significantly involved, professionals and those close to the patient. Even at critical moments it helps not to proceed with undue haste. It is really beneficial to carry significant others along with the decision-making processes by talking things through. What more can be humanly done?

A story

A couple of years ago an article about life expectancy and multiple sclerosis appeared in a popular magazine for people with multiple sclerosis (MS). It received a strongly negative response. Many people wrote in to say they had found the article very upsetting and inappropriate because they had always been told that MS has a minimal effect on life expectancy and people do not die from but only with MS. Any suggestions to the contrary were understandably unwelcome and even threatening. Some people were clearly either angry or very distressed. In the next edition of the magazine another letter was published in response. It came from a bereaved husband who had actually found the article helpful. Here is what he wrote.

"Hannah died after an extended and horrible period of illness. The death is recorded as due to broncho-pneumonia and multiple sclerosis. In brief, over a period of a few months, she suffered from practically every symptom recorded as attributable to multiple sclerosis. She was terrified about what would happen until mercifully she apparently stopped being able to comprehend the future. In her last weeks she perhaps even stopped registering pain.

At no time were Hannah and I made aware that progression of MS could be as severe or as rapid as it turned out to be. Nor that the condition was likely or perhaps certain to be terminal. Perhaps I should have been able to infer that but I didn't.

"No one actually spoke to us (about death and dying). And we never actually asked anyone. This is despite having a very large team of medical professionals including neurologists, MS nurses, a psychiatrist, a psychologist, a physiotherapist, an occupational therapist, a good GP and a strong palliative care team... Despite the wealth of good medical care around us, no-one was helping us to prepare for the act of dying."

Star ratings for end of life situations
I've been wondering how it might be possible to illustrate what makes for good end of life situations. Here is a suggestion for a simple 3 star rating based on patients' perspectives.

It goes like this...

Award one star for the patient who has made some preparation for death.
This is most obvious when a patient has engaged in significant conversations about advance care planning and formally made personal preferences known in advance.
No preparation – no star.

Award one star for whoever or whatever gives support to or anchors the patient.
Support and anchorage are usually to do with significant relationships – family, friends, pets, places, especially gardens and countryside – and connectedness that goes deep – trust, satisfaction, contentment, faith, spiritual needs met, and love.
None of these – no star.

Award one star for a good professional care team and half a star for an adequate professional care team.

This is a rough guide as to how it might look.

3 STARS
Patients prepared + with support & anchors + a good care team

2.5 STARS
Patients prepared + with support & anchors + an adequate care team

2 STARS
Version 1
Patients prepared + no support or anchors + a good care team
Version 2
Patients unprepared + with support & anchors + a good care team

1.5 STARS
Version 1
Patients prepared + no support or anchors + an adequate care team
Version 2
Patients unprepared + with support & anchors + an adequate care team

1 STAR
Patients unprepared + no support or anchors + a good care team

0.5 STAR
Patients unprepared + no support or anchors + an adequate care team

Questions to reflect on
What might it mean to be prepared?
What stops people from being prepared?
How can we ensure that patients are not ignored or misjudged?
Should patients have a right to change their minds regarding their advance statements, advance decisions, and advance decisions to refuse treatment in to fit recent or current circumstances?
What supports and anchors make a difference to patients?
What does it take to foster quality communication?
Could there be a role for 'neutral' people in communication?
What people become champions for patients, family and friends?
Can public policy and individual needs always be met?

Another story
I was told Diana's story by the Palliative Care Consultant concerned, who has given me permission to share it.

Diana didn't know what actually happened in the Intensive Care Unit. She never should. She was already on a ward when she came to and found two tubes in place, one to help her breathe and a feeding tube, and a doctor she recognised at her bedside.

Diana had been admitted acutely unwell with severe aspiration pneumonia and ventilated by an endotracheal tube. The next procedure for the team at ICU would have been to insert a tracheostomy tube except that Diana had stated on her advance directive that was something she did not want. At this point the ICU team wanted to withdraw ventilation and called in the palliative care consultant for a second opinion, and handed over the case notes. On the referral form were written three words 'Allow to die'.

The consultant questioned their decision. The explanation was that the ventilation tube could only be a short-term option and had already been in place for 48 hours. The consultant disputed the haste and insisted that the patient be given more time. When the team leader would not back down, the consultant asked to see the patient.

That was enough. She knew immediately that she really needed to fight for this young woman's life. In her professional opinion it was too soon to withdraw the tubes and 'let her go'. The consultant physically stood guard over Diana until arrangements had been made to move her out of ICU and onto a ward. Why?

Some six or seven years earlier that same consultant had visited Diana at home to interview her as part of a research project into the value of palliative care for people with multiple sclerosis. As a consequence Diana made an advance directive that said she was prepared to be admitted to ICU whenever necessary for life-saving treatment for any infections. She also stated quite clearly that she would not want permanent ventilation or a PEG feeding tube.

