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COUNTRY REPORTS ON ADVANCE DIRECTIVES

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CONTENTS

AUSTRIA

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1) Regulatory situation of advance directives and beyond

a) Binding nature and scope of living will

The *Patientenverfügungs-Gesetz* (PatVG), which regulates the conditions and effectiveness of living wills, has been in force since 1 June 2006. A living will is a declaration of will with which a patient refuses certain medical treatment for the case that he is no longer able to understand the situation, make a judgement or to express himself.

The living will is a further form of self-determination available to a patient. In contrast to the non-anticipatory rejection of treatment, the legislator demands, in the case of anticipatory rejection, the fulfilment of certain conditions.

The law provides for two forms of living will:

- the non-binding living will
- the binding living will.

See the full text of the law (in English) at:
http://www.patientenanwalt.com/pdf/FEDERAL_LAW_GAZETTE.pdf

Binding Living Will (chapter 2)

In the case of a binding will, if the patient is no longer able to understand the situation or to make a judgement and/or is unable to express himself, the doctor has to respect the living will and under no circumstances is allowed to carry out the measures which the patient has refused.

The conditions for the drafting of a living will are:

- Personal execution and submission of the ability of the applicant to comprehend and make a judgement
- Medical information
- Drafting of the living will in the presence of a lawyer/notary or legal representative of the patient
- Refusal of certain medical treatment
- Topicality (in principle the binding living will is valid for five years).

Non-Binding Living Will (Chapter 3)

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If one of the conditions mentioned above for a binding living will is not fulfilled, the living will is non-binding. However, the greater the number of conditions which are fulfilled, the more likely it is that a doctor will consider it binding.

If the living will does not fulfil all the conditions listed above, a legal agent will be appointed with the task of ensuring that the wishes of the patient are taken into account.

b) Possibility of appointing a proxy decision-maker

1. Power of Attorney in Health Matters (Vorsorgevollmacht in Gesundheitsangelegenheiten) (§ 284f ABGB)

A health care power-of-attorney is a power-of-attorney which becomes effective when the principal loses the required legal capacity to comprehend or judge or express himself in the matters which become subject of a proxy.

The power-of-attorney can also include consent to medical treatment. For this to occur, the power-of-attorney – under the express term of this power-of-attorney – must be drafted by a lawyer, notary or at a court. There is the possibility to have different persons for different fields of decisions (medicine, finances, place of living, etc.) as a proxy decision-maker.

If a patient is no longer able to comprehend and/or able to make a judgement and has a proxy decision-maker (the confirmation of the registration of the validity of the health care power-of-attorney in the Austrian Central Register of Representatives has to be submitted), this proxy has to act according to the will of the principal (patient) and to allow or reject medical treatment. The proxy decision-maker cannot transfer the power-of-attorney for consent to medical treatment.
If the patient is not able to comprehend and/or make a judgement but has drawn up a health care proxy agreement, a legal agent cannot be ordered for these matters. Only in the case where the proxy decision-maker does not act within the terms of the power-of-attorney agreement or in accordance with the wishes of the patient, an application for a legal agent can be made.

If the patient has drawn up a living will in addition to a health care proxy agreement for medical treatment, the health care proxy decision-maker is bound to the fundamental will of the patient stated in the living will.

The health care proxy decision-maker can deviate from the living will only in the case that the patient has also stated in the health care proxy agreement that the health care proxy is entitled to revoke the living will.

2. Representation by Close Relatives (Vertretung nächster Angehöriger) (§§ 284 b-e ff ABGB)

A new feature of the Law is the regulation concerning the possibility of representation by close relatives (§§ 284 b-e ff ABGB). The close relative can now give his or her consent to medical treatment to the extent that this usually does not lead to a serious or lasting detriment to the physical integrity or personality of the patient and the represented person lacks the required ability to comprehend and make a judgement.
Close relatives are parents, full age children who live in the same household as the represented person, spouse and co-habiting partners if they have lived with the represented individual for at least three years.

The close relative has to have his/her entitlement to represent registered in the Austrian Central Register of Representatives prior to the execution of the representation. A doctor can rely on the entitlement to represent if the close relative submits the confirmation of the registration.

The relative entitled to represent the patient will promote the well-being of the represented individual to the best of his/her ability and seek to ensure that the patient can organise his/her life in accordance with his/her wishes, taking their abilities and possibilities into account. If a living will exists, the relative entitled to represent has to abide by the wishes stated therein.

If several relatives are entitled to represent the patient, the assent of one person is sufficient. If contradictory declarations exist, none is valid.

The representation authorization is not valid or ends if the represented patient – regardless of whether able to comprehend or make a judgment – has objected or objects to it.

c) Right to patient self-determination and limits of patient autonomy

In case of a binding living will when the patient is unable to understand, judge or express himself at the moment of the treatment the practitioner has to desist from the medical treatment the patient has denied, even though that decision my lead to his death. There are no limits of patient autonomy in denying medical treatment, excepting those treatments that are imposed by special legislation (e.g. Epidemic Act –*Epidimiegesetz*- of 1950).

Furthermore, **care measures,** such as the basic supply of food and liquid cannot be rejected by a living will. The inserting of a stomach tube and the implementation of tube feeding through an existing stomach tube are medical activities and may therefore be refused by the patient using a living will.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

The PatVG does not affect the criminal prosecution of assisting a suicide and of homicide on request. The so-called “active, direct euthanasia” remains illegal, and therefore, the wish for active, direct euthanasia in a living will does not have any efficacy.

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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

So far no exact numbers have been published, less than 3000 (<1‰) fully binding living wills known in the registration system (combination of statistical databases).

Non-representative research shows that three groups take an interest in living wills:

1) People with terminal illnesses (cancer, MS, ALS): they usually have a good relationship with their physician, the living will is used to communicate about the next steps towards dying and to provide the practitioner with a valid tool to decide and act without having to fear legal measures.

2) People, who object to special medical treatments because of their religious belief or world view, for example Jehovah's witnesses (blood transfusion) or people how object to western medicine. For this group, because they are not conform to what is considered normal, it is very difficult – even with a living will – to have their wishes accepted.

3) Old people without special illnesses: they are usually well educated and well of people, they want a living will because of bad experiences with dying and long suffering in their families or because they think a living will is necessary to ensure dying without pain, without over-treatment, without life being prolonged inhumanely.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

No exact numbers published so far. Physicians report low numbers (<< 10%) from their own work life.
Percentages differ widely in different settings (hospice, local practitioner, ICU etc.)
Good communication between physician and patient usually is not seen as, but can be interpreted as an oral living will

c) How high is the acceptance of advance directives by physicians and other care takers?

No studies for Austria so far.
Discussions with physicians and problems in field access with local practitioners in our own project show that physicians have problems in accepting living wills and feel irritated.

d) What are the 3 main practical problems in writing and/or applying advance directives?

- The necessity of medical and legal consultation for a fully binding living will is felt as a hurdle (costs, access).

- Positive visions and wishes to die peacefully without medical overtreatment have to be translated into the formal denial of special medical treatments during the consultations; the translation and formulation of a patient's wishes have to meet special requirements that are interpreted differently by physicians and lawyers who often start to argue about the living will between themselves without asking the patient anymore. Furthermore the consultations are not value free, special wishes are still seen as weird and it is difficult for patients to maintain their autonomy.

- In which situations of emergency should the living will be binding and for whom? This question is unsolved, especially in those cases where people want to die at home and relatives call the ambulance during their process of dying.

e) Bibliography of empirical studies and/or other sources of information:

- Own research project is done at the moment (publications forthcoming)

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3) State of debates on advance directives

a) What are the major issues and concerns?

- In which cases of emergency or actions of emergency services should a living will be binding?

- How can a living will be made known to physicians? Is a central register a good solution? Should it be optional or obligatory for physicians to search for a living will?

- How to deal with a living will that includes wishes that seem abnormal/undesirable, unsuitable, i.e. look like a wish for euthanasia, like ill-conceived, not meant like that?

b) What are the hopes and expectations?

- Improvement and increase of trust in the doctor-patient relationship.

- To strengthen patients' autonomy and improve the dialog between physicians and patients about their wishes concerning the end of life.

c) Bibliography of literature and/or other sources of information

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BELGIUM

Chris Gastmans (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

In Belgium, advance directives are regulated by two Acts: The Act on Patients' Rights of August 22th, 2002 and the Act on Euthanasia of May 28th , 2002.

The Act on Patients' Rights regulates the right of the patient to refuse or withdraw consent for a medical service.

If the patient has made a written statement refusing a given medical service at the time when he/she was capable of asserting the rights covered in the law on patients' rights, this refusal shall be respected as long as the patient does not revoke it in a period when he is competent to exercise his rights himself (Art. 8, 4°, fourth paragraph).

This provision establishes the binding character of a so-called advance refusal. According to the explanatory report, an advance refusal has in principle the same legal effect as a currently expressed refusal: the health professional is not authorized to act, and must respect the refusal. In order for an advance refusal to be binding, two conditions must be met. Firstly, it must apply to a 'well-defined medical service'. A refusal that uses vague terms is not binding. Secondly, there may be no lingering doubt that the refusal comes from the person involved. In an emergency situation a physician will often not have enough time to verify this and the duty to provide assistance will take precedence.

The Act on Euthanasia regulates the use of advance directives with euthanasia requests.

For the purposes of this Act, euthanasia is defined as intentionally terminating life by someone other than the person concerned, at the latter's request (Art. 2).

In cases where one is no longer able to express one's will, every legally competent person of age, or emancipated minor, can draw up an advance directive instructing a physician to perform euthanasia (Art. 4, §1).

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An advance directive is only valid if it is drafted or confirmed no more than five years prior to the person's loss of the ability to express his/her wishes.

The advance directive may be amended or revoked at any time.

The physician who performs euthanasia, in consequence of an advance directive as referred to in §1, commits no criminal offence when he ensures that:
- the patient suffers from a serious and incurable disorder, caused by illness or accident;
- the patient is unconscious;
- and this condition is irreversible given the current state of medical science;
- and when he/she has respected the conditions and procedures as provided in this Act.

Many proponents of the act and also the general public have underestimated the consequences of the second condition. In their mind an advance euthanasia directive could also be valid when a patient suffers from severe dementia. Meanwhile a consensus has developed that this is not the case and that Art. 4 has a very limited scope. Only patients in a so-called persistent vegetative state can profit from it.

b) Possibility of appointing a proxy decision-maker

The Act on Patients' Rights

The law contains rules to protect the rights of patients who are legally (Art. 13) or factually (Art. 14) not capable of exercising their rights as a patient.

The rights of adult patients who are factually not capable of exercising their rights as a patient, are exercised by the person previously designated by said patients to act on their behalf when and for as long as they are unable to exercise these rights themselves. This so-called 'patient-designated representative' has to be designated using a specific written mandate, dated and signed by the patient and by this person, clearly showing the latter's consent. Patients or patient-designated representatives may revoke this mandate (Art. 14, §1).

If there is no patient-designated representative or if he fails to act, the rights of the incapable adult patient can be exercised by the cohabiting spouse, the legally cohabiting partner or the actual cohabiting partner. If this person refuses or if there is no such person, the rights can be asserted, in descending order, by an adult child, a parent or an adult brother or sister of the patient. If these persons refuse or if there are no such persons, the health professional concerned has to take care of the patient's interests, possibly after multidisciplinary consultation.

The Act on Euthanasia

In the advance directive, one or more person(s) taken in confidence can be designated in order of preference, who inform(s) the attending physician about the patient's will. Each person taken in confidence replaces his or her predecessor as mentioned in the advance directive, in the case of refusal, hindrance, incompetence or death. The patient's attending physician, the physician consulted and the members of the nursing team may not act as persons taken in confidence.

The advance directive may be drafted at any moment. It must be composed in writing in the presence of two witnesses, at least one of whom has no material interest in the death of the patient and it must be dated and signed by the drafter, the witnesses and by the person(s) taken in confidence, if applicable.

If a person who wishes to draft an advance directive is permanently physically incapable of writing and signing an advance directive, he/she may designate a person who is of age, and who has no material interest in the death of the person in question, to draft the request in writing, in the presence of two witnesses who have attained the age of majority and at least one of whom has no material interest in the patient's death. The advance directive indicates that the person in question is incapable of signing and why. The advance directive must be dated and signed by the drafter, by the witnesses and by the person(s) taken in confidence, if applicable.

A medical certificate must be annexed to the advance directive proving that the person in question is permanently physically incapable of drafting and signing the advance directive.

c) Right to patient self-determination and limits of patient autonomy

The Act on Patients' Rights:

An adult, incapacitated patient has to be involved as much as possible and depending on his comprehension, in the exercise of his rights (Art. 14, §3).

A health professional, possibly after multidisciplinary consultation, has an obligation to deviate from the decision taken by the legal representative of the patient, in the interest of the patient, to avert a threat to the patient's life or serious damage to his health. However, when the decision was taken by a so-called 'patient-designated representative', the health professional may deviate from this decision only in so far as this representative is unable to refer to the patient's expressed will, such as an expressed refusal of a life-saving treatment (Art. 15, §2).

Up to now, it is very exceptional in Belgium that a patient appoints himself a representative so that in most cases an advance refusal will not have the binding effect that Par. 8, §4 accords to it.

The Act on Euthanasia:

Without prejudice to any additional conditions imposed by the physician on his/her own action, before carrying out euthanasia he/she must:

- consult another physician about the irreversibility of the patient's medical condition and inform him/her about the reasons for this consultation. The physician consulted consults the medical record and examines the patient. He/she reports on his/her findings. When the advance directive appoints a trustworthy person, this latter will be informed about the results of this consultation by the attending physician. The physician consulted must be independent of the patient as well as of the attending physician and must be competent to give an opinion about the disorder in question;
- if there is a nursing team that has regular contact with the patient, a discussion of the content of the advance directive with that team or its members;

- if a trustworthy person is appointed in the advance directive, a discussion between the patient and that person;
- if a trustworthy person is appointed, a discussion between him/her and the patients' relatives.

d) Options of end-of-life-decisions (e.g. active/passive euthanasia, regulations for provision of artificial nutrition and hydration)

The Act on Patients' Rights regulates the right to refuse or withdraw consent for a medical service (e.g. life sustaining treatment at the end of life, artificial nutrition and hydration).

