



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

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Room 1, Palais de l'Europe, Strasbourg

Conference organised by
the Steering Committee on Bioethics (CDBI) of the Council of Europe

The speakers: abstracts and biographical notes

Introductory message

Mr Jean Leonetti (France)

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



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

Session 1 - Introduction

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

Prof. Eugenijus Gefenas (Lithuania)

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.

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)

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 encompasses 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 developed 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 Associa-

tion 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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- (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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<http://www.kcl.ac.uk/schools/medicine/depts/palliative/arp/prisma/news/>
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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), Coordinator

Senior administrative officer

Head of the department of bioethics and patient's rights in the law, ethical and legal support division

Ministry of Health and Sports

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.

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)

Medical Director, General and Medical Intensive Care Unit, Hospital Rudolfstiftung, Vienna

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 dyspnoea. 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.

Biographical notes

Prof. Andreas Valentin, MD, MBA
Consultant in Internal Medicine, Intensive Care Medicine, Cardiology
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Current Appointment

Medical Director of the General and Medical ICU
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Scientific Focus

Intensive Care Medicine: Organisation, Ethics, Quality Improvement, Patient safety
Cardiovascular Medicine

Activities in Scientific Societies

- European Society of Intensive Care Medicine (ESICM):
Head of the Research Group on Quality Improvement
- European Society of Intensive Care Medicine (ESICM):
Deputy chair Section of Health Services and Outcomes
Research
- European Society of Intensive Care Medicine (ESICM):
Austrian representative to the ESICM council
- Austrian Society of Medical and General Intensive Care
Medicine: Secretary
- Austrian Center for Documentation and Quality Assurance in
Intensive Care Medicine: Member of the steering committee

Reviewer for scientific journals:

Critical Care Medicine, Intensive Care Medicine, American Journal of Respiratory and Critical
Care Medicine, Acta Anaesthesiologica Scandinavica, Wiener Klinische Wochenschrift (Mid-
dle European Journal of Medicine), British Medical Journal, Critical Care

Faculty member of "Faculty of 1000s" (www.f1000.com)

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
- Errors in administration of parenteral drugs in intensive care units:
multinational prospective study. Valentin A, Capuzzo M, Guidet B,
Moreno R, Metnitz B, Bauer P, Metnitz P. British Medical Journal 2009;
338:b814
- The importance of risk reduction in critically ill patients. Valentin A. Curr Opin Crit
Care 2010; 16(5):482-486

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Session 2 - Nature of possible decisions in end of life situations

Prof. Inez de Beaufort (The Netherlands)

Full Professor of Health Care Ethics, Erasmus Medical Centre Rotterdam

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.

Biographical notes

Inez de Beaufort is professor of health care ethics at the Erasmus Academic Hospital in Rotterdam. She is member of the European Group on Ethics in Science and New Technologies. She is an honorary member of the Dutch Health Care Council. She is among others a member of the International Board of Bioethics, a Euthanasia Review Committee, the Dutch Committee for Public Debate on Nanotechnology and the Appraisal Committee for the Health Care Insurance of the Dutch Organisation for Health Care Insurance. She has written on personal responsibility for health, the end of life, research ethics, ARTs, beauty and ethics, and ethics and obesity. She has coordinated EU projects on Medical Ethics in Fiction, Beauty, and Obesity and Ethics (Eurobese). She has a special interest in the role of fiction for ethics teaching.

Session 3 - The person can participate in the decision

The person, even though sick, is in full capacity to participate in the decision process

Prof. Dr. Dr. Jochen Vollmann (Germany)

Psychiatrist and Specialist of Ethical Medicine, Institute of Ethical Medicine, Bochum University

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.

Biographical notes

Professor Dr. med. Dr. phil. Jochen Vollmann
Institute for Medical Ethics and History of Medicine
Ruhr-University Bochum, Germany

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.

He is member of the German Academy of Medical Ethics, the Ethics Committee of the Ruhr-University Medical School and served as Secretary of the Medical Ethics Committee of the World Federation of Societies of Biological Psychiatry (WFSBP) and was member of the Central Ethics Commission at the German Medical Association (Bundesärztekammer).

Prof. Vollmann's research interests include informed consent and capacity assessment, ethics in psychiatry, end-of-life decision-making, advance directives, medical professionalism, allocation ethics, personalized medicine, clinical ethics committees and clinical ethics consultation.

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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)

Associate Professor of Paediatrics and Bioethics, University of Montreal

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.

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)

Professor of Civil Comparative Law and EU Private Law, University Faculty of Law, Istanbul

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.

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-Planck 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).

Professor Özsunay serves at present as the Turkish delegate in the *CDBI of the Council of Europe* (Strasbourg); in the UN UNCITRAL Working Groups II (Arbitration) and VI (Security Interests).

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)

Doctor of Laws L.LD

Executive director, HIV-Foundation

Abstract

Previously expressed wishes: advance 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 Bio-medicine 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 roleⁱⁱⁱ : 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)

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ⁱⁱ i and iii

ⁱⁱⁱ Beauchamp, T L and Childress, J F. Principles of Biomedical Ethics, 4th edn. Oxford University Press 2001.

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Pahlman, I. Physician's Decision-making and the patients' rights. In Vainio, A – Hietanen, P (ed.). Palliative care. Saarijärvi 2004, pp. 352-366. (In Finnish)

Biographical notes

Irma Pahlman, born 1957 in Valkeala, Finland.

Doctor of Laws, University of Helsinki, Finland.

Trained on the Bench.