Diana was only 28 years old at that first meeting. A former dancer, she was slim, attractive and always immaculately dressed. The family lived simply and sparsely in local authority social housing. She was always in bed – right in the middle of the room with bare floorboards and little furniture. Diana had primary progressive MS, which was very advanced and left her completely dependent on others for her care. Because she could do nothing for herself, and was immobile with a very poor swallow, she had been given a 24-hour care package. She could only communicate by blinking and nodding. Any noises she managed to make were unintelligible to everyone except her two sons, then aged seven and eleven, who could sometimes guess what she meant and interpret the noises. Blinking worked best. In fact it worked brilliantly! Diana was 'all there'. She knew exactly what was going on and what she wanted out of life. She had full capacity.

Diana lived for her sons and received wonderful support from her parents. She was adamant that she had good quality of life. The room may have looked bare but the walls were plastered with certificates and prizes that had been awarded to her boys. A very proud mother.

As soon as Diana was strong enough and able to breathe unaided, the consultant spent time with her, discussing options in the light of what had happened in ICU. Diana's sons and parents were invited to join in the conversations, which they had not been given opportunity to do in ICU. Diana changed her mind and had the PEG feeding tube fitted. Diana is now totally convinced that the tube is worth tolerating. It means she can enjoy watching her sons grow up. She is still alive and a proud mother indeed.

Biographical Notes

Cynthia Benz has been described as a 'professional' volunteer. This is thanks to living with the relapses and remissions of multiple sclerosis, which moved her on from full-time lecturing and counselling into doing some writing, completing a PhD in Theology, and enjoying voluntary work. Her book, *Coping with Multiple Sclerosis*, in its 4th edition, has had its 21st birthday, and she contributed the chapter on 'Patients' Perspectives' in *Palliative Care for Non-Cancer Patients.* Cynthia visits patients

on an oncology ward at Royal Berkshire Hospital every week as a chaplaincy volunteer. She is also a member of various committees that focus on ethics, neurological conditions, especially MS, palliative and end of life care at the National Council for Palliative Care, the Multiple Sclerosis Society, and the Department of Palliative Care at King's College, London.

RAPPORTEURS

General rapporteur: Dr Regis Aubry (France)

Head of the Department of Pain Management–Palliative Care, University Hospital of Besançon, Jean Minjoz Hospital
Coordinator of the National Programme on Palliative Care Development

Biographical notes

Hospital practitioner in charge of the Pain Palliative Care Department, Jean Minjoz University Hospital (CHU), Besançon 25000, France

Associate Professor (medical disciplines), Faculty (UFR) of Medical and Pharmaceutical Sciences, University of Franche-Comté

Secretary General of the Bourgogne Franche Comté Inter-regional Ethics Forum, established on 6 April 2009 under Law No. 2004-800 of 6 August 2004 on bioethics

President of the National Observatory on the End of Life, Paris, France

Co-ordinator of the National Programme for the Development of Palliative Care and Support, 2008-2012 – appointed on 18.12.08 by the Ministry of Higher Education and Research, the Ministry of Health and Sport and the Ministry of Labour (State Secretariat for Solidarity)

Research activities and publications linked to the theme of the symposium

Principal research theme: medical decision-making in complex situations
Examples of activities implemented since the launch of this research in 2006

- National PHRC (Hospital Clinical Research Programme) 2006. 3D Study: "Factors in deciding whether or not to treat elderly persons with advanced Alzheimer type disease in end of life situations"
- Inter-regional PHRC 2007 (Besançon, Dijon, Nancy, Reims, Strasbourg): REALIST study "How should decision-making criteria for implementing or stopping neonatal resuscitation be analysed?"
- National PHRC 2008. NUTRIVEG study: "Artificial feeding and hydration of persons in a persistent vegetative state: care, treatment or therapeutic obstinacy?"
- AAP Fondation de France 2010: Research into care and support for seriously ill persons
- National PHRC project 2011: Appropriateness of using artificial feeding in anorexic patients with progressive metastatic cancer
- National PHRC cancerology project 2012: "What else" study: "Cross-disciplinary approach to therapeutic decision-making in oncology and onco-hematology for patients with advanced forms of cancer"

Activities performed as associate researcher

- National Research Agency (ANR) research into Alzheimer's disease and similar diseases 2011. Evaluation of decision-making capacity and its alteration according to Alzheimer sufferers' neurocognitive state. Head researcher: Pr Pierre Pfitzenmeyer, Faculty of Medicine and Pharmacy (UFR MP), University of Burgundy, Dijon Teaching Hospital (CHU)
- Co-ordinator of a formalised expert consensus: Recommendations concerning sedation of distressed terminal stage patients and in specific, complex situations. 2008-2010. Haute Autorité de Santé (HAS - French Health Authority) and Société Française d'Accompagnement et de Soins Palliatifs (SFAP - French Society for Support and Palliative Care). Label awarded by the HAS in 2010.
- Associate researcher, National Institute for Demographic Studies (INED): "National survey of end-of-life conditions in France and related medical practice". Survey of a representative sample of doctors, conducted from 2010 to 2011. Research team: S . Pennec, A. Monnier, N. Brouard, R Aubry, S. Pontone. Results expected in 2011