The Act on Euthanasia regulates advance directives with euthanasia requests.

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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

At the current time there is no national advance directive register in Belgium.

Advance directives

It is estimated that advance directives are available for fewer than 5% of patients in Belgium.

Advance euthanasia directives

No empirical results available

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Advance directives: No empirical results available

Advance euthanasia directives: Use of advance euthanasia directives based on the Report of the Federal Control and Evaluation Committee for Euthanasia:

2004: 5 reported euthanasia cases were based on an advance euthanasia directive (344 reported euthanasia cases were based on actual request). This makes that 1% of all reported euthanasia cases were based on advance directive.

2005: 8 reported euthanasia cases were based on an advance euthanasia directive (385 reported euthanasia cases were based on actual request). This makes that 2% of all reported euthanasia cases were based on advance directive.

c) How high is the acceptance of advance directives by physicians and other care takers?

Advance directives

In a rather old study about Belgian doctors' attitudes on the management of patients in persistent vegetative state (PVS) (Dierickx et al. 1999), all doctors were asked about the extent to which the known views of the patient (via advance directives) should influence a decision to withdraw artificial nutrition and hydration. According to 41% of doctors, the patients' advance directives should have a *decisive influence* on the doctors' decision. Forty-three percent of doctors accorded a *contributing influence* and according to 15% of doctors, the advance directives should have *no influence* on their decision.

Advance euthanasia directives

In 2005-2006 we conducted two survey studies on the prevalence, content and communication of ethics policies on euthanasia in all Flemish hospitals (n=81) and nursing homes (n=737). These studies had an 88% (hospitals) and 83% (nursing homes) response rate.

In *hospitals*, euthanasia based on advance euthanasia directives was prohibited in 23% of hospitals. Frequently mentioned reasons were euthanasia conflicted with the religious identity of the institution and frequent problems with advance directives. Euthanasia based on advance euthanasia directives was permitted only in exceptional cases (with additional procedures) in 57% of hospitals. In 21% of hospitals, euthanasia based on advance euthanasia directives was permitted in accordance with the law. Catholic hospitals had a more restrictive attitude towards euthanasia based on advance euthanasia directives than neutral hospitals.

In 52% of *nursing homes*, euthanasia based on advance euthanasia directives was prohibited. Frequently reported reasons were that euthanasia was believed to conflict with the religious identity of the institution; belief that the Belgian Act on Euthanasia forbids euthanasia based on advance euthanasia directives; frequent problems interpreting advance directives; and irreversibility of euthanasia. Twenty-eight percent of nursing homes permitted euthanasia based on advance euthanasia directives only in exceptional cases (with additional procedures), and 19% permitted euthanasia in accordance with the law.

d) What are the 3 main practical problems in writing and/or applying advance directives?

- Authors of advance directives are not always sufficiently informed about the legal regulations of advance directives and about the medical aspects of their decisions.

- Interpretations of advance directives seem to be difficult; communication between all partners involved in the clinical decision-making process is necessary.

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3) State of debates on advance directives

a) What are the major issues and concerns?

In the legal and ethical debate in Belgium, an advance directive is defined as "a written document in which a person, prior to his possible state of incapability, gives precise instructions as regards the medical decisions that he wishes or does not wish to be taken, and possibly designates a person of trust (doctor or otherwise) whom the doctor will consult when it comes to taking the most important end-of-life decisions."

From an ethical point of view, there is a broad consensus considering that:
- such a directive has to be accompanied as far as possible by the designation of a 'person of trust' empowered to hold a dialogue with the doctor on the subject of the decisive therapeutic choices.
- such a directive allows the patient to define his position as regards prolongation of life by medical means, resuscitation, unusual treatment, state of indignity, etc., thus providing the doctor with important indications as to the decision that he must take in his respect.

Very recently, bills have been put forward in the Belgian Senate to extend the current Act on Euthanasia towards persons suffering from dementia. There is strong ethical disagreement whether an advance directive could be used to conduct euthanasia in patients with dementia. - For some ethicists, the advance euthanasia directive, regarded as an integral part of the confidential consultation (*colloque singulier*) between the doctor and the person of trust, is in accordance with the ethical requirements.
- A second group of ethicists would like to include the advance euthanasia directive in the consultation that must be established with the patient's relatives and the nursing team before a decision is taken.
- A third group of ethicists considers that – in an ethical dialogue with the patient's relatives and the nursing team – the doctor must do everything possible to procure a dignified death for the patient, without transgressing the two limits (prolongation of life by medical means and active termination of life) rather than base himself on the advance directive. According to this group, the advance euthanasia directive cannot be legally binding on the doctor, who is ultimately responsible for the decision to be taken.

Several specific objections are raised with regard to performing euthanasia in a person suffering from severe dementia, as directed by the person's advance euthanasia directive.

- Some can draft an advance directive in a state op panic or depression, or with having little or unclear information about the course of dementia.
- How much does social environment pressure an elderly person into believing that it is their moral duty to complete an advance euthanasia directive?
- The risk of being discriminated against by society can motivate elderly people to draft an advance euthanasia directive.
- It is impossible for a person suffering from dementia to reconsider the decisions outlined in his advance euthanasia directive (issue of irreversibility).
- When writing an advance euthanasia directive, the author has the almost impossible task of determining the moment of euthanasia. As a consequence, the physician has the difficult task of determining whether the current situation does indeed match the circumstances specified by the author in his advance euthanasia directive calling for euthanasia to be performed. Even carefully formulated specifications about the chosen moment of death require interpretation.
- The decision to perform euthanasia at a certain moment in time has to be made by someone other than the patient himself. This can create dissensions between the parties involved (physicians, close relatives, etc.)

b) What are the hopes and expectations?

In Belgian nursing homes, the debate on advance directives is linked with the increasing interest in the 'advance care planning' model. We conducted a qualitative study on the experiences of general practitioners with advance directives, end-of-life decision processes and advance care planning. The results of this study will be available at the end of 2008.

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BULGARIA

Assya Pascalev [(*)]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Living wills are not currently available or legally binding in Bulgaria.

b) Possibility of appointing a proxy decision-maker

The decision-makers for minors and incompetent persons are the closets of kin. There are no legal provisions for appointing a proxy for health care.

c) Right to patient self-determination and limits of patient autonomy.

Beyond the general texts in the Constitution, there is no legally recognized right to self-determination in Bulgaria. Patient autonomy is *de jure* acknowledged and informed consent is necessary for treatment. Patient autonomy is *de facto* limited by a long-standing culture and tradition of medical paternalism and civic passivity cultivated during socialism. The professional judgment of doctors is rarely questioned and physicians are perceived as persons of authority and social power. Physicians do not routinely discuss treatment options with patients nor do they solicit patient opinion and participation in treatment decisions.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Euthanasia of any form is against the law in Bulgaria. Anecdotally, passive euthanasia and discontinuation of life-sustaining treatment are practiced by health care providers daily and on an *ad hoc* basis. No sociological studies or legal cases have been officially studied and/or recorded. There are no known legal precedents involving end-of-life issues. Artificial nutrition and hydration is considered medical care that is governed by medical judgement. The value components of such judgments are not recognized, explicated or addressed.

e) Bibliography

- Constitution of Bulgaria
- Bulgarian Penal Code

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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

None.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Never.

c) How high is the acceptance of advance directives by physicians and other care takers?

Due to the absence of AD, only their possible acceptance could be studied. So far, no such studies exist but if anything changes in the meantime, the information will be made available at the workshop.

d) What are the 3 main practical problems in writing and/or applying advance directives?

Since there are no AD in Bulgaria, here I can only speculate based on background knowledge of the general situation in the country:
1. The cultural taboo against talking about death in public.
2. The lack of good medical record keeping and lack of capacity to access such information when needed.
3. The lack of resources and a related lack of trust in the system that may create suspicion and fears that AD are a means for shortening patients' lives and for saving money by an already strained national health care system that would not be used in the patient's best interest.

e) Bibliography of empirical studies:

No such studies known in Bulgaria.

3) State of debates on advance directives

a) What are the major issues and concerns?

The issue of AD has not yet been raised in Bulgaria and such debate has not started yet. The Bulgarian Bioethics Center will initiate a debate by organizing a national conference in June 2008.

b) What are the hopes and expectations?

N/A

c) Bibliography of literature and / or other sources of information

N/A

4) Other remarks

The Bulgarian Center for Bioethics is planning a conference on the topic of advanced directives for the summer of 2008. The conference will be interdisciplinary including medical professionals, administrators, clergy, patient advocates, policy makers and lay people. Should the results become available prior to the EST workshop, they will be shared there. If not, they will be presented at the World Congress of Bioethics in Rijeka, September 2008.

FINLAND

Pekka Louhiala (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

A living will is binding unless there is a reason to believe that the patient's will has changed since completing the living will.

b) Possibility of appointing a proxy decision-maker

No formal regulations about this but according to the law: "If a major patient because of mental disturbance or mental retardation or for other reason cannot decide on the treatment given to him/her, the legal representative or a family member or other close person of the patient has to be heard before making an important decision concerning treatment to assess what kind of treatment would be in accordance with the patient's will. If this matter cannot be assessed, the patient has to be given a treatment that can be considered to be in accordance with his/her personal interests."

c) Right to patient self-determination and limits of patient autonomy

In principle, the patient has a right to refuse any, even life-saving treatment.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Active euthanasia is illegal. Passive euthanasia is common practice (but the term is considered questionable).

e) Bibliography

ACT ON THE STATUS AND RIGHTS OF PATIENTS
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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Less than 5% of hospital patients. No data on general population.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

According to one study, if a living will was available, 86% of the responding doctors said that it had, in general some or marked effect on treatment decisions.

c) How high is the acceptance of advance directives by physicians and other care takers?

In principle, advance directives are generally accepted and welcomed, but at the same time their value in real life situations is questioned.

d) What are the 3 main practical problems in writing and/or applying advance directives?

1) The text of living wills is too general and does not help in practice.
2) The living will has been completed many years ago when the situation has been different
3) "Wrong" reasons for making the will (depression; fear of being a burden to the family)

e) Bibliography of empirical studies and/or other sources of information:

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Louhiala P, Hilden HM. Finnish physicians' attitudes towards euthanasia in 1993 and 2003. Journal of Medical Ethics 2006;32:627-628.

3) State of debates on advance directives

a) What are the major issues and concerns?

The role of a proxy decision-maker (the patient law will probably change and make this clearer in the future)

b) What are the hopes and expectations?

1. Wider knowledge among the general public about living wills.
2. Clearer role of proxy decision-makers.

FRANCE

Jean-René BINET (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

There is no bindingness for the living will. The n°2005-370 law, published on April 22nd 2005, explains that doctors, in end-of-life situations, must take all the necessary decisions regarding any treatment themselves, especially when the patient is unable to express his own wishes. However, the law also says that, when the patient has written advance directives, doctors must take them into account. To be valid, these directives must be renewed every three years.
As far as their scope is concerned, advance directives are limited by the aim of the n°2005-370 law which is only to prevent doctors from taking extreme measures to prolong life. In this area, the patient is the only one who can declare that he wants doctors to discontinue life-prolonging treatment.

b) Possibility of appointing a proxy decision-maker

Since the vote of the n°2002-303 law, on March, 4th, 2002, any 18-year-old person can appoint someone to be consulted when he isn't able to express his will. This possibility is codified in Public health Code (art. L. 1111-6). The person is not really a decision-maker, but rather a trustworthy person. According to the end-of-life decision, the n°2005-370 law, published on April 22nd 2005, explains that this trustworthy person must be consulted about the decision. Then, her advice will overpass any other advice, except that of medical doctors and advance directives.

c) Right to patient self-determination and limits of patient autonomy

Since the vote of the n°2005-370 law, on April 22nd 2005, a patient can decide to limit or to stop any treatment. Then, doctors must respect his choice. They must also give him palliative care in order to guarantee his dignity and his end of life quality (art. L. 1111-9).

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

In France, euthanasia is prohibited, and seen as an assassination or a poisoning. The debate between active or passive euthanasia exists in society

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but there's no legal provision. However, law n°2005-370 permits doctors to give painkillers, even if the dose could, as a side effect, shorter the patient's life (art. L. 1110-5). It also permits to stop any treatment, including artificial nutrition and hydration.

e) Bibliography

BATTEUR (Annick), CERF (Agnès) & RAOUL-CORMEIL (Gilles), « La mort, le malade et le médecin (Commentaire de la loi n°2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie), *Rev. Lamy Dr. Civil,* sept. 2005/19, p. 53 à 64.

CONTE (Philippe), « Le Code de la santé publique et le choix de mourir exprimé par le malade : scène de crimes à l'hôpital », *in Droits & Droit, Mélanges Bernard Bouloc,* Dalloz, 2007, p. 229 à 232.

CORPART Isabelle, Nouvelle loi sur la fin de vie : début d'un changement, Dr. Famille, juin 2005, étude 14, pp. 5-11.

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MÉMETEAU (Gérard), « 'La mort aux trousses' Le rapport n°63 du Comité Consultatif National d'Éthique pour les sciences de la vie et de la santé, du 27 janvier 2000, sur la fin de vie, l'arrêt de vie et l'euthanasie », RRJ. 2000, p. 913 à 933.

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RAOUL-CORMEIL (Gilles), « Les directives anticipées sur la fin de vie médicalisée. Commentaire du décret n°2006-119 du 6 février 2006 pris en application de la loi relative aux droits des malades et à la fin de vie », Revue Lamy Droit Civil, sept. 2006/30, n°2209, p. 57 à 65.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

The only available empirical study was published in 2003 (see the bibliography), before the legalization of the advance directives.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

The only available empirical study was published in 2003 (see the bibliography), before the legalization of the advance directives.

c) How high is the acceptance of advance directives by physicians and other care takers?