Master of Business Administration, University of Wales, UK.

Executive Director of HIV-Foundation and the Member of the National Advisory Board on Social Welfare and Health Care Ethics (ETENE). ETENE operates under the Ministry of Social Affairs and Health.

Previous positions:

Ministry of Social Affairs and Health, Lawyer.

Director of Research and Networking, Kuopio University, Finland.

Judge of a District Court of Kotka, Finland

Researcher, Faculty of Law, University of Helsinki.

Main research areas: Status and rights of patients and health care professionals; Patients's self-determination, euthanasia, advanced directives; Confidentiality and data privacy.

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)

Lecturer on Bioethics of the Department of Citizenship & Ethics. Andalusian School of Public Health, Granada

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.

Biographical notes

Born in Zaragoza (Spain) in 1965

Doctoral degree in Medicine (1996), University of Santiago de Compostela (Spain)
Specializing in Family Medicine (1991 – 1993), Hospital Ramon y Cajal of Madrid (Spain).
Master in Bioethics (1992-1993), Complutense University of Madrid (Spain)

Reader on Bioethics of the Department of Citizenship & Ethics. Andalusian School of Public Health in Granada. Autonomous Government of Andalusia. Spain.

Member of the National Bioethics Committee of Spain (<http://bit.ly/bUyksF>).
Member of the Regional Committee on Ethics and Research of Andalusia. Spain.

RESEARCH FUNDED BY GOVERNMENTAL AGENCIES

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* Simón-Lorda P et al. [Knowledge and Attitudes of Medical Staff in Two Health Districts Concerning Living Wills.] *Aten Primaria*. 2008 Feb 1;40(2):61-66. Spanish.

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Alzheimer Europe (Patient organisation)

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.

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)

Dean, Faculty of Theology, University of Malta
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.

Biographical notes

Prof. Emmanuel Agius is the Dean of the Faculty of Theology at the University of Malta. He studied philosophy and theology at undergraduate (S.Th.B.) and postgraduate (S.Th.L.) levels at the University of Malta and then at the Catholic University of Leuven, Belgium, where he obtained an M.A. in philosophy and S.Th.D. He pursued post-doctoral research in the field of bioethics at the University of Tübingen, Germany as a fellow of the Alexander-von-Humboldt Stiftung, at Georgetown University, Washington, D.C. as a Fulbright scholar, and at the University of Notre Dame, Indiana. He is professor of Moral Theology and Philosophical Ethics at the University of Malta. He is the Head of the Department of Moral Theology at Faculty of Theology, a member of the European Group of Ethics in Science and New Technologies (EGE) and a member of Malta's National Bioethics Committee. He is also the coordinator of the *Euro-Mediterranean Programme on Intercultural Dialogue, Human Rights and Future Generations* which is supported by UNESCO. Prof. Agius is the author of three books and co-editor of five publications on future generations. His articles on bioethical issues, including on end-of-life issues, have appeared in a number of international academic journals.

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

Prof. Jane Seymour (United Kingdom)

Sue Ryder Care Professor in Palliative and End of Life Studies, School of Nursing, Midwifery and Physiotherapy, University of Nottingham

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 care¹ 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 outcomes². A number of interactional strategies may be used by clinical teams to help them cope with these issues, including diffusion of responsibility³. 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

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
- Seymour JE, French J, Richardson E (2010) Dying matters: let's talk about it. *BMJ* 2010; 341:c4860
- Hill J and Seymour JE (2010) The Mental Capacity Act 2005: Making decisions on capacity. *British Journal of Neuroscience Nursing*, 6(4), 182-185.
- Seymour JE, Almack K, Kennedy S (2010) Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*. 9:4doi:10.1186/1472-684X-9-4
- Zeilani R, Seymour JE, (2010) Muslim women's experiences of suffering in Jordanian intensive care units: A narrative study. *Intensive Critical Care Nursing*, doi:10.1016/j.iccn.2010.02.002
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- Seymour, JE, Payne, S., Chapman, A., Holloway, M (2007) Hospice or Home? Expectations about end of life care among older white and Chinese people living in the UK. *Sociology of Health and Illness*, 29(6):872-890.
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- Seymour JE, Janssens R and Broeckaert B (2007) Relieving suffering at the end of life: perspectives on palliative sedation from three European countries. *Social Science & Medicine*, 64: 1679-1691.
- Seymour, J.E, Clark, D. and Winslow, M. (2005) Pain and palliative care: the emergence of new specialties. *Journal of Pain and Symptom Management*, 29(1): 2-13.
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- Seymour, J.E. (1999) Revisiting medicalisation and 'natural' death. *Social Science and Medicine*, 49: 691-704.

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

Prof. Anatoly Zilber (Russian Federation)

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.

Legislation on Clinical Experimentation in Russia: History and Present status. – In: "Science, Law, Ethics", Haifa, 2005, p.80-89.

Essays on Medical Law and Ethics. – Moscow: Medpress, 2008.- 848 p.

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

Mrs Andrée Endinger (France)

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).

The limits to the taking of decisions for others

- 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).

The respective roles of the persons concerned

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).

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.

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

European Multiple Sclerosis Platform (patient organisation)

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.

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.

RAPORTEURS

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, Viillard 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, Viillard ML. "Sedation of distressed adults in specific, complex situations", *Medpal*, 2010, 9:71-79.
- Viillard M.L, Suc A, De Broca A, Bétrémieux P, Hubert P, Parat S, Chabernaude 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 promethan 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 of or 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

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

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.