Papers published in specialist medical journals in 2010

- Blanchet V, Viallard ML, Aubry R. "Sedation in palliative medicine: recommendations concerning adult patients and particularities for patients living at home or in geriatric care", Medpal, 2010, 9:59-70
- Aubry R, Blanchet V, Viallard ML. "Sedation of distressed adults in specific, complex situations ", Medpal, 2010, 9:71-79.
- Viallard M.L, Suc A, De Broca A, Bétrémieux P, Hubert P, Parat S, Chabernaud J.L, Canouï P, Porée N, Wood C, Mazouza W, Blanchet V, Aubry R. "Indications for sedation in terminal phase or end-of-life child patients; proposals based on a survey of the literature", Medpal, 2010, 9: 80-86
- Aubry R. "Ethical issues linked to the development and funding of palliative care: follow-up to Opinion 108 of the National Consultative Ethics Committee", Les cahiers du CCNE, 2010, 62: 8 10.
- Aubry R. "Can and must we do everything that scientific progress makes possible?", Les cahiers de l'information hospitalière, 2010, 5: 55-56
- Aubry R. "Targeted therapies - a progress or the most recent manifestation of promethean medical science?" Editorial, Medpal, 2010
- Caillol M, Le Coz P, Aubry R, Bréchat PH. "Health care reform, economic constraints and ethical, professional and legal principles", Santé publique, 2010, in press
- Aubry R. "Can palliative care and support be taught?" Editorial, Medpal, 2010

Co-ordination for participation in medical publications

- Aubry R. "Health care policy and palliative care" in Jacquemin D, De Broucker D. Coord. "Palliative Care Manual", 3rd edition, St Just la pendue: ed Dunod, 2009, p. 46-56.
- Aubry R. Chapter 6: "The ethical problems posed by end-of-life situations" in Module 6 – Acute or chronic pain, palliative care; clinical cases of palliative care for acute or chronic pain. Paris, Ed Med-Line, 2010
- Aubry R. Dayde M.C. "Palliative care, ethics and the end of life: a practical guide for care practitioners and the general public", 2010

Supervision of doctoral theses under preparation in 2010

- Cretin Elodie. Artificial nutrition and hydration of persons in a persistent vegetative state: the influence of care practitioners' and relatives' views. Doctoral thesis in philosophy. Co-supervised with Pr Thierry Martin, Head of the Philosophy Faculty of Franche Comté University. Viva scheduled for 2012
- Lamyaa Fahdi**.** What sufferings do persons with a chronic neurodegenerative disease endure and how do they experience the gradual loss of autonomy? Analysis of the literature and survey of patients. Doctoral thesis in medicine. Viva scheduled for 2012
- Terrin Amélie. Medical and economic evaluation of a health care network providing palliative care in patients' homes. Viva scheduled for 2011
- Vernaz Samuel. The borderline between sedation and euthanasia in paediatric resuscitation. Viva scheduled for 2011
- Baudet Cédric. Evaluation of the need for a palliative approach in paediatrics at Besançon teaching hospital. Viva scheduled for 2011
- Audran Charmarty. Emotional perception of others' pain, thesis in neuro-science.

Dr Beatrice Gabriela Ioan (Romania)

Associate Professor, University of Medicine and Pharmacy "Gr.T. Popa", Iasi

Full text

REPORT
ON THE SYMPOSIUM ON DECISION MAKING PROCESS REGARDING MEDICAL TREATMENT IN END OF LIFE SITUATIONS (SESSIONS 1, 2, 3.1)

DRAFT 1

Objectives of the symposium:

- to clarify concepts
- to remove possible misunderstanding
- to identify convergences and divergences with a view to the elaboration of possible guidelines on decision making process in end of life situations

PRESENTATIONS

SESSION 1

1. Medical End-of-Life Decisions. Conceptual clarifications and ethical implications-
Prof. Eugenijus Gefenas

Premises:

- increasing relevance of MELD decisions
- shift from acute death due to infectious diseases to death caused by cancer and other chronic conditions- unexpected/unpredictable vs expected/predictable deaths

Fundamental dilemma

- death as a process rather than a moment
- effects of MELD decisions:
    - shortening life vs. prolonging death
    - overtreatment vs. undertreatment

Types of MELDs
EURELD

- most frequent MELDs are the non-treatment decisions (tendency not to initiate rather than then to stop the treatment) and intensification of medication to relieve pain
- less frequent- administering of drugs with explicit purpose of hastening death with or without patient's request and consent.