The only available empirical study was published in 2003 (see the bibliography), before the legalization of the advance directives.

d) What are the 3 main practical problems in writing and/or applying advance directives?

The only available empirical study was published in 2003 (see the bibliography), before the legalization of the advance directives.

e) Bibliography of empirical studies and /or other sources of information:

Rodriguez-Arias David, *Les directives anticipées en France : expériences et attitudes des professionnels en réanimation,* Mémoire de DEA d'éthique médicale et biologique, Université Paris V, 2003.

3) State of debates on advance directives

a) What are the major issues and concerns?

The Chantal Sébire case, in March 2008, has renewed the interest about the end of life decision. This woman, who was horribly disfigured, had fought in vain for the right to obtain prescribed barbiturates and to be assisted in her suicide by her family and a doctor.
Since it happened, some people now want to legalize euthanasia in rare cases (Dr Kouchner, Foreign Minister). Some others want to allow assisted suicide (Mr Fabius, an ancient socialist prime minister has made a law proposition on this subject).

b) What are the hopes and expectations?

Actually, hope and expectations are very different for ones or the others. Pro-euthanasia militants hope that recent tragedies will turn public opinion to accept euthanasia. But the government seems to be hostile to this idea and now promote a large public information campaign on the actual legal provisions that are not enough well-known.

c) Bibliography of literature and / or other sources of information

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http://lesrapports.ladocumentationfrancaise.fr/BRP/074000616/0000.pdf

GERMANY

Arnd T. May (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

An advance directive normally expresses the patient's refusal of treatment (or further treatment). At present the use of advance directives is not ruled by law in Germany, but different proposals/bills of committees and assemblymen have been discussed in the German Parliament since 2007.
The bills differ fir example regarding the degree of bindingness and scope of living will, ranging from a low degree of bindingness and a scope that only encompasses the final stage of life for terminally ill patients (Bosbach et al.-bill, 2007) to a high degree of bindingness and a scope that encompasses also stages of illness, in which death is not immanent (Stünker et al.-bill, 2007).
This unclear situation leads to a lot of uncertainty among medical practitioners and nursing staff regarding the bindingness and scope of advance directives.

The current legislative procedure follows the court order of the Federal High Court (from March, 2003), according to which an advance directive is binding. Moreover it states that an attendant can refuse medical measures with the approval of the guardianship court (BGH 2003).
According to that order, an advance directive is valid if:

- the patient's disease is terminal
- the patient shows no signs of revocation
- the patient has drawn up the ad in a condition of having the capacity to make a decision
- the ad describes the medical situation at hand

In case an advanced directive does not clearly describe the concrete situation, it can still assist the medical staff in decision-making.

The statement of the German Medical Association (Bundesärztekammer, 2007) on the other hand does not limit the validity of an ad to the terminal stage of a disease. It says that statements concerning medical treatment, which are expressed in an advance directive, are binding under the following conditions:

1. The stated will is precise and clear
2. It describes the situation at hand

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3. It does not demand measures that are against the law (like active euthanasia)

The patient's autonomy has priority and their will has to be followed regardless of the stage of disease. If no advance directive is at hand, the probable will of the patient has to be determined.
Others who speak out against a limited scope of an advanced directive are Neitzke et al. (2006), Juristentag (2006), Evangelische Kirche (2007).

b) Possibility of appointing a proxy decision-maker

Preferably the author of an advance directive names a proxy decision-maker (in a proxy directive), who then can decide in the patient's place, and who makes sure that the current will of the patient corresponds to the will at the time of writing the advance directive.

Every competent person can designate such a person (preferable a trusted individual) to make decisions of various kinds such as health care matters (through an enduring power of attorney).
If the person has not designated a proxy decision-maker by an enduring power of attorney the court has to appoint a representative. Therefore everybody can nominate a person to be appointed by the court as their representative (in a directive as to representation).

If the patient has not stated their will for the situation at hand, it is the duty of the proxy decision-maker to identify the conjectural will of the patient.
For medical decisions that involve the risk that the patient could come to harm or die as a result of the treatment, the proxy directive must address these situations and explicitly authorize the proxy decision-maker.

c) Right to patient self-determination and limits of patient autonomy

The right to self-determination in regard to one's body is a key element of human dignity and freedom. In Germany, it is constitutionally enshrined in the guarantee of human dignity (sentence 1 of Article 1(1) of the Basic Law), in the general right of personality (Article 2(1) in conjunction with sentence 1 of Article 1(1) of the Basic Law) and, most concretely of all, in the right to physical integrity (sentence 1 of Article 2(2) of the Basic Law).

This right of self-determination applies equally to healthy and to sick people. Hence everyone has the right either to permit or to refuse medical treatment. Under current law, any measure carried out against the patient's will (whether an operation or merely the insertion of a gastric tube) is deemed to constitute the infliction of bodily harm. Persons who are seriously ill or dying have the same right to self-determination as everyone else. All these situations may involve life and death decisions that are difficult and burdensome for all concerned.

In legal terms, the right of self-determination has the consequence only of a right of defence against interference with an individual's bodily integrity, but not of entitlement to active interventions by others. The attending physician can thus, for instance, refuse to adopt a measure that is not medically indicated. The limit of the right of self-determination is at any rate set by the fact that a person cannot invoke it to oblige others to kill him on demand or to help him commit suicide. However, whether a doctor can refuse on grounds of conscience to terminate previously initiated life-sustaining measures (e.g. by

switching off a respirator) is disputed. If the doctor refuses so, another way must be found to comply with the patient's wish not to have further treatment – for instance, calling in another doctor.

As stated above, there are different bills of committees and assemblymen. They also differ concerning the degree of patient autonomy. Some bills allow a high degree of patient self-determination (like the Stünker et al.-bill), others (like the Bosbach et al.-bill) rather stress the ethical duty of the government and medical staff to protect the life and health of a patient.

At present there is not a clear consent regarding the patient's wish to revoke their will, if they are in a state in which they cannot think rationally/in which they do not have a sound mind.
There seems to be a lot of tension between medical and social care (welfare of the patient) on the one hand and respect for the patient's autonomy on the other hand.

As stated above, according to the German Medical Association the patient's autonomy has priority. This also includes the patient's right to refuse operations or blood transfusions, but physicians always support the patient to make an informed decision. Furthermore physicians can not be forced to undertake means that are against their medical reasoning.

Naturally children, mentally retarded persons or demented patients have limited autonomy and need a surrogate decision-maker.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Section 216 of the Penal Code provides that killing on demand is a criminal offence. (§ 216 StGB)
Passive euthanasia, though, is legally permitted.
If a patient has stated in their advance directive that they want to refrain from seeking medical treatment in a specific situation (passive euthanasia), their will must be followed. The patient will be provided then only with basic care. But a patient can also decide upon what kind of basic care they want to receive. If they state f. e. that they do not want artificial nutrition, the nursing staff only provides hydration. If the patient does not want hydration either, drugs can be administered to inhibit the sensation of thirst.

Regarding end-of-life-decisions professionals state that there is still a considerable lack of structures in Germany concerning requirements for medication and medical aids, palliative care and hospice, outpatient palliative care and outpatient hospice care. (e.g. Tolmein 2007)

e) Bibliography

Major Papers:
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Major Websites:
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http://www.medizinethik.de/Bosbach-GE-PV.pdf
http://www.patientenverfuegung.de/pv/aktuell.htm

Statements:

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National Ethics Council (Nationaler Ethikrat) (2006): The advance directive. Opinion
„Bundesärztekammer“ ((2007)

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

An Emnid-survey from 2000 states that 81% of Germans would like to prepare an advance directive. The primary reason for most people is that they are afraid of overtreatment by medical instruments.
It is further stated that in 2005 8,6 million people (approx. 10% of the German population) had prepared an advance directive.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

The tendency is increasing, but still there are cases in which the physician in charge either does not know about the patient's advance directive, or deliberately acts against the patient's will. (reasons for this you find under 2.c).

c) How high is the acceptance of advance directives by physicians and other care takers?

Passive and indirect means of assistance to die are legally permitted, if the patient is terminally ill and if it is the patient's wish. But still physicians and other care takers implement these means only with hesitation, even if they are described by the patient in their advanced directive.
For one thing this hesitation is often caused by the misunderstanding that passive assistance was active (thinking that withdrawing life-saving procedures would actually cause the patient's death).
Second, there is often a psycho-emotional barrier to implement such means.
Third, many physicians are reluctant, because they think that the medical treatment still benefitted the patient and was in the patient's best interest. (paternalism)

d) What are the 3 main practical problems in writing and/or applying advance directives?

Major problems in writing an AD are:
1. lack of information and (qualified) consultation
2. vague imagination of future situations
3. confrontation with death and dying
4. unclear legal situation (people are often put off)

Major problems in applying an AD:
1. AD is not precise/does not describe the situation at hand
2. psycho-emotional barrier to implement an AD
3. lack of knowledge about legal situation
4. physician does not know of its existence/does not ask for an AD

5. paternalism

e) Bibliography of empirical studies and/or other sources of information:

Major Websites:
http://www.medizinethik.de/Stuenker-GE-PV-2008.pdf
http://www.medizinethik.de/Bosbach-GE-PV.pdf
http://www.patientenverfuegung.de/pv/aktuell.htm

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„Bundesärztekammer“ ((2007)

3) State of debates on advance directives

a) What are the major issues and concerns?

1. the degree of bindingness
2. the scope of will/ limits of patient autonomy
3. revoking one’s will in an unsound state
4. the issue of standardizing an ad (to prevent unclear formulations)

b) What are the hopes and expectations?

1. legal certainty for medical practitioners and nursing staff
2. being able to take precaution ahead of times and having legal backup that one’s ad will be adhered
3. strengthening and sustaining self-determination/patient autonomy

c) Bibliography of literature and / or other sources of information

- Michalsen, Andrej (2007): Care for dying patients – German legislation.
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http://www.patientenverfuegung.de/pv/aktuell.htm

GREECE

Takis Vidalis [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

In Greek law, the only relevant provision is that of art. 9 of the Oviedo Convention (ratified by law 2619/1998). There is no special national legislation regulating advance directives in detail. Also, as far as I know, the courts have never addressed a relevant case.

b) Possibility of appointing a proxy decision-maker

There is not such a possibility, at least mentioned explicitly in the law. The Civil Code accepts the appointment of a proxy decision-maker only for concluding contracts (art. 216). In medical law, proxy consent for medical interventions is acknowledged according to the general provisions (art. 6 of the Oviedo Convention, art. 12 par. 2 of the l. 3418/2005 on "medical ethics"), but of course, in these cases, we don't have an "appointment" by the interested person.

c) Right to patient self-determination and limits of patient autonomy

In Greek law patient self-determination is covered by
- A constitutional (individual) right to health (art. 5 par. 5 Const.)
- The Oviedo Convention (l. 2619/1998) acknowledging the informed consent principle (art. 5, etc)
- Art. 11 and 12 of the l. 3418/2005 confirming the same principle
- Similar provisions in laws regulating special fields (ART, abortion etc.)

Art. 300 of the Criminal Code, prohibiting active euthanasia ("killing"), reflects a clear limit to patient autonomy.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Art. 300 of the Criminal Code describes active euthanasia as a physician's crime.
Art. 29 of the l. 3418/2005 seems to accept passive euthanasia, since it engages a physician to provide only palliative care "until the end of life", in cases where treatment is proved futile.
There are no provisions on artificial nutrition and hydration.

e) Bibliography

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Hellenic National Bioethics Commission, Opinion and Report (K. Manolakou, T. Vidalis) on "Artificial Prolongation of Life"
See:
http://www.bioethics.gr/document.php?category_id=55&document_id=356
http://www.bioethics.gr/media/pdf/reports/report_apl_en.pdf

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

There are no available data (from official statistics or empirical studies). From personal information, in the last few years, an increasing number of interested persons (patients and their relatives) ask about this possibility. Still, due to a lack of relevant information or public discussion, people in Greece are not yet familiar with advance directives, so this number must be relatively low.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

No available data, or medical reports.

c) How high is the acceptance of advance directives by physicians and other care takers?

No available data, or medical reports.

d) What are the 3 main practical problems in writing and/or applying advance directives?

From personal information, the major problem is that most of patients and their relatives show their interest only when they are facing the intensive care unit, and not in previous time. Thus their wishes risk to be considered as forced, due to an emergency situation.
Another problem seems to be the uncertainty of law, that is, of the concrete legal consequences that may have the formulation of the interested person wishes, especially with regard to medical liability.

e) Bibliography of empirical studies and /or other sources of information:

No available data.

3) State of debates on advance directives

a) What are the major issues and concerns?

- To manage conflicts between a will expressed by a healthy person and his/her potential new approach, as patient, that cannot be physically expressed during an emergency situation

- To propose a reliable method for assuring the authenticity of informal advance directives or of living wills
- To address the general issue of end-of-life-decisions, as advance directives affect the debate on that issue directly. The institutionalisation of advance directives may be discouraged if both physicians and the general public are eventually proved unwilling to participate in a relevant dialogue.

b) What are the hopes and expectations?

- To give an important option for expressing personal autonomy
- To avoid disagreements between close relatives, about the patient's best interest
- To provide physicians with a genuine expression of the patient's will, as an important factor for determining medical duty in hard cases

c) Bibliography of literature and / or other sources of information

Hellenic National Bioethics Commission, Opinion and Report (K. Manolakou, T. Vidalis) on "Artificial Prolongation of Life"
(see
http://www.bioethics.gr/document.php?category_id=55&document_id=356
http://www.bioethics.gr/media/pdf/reports/report_apl_en.pdf

4) Other remarks

The Hellenic National Bioethics Commission suggested in its Opinion (on "Artificial Prolongation of Life") the institutionalisation of advance directives, that is, the explicit acknowledgment of the legal option to assign a proxy for end-of-life-decisions. This suggestion attracted to some extent public attention, as some important national media dedicated relevant publications and debates.
In addition, the general issue of end-of-life-decisions has started to occur constantly in ethics conferences, meetings and workshops. This is probably an indication of a certain maturing of the general public to discuss and accept potential legislative initiatives.