Continuous deep sedation

- with or without provision of food and fluids
- ethical problem – continuous deep sedation followed by interruption of food and fluid provision
- what type of decision is continuous deep sedation? - seems to shorten life but there is no intention of life shortening

MELDs in ICUs

- how often patients and families are involved
- differences between European countries and the US, between southern and northern European countries

Challenges:

- transparency in the decision making process in end of life situations
- empirical research in the field of end of life decisions
- policy guidelines to acceptable practices
- better communication between health care professionals and patients

- training of staff members for a better communication with patients and patients' families and implementation of existing policies
- cultural sensitivity

2. Evolution of the way patients in end of life situations are cared for (in time and between countries) – Prof. Stein Kaasa

Premises:
- Palliative care represents the health care at the end of life when treatment is no longer useful
- Generally, patients do not want to die → living as long as possible vs. death and dying

Challenges:
Cultural
- death and dying are not part of the daily life
- technology does not solve the challenges of death
Public priorities
- increased cancer incidence and elderly population - who shall care for dying elderly?
- what is the optimal place for care and dying?
Clinical priorities
- younger patients
- new technology
- during the last 20 years, hospital care became better than home care - this is a problematic issues and it should be changed
Clinical priorities- education
- future MDs, nurses
- palliative care as a medical specialty in all European countries
Clinical priorities- research
- collaboration between European countries
- more funding
- training of researchers in the field of Palliative Care

Solutions:
- to widen access to Palliative Care
- to improve the quality of Palliative Care
- to provide higher competence in communication to health care professionals – to focus the discussion with the patients in order to save time (time vs. competence)
- to integrate Palliative Care in the mainstream health care system (Supportive care- Palliative Care – end of life care)
- to organize the health care system for the patients to die at home/their home, surrounding by their family, but with optimal care
- to conduct research in the field of end of life situations – Evidence Based Medicine - results of the research have to be translated in regulations and guidelines – positive impact on clinical care

3. What is at stake in the symposium in relation to the principles of the Convention on Human Rights and Biomedicine – Mrs. Isabelle Erny

Premises:
- Oviedo Convention provides the legal premises for protection of human rights
- In the era of new technology we live longer. As a result, there are new issues raised by the end of life care and more specific answers are needed

Human rights in relationship with end of life situations:
- right to life
- interdiction against torture
- respect for private and family life- the right to autonomy and decision over the own body- imposition of a treatment without the accept of the patient would be interpreted as a violation of the body integrity
- recommendation 1976, 1418 (1999), resolution 1649 (2009)- principle of double effect, promote palliative care, consider autonomy and advance directive as essential elements at the end of life care

Oviedo Convention:
- the interests of the human being are above the interests of society and science
- standards of decision: autonomy (personal wishes) - family decision- best interest
- equitable access to health care resources
- appropriate treatment in end of life situations
- organization of the health care system - prioritization of resources

Professional duties of the health care professionals:
→ relevant legal and ethical obligations
→ respect for the ethical principles: autonomy, beneficence, non-maleficence, justice
→ decisions should be guided by the patient's informed consent - no intervention is possible without the patient's free and informed consent
→ to recognize and accept refusal for treatment
→ physicians should refrain from providing unreasonable care - limitation and withdrawing the treatment, double effect
→ to respect confidentiality

- patients are extremely vulnerable in end of life situations - protection of persons unable to consent
→ legal representation, guardianship - very difficult to decide on behalf of somebody else, especially in end of life situations
→ opinion of the patient, where possible- essential
→ patient's previously expressed wishes- advance directives- are not binding according to Oviedo convention

How can we define the interests of the patient?
Vulnerability of the terminally ill patients

General conclusion: the provisions of the Oviedo Convention should be applied to real life situations → aim of the symposium

Discussions following session 1

- Medical profession is driven not only by money and resources but also by professional interests - Young MDs may be attracted by the palliative care field because they are attracted in treating patients as subjects and not as objects

- *Challenges in developing the palliative care network:*
- Adequate funding - optimal palliative care is not cheap
- Cost of PC- heavily influence the level of palliative care
- Improving competence and quality

- Council of Europe- 47 countries- *different cultures, legislations, different levels of palliative care*

- *How palliative care should be organized?*
2 models:
- Palliative care as medical specialization (UK, New Zealand)
- Training in one of the mainstream specializations followed by a 2-3 years specialization in palliative care (Norway, Finland)

- *Relationship between palliative care and euthanasia* - would palliative care prevent terminally ill from requesting euthanasia?
- no empirical data
- PC as part of respecting human rights
- No opposition between euthanasia and PC- PC must be available in order to respect human rights

Patient refusing palliative care vs Oviedo convention
- possible motivation- inadequate information provided by health care professionals (MDs, nurses)

- generally, patients do not want to die - communication issues

Patients' perspective
- place of death- it is important to be a place where the patient feels that he/she is safe

SESSION 2 – Nature of possible decisions in end of life situations

1. Withholding and withdrawing of treatment, including artificial nutrition and hydration
2. Alleviation of pain, including palliative sedation
3. Palliative care: a right and not an alternative

I. EOL decisions in ICUs - Prof. Andreas Valentin

- *Recommendation 779 (1976)* - prolongation of life is not necessarily the aim of medical profession
- ICU medicine- a different paradigm – "not everything possible benefits patients"
- Principle - each treatment needs a medical indication
- End of life treatment - effect vs overall benefit for the patient

Medical futility
- medical situations can change from treatable to non-treatable condition
- the ***level of prognosis*** should guide the medical end of life decision
- permanent therapeutic task - to comfort the patient

Study - end of life decisions in the ICUs are based in 92% of the cases on medical reasons → great implication of ICU physicians in end of life decision making process

Withdrawal of ICU treatment:
- no intention to hastening death
- no intention to prolonging life

Palliative Care begins most of the times at the admission in the ICU

Medical practice- protocols for withdrawal of life support measures

Palliative sedation

Double effect doctrine

Is artificial nutrition and hydration appropriate in Palliative Care?

Keypoints
→ Treatment – guided by the potential benefit for the patient
→ Futile treatment prolong the process of dying without bringing any improvement in the patient's condition
→ End of life situations- *science and charity*

II. A good death – Prof. Inez De Beaufort

- Death at home surrounded by family members vs. death in the hospital alone - death and death place have been "medicalized" during the last decades

- Many times the place of death is not a matter of personal choice

- End of life decisions - personal decisions- dignity is the core value
Dignity- reflects the very nature of each person- people are different and we should allow for these differences

- Physician has the duty to tailor the good death as it is seen by the patient- *information and communication with patient*

- Autonomous patient should be informed about prognosis of her/his disease and consent to the end of life treatment - variations between countries (99% in Sweden, 52% in Italy)
Autonomous patient has the right to refuse the end of life treatment

- Autonomous patient asks for more pain relief treatment

- Terminal palliative sedation- the patient dies from his/her disease
The Netherlands- conditions for initiating terminal palliative sedation:
- patient's life expectancy is less than 2 weeks
- pain cannot be relieved in a different way

- The slippery slope argument- dangerous argument- "danger of the slippery slope of slippery slope"

Discussions following session 2

End of life decisions - conflicts between:
- beneficence and respect for human dignity
- human rights and patients' rights

Cultural issues in end of life decisions

Involvement of the Clinical Ethics Committees
- in unclear situations (Austria)
- no such committees in some countries

Withdrawal of treatment
- death from natural causes vs death from withdrawal of treatment
- decision based on adequate information
- withdrawal is justified if there is evidence that the medical treatment is futile

Withdrawal of artificial nutrition and hydration
- some opinions- artificial nutrition and hydration are not medical treatments- they cannot be stopped
- is not a relevant question in the ICUs - the time spent by the patient in the ICU is too short
- the treatment should be guided by symptoms
- in the context of deep sedation - withdrawal of artificial nutrition and hydration in order to allow death to come
- the Netherlands → people who are not in a terminal stage may stop eating and drinking in order to meet the criteria for initiating terminal sedation
- to discriminate between terminal patients who are able to eat and drink and patients who have to be artificially fed and hydrated

Futile treatment
- it is a purely medical assessment
- patients cannot ask for futile treatments
- in case of disagreement among the members of the medical team regarding futility, further discussion and evaluation are needed in order to reach consensus
- patients or families may not understand/accept that the medical treatment is futile- a good communication between medical team and the patient/patient's family is needed – the need for educating young doctors in communication techniques/issues related to end of life situations/palliative care

Doctors have the duty to inform the patients about the prognosis of their disease

Personalized end of life decisions - differences between persons, in what they consider to be a "good death"

The relevance if ***intention*** in end of life medical treatment

Withholding vs withdrawing treatment- psychological difference

Dignity has a social value- we are socially responsible for respecting dignity - Wider societal responsibility in end of life decisions

The social context is particularly relevant in end of life decision making process

The role of the next of kin/family members and the role of the clinical ethics committees in end of life decision making process

No end of life decisions should be made because we do not want to spend time or money- slippery slope- How open and transparent people can be about their decisions

The context in which end of life decisions are taken- determinants of decision making process, such as: knowledge, restrictions, by whom decisions are to be taken

Many hospitals do not offer proper conditions for the relatives to join their beloved.

SESSION 3 – The person can participate in the decision

3.1. The person, even though sick, is in full capacity to participate in the decision process – Prof. dr. Jochen Vollmann (Assessment of patients' capacity in end of life situations)

The guiding principle in end of life decision making process is respect for the patient's autonomy → the patient has to be in full mental capacity in order to decide autonomously

Study → the vast majority of the end of life decisions are no-treatment or alleviating the pain decisions - only small part of the end of life decisions concern euthanasia

Intention to hasten death
- often associated with euthanasia
- EURELD- 45% of all the cases- explicit intention of hastening death by withdrawing or withholding treatment

2/3 of all deaths- expected by the physician- 50% involved medical end of life decisions (70% in ICUs)

Ethics of medical end of life decision making process:
- medical indication- treatment according to medical indication ("good medicine")
- respect for the patient's autonomous choice ("autonomous patients are allowed to make bad choices")
- evaluation of patient's capacity/competence