HUNGARY

Judit Sándor [(*)]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Based on the § 22(1) of the **Health Care Act of 1997** (thereafter referred to as "HCA"), living wills made in front of a notary constitute a public document with binding force. These declarations have to be renewed every two years.

b) Possibility of appointing a proxy decision-maker

Based on the § 22(2) of the HCA, a proxy can be appointed to make a decision on the refusal of life saving and life extending treatments.

Only persons with full legal competence can appoint a proxy in advance.

c) Right to patient self-determination and limits of patient autonomy

Constitution

Section 54 (1) provides that in the Hungarian Republic everyone has the inherent right to life and human dignity. No one shall be arbitrarily denied of these rights.

The Health Care Act (Articles 20-23) deal with the right to refuse medical treatment

After 1997, following the legal reform in health care law, all forms of active euthanasia, assisted suicide and mercy killing remained serious crimes under the Hungarian law. Nevertheless, some forms of passive euthanasia were legalized by the 1997 HCA by providing explicit rights for the competent patients to refuse life saving and life supporting treatment when they have a grievous and incurable disease

Although the Hungarian law does not use the term" advance directive" the concept to refuse life sustaining medical treatment in advance exists.

Under the HCA a person with full disposing capacity in case he should become incapable in the future may refuse in a public deed, certain medical examinations and interventions and life supporting or life saving interventions if he/she has an incurable illness and as a consequence of the illness is

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unable to take care of himself physically or suffers from pain that cannot be eased with appropriate therapy.

A person with full disposing capacity may name in a public deed, for the event of his possible subsequent incapacity, the person with full disposing capacity who shall be entitled to exercise the right in his stead.

Detailed rules on the refusal of medical treatment can be found in the **Governmental decree No 117/1998** (VI.16.)

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Active euthanasia constitutes a criminal offence (Criminal Code, § 166: homicide)

The Decision No 22/2003 (IV.28.) of the Hungarian Constitutional Court explicitly rejected the decriminalization of active euthanasia.

Assisted suicide is also penalised (Criminal Code § 168), punishable up to 5 years of imprisonment: "Anyone who persuades someone else to commit suicide, or provides assistance to it…"

Some forms of passive euthanasia are nevertheless authorized based on the provisions of the HCA.

Conditions:

1. A three-member Committee has to examine the patients who requested the refusal of the life saving or life sustaining medical treatment.

2. The Committee has to make a decision whether the patient suffers from an incurable disease and has to ascertain that the patient even treated by utmost care would die in a short period of time.

3. The Committee has to verify also that the patient was aware of the consequences of his/her decision.

4. Subsequent to the decision of the three-member committee, the dying patient has to reconfirm within three days his/ her refusal of the life-saving treatment

e) Bibliography

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Polcz, Alaine: (2001) Gyermekek a halál kapujában Pont Kiadó, Budapest.

Sajó, András, Judit Sándor (1996) A gyógyíthatatlannak vélt "halálos" beteg jogi helyzete a tételes jog tükrében. (in English: Legal Status of the Terminally Ill in the Hungarian Law) In *Magyar Tudomány*, 7/1996: 771–786.

Filó, Mihály(1999). Az eutanázia jogi szabályozásának problémái. Kharón, 1999; 3 (1-2): 71-122. A gyógyíthatatlan betegek és haldoklók emberi

jogainak és méltóságának védelme. Az Európai Bizottság Közgyűlésének 1418 (1999) sz. ajánlása Kharón, 2001; 5 (2-3) 51-57.

Hegedűs, Katalin (2000). Hospice alapismeretek Az emberhez méltó halál. Budapest, Osiris Kiadó 2000.

Bitó, László (2005) Boldogabb élet- Jó halál (in English: Blissful Life-Peaceful Death Budapest Atheneum 2000

Filó Mihály, Molnár G, Fruzsina (2006) 'History of suicide in law' in: *Jogtörténeti* Szemle 2/2006: 32-37.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

No data are available

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

No data are available

c) How high is the acceptance of advance directives by physicians and other care takers?

No data are available, but according to the law declarations must be respected by physicians.

d) What are the 3 main practical problems in writing and/or applying advance directives?

- Unfortunately the current law does not distinguish between the life-saving and life supporting treatments. The refusal of life-saving or life-supporting treatment has to be respected by the physician provided that a three-member committee had examined the patient

- Some experts criticise this very bureaucratic and long procedure for the withdrawal of medical treatment.

- It is hard to justify why it is necessary to validate the decision made by a competent patient.

Note: The Hungarian law does not use the term "advance directive", moreover the word "declaration" is used only in the sense of refusal. There is no possibility to make and reaffirm positive requests and the wish to take all medically possible means to prolong life.

e) Bibliography of empirical studies and/or other sources of information:

Medián survey conducted in 2000.
-Majority of the Hungarian population supports euthanasia
-Representative sample of 1200 people

-64% of the respondents supported euthanasia and among them 67 % would have legalized even the active euthanasia

http://www.median.hu/object.258635d4-0161-4ab6-abf3-43138ff9fb47.ivy

3) State of the debate on advance directives

a) What are the major issues and concerns?

Euthanasia and other forms of the end of life decisions are frequently discussed in the Hungarian media and in public debates.

The major issue in the Hungarian debates is whether the present regulation in the HCA with the 3-member Committee decision is flexible enough and whether it guarantees the dignity of life

The Hungarian Constitutional Court has two times delivered an opinion on the matter of euthanasia [36/200 (X.27.) AB and 22/2003 (IV. 28.) AB hat.]

László Bitó (physician) launched a campaign for the so-called “euthelia” as an alternative for euthanasia.

b) What are the hopes and expectations?

Practice has to be monitored and the law should be further developed

c) Bibliography of literature and / or other sources of information

Relevant laws:
http://net.jogtar.hu/jr/gen/hjegy_doc.cgi?docid=99800117.KOR

Patients’ rights organizations:

Szószóló Foundation on Patients’ rights
http://www.szoszolo.hu/02betegjogi_szab/221218.eutanazia.htm

Cancer patients
http://www.daganatok.hu/betegjogok-es-a-beteg-kotelezettsegei/az-ellatas-visszautasitasanak-joga

Position of the Hungarian Civil Liberties Union:
http://tasz.hu/files/tasz/imce/eutan__ziaangol_uv.pdf

ITALY

Fabrizio Turoldo [(*)]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

The Italian legal system does not regulate living wills. There is a debate in progress at the Hygiene and Health Commission of the Italian Senate regarding the introduction of advanced directives concerning health treatments into the Italian legal system, but this running debate has not led, up to now, to any positive result. Therefore living wills are still non binding documents.

b) Possibility of appointing a proxy decision-maker.

There is not the possibility, for the patient, of appointing a proxy decision maker. Decisions, if the patient is not competent, are taken by relatives, even if they disagree with the patient's opinions regarding end-of-life decision and even if the patient during his life has had bad or difficult relationships with them. Sometimes a judge can appoint, if needed, a proxy decision-maker for an incompetent patient (a "legal tutor" or a "support administrator"), but this is not a choice made by the patient. Moreover, this decision-maker hasn't any power to refuse life-saving treatments.

c) Right to patient self-determination and limits of patient autonomy

At present, although the article 32 of the Italian Constitution (1948) establishes the freedom of self-determination in choosing the cure and therapy and the new deontological medical code (2006) forces the physician to restrain himself from performing diagnostic and therapeutic treatments without patient's consent, there is still a legal gap. This gap is caused by contradictions between Constitution and deontological codes on one side and, on the other side, civil and penal codes. Italian penal and civil codes are, in fact, older than Constitution, they were approved during the fascist dictatorship and their inspiring philosophy is based on a strong commitment with the principle of "non availability of human life".

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

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1. Active euthanasia is clearly forbidden by Italian penal code (Article 579 regarding “assenting murder”; see also article 580, regarding “assistance to suicide”) and also by the civil code (Article 5 that forbids everyone to harm himself, causing a permanent loss of his physical integrity);

2. More complex is the case of passive euthanasia. From a formal point of view we must say that it is forbidden, according to article 41 of the penal code (when someone has a professional duty of saving someone other’s life and he doesn’t accomplish this duty, his behaviour could be considered equal to an active murder), or according to articles 328 and 593, regarding professional omissions and omissions in lending assistance. But, at the same time, a physician cannot compel a patient to undergo a medical treatment using violence and coercion, according to other provisions of the penal code. Thus, in practice, a physician who lets die a patient because of a refusal of a medical treatment will not be considered guilty by the legal system, which will consider him as someone who was unable to accomplish a duty, against his will and owing to a cause beyond control;

3. Passive euthanasia of incompetent patients is always forbidden, because incompetent patients can’t refuse treatments and their previous wishes, expressed in advance directives, have no legal value;

4. For the same reason is not allowed to withdraw artificial nutrition and hydration to an incompetent patient.

e) Bibliography

- Italian Penal Code (1930);
- Italian Civil Code (1942);
- Italian Constitution (1948);
- Document of the Italian National Bioethics Committee on Advance Directives (18.12.2003);
- Italian Deontological Medical Code (16.12.2006)

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Very few (less than 1%), because advanced directives are not legally binding in Italy.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Usually the most important factors in medical decision-making, if a patient is not competent, are relatives’ and physicians’ opinions. Obviously, if a patient is competent and able to decide, his opinion is the most important factor in decision-making in most of the times, but not always: there are some exceptions, when patient’s life is at risk.

c) How high is the acceptance of advance directives by physicians and other care takers?

In spite of Italian legal uncertainties regarding this subject, the acceptance of advance directives by physicians and other care takers is high. Physicians, as a matter of fact, are asking for a law on advanced directives. Moreover, in the new deontological medical code (2006), Italian physicians included an article (art. 38) on advance directives, saying that advanced directives are morally binding, even if they are not yet legally binding.

d) What are the 3 main practical problems in writing and/or applying advance directives?

1. The first problem is that advance directives are not legally binding;
2. The second problem is that, in some cases, a physician who accepts to take into consideration an advance directive could be legally prosecuted, because Italian penal and civil codes are very strict regarding withdrawing and withholding treatments;
3. The third problem originates from the statistical and probabilistic character of medical judgment and prognosis. Some patients, for example, ask to withdraw a treatment, but only if there is a scientific certainty that they will not regain consciousness anymore. In such situations physicians are puzzled, because they cannot have absolute certainties, but only statistical probabilities.

e) Bibliography of empirical studies and/or other sources of information

1) SENATE OF THE ITALIAN REPUBLIC*, Dichiarazioni anticipate di volontà sui trattamenti sanitari. Raccolta di contributi forniti alla Commissioni Igiene e Sanità*, Senato della Repubblica, Roma 2007.

2) M. DE TILLA – L. MILITERNI – U. VERONESI (editors), *Il testamento biologico. Verso una proposta di legge*, Sperling – Kupfer, Milan 2007;

3) A. BORASCHI – L. MANCONI (editors), *Il dolore e la politica. Accanimento terapeutico, testamento biologico, libertà del paziente*, Bruno Mondadori, Milan 2007.

3) State of debates on advance directives

a) What are the major issues and concerns?

The main critical issues of the debate concern mainly the binding nature of the advance directives and the possibility that living wills could legitimate, in the long run, even euthanasia.

b) What are the hopes and expectations?

The main hopes and expectations are: 1) To have a tool ensuring the free self-determination for cures and therapies, against abuse of prolonged artificial life supports; 2) To extend in time the right to informed consent; 3) To protect the physician who, today, is left alone to his decision; 4) To prevent controversies among relatives.

c) Bibliography of literature and / or other sources of information.

F. TUROLDO – G. VAZZOLER (editors), *Il testamento biologico*, Cafoscarina, Venice 2005;

FONDAZIONE UMBERTO VERONESI, *Testamento biologico. Riflessioni di dieci giuristi*, Il Sole 24 Ore, Milan 2006;

F. TUROLDO (editor), *Le dichiarazioni anticipate di trattamento. Un testamento per la vita*, Gregoriana, Padua 2006;

M. ARAMINI, *Testamento biologico*, Ancora, Milano 2007.

LITHUANIA

Eimantas Peicius [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

There are no laws or official statements directly related to AD in Lithuania (and the Baltic states). The recomendations on AD are only provided by Lithuanian Association of Physians, which adopted (translated and published) the THE WORLD MEDICAL ASSOCIATION STATEMENT ON ADVANCE DIRECTIVES ("Living Wills") by the WMA General Assembly, Helsinki 2003.

b) Possibility of appointing a proxy decision-maker

There is such possibility recommended regarding a minor and mentally ill patients in Lithuanian Law on Patient Rights and the compensation of the damage to their health:
Information to a patient who is a minor, his parents and guardians must be furnished in a form comprehensible to them. If disagreements arise between the minor and his parents or guardians, the treating physician, in presenting the information, must be guided by the interests of the minor patient (art. 6.7).
A minor patient, who in the opinion of the physician is capable of accurately appraising the condition of his own health, shall have the right to independently initiate and decide the treatment that has been proposed for him. Upon request by the parents or custodians of the minor patient, the treating physician must advise the legal representatives of the minor, regarding the treatment, however such information may also remain withheld, with the minor having requested this, if this might harm the interests of the minor patient considerably, if other legal acts do not establish otherwise. If the minor is hospitalised, his parents or custodians must be advised of this (art. 6.8).

c) Right to patient self-determination and limits of patient autonomy

The right of patient self-determination and its limits are presented in the art. 8 of Law on Patients rights and art.3-6 of the Law of Mental Health:
1. A patient may not be treated or be provided any other health or nursing care against his will, if it shall not be otherwise established by the laws of the Republic of Lithuania. If the possibility exists, the patient must be offered other treatment or other health care services.