Instruments for assessing mental capacity/competence (MacCAT scale)- elements of evaluation:
- Understanding of disorder and treatment
- Reasoning
- Appreciation of disorder and treatment

Depression - more than 50% of the patients with cancer suffer from depression
- patient shows a pretty good understanding of disorder and treatment
- reasoning might be problematic - e.g. what is the impact of the disease/ treatment on the patient's life

Clinical assessment vs. MacCAT scale (compound standards)

Criteria for clinical assessment
- Doctor-patient relationship
- Understanding
- Reasoning
- Social factors

- Psychopathology
- Appreciation of disorder
- Patient request

Shared decision-making process
- medical information
- medical indication
- autonomous wish of the patient is crucial- if we plan to build our society in respect of autonomy, we should find a way for the physician to respect the competent patient's wish and not override his/her decision if it conflicts with the physician's opinion. The custom of requesting a psychiatric examination every time when the physician's and patient's decisions conflict, is itself problematic
- assessment of mental capacity
- communication between health care professionals and patient/patient's family

Capacity is a relative concept - Variable competence/capacity - even during the day

People must be helped to understand information

Transparency of the process of capacity assessment

Necessity to identify ***the best tool for capacity assessment***

Discussions following session 3.1

Intention
- is not the issue but the objective of the medical intervention
- intention has a moral relevance

The need for a semantic change- new terminology to describe exactly what is happening in the context of end of life decisions (e.g., terms such as active/passive euthanasia are rather confusing)

Involvement of all medical team members in the decision making process.

Clinical ethics committees do not make decisions (clinical ethics committee members do not know details about a given patient) but may be of help in the decision making process.

End of life decisions are context and person dependent

<u>POINTS OF CONVERGENCE</u>

I. Dramatic changes in the process of death and dying
1. Decrease of the number of unexpected and unpredictable deaths
2. Increase of the number of expected and predictable deaths
3. Increasing importance of medical decisions in end of life situations that influence the process of dying and the moment of death
4. "Medicalization" of death and dying - people do not want and cannot die at home anymore
5. Death as a process- process of dying

II. Vulnerability of terminally ill patients

III. Important cultural issues in end of life decision making process
1. MELDs are context and person dependent
2. The need for cultural sensitivity in the medical end of life decision making process
3. Europe is heterogeneous in terms of culture, legislation, level of palliative care, existence of clinical ethics committees. As a consequence great discrepancies exist between countries in end of life decision making process.

IV. The need for a semantic change

- New terminology to describe exactly what is happening in the context of end of life situations (e.g., the use of active/passive euthanasia is rather confusing) and to avoid confusions

V. Futile treatments

- "Good medicine"- the treatment must have a medical indication
- Physicians do not have a duty to provide futile treatments
- Futility is essentially a medical assessment

VI. The need for transparency of the end of life decision making process

VII. The need for further education of health care professional

1. Need for education of health care professionals in the field of palliative care and end of life situations
2. Need for education in communication techniques
3. All health care providers/professionals should be involved in MELD

VIII. End of life situations are very diverse and complex and there are **great differences between countries** in terms of legislation, resources, level of palliative care, etc → **guidelines** are necessary to both health care professionals and patients/patients' families

Biographical notes

Beatrice Gabriela Ioan is currently employed as associate professor at the University of Medicine and Pharmacy „Gr.T.Popa" of Iasi, Romania, and as forensic pathologist at the Institute of Legal Medicine of Iasi, Romania.
She is the vice-dean of the Faculty of Medicine of Iasi.
She is the president of the Bioethics Commission of the Romanian College of Physicians and the president of the Disciplinary Commission of the Romanian College of Physicians.
She is the vice editor in chief of the Romanian Journal of Bioethics.
She is representative of Romania in the National Ethics Committees (NEC) Forum and member of the Romanian delegation in the CDBI, Council of Europe.
She graduated the Faculty of Medicine of Iasi in 1993, the Faculty of Psychology, University "Al Cuza" of Iasi, in 2002, and the Master's program in Bioethics at Case Western Reserve University in 2004. She became a PhD in Medical Sciences in 2003.
She is the author/co-author of 11 books and over 50 scientific papers on topics of bioethics and forensic pathology.

Dr Takis Vidalis (Greece)

National Bioethics Commission

Full text

Session 3: The person can participate in the decision

3.2: The person is in a situation that affects or limits his/her capacity to express will

In this part, two particular situations have been discussed:

a. Minors needing palliative care
b. Incapacitated adults supported by guardians or custodians

A. *Regarding minors*, parents have the parental care and act as legal representatives, according to the law. Their autonomy and the preservation of the child's best interest (v/s both, the parents' self-interests and the interests of the other children) are crucial factors that need to be taken into account.
Decision-making should be based on a multi-disciplinary approach and appropriate communication with parents is the central point here. This communication has an informative purpose concerning treating or palliative care methods, but it raises also critical questions such as the best method for approaching parents, or the determination of the starting point for palliative care protocols at the clinical setting (GAGNON).
It is also questionable if the child's opinion in decision-making for end-of-life-care should play a role, even if we accept that, in general, minors may produce valid decisions for themselves in other medical circumstances, and although we agree that special attention should be paid to children facing such a difficult condition (ÖZSUNAY).

B. *Regarding incapacitated adults*, a key element is to consider the role of previously expressed wishes of the person concerned, especially with regard to the role of guardians or custodians. Questions that need to be addressed, here, are i) the legal principle "no treatment against the patient's wishes" (in the U.S. system, for example), which clearly restricts guardians as decision-makers, and ii) if a guardian should obtain a special order from the Court of guardianship, related to such decisions (ÖZSUNAY). A concrete legal framework exists at the European level (Oviedo Convention) and in national legislations as well, for supporting adequate answers.

Session 4: The person cannot participate in the decision

4.1. Previously expressed wishes: Advanced directives / living will / continuing power of attorney

In this part, we focused on the issue of previously expressed wishes of a patient.
Their two basic scopes are i) to design a "good death" for patients, based on their own values and beliefs, and therefore ii) to be rooted on patients' autonomy.
Despite of legal differences, a common place in all systems accepting such wishes is the prioritization of the patient's dignity, self-determination and health care.
A number of conditions that should be met in advance directives, is to be considered: the patient's age, his/her competence to decide, that he/she lacks capacity to consent at a certain time, that advance directives should have some formal type (written document, presence of witnesses etc).
Living wills, in particular, contain concrete orders regarding a certain type of care (usually refusing some therapies), or appoint an attorney competent to decide on behalf of the patient. They are very specific, revocable at any time, and they need to be updated regularly.
Serious questions are raised, particularly, about i) the binding force of advance directives (countries like Spain and Finland accept their binding nature by law), and ii) the extent that may cover a previous wish (if for example, this includes a right to refuse treatment as well) (PAHLMAN).
If we tend to consider advance directives as "clinical tools", there are practical problems that should be addressed, such as to avoid a bureaucratic approach (especially, without direct participation of health professionals), or to make known advance directives to the wider public.
Regarding the content of advance directives, important questions on the patient's wishes for participating in clinical trials or for organ donation have, similarly, a practical aspect in clinical settings.

Spain, a country with extensive experience in regulating and reflecting on advance directives in Europe, provides a good example that illustrates practical problems, deriving, for instance, from a variety of regional regulations in relevance (SIMÒN LORDA).
A major substantial problem is that of dementia situations (meaning a progressive loss of capacity and therefore needing to be diagnosed in an early stage, in order to enable the patient to express wishes timely). The crucial point, here, is to avoid an "all-or-nothing" conceptualization of capacity. This means that discrepancy between past and current wishes of the patient may occur at any time. On the other hand, to accept an unlimited duration of advanced directives is important, since it is unpredictable when the patient will have no longer the option to update his/her already expressed wishes. In dementia situations, advance directives may be considered as a "right" of the person concerned. A balanced view of such situations against stigmatization and ageism is a presupposition for adopting this stance (GOVE).

4.2. Decision process

Evidence-based medicine may be the appropriate method to reach end-of-life decisions, in an ethically sound way. This means that we need to justify palliative sedation, withdrawing or withholding of artificial nutrition or hydration on the basis of objective medical indications. In this view, futility assessments should necessarily confirm that any treatment would be ineffective, non-beneficial and disproportional regarding the patient's particular situation (AGIUS).
To look for objective indications in order to choose the best solution raises, nevertheless, questions on what should be done if simply the patient's request is different, or what is the role of autonomy when objective data do not exist. The major issue here is to balance the need for rational justification in decision-making with the requirement for respecting the patient's own wishes.
Perhaps, the "best interest" of patients provides a solution, if understood as their "overall benefit". Prolonging life is certainly included to that concept, as well as the patient's personal views and values (which may be in contrast, though), and the scope to promote the least restrictive choices for the patient's future life. But, still, such a guidance could be useful on condition that practical problems of poor understanding, lack of communication and interactional strategies are to be addressed properly by all persons involved in this complex social context (physicians, patients, family members, other health professionals) (SEYMOUR).
In France, the "loi Leonetti" on end-of-life-decisions has proved its importance in facilitating health professionals addressing difficult situations in every-day-work with patients incapable of expressing wishes (like patients in neurological coma or vegetative state). In this law, special provisions on advance directives (including the option for patients to appoint surrogate persons) exist as well.
Practical experience shows considerable differences concerning the decision-making process before and after the adoption of this new legal framework. Nonetheless a central element of this process (which is the collective work of the team in charge, along with family members and surrogate persons, ensuring interactive approach and consultation) stands as a permanent characteristic, already acquired from the past experience in palliative care (ENDINGER).
An alternative approach to the end-of-life decision-making is to consider patients, physicians, other health professionals, family members, social workers, ethicists, lawyers etc as the actors of a complex piece of theatre. They are playing roles that may lead to various combinations (clearly represented by using a "star" image), indicating "good" or "bad" final outcomes, when reaching decisions. But an interesting thing is that the principal players, the patients and their carers, are not the only ones that take eventually the critical decisions on life and death. To enable these persons to "make their own preferences heard" makes sense in this drama (BENZ).