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2. A minor patient must be informed of the treatment and, with his age and level of development permitting a correct appraisal of the status of his health and proposed course of treatment (the treating physician shall decide this), the minor may not be treated against his will, unless provided otherwise by the Republic of Lithuania laws. The physician shall select the methods of treatment which shall most suit the interests of the minor.
3. If the patient is unconscious or if his will can not be known for another reason and a serious threat is being posed to his life or health, while vital (first or urgent) medical assistance is being provided for him, such medical assistance must be rendered without his consent.
4. The Law on Mental Health Care shall establish the nature of treatment of a patient, mental patient, who is unable to correctly assess the condition of his own health.
5. In the course of providing required (first aid or urgent) medical assistance, which requires the consent of the legal representative of the patient, such may be provided also without the legal representative's consent, if this can not be obtained in time or if the legal representative refuses to give his consent, while according to the treating physician or nursing staff member, the rendering of medical assistance is in keeping with the interests of the patient. The case history of the illness of the patient must include a record of this.
6. Should the legal representative of a patient refuse to give his consent for treatment, which is not urgent and the treating physician be of the opinion that the treatment being provided is in keeping with the interests of the patient, the medical ethics commission of the health care institution or the Committee for Medical Ethics of Lithuania has the right to give consent for such treatment. The administration of the health care institution or the treating physician shall have the right to appeal to this commission or committee.

e) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Such options are presented in article 8.3 and 8.6 of Lithuanian Law on Patient Rights and the compensation of the damage to their health.

f) Bibliography

1. THE WORLD MEDICAL ASSOCIATION STATEMENT ON ADVANCE DIRECTIVES ("Living Wills"). The WMA General Assembly, Helsinki 2003. http://www.wma.net/e/policy/w14.htm
2. REPUBLIC OF LITHUANIA LAW ON THE RIGHTS OF PATIENTS AND COMPENSATION OF THE DAMAGE TO THEIR HEALTH, 1996. No I – 1562.
3. REPUBLIC OF LITHUANIA LAW ON MENTAL HEALTH CARE,1995,. No. I-924.

http://bioetika.sam.lt/index.php?-2078631572

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

There are no official statistics on this issue.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

The AD are not officially integrated into the medical decision-making in Lithuania.

c) How high is the acceptance of advance directives by physicians and other care takers?

Some surveys (however which are not representative or not directly addressed the issue of AD) indicated quite high acceptance of potential AD among physicians of the secondary and third health care levels and among nursing students (approximately, 3 from 4 expressed their positive attitude to the AD).

d) What are the 3 main practical problems in writing and/or applying advance directives?

1. The public is not adequately informed about the use and application of AD in general in Lithuania.
2. The absence of juridical basement of application and legislation of AD.
3. The absence of systemic scientific empirical studies, research projects and attention of academic communities on the issues of AD in Lithuania.

e) Bibliography of empirical studies and/or other sources of information

1. Peicius E. Attitudes of nursing students to dying and advance directives: results of pilot study. Lietuvos praktikos gydytojas 2008, no.6 (in press; in Lithuanian).
2. Toliusiene, J.; Peicius, E. Changes in nursing ethics education in Lithuania. Nursing Ethics: An International Journal for Health Care Professionals 2007, vol. 14, no. 6: p. 753-757 (relevant indirectly).
3. Lesauskaitė V, Macijauskienė J. The Need and Necessity of Geriatric Care In The Health Care System of Lithuania. Sveikatos Mokslai 2005, Nr. 3, P.97-103. www.sam.lt/repository/dokumentai/sveikata/sm3(iii%20dalis).pdf

3) State of debates on advance directives

a) What are the major issues and concerns?

Unofficially, there is real need of AD application in medical decision making, especially in the clinical geriatric and intensive care settings; however these expectations are still not met because of the absence of the reciprocal laws, regulations and recommendations in Lithuania.
The lack of information and initiatives from authorities leave the public unaware about the potential advantages and possibilities of AD. The concept and system of palliative care is also not developed in Lithuania. The other concern is about the hidden euthanasia practices within so palliative care clinical settings.

b) What are the hopes and expectations?

To help elderly and future patients to have a right for dignity in dying process in legislative and ethically grounded manner; to respect their living will in every complex circumstances in the cases of unconscious or incapable to consent condition; to implement AD practice according to the experience and outcomes of other European countries; to balance the sharing responsibilities between health care providers and their patients in the end of life decisions.

c) Bibliography of literature and / or other sources of information

1. http://www.hope.lt/hot-legal-topics/power-of-attorney/do-you-need-a-living-will-form-or-a-health-care-power-of.php
2. http://www.sveikatosdraudimas.com/lt/faqs/GettingYourAffairsInOrder.pdf
3. http://www.vritdraugija.lt/index_files/ERCguidelines_forResuscitation2005.pdf
4. http://aurimas.net/CD/EN/m6-8.html

THE NETHERLANDS

Mette Rurup [(*)]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

In the Netherlands, the advance treatment refusal is legally binding since the enactment of the Medical treatment contract act (WGBO) in 1995. (Prior to that is was already legally binding according to the constitutional right to refuse treatment, but not explicitly)

The Netherlands also has another legally recognised type of living will, the 'advance euthanasia directive', in which people can request euthanasia. This type of living will is non-binding (an oral request for euthanasia is also non-binding). Euthanasia can be legal in the Netherlands, if the 'requirements of due care' are met, and if it is reported to the authorities. In practice, a case of euthanasia based on a written request has never been reported to the authorities.

b) Possibility of appointing a proxy decision-maker

It is possible to appoint a proxy decision-maker. If no one was appointed, the physician has, according to the Medical Treatment Contract Act (WGBO), the duty to consider the partner as a proxy decision-maker. If there is no partner, or he/she is unable or unwilling, a parent, a child, a brother/sister becomes the proxy decision-maker according to this Act.

c) Right to patient self-determination and limits of patient autonomy

Theoretically, the patient has the right to refuse treatment, but in practice, such refusals are not always respected (see below).

Furthermore, people do not have a right to euthanasia or physician-assisted suicide, but they do have the right to ask. A physician can refuse for any reason, if a physician wants to grant a request, he or she must adhere to the requirements of due care (see Bibliography for a reference to online access to the euthanasia act where the requirements of due care are described).

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

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In the Netherlands, the terms "active" and "passive" euthanasia are not used anymore, because they were considered too confusing.

In the Netherlands, euthanasia is defined as the act where a physician grants the explicit request of a patient for euthanasia, by actively ending his or her life by administering drugs. If a patient ends his or her own life by using drugs that were provided by a physician at the explicit request of the patient, this is physician-assisted suicide. As mentioned above, there is a law in the Netherlands that provides legal security for physicians who perform euthanasia or physician-assisted suicide if they follow "the requirements of due care".
Giving or forgoing artificial nutrition and hydration (ANH) is considered a medical decision since a court decision in 1990 (Stinissen case). Physicians are allowed to forgo ANH in case of medical futility and people have the right to refuse ANH (in advance) as with other treatments (Pasman, 2004).
Research has shown that tube feeding does not provide survival benefit in incompetent patients and several studies showed that starting artificial nutrition can be burdensome and counterpalliative for the patient. The advice of the Association of Nursing Home Physicians is therefore to be restrictive with starting ANH in incompetent patients if ANH is a medically futile treatment for the patient (Pasman, 2004).

e) Bibliography

Dutch euthanasia Act including the requirements of due care in English:
http://www.minbuza.nl/binaries/en-pdf/pdf/euth-amendedbill-en.pdf

Medical Treatment Contract Act (WGBO) in English:
http://www.healthlaw.nl/wgboeng.html

Pasman HRW. Forgoing artificial nutrition and hydration in nursing home patients with dementia. decision-making, clinical course, and quality of dying. Dissertation VUmc, April 2004.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Older people (61-92 yrs): 10% had a living will.
Younger people (20-60 yrs): 3% had a living will.
The majority of people who had a living will, had an advance euthanasia directive. These advance euthanasia directives usually describe a hypothetical future situation in which euthanasia is requested, and they usually describe a refusal of treatment for this same situation (Rurup, 2006A).

It is estimated that 7% of people with dementia who died in the Netherlands in 2001 had written down treatment preferences (Rurup 2005, Klinkenberg 2004).

The incidence of advance directives may be increasing because the new generation of older people seems to be more outspoken, and may attach more importance to autonomous decision-making. We are currently collecting new data about this.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

We do not have data about how often advance directives are used in medical decision-making in general.
We do know that, as mentioned above, about 7% of people with dementia who died in 2001 had an advance directive, and that whether or not to comply with advance euthanasia directives of these patients was discussed in 76% of the cases (Rurup 2005).
It was found that, although physicians strive to reach agreement with family and nurses which decision is in the best interest of the patient, the nursing home physician has the greatest influence on decision-making (Pasman, 2004).

Furthermore, a study in 2005 showed that, although the advance treatment refusal is legally binding in the Netherlands, most physicians use advance treatment refusals only as additional information, and do not consider them binding. They only follow them when they corroborate their own judgement; otherwise they let their own judgement prevail above the advance treatment refusal (Vezzoni, 2005).

c) How high is the acceptance of advance directives by physicians and other care takers?

Although 80% of the physicians are of the opinion that everybody has the right to decide about his/her own life and death (Rurup 2006B), they only follow advance treatment refusals when they corroborate their own judgement. Otherwise they let their own judgement prevail above the advance treatment refusal (Vezzoni, 2005).
Explanations that were given for this are the poor quality of the advance treatment refusals and uncertainty on how to interpret the refusal. Some say that physicians are simply not willing to accept the binding nature of advance treatment refusals (Vezzoni, 2005).

d) What are the 3 main practical problems in writing and/or applying advance directives?

1) It is unclear what the minimum requirements are for advance treatment refusals to acquire their binding status.
In the Netherlands, consensus consists that treatment refusals should be dated and signed (legal requirements), but other requirements have not been specified. The law provides only one exception to the binding status: if the physician has "well-founded reasons" not to follow the treatment refusal. This provision should be interpreted in a restrictive way, and only include doubts about e.g. the authenticity of the directive, and not about personal objections. However, questions may also arise e.g. about its applicability to a specific situation, its well-considerateness (especially physicians in hospitals and nursing homes usually have not talked to people at the time of completion of the advance treatment refusal, and only meet them at the time of admission, when competence is already compromised), the maximum period of validity after signing (considering the possibility that wishes changed). In some other countries more requirements have been specified than in the Netherlands (e.g. co-signing witnesses).

2) It is unclear how competence to make medical decisions has to be judged.

If a person is still able to make medical decisions, the advance treatment refusal is not yet relevant, because it is inferior to the current wish of the person. This is less straightforward than it may seem, because it is difficult to judge whether a person is still able to make medical decisions. Competency has four domains: understanding, appreciation, reasoning and expressing a choice. If people have dementia, each domain becomes more compromised as the dementia progresses, but not at the same pace. Expressing a choice is maintained the longest which can be misleading, because understanding of consequences can be completely absent when a person is still able to express a choice. When a patient is able to express consent to treatment without understanding or appreciating the choice or its consequences, this has been described as “incompetent consent”. Incompetent consent has been -ironically- described as "sometimes being practical when applying a treatment, but presenting ethical and legal objections".

Instruments have been developed to support the judgement of the competence of patients to make medical decisions. Such instruments can make the borderline for physicians clearer of when the advance treatment refusal becomes actual and therefore should be followed, but are almost never used in the Netherlands.

3) There is -among physicians and the general public- a general lack of knowledge of the options, the definitions and the rules, concerning end-of-life decisions and advance directives.

e) Bibliography of empirical studies and/or other sources of information:

Klinkenberg M, Willems DL, Onwuteaka-Philipsen BD, Deeg DJ, van der Wal G. Preferences in end-of-life care of older persons: after-death interviews with proxy respondents. Soc Sci Med 2004;59:2467-77.

Pasman HRW, Onwuteaka-Philipsen BD, Ooms ME, van Wigcheren PT, van der Wal G, Ribbe MW. Forgoing artificial nutrition and hydration in nursing home patients with dementia: patients, decision making, and participants. Alzheimer Dis Assoc Disord. 2004;18:154-62.

Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, van der Maas PJ. Physicians' experiences with demented patients with advance euthanasia directives in the Netherlands. J Am Geriatr Soc 2005;53:1138-44.

Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, Deeg DJ. Frequency and determinants of advance directives concerning end-of-life care in The Netherlands. Soc Sci Med 2006A;62:1552-63.

Rurup ML, Onwuteaka-Philipsen BD, Pasman HRW, et al. Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. Patient Education & Counseling 2006B;61:372-80.

Vezzoni C. The legal status and social practice of treatment directives in the Netherlands [thesis]. Groningen 2005. Free download (complete thesis) from: http://irs.ub.rug.nl/ppn/28903504X

3) State of debates on advance directives

a) What are the major issues and concerns?

Debate in the Netherlands is not well-informed, most concerns that are voiced are in fact irrelevant, e.g. what if you change your mind but have already signed an advance directive? A more realistic concern that has been voiced is that people do not know enough about illnesses and end-of-life decisions and base their AD on a few personal experiences or a story in the media. (The question then becomes one of respect for autonomy vs. paternalism).
The current debate is often focused on what options there should be for people who do not wish to live in a nursing home in the advanced stages of dementia. Most people who write advance directives, write advance euthanasia directives for the situation of dementia (70%). In practice, they are (almost) never followed, but most people who write them do not know that, until they or their next of kin are in that particular situation. The debate is usually clouded with concerns that the quality of care is not high enough in nursing homes, and should be improved. However, the budgets for the nursing home care are not increasing.

b) What are the hopes and expectations?

Among physician associations, the current tendency seems one of resignation and acceptance that advance directives are not practicable. Among the general public, people are not aware of the fact that advance directives are often ignored. There seems to be a large gap between physicians and patients on the issue of advance directives: e.g. 88% of relatives of dementia patients are of the opinion that an advance directive should always be followed, while 37% of the physicians think so. Furthermore 89% of the relatives are of the opinion that euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent, while only 16% of the physicians agree with this (Rurup, 2006).

Personally, I think the most important point currently, is to improve the usability of -and then the adherence to- advance treatment refusals. The route to improve this is -in my opinion- addressing the 3 problems I have explained in 2d:
1) It is unclear what the minimum requirements are for advance treatment refusals to acquire their binding status;
2) It is unclear how competence to make medical decisions has to be judged;
3) There is -among physicians and the general public- a general lack of knowledge of the options, the definitions and the rules, concerning end-of-life decisions and advance directives.

c) Bibliography of literature and / or other sources of information

Rurup ML, Onwuteaka-Philipsen BD, Pasman HRW, et al. Attitudes of physicians, nurses and relatives towards end-of-life decisions concerning nursing home patients with dementia. Patient Education & Counseling 2006;61:372-80.

4) Other remarks

I would be very interested to hear what standards or requirements (legally, in medical guidelines or in practice) for advance treatment refusals are used in

other countries, to consider advance treatment refusal valid/binding, and I would be very interested to hear how competence to make medical decisions is judged in other countries if e.g. patients are in the advanced stages of dementia. Are instruments to support the judgement of competence used in practice in other countries?

NORWAY

Per Nortvedt [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Living wills in Norway are not judicially regulated and are not legally binding. There is an independent organisation issuing living wills according to a specific formula. Approx. 4000 Norwegians have this kind of will. However nothing is said about its bindingness, and according to medical practice as well as law, it is up to the doctor in cooperation with other health care personnel to consider the validity and relevance of the will and to decide upon the medical treatment.

b) Possibility of appointing a proxy decision-maker

A patient can appoint a proxy, but this latter has no legal authority. The proxy cannot issue any binding decisions which in any way restricts the decision-making of the medical doctor and personnel. However, it should be taken into account as any other information relevant to medical decision-making in the actual case of patient care.

c) Right to patient self-determination and limits of patient autonomy

The patient has a right to refuse health care, but according to Norwegian legislation, there are some restrictions upon patient autonomy even when patients are fully competent to make their own decisions. For instance, when the need for health care is urgent and life saving, in which case health care personnel has an obligation to treat, even if patients are fully competent and refuse treatment. Situations in which patients have a full right to refuse treatment are, for instance, Jehova's Witnesses patients, who can refuse blood transfusion; dying patient and patients performing hunger strike.
Many also within medical ethics and health care would argue that Norwegian Law is too restrictive and paternalistic advocating the primacy of emergency care above any right to competent refusal of medical care

d) Options of end-of-life-decisions (e.g. active/passive euthanasia, regulations for provision of artificial nutrition and hydration)

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Within the Norwegian setting of health care one is currently working on national guidelines for withholding or withdrawing medical care for seriously ill and dying patients. Norway has not previously been having guidelines within this area.
Active euthanasia and physician-assisted suicide are according to law prohibited; nutrition and fluids, and other life sustaining medical treatment can be withdrawn. Relatives have no legal right to decide on behalf of their patient and family member. Parents have a right to decide on behalf of their child, but not against the child's best interest

e) Bibliography

Førde R, Aasland OG, Steen PA. Medical end-of-life decisions in Norway. Resuscitation 55 2002: 235-240.

Når kan pasienten nekte helsehjelp? m/ Reidar Pedersen Tidsskriftet Kritisk juss, 2006.

Døendes Rettsstilling, Tidsskrift for den norske legeforening nr. 8 2006.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?
About 4000 living wills are issued

-600 of dying patients per year have issued a living will from the organisation Right to death with dignity.. : "A total of 23% of the physicians had seen patients with written advance directives" (Førde et al 2002)

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

We really have little systematic knowledge about this.

c) How high is the acceptance of advance directives by physicians and other care takers?

Generally health care personnel and doctors take a directive very seriously if the patient is competent. There might be problems if the wish seems contradictory to the patient's best interest.

d) What are the 3 main practical problems in writing and/or applying advance directives?

There is no tradition for it in Norway, patients are generally not aware of their rights within this area of respect for patient autonomy, and do not know how to get a written formula.

e) Bibliography of empirical studies and/or other sources of information:

There are no empirical studies available.

3) State of debates on advance directives

a) What are the major issues and concerns?

In Norway it will be important to discuss the legal authority of advanced directives. It will also be a major concern to increase the awareness among clinicians about the importance of such directives and in particular to communicate thoroughly with patients and relatives about their preferences for future end of life care.

Another issue will be the status and reliability of these directives when authorised by a previous competent patient who is no longer competent. Further Norway has had heated debates about the role of relatives as proxies for children in intensive care medicine when parents and doctors disagree about end of life decisions and what is the child's best interests.

b) Bibliography of literature and / or other sources of information

Buchanan A. Deciding for others : the ethics of surrogate decision making / Allen E. Buchanan and Dan W. Brock. 1999.

Emanuel. Proxy decision making for incompetent patients. An ethical and empirical analysis. JAMA 1992; 267(15):2067.

Stratling M, Scharf VE, Schmucker P. Mental competence and surrogate decision-making towards the end of life. Medicine, Health Care & Philosophy 7(2):209-15, 2004.

Duffield P, Podsamsky JE. The completion of advance directives in primary care. J Fam Pract 1996; 42: 378 - 84.

Perkins HS. Controlling death: the false promise of advance directives. Ann Intern Med. 2007;147:51-7.

Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166:493-7.

Wrigley A. Proxy consent: moral authority misconceived. J Med Ethics. 2007;33:527-31.

Førde R, Aasland OG, Steen PA. Medical end-of-life decisions in Norway. Resuscitation 55 2002: 235-240.

PORTUGAL

João Carlos Loureiro (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

In Portugal there is no specific regulation concerning advance directives. Portuguese scholarship use different expressions, such as *directivas* (PEREIRA: 2004; LOUREIRO: 2008); *decisões* (MARQUES: 2005, 356), *disposições* (BORGES: 2003, 170), *directrizes* (OTERO: 2004, 181) *antecipadas* or *prévias* (LOUREIRO: 1994, 40; using, without translation, the English formula, see ARAÚJO: 1999, 140-142, n. 253). Rui Nunes and Helena Melo use *directivas antecipadas de vontade*, a phrase they propose in their Project on advance directives (see below). For living wills a plurality of expressions has been suggested: *testamentos de paciente* (ANDRADE: 1991, 457; 2004; LOUREIRO: 1994, 41; DIAS: 1999, 14; PEREIRA: 2004; BRITO: 2005; 2007, 54; MELO: 2006, 77), *vitais* (NUNES: 1993, 27; 1996; SILVA: 1997, 47), *de vida* (RAPOSO: 2001, 258; COSTA: 2003, 793), *em vida* (RODRIGUES: 2001, 366), *de cuidados médicos* (SÁ: 1993, 371), *biológicos* (CANOTILHO/ MOREIRA: ^{4}2007, 450; COSTA: 2003, 793; NETO: 2004, 791), or *de morte* (CARDOSO: 2005, 249, as he discusses *testamento de vida*, he remarks that other call it *testamento de morte*). A lot of scholars, though, use more than one expression as they talk about living wills. Concerning health-care proxies, forms such as *procurador de* or *para cuidados de saúde* (LOUREIRO: 1994, 41; PEREIRA, 2004, 240-241; VÍTOR: 2004), or *procurador de saúde* (MARTINS: 2007, 202) can be found as well.

Nevertheless, absence of a particular statute relating to advance directives should not be understood as total silence from the legal system or scholarship.

To begin with, there is a constitutional framework that takes autonomy seriously, as we will see in detail. Second, the Convention on Human Rights and Biomedicine came into force on December 2001; third, the appeal to general institutes of civil law seem to mitigate the absence of special rules; fourth, the Penal Code should be taken into account as far as respect for the will is concerned.

Last, but not least, in 2006, the *Associação Portuguesa de Bioética* (http://www.apbioetica.org/) presented a project on advance directives (*Directivas antecipadas de vontade*) and on the establishment of the *Advance Directives National Registry* (RENDAV – *Registo Nacional de Directivas Antecipadas de Vontade*).

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1. Sources of law

1.1. (Bio)constitution: the patient's right to autonomy

The 1976 Portuguese Constitution recognizes the dignity of the human person as the fundamental principle of the juridical system. We may talk about a Portuguese bioconstitution, that is, a set of norms (principles and rules), formally and/or materially constitutional, whose subject is actions or omissions either from the state or from private entities, centred on the protection of life, on identity and personal integrity, and on the health of today's or future human beings, especially as biomedical threats are at stake.

Despite some discrepancies among the different bioethical communities (see the divergences between Mediterranean and Anglo-Saxon communities in the field of bioethics, a point stressed by Diego Gracia, among others: GRACIA: 1993), self-determination has become a fundamental value in Western societies. As we seek to grasp the community's "fundamental values" (*Grundwerte*) from a juridical standpoint, we shall start with the Portuguese Constitution. Undoubtedly, the patient's right to self-determination is one of the pillars of the Portuguese basic law (see below).

1.2. The Convention on Human Rights and Biomedicine

Article 9 of 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* set out that: "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". Insofar as Portugal has ratified the Convention, and insofar as the Portuguese Constitution lays down so-called "automatic reception system", this treaty ends up being law of the land. Conventional norms have a special status in the sources system of Portuguese law: though infraconstitutional, they are supralegal (Article 8/2; COSTA: 2006, 83-84). In other words, statutes ought to respect Conventional solutions: they cannot change them.

As far as living wills are concerned, Article 9 lays down that, although they could not be considered irrelevant, this does not entail that national legislators have a conventional-founded duty to ascribe binding-force to advance directives (for the Portuguese bibliography, see: PEREIRA: 2004, 253; for the scope of the article, see Council of Europe, *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 Explanatory Report*, Strasbourg, 1996).

1.3. Civil law

There is nothing in the Portuguese civil law forbidding decision directives (concerning the proxy directives, see below 1.b.). Of course, only competent persons may sign an advance decision. Whether contracting capacity (*Geschäftsfähigkeit*) is required, or whether competence to consent is enough (*Einwillungsfähigkeit*), is a matter of dispute (PEREIRA: 2004; PEREIRA: 2006).

1.4. Criminal law

Even though a lot of scholars have endorsed the idea that the value of living wills is only indicatory (see ANDRADE: 1991), Faria Costa has

recognized the binding value of these documents, not only with regard to the omission of live-support treatments but even with regard to certain cases of active euthanasia as well (COSTA 2003, p. 793-794). Recently, Figueiredo Dias argued for *prima facie* binding force of living wills (DIAS: 2007, p. 487-488; 492-493). So, living wills should, in principle, be respected; non-enforcement may only be dependent on knowledge of post-writing circumstances of the will that might be indicative of a shift of will.

1.5. The Portuguese Association of Bioethics Project (*Associação Portuguesa de Bioética*)

Approval of the Portuguese Association of Bioethics project (*Associação Portuguesa de Bioética*) is still being awaited. As explained in the Opinion, the leading idea aims at the recognition of binding force to advance directives, by creating a legal framework and establishing a National Registry.

2. Portuguese legal doctrine: the chief trend

For the time being, according to the main trend of the Portuguese legal doctrine, a living will has a merely indicative value. It should be taken into account in order to find the patient's presumed will (*vontade presumida*) (ANDRADE: 1991, 457-458; PEREIRA: 2004) and *in dubio pro vita* (*favor vitae* principle).

It is worth noting that if the Parliament will approve such a project without changing its trend, the legal panorama is bound to change. Within the legal framework, art. 11 recognises a binding effect to advance directives, i.e., physicians and other health care professionals ought to respect the patient's will.

3. Official institutions' opinions: the National Council of Ethics for Life Sciences

Even though the National Council of Ethics for Life Sciences has not issued, until now, a specific opinion on advance directives, the problem has already been mentioned in three opinions dealing with other related topics:

a) Opinion on the Ethical Aspects of Health Care Regarding the End of Life (11/CNECV/95);

b) Opinion on the persistent vegetative status (45/CNECV/05);

c) Opinion on the objection to the use of blood and blood products for therapeutic purposes on religious basis (46/CNECV/05).

The latter displays a more developed approach on the issue and focuses on the Jehovah's Witnesses' refusal to receive both blood and blood products (on the legal discussion, see DIAS: 2007; FARIA: 1998), auto-transfusions aside. As a matter of fact, as they are admitted to hospitals, believers of this confession carry with them documents titled "Advance Medical Directive"/"Release from Responsibility" (GUERRA: 2007). According to the National Council of Ethics, "[t]he advance medical declaration is merely an indication of will and informed consent must still be obtained providing effective clarification of the consequences of refusing treatment" (n. 8).

André PEREIRA (2006) stresses some possible divergences on the 2005 opinions. It seems that the PVS opinion gives more weight to advance directives. Actually, the opinion lays down: "3. any decision upon the beginning or suspension of basic health care of the person in a Persistent Vegetative State should respect the will of that person: 4. that will may be expressed or presumed or indicated by a person of trust previously designated by the person in a Persistent Vegetative State; The refusal of

blood transfusion Opinion states: “8. The advance medical declaration is merely an indication of will and informed consent must still be obtained providing effective clarification of the consequences of refusing treatment” (on the discussion, see also BRITO: 2005).

b) Possibility of appointing a proxy decision-maker

Despite the absence of statutory regulation on health-care proxies, those are not uncharted waters. Since a lack of specific regulation does not mean juridical inexistence, appeal to power of attorney (*procuração*) has been proposed [LOUREIRO: 1994, 41, n. 46]; moreover, the absence of any interdiction concerning living wills is stressed along with the advantage of taking legislative steps in order to clarify the value and requirements of advance directives in Portugal. This trend may be found in some Portuguese legal literature (PEREIRA: 2004; VITOR: 2004).

c) Right to patient self-determination and limits of patient autonomy

Although a search for expressions such as “patient autonomy” in our constitutional text might be unsuccessful, everybody assumes that to be a juridical position there. Articles such as 25 (on personal integrity), 26 (on the development of the personality), article 41 (on freedom of religion, and on freedom of conscience), are the relevant norms to ground the right to patient’s self-determination.