If we have to point out the most important conclusions from a very rich in contributions (either as presentations or as comments or even as simple questions) symposium regarding medical treatment in end-of-life situations, I would choose the following ones:

a. It is crucial for everybody to take seriously the patient's autonomy. Autonomy has a very sensitive status in end-of-life situations for two reasons: i) because the patient's free will presupposes specific information provided by an "external" factor (the attending and maybe other physicians), disposing specialized knowledge, and cannot be based only on common experience, which is sufficient for other decisions, ii) because almost the whole spectrum of the patient's values (including philosophical and religious beliefs) is engaged in this particular will's formation and final expression. Since the patient's will needs "external" information from specialized persons, a risk of a covered paternalistic guidance is inevitably present, and should be avoided. Advance directives are eventually a sort of "trumps", for ensuring authentic autonomy

in this life-game. To take seriously autonomy means, in this sense, that a patient may decide differently from the physician's opinion and that we have to respect such a decision even if we may consider it "wrong" judging with medical or other scientific criteria.

b. It is equally crucial to take seriously medical evidence, the objective medical indications for every single concrete case. Medical evidence constitutes the core of the information provided to the patient, in order to enable him/her to reach a sound decision. It is not the only information that contributes to this decision, but its role cannot be underestimated. And the more technology opens new diagnostic and therapeutic options, the more the informative importance of medical evidence is confirmed. Evidence-based medicine is, in that sense, a necessary tool for restricting vagueness and controversial medical assessments as much as possible, in order to ensure certainty in patient's information. The crucial turning point of "futility", in particular, would be just an irrational thought, without confirmed and statistically supported medical evidence.

c. Finally, it is now important to focus on practical guidance in decision-making. Currently we have created a more or less sufficient legal framework for addressing end-of-life situations at the international level, at the European level and in national legal systems as well. Moreover, this framework is enriched with a number of very instructive judicial decisions, and with considerable theoretical contributions. But how to implement existing legal provisions in practice, taking into account both, the need for concrete approaches, on the one hand, and the requirement for equal respect of human dignity and fundamental rights in all cases, on the other, is a real challenge. A very special advantage of this symposium was precisely a clear attention that was paid to practical aspects of the decision-making process. And this reflects a clear spirit of protecting human rights not in academic settings but in the real world, which is the spirit of the Council of Europe *par excellence*.

Biographical notes

Born in Athens, Greece in 1963. He completed his basic legal studies at the University of Athens (1986). In 1995, he received his Ph.D. from the same University (summa cum laude - *The Constitutional Dimension of Power in Marriage and Family,* A. N. Sakkoulas Publ., 1996).

In 1999, he published the postdoctoral study *Life with no Face. The Constitution and the Use of Human Genetic Material* (A. N. Sakkoulas Publ., 2nd ed. – 2003), and in 2007 the first volume of a study under the general title *Biolaw* (*vol. 1, "The Person"*), (Sakkoulas Publ.). He is also the author of more than 30 academic papers on bioethics, biolaw, constitutional law, philosophy of law, sociology of law and environmental law.

He has presented papers at international and national congresses, conferences, workshops, and academic seminars. Recent participations:

- ESF Exploratory Workshop on Advance Directives, Institute of Biomedical Ethics, Center for Ethics, University of Zurich, Switzerland 2008 *(National Report on Advance Directives)*
- 21th Annual Conference on "Bioethics in the Real World", EACME, Institute of Biomedical Ethics, University of Zurich, Swiss Academy of Medical Sciences, Switzerland 2007 *("Policy-Making in Bioethics: The Gradual Emergence of Biolaw")*
- 20th International Conference on "New Pathways for European Bioethics", EACME, Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven, Belgium 2006 *("Regulating Assisted Reproduction in the EU: Time for a New Directive?",* already publ. in the *Journal of International Biotechnology Law 4, 2006,* pp. 12 - 15*)*

He participated in international and national research projects, concerning especially issues of law and new technologies. Among them:
"Discrimination against people with HIV and AIDS: Good practices in legal advice and litigation concerning employment, insurance, credit, housing, education and health care" E.U. – University College, London, 2000 – 2002.

He was a member of the lawmaking committee for the Greek Act on Transplantations (l. 2737/1999), and contributed to the ratification process of the Oviedo Convention on Human Rights and Biomedicine.

He participates as an independent expert in ethical reviews of biomedical and biotechnology research projects, under the EU Research FPs (FP 6, 7), since 2005.

In 2001 he was elected a senior scientist and legal advisor of the Hellenic National Bioethics Commission.

Since 2004 he teaches "Bioethics and Law" at the University of Crete (interdisciplinary PGP in Bioethics).

He is an attorney-at-law and a member of the Athens Bar Association since 1988.

Linguistic skills: English, French.