Since I am not writing an essay on the general limits of patient autonomy, where issues such as the compulsory detention and treatment of persons suffering from some diseases (e.g. typhus) would have do be deal with, I am confining my remarks to the limits of medical treatments and care in the context of advance directives. First, it is worth pointing out that there are *factual* and *juridical* limits to autonomy. There are human beings that are not yet, or will never be, autonomous: in such cases, to speak about a substituted judgement (*vontade presumida*), for instance, is definitely non-sense. Although time and space preclude my going into details, I must take into account those cases when an actual autonomy is absent — an increasing challenge in ageing societies. As we are dealing with the juridical limits to autonomy, we have to consider that autonomy, understood as an expression of a relational perspective – being-with-others and living in communities –, should not be taken according to a radical autonomist way (“autonomism”). The rights of others and collective goods constitute themselves as limits to patient autonomy. Setting aside the question of temporal limits to autonomy, which is itself rooted in a diachronic stance (see below), limits of scope (subject) do exist. Voluntary euthanasia, for instance, as well as assisted suicide – transitive acts requiring the collaboration of others –, are forbidden by the Portuguese law (see below).

Autonomy has another side to it that usually is forgotten, namely, the health care professionals’ side. The *Associação Portuguesa de Bioética’s* proposal recognizes a right to conscientious objection in these cases.

Last but not least one should not ignore that arbitrary medico-surgical interventions and treatments, i.e., without the consent of patient, shall be punished according to Art 156 of the Portuguese Penal Code.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

1. Concepts

Since at this initial stage of the project, a definition of some of the concepts used (such as active euthanasia, passive euthanasia) is not advanced, and since from a doctrinal and a comparative approach such concepts are controversial, the notion of euthanasia that I am dealing with. Euthanasia is a set of actions (active euthanasia) or omissions (passive euthanasia) performed by someone else other than the patient, usually by a health care professional (*maxime*, a physician), at the patient's request (or not), aiming at causing death, and the action should hinge on motivations such as a sheer respect for autonomy (in case of voluntary euthanasia alone) or further indications, traditionally, pain or suffering, in case a dying or incurable patient is at stake (see, for further developments, LOUREIRO: 2004).

Very often, the concept of passive euthanasia is used in a way that covers legitimate withholding, or withdrawing, of treatments. If such notion of passive euthanasia is consistent with the one being used in this report, therefore it is allowed in Portugal too (concerning passive euthanasia, and with a strong German influence, see: ANDRADE: 1991; DIAS: 1999, 13; also MORÃO: 2005).

2. Regulation(s)

Though the term "euthanasia" is absent in the Penal Code, both involuntary and voluntary euthanasia are prohibited in the Portuguese legal system. Voluntary euthanasia is framed within a more general *Tatbestand*, namely, "*homicide at request of the victim*" (Article 134: *morte a pedido*); involuntary euthanasia is covered by the institute of *privileged homicide* (Article 133: *homicídio privilegiado*). However, the Deontological Code of the Medical Council uses the word euthanasia, as it lays down its prohibition (Article 47). Assisted suicide (*ajuda ao suicídio*) is also criminalised under Portuguese law (Penal Code, Article 135) [concerning the Portuguese legal framework regarding end-of-life decisions, see MONTEIRO/PEREIRA: 2000; Steering Committee on Bioethics (CDBI), *Replies to the questionnaire for member States relating to euthanasia*, Strasbourg, 2003].

Concerning regulations dealing with provision of artificial nutrition and hydration, our system advances no specific norms. Debate over this issue is being held, along American and European lines, at the doctrinal level (LOUREIRO: 1994; BRITO: 2005). The existence of the aforementioned Opinion, issued by the National Council of Ethics for Life Sciences, is worth noting.

d) Bibliography

Opinions

Conselho Nacional de Ética para as Ciências da Vida (*National Council of Ethics for Life Sciences*)

- 11/CNECV/95 - Opinion on the Ethical Aspects of Health care Regarding the End of Life.
- 45/CNECV/2005 - Opinion on the Persistent Vegetative State.
- 46/CNECV/2005 - Opinion on the objection to the use of blood and blood Products for therapeutic purposes on religious basis.

The English text of these opinions are available at the *National Council of Ethics for Life Sciences* homepage (http://www.cnecv.gov.pt/cnecv/en).

Associação Portuguesa de Bioética (*Portuguese Association of Bioethics*)

Parecer n.º P/05/APB/06 sobre directivas antecipadas de vontade (Relatores: Helena Melo, Rui Nunes): also in Rui NUNES/ Cristina BRANDÃO (Coord.), *Humanização da saúde*, Coimbra, 2007, p. 287-311.

Projecto de diploma n.º P/06/APB/06 que regula o exercício do direito a formular directivas antecipadas de vontade no âmbito da prestação de cuidados de saúde e cria o correspondente registo nacional (Relatores: Helena Melo, Rui Nunes)

Guidelines sobre suspensão e abstenção de doentes terminais (15 de Janeiro de 2008)

Procuradoria-Geral da República (*Office of the Attorney-General*)

Parecer da PGR n. 99/82, de 14 de Junho, *Boletim do Ministério da Justiça* 321 (1982).

See also the bibliography cited at the end of this chapter.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Since there is no specific regulation in our country, and, therefore, no registry, in the absence of empirical studies it is not easy to know how many advance directives are tabled in Portugal. As far as I know, cards laying down one's refusal of any kind of blood transfusions are usually carried by Jehovah's Witnesses alone. Out of this religious-motivated universe, some isolated cases could be traced: for instance, one famous Professor of Medical Ethics said once that he was planning to write on advance directive; likewise, the Monsignor Feytor Pinto, the Roman Catholic chair of health care pastoral in Portugal, announced that he had written a will rejecting both "active euthanasia" and "disproportionate treatments"; in the Internet, a citizen wrote his own will, and he did so drawing upon the New York living will. See: (http://abnoxio.weblog.com.pt/2007/11/ a_vontade_de_laura_minha_irma).

More than twenty-five years ago, there was a discussion on compulsory measures applicable to a case in which a prisoner in hunger strike had written a declaration. According to the document, should he become unconscious, he was willing to refuse receiving both nutrition and medical treatment [see a legal opinion of the *Office of the Attorney-General (Procuradoria-Geral da República)*: Parecer da PGR n. 99/82, de 14 de Junho, *Boletim do Ministério da Justiça* 321 (1982), p. 194].

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Given the reasons mentioned above, and in the absence of empirical studies, it is impossible to present data on the issue.

c) How high is the acceptance of advance directives by physicians and other care takers?

As already referred, we face here the same lack of data. However, we could stress that, for the time being, advance directives are only one of the elements to be taken into account in the process of finding the will of patient. Concerning the religious-motivated advance directives, part of the medical staff is still cautious regarding this kind of documents, given that they have doubts on the issue of freedom of will. The ongoing discussions in the medical field, especially after the initiative of the *Associação Portuguesa de Bioética*, indicate that the adoption of a clear legal framework, could change the situation (see below 3).

d) What are the 3 main practical problems in writing and/or applying advance directives?

Though I am aware of the subjectivity inevitably involved therein, I would stress:

(1) the *time gap* between writing and applying advance directives;

(2) usually, the *lack of knowledge* and *vagueness* of many advance directives;

(3) *fear of unduly pressures* able to adulterate the patient's will, especially in religious-motivated advance directives cases.

e) Bibliography of empirical studies and/or other sources of information:

A specific study on euthanasia might be indirectly relevant: a number of institutionalised aged persons were in favour of a regulation allowing physicians to end life (see http://www.apbioetica.org/fotos/gca/1196428170estudo_e_10_apb_07_inquerito_nacional_eutanasia.pdf, p. 6).

3) State of debates on advance directives

Before considering the state of the debates on advance directives in Portugal, we may stress that our "public sphere" is not as robust as in other Western societies. Time and space preclude my going into the details of a characterisation of contemporary Portuguese "pluriform society", one which is increasingly facing the challenges of diversity. Conversely, if one looks at the ongoing discussions in the legal doctrine and bioethics fields, especially at a scholarly level, the picture changes. Concerning biomedical issues, over the last years a boom of research in the fields of health law and bioethics is a matter of fact.

Worth mentioning is, in particular, the Jehovah Witnesses' stance. Over the last few years, they got in touch with the academic experts on biomedical law, constitutional law and bioethics, in order to advocate their own positions on the issue. To the member of their own congregations, they have also launched the so-called "Advance medical directive/release", in which the transfusion of blood or blood components is precluded GUERRA: 2007).

Blogosphere plays an increasing role in the public discussion as well. A few examples may be sufficient:
http://devenire.blogspot.com/2006/10/directivas-antecipadas-de-vontade.html

http://odoloeventual.blogspot.com/2006/11/respeitar-vontade-de-cada-um.html ; http://rxtuga.blog.pt/1057056/

One point is held in common by them all: usually there are no comments, or only a few.

a) What are the major issues and concerns?

Given the lack of empirical information, a proper answer is not easy. Some newspapers have published articles presenting an overview of the *Associação Portuguesa de Bioética*'s proposal.

Concerning scholarly discussions, the main information has already been alluded to. One point stressed in the public debate is the time gap between the advance directives writing and the enforcement of it [e.g., Pedro Nunes, President of the Portuguese Medical Council (*Ordem dos Médicos*): www.inverbis.net/actualidade/testamento-vital.html]. Pedro Nunes also refuses binding force to advance directives (see Ângela FERNANDES/ Hermana CRUZ, "Doentes poderão recusar manobras de reanimação", *Jornal de Notícias*, 18 de Outubro de 2006). He adds, "I am not against that. I just cannot understand how such a document should be binding. That would be a major risk. It is dangerous to ascribe too much importance to a document that may have been conceived for a different context". Along this line, Pedro Nunes argues that living will ought to be used to "provide information for the doctor". So, "should the doctor strongly hope that the patient will recover, the treatment should be done".

Medical discussion (e.g., XIV Reunião Nacional do Núcleo de Medicina Interna dos Hospitais Distritais, October 27th) on the issue fuelled by the presentation of the project, is going on. Isabel Galriça Neto, President of the Portuguese Association of Palliative Care (*Associação Portuguesa de Cuidados Paliativos*) agrees that a statute is needed, but she also defends wide debating on the issue. She finally stresses the importance of communication between doctors and patients (source: *Diário de Notícias*).

In the blogosphere, Sérgio Catarino (http://devenire.blogspot.com) qualifies "living will" as a somewhat dubious legal figure" ("figura jurídica algo duvidosa").

b) What are the hopes and expectations?

The main hope is to find a legal framework so as to ensure that patient autonomy should be respected. There is no information as to when the discussion and final approval of the bill should take place. Only a strong expectation exists that, in a near future, a statute will come out. In June 22nd, 2007, *Jornal de Notícias* published an article showing that deputies of different parties recognise the need of regulation. Maria de Belém, President of the Parliamentary Committee on Health Affairs, affirmed that it might be possible that a discussion will be held during 2007/2008.

c) Bibliography of literature and / or other sources of information

ANDRADE, Manuel Costa, *Consentimento e acordo em direito penal* (*Contributo para a fundamentação de um paradigma dualista*), Coimbra, 1991.

____, "Consentimento em direito penal médico: o consentimento presumido", *Revista Portuguesa de Ciência Criminal* 14 (2004/1-2), p. 117-148 [também em: Luciano Nascimento SILVA (Coord.), *Estudos jurídicos de Coimbra,* Curitiba, 2007, p. 34-62; German translation: Wolfgang Frisch (Hrsg.), *Gegenwartsfragen des Medizinstrafrechts: Portugiesisch-*

deutsches Symposium zu Ehren von Albin Eser in Coimbra, Baden-Baden: Nomos, 2006, p. 71-92].

ARAÚJO, Fernando de, *A procriação assistida e o problema da santidade da vida*, Coimbra, 1999.

BORGES, Anselmo, "A dignidade da pessoa no ocaso da vida: antropologia do processo de morrer: a eutanásia", in: idem, *Corpo e transcendência*, Porto, 2003, p. 153-182.

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SERBIA

Violeta Besirević [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

There is no law in Serbia enabling people to use living will. This kind of advance directives has not been introduced in the country.

b) Possibility of appointing a proxy decision-maker

The Health Care Act, adopted in 2005, introduces a possibility of appointing a proxy decision-maker in case of incompetency. Article 32 (4) reads: A patient is entitled to designate a health care surrogate who will consent to treatment on the patient's behalf or instead of the patient will be informed about health care measures to be performed, in the event the patient is unable to decide on consent.
However, apart from this statutory provision, neither this law nor other regulation speaks about who may be a proxy, a form to designate a proxy or scope of the surrogate's authority. Most importantly, the Health Care Act does not specify whether a heath care surrogate may make a decision to withhold or withdraw life-sustaining or life-saving procedures although, according to its provisions, the patient has a right to forgo any kind of medical treatment.

c) Right to patient self-determination and limits of patient autonomy

The Health Care Act of 2005 has introduced patient bill of rights for the first time in Serbia (Articles 26-40).
The Health Care Act explicitly recognizes the patient's right to self-determination: the patient is entitled to decide freely about all matters concerning her life and health except in cases when this endangers life or health of other persons. The law specifies that, as a rule, no treatment can be imposed on the patient without her consent. A medical treatment against the patient's will or against the will of the legal guardian of the incapacitated patient can be carried out only in exceptional cases if specifically permitted by law and confirming to the principles of medical ethics. Exceptions pertain to the emergency treatment in circumstances in which the patient is unable to give her consent (including the impossibility of obtaining the timely consent of patient's guardian or legal representative) and if he, for reasons of unconsciousness cannot consent to medical treatment. In the latter case

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medical treatment may be performed only upon a decision of the consilium of physicians.
For other incompetent patients, the consent must be given by their parents or legal representative. A child older than 15, capable of making self-regarding decisions, may give consent by herself. The law requests that in all circumstances in which legal representative needs to give the informed consent, the patient, whether a minor or an adult unable to understand, must still be as involved as possible in the decisions regarding him or her.
The Health Care Act also insists on the patient's right to information: in order to make a decision whether to give or withhold consent about proposed treatment, the patient has a right to receive information from a health care professional. Thus, the patients must be timely informed on the following: diagnosis and prognosis, proposed medical treatment, its benefits, risks and outcomes, availability of alternative treatment, non-treatment risks as well as of particular effects of medications. The act envisages an exception from the obligation to inform the patient of the diagnosis if that would endanger patient's health, but in that case, a relative of the patient must be informed of the diagnosis. A patient can waive her right to information with the exception regarding the information about necessity of treatment, its potential risks as well the risks of non-treatment. Next, heath care providers and professionals must use a language known to the patient or interpreter's service and communicate with the patient in layperson's terms. Finally, a heath care professional is obliged to enter into medical records the fact that the patient has given an informed consent.
Note that the patient also has a right to complain and right to compensation. The Heath Care Act introduces a protector's of the patient's rights within the health institutions who is empowered to review the patients' complaints. A protector is an independent in her work and must decide on a complaint within eights days. If the patient is dissatisfied with the decision, she may complain to the health inspectorate.
Regrettably, the Health Care Act does not stipulate that health care providers and professionals have to provide patient-tailored information, particularly taking into account the religious or ethics specificities of the patient. It does not request either the information must be given with enough advance time (at least 24 hours notice) to enable the patient to actively participate in the therapeutic choices regarding his or her state of health.
Finally note that apart of the right to self-determination, the primary rights that should be accorded all patients include also the right to all the information contained in the patient's medical record, the right to privacy and right to have private medical information kept confidential.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

The Serbian legislation regulates passive euthanasia in terms of non-treatment options.
Article 33 (1) of the Health Care Act allows the patient to forgo any kind of medical treatment even that of life-saving or life-sustaining. A health care professional must inform the patient of the consequences of her decision to forgo the treatment. If the patient refuses the proposed medical treatment of any kind, the patient must do that in a written form which is to be kept in the medical record. In case the patient refuses to provide her refusal in a written form, this must be officially noted in the record.
The act, however, does not speak about procedure in which this right may be exercised or about its legal limits.

Active euthanasia, including physician-assisted suicide is prohibited by the Criminal Code of 2006. Yet, the law reflects the cotemporary sentiment on euthanasia: it makes distinction between homicide and mercy killing of a seriously ill person upon the person's serious and explicit request. A punishment for mercy killing is more lenient than the one prescribed for homicide and amounts to imprisonment of six months to five years.
The Code of Professional Ethics of the Serbian College of Physicians adopted in 2006 also speaks about euthanasia. The code condemns this practice and treats it as a false humanism. It clarifies that an intentional shortening of life stands contrary to medical ethics. However, the code specifies that a physician shall respect a wish of terminally ill person regarding the artificial prolongation of life, provided that the patient is competent and that his or her decision is based on informed consent. In case of an incompetent or comatose patient, the physician makes a final decision.

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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

No data are available. A possibility to designate a health care surrogate is still unknown to many in Serbia.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

There has been no official information or statistical data on this point.

c) How high is the acceptance of advance directives by physicians and other care takers?

Generally speaking, physicians and other care takers have not taken enthusiastically a patient bill of rights. The whole concept is still a kind of new for both the patients and health care professionals. An old, paternalistic approach, still dominates in the everyday health care practice.

3) State of debates on advance directives

a) What are the major issues and concerns?

Unfortunately, there is neither continued and informed debate nor public awareness campaign on advance directives.

b) What are the hopes and expectations?

There is a hope that with the country's closer European integration, the present state of art will be significantly improved.

SLOVAKIA

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1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

There is no such term as “living will” defined in the Slovak legislation. There is no known practice of comparable meaning and effect in the country’s health care system.

There are not yet any legal provisions, policies, guidelines, or declarations in Slovakia on this matter.

There are, however, some relevant provisions with regard to the end-of-life decisions and with regard to the consent to, or refusal of the particular health care to be provided to the patient in the Slovak health law (i.e. Law No. 576/2004 Coll. – as later amended). These provisions are contained in the paragraphs on the “informed consent” and on the “informed refusal” of the patient, and in the paragraphs on patients’ rights. The informed consent/refusal, however, are only available to the legally competent patient.

If the patient is not competent under the law, then these decisions are to be made by his/her legal representative provided for by the law – it is usually the closest relative of the patient. If such person does not exist, then a legal representative is nominated as provided for by the law (usually it is the patient’s caregiver), or, if unclear, by the decision of the court.

b) Possibility of appointing a proxy decision-maker

The possibility of an “active” appointing of a proxy decision maker with regard to the health care decision making are not provided for in the Slovak legislation. Slovak law, however, does not preclude such actions of the patient.

If such proxy would be accepted by the health care professionals, especially the physicians and the health care administrators, is not at all clear at present. It is very probable, however, that any ”decision” of such proxy that would go against the “patient’s best interest” as understood by his/her health care givers, will NOT be accepted. How such case would be handled by Slovak courts is also unclear at present. To my knowledge, there have been no such cases handled by the Slovak courts yet.

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c) Right to patient self-determination and limits of patient autonomy

The respect for the right of the patient to self determination with regard to the decisions concerning his/her health care is provided for in the Slovak health law – paragraphs on patients' rights.
This respect of the patient's autonomy goes so far that the *competent* patient is effectively able to refuse even the health saving and the life saving treatment proposed to him/her by his/her physician or by the health care team.

The same refusals could effectively be made on behalf of the *incompetent* patient by his/her legal representative. If such proxies' "decisions", however, would go against the "patient's best interest" as understood by his/her health care givers, they will NOT be adhered to. The matter then should be decided by the court.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Euthanasia, as well as assisted suicide is prohibited by the law in Slovakia (by both the health law and by the penal code). Those are also prohibited by the professional codes of conduct of the Slovak health care professions.

On the other hand, the treatment deemed by the physicians to be futile could be stopped. Such decisions are usually to be taken by the head of the health care team, or, in some specific situations, such as in brain dead patients, by a group of physicians provided for by the law (so-called "physicians consilium").

The provision of nutrition and hydration, whether by natural or by the artificial means, is regarded a part of the *care* given to the patient, not strictly as a part of the *treatment*. The care provision to the patient, unlike the treatment, cannot be stopped.

e) Bibliography

There is no specific bibliography on "living will" in Slovakia.

The replies under a) – d) are based on the following legal, or other texts:

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2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

None. There are no statistics, report, estimates, surveys or studies on the matter in Slovakia.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Never.

c) How high is the acceptance of advance directives by physicians and other care takers?

There is no practical experience with advance directives in Slovakia.

d) What are the 3 main practical problems in writing and/or applying advance directives?

There is no practical experience with advance directives in Slovakia.

e) Bibliography of empirical studies and/or other sources of information:

No specific literature on the matter exists at present in Slovakia.

3) State of debates on advance directives

a) What are the major issues and concerns?

The problem of “advance directives” is not a hot topic in Slovakia.

Professional and also the general public, as well as the media, are somewhat hesitant to enter into a deeper discussion on the matter. This is probably due to the experience so far with the debate on euthanasia and lack of clarity in distinguishing between the both terms in the public square.

As indicated above, the public and the professional attitudes to euthanasia and assisted suicide are mostly negative in the country. This is also bound to some negative connotations these terms bear on them from the past, especially with regard to so-called “social euthanasia”, i.e. insufficient health care provision to ordinary citizens in the ‘communist’ past, and fear of misuse by health professionals when allowed by the law.

There is a starting debate on the advance directives, however, in health professionals’ circles, and also by individual citizens. These conversations, however, have not yet reached the spotlight of the public square.

b) What are the hopes and expectations?

I think the health care professionals, as well as 'ordinary' citizens would welcome advance directives, if appropriately designed by the law, as a honourable 'way out' in the difficult situations in health care, especially situations occurring in the intensive health care, and in palliative health care settings.

Neither of those, however, would accept any such provisions on advance directives that would in fact allow provision of euthanasia or physician assisted suicide in Slovakia. Moreover, sufficient legal safeguard to that effect would be seen as a *sine qua non* prerequisite for any advance directive legislation to be enacted.

c) Bibliography of literature and / or other sources of information

- Glasa, J., Ďačok, J., Glasová, K.: *Zur Diskussion der biomedizinischen Ethik in der Slowakischen Republik (1990-2007)*. Zeitschr. für med. Ethik, 53, 2007, p. 343-356 (in German).

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4) Other remarks

I believe that the problem of "advance directives" will be of growing theoretical and practical importance in Slovakia and in Europe. I think, on the theoretical level, it should be dealt from an interdisciplinary perspective. The international exchange of information on European and even global levels are welcome.

The legal decisions on the matter, however, should respect the legal, cultural, spiritual and religious traditions of the respective communities and countries. Therefore, I believe that they should be adopted on the level of states, while respecting the international instruments on human rights and fundamental freedoms.

SPAIN

José Antonio Seoane and Pablo Simón [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Bindingness. The living will comes into force only when the patient becomes unable to take autonomous decisions by his/her own.
It is required to be competent and over 18 (legal age of majority), despite some regional laws allow the living will of mature minors (over 16).
Its bindingness also demands the fulfilment of some procedural requirements (in some regional laws is required an official registration).
Scope. There are three main areas: 1) health treatment or cares that should be provided when the patient is no longer able to take autonomous decisions; 2) organ, and tissues, donation; 3) appointment of a proxy.
A fourth area is pointed out by authors and guidelines, but it is only included in some regional laws: 4) the expression of patient´s personal values, preferences, objectives and expectations, in order to clarify his/her decisions and to help its interpretation and application.

b) Possibility of appointing a proxy decision-maker

The appointment of a proxy is a general and common feature stated in laws, as well as in policies, guidelines and authors. The proxy is chosen by the patient, who can also appoint a substitute proxy. The proxy must accept the patient's appointment in a written form.
The proxy acts as an interlocutor with health professionals, and watch over the respect of patient's values and previous decisions.
Nevertheless, his/her nature and functions, as well as the scope of his/her decisions are a controversial matter, even in some regional laws.

c) Right to patient self-determination and limits of patient autonomy

The right to self-determination embraces which is stated in section 1.a). Nevertheless, these decisions, namely the first (health treatments and care), are subjected to limits laid down by the laws. The patient's advance directives are not to be put into practice when they are opposed to 1) legal system, 2) *lex artis*, or 3) do not fit with the clinical event or situation stated by the patient in the living will.

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Some regional laws include a controversial fourth limit: 4) medical conscientious objection.
Some regional laws use diverse terms to state the limits to advance directives. Sometimes their choice is a clarifying one (not contraindicated treatments), sometimes not (medical or professional ethics).

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Euthanasia (named here as "active euthanasia") is forbidden. The Spanish Criminal Code (article 143.4) considered euthanasia –without using this term- as a criminal offence against life with extenuating circumstances.
What has been named "passive euthanasia" is not punished nor forbidden. The voluntary rejection of medical treatment, including life-sustaining treatment and artificial nutrition and hydration, can be protected under the European Convention on human rights and biomedicine (1997, that came into effect in Spain on 2000 January 1st) and the Spanish Basic Law 41/2002, 14th November, on patient autonomy and rights and obligations regarding medical information and documentation. Nevertheless, it remains controversial.

e) Bibliography

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COUCEIRO VIDAL A. Las directivas anticipadas en España: contenido, límites y aplicaciones clínicas. Rev Cal Asist 2007; 22: 213-222.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

At 1st January 2008: 43,668 individuals (61% women; 39 % men) have filled in and registered advance directives in regional registry offices (96/100,000 inhabitants; approx. 0,1%. 120/100,000 over 18 inhabitants; 0,12%) (Observatorio de voluntades anticipadas. Escuela Andaluza de Salud Pública, *Informe semestral sobre voluntades anticipadas en España (1 de enero de 2008)* [Observatory on advance directives. Andalusian School of Public Health, *Semestral Repport on advance directives in Spain (1st January 2008)*]. Information provided by Pablo Simón, EASP).

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

There is hardly data about the influence of AD in health care decision-making. Nevertheless, the increasing empirical studies show both medical and nursing professionals are generally in favour of using AD in advance care planning.
It is also remarked there is not a sufficient knowledge of legal regulation and legal and ethical meaning of AD, neither appropriate training of health care professionals in advance care planning processes. Furthermore, in end-of-life decisions, specially in some critical ones (e.g. vital support refusal), the consensus does not exist and this has influence in attitudes regarding AD.

c) How high is the acceptance of advance directives by physicians and other care takers?

Some professional organizations have expressed their support to the use of AD (e.g. SEMICyUC: Spanish Society of Intensive Medicine, Critical Care and Coronary Units)
Neither the Medical Ethics and Deontology Committee of the General Medical Council nor General Nursing Council have issued any explicit statement or report on AD.
Some regional Bioethics Commissions (e.g. Catalonia, the Basque Country, Andalusia, Valencia) have issued reports on AD, supporting the use of AD by health care professionals and citizens.
It must be also noticed that some academic and ethics institutes or societies and other social institutions, as the Catholic Church, have expressed their opinions on AD in brief reports or statements.

d) What are the 3 main practical problems in writing and/or applying advance directives?

AD are relatively new in Spain: the first legal norms have appeared in 2000. It must be waited for a longer period of time to obtain valid results. Nevertheless, there are some practical problems:
Inadequate knowledge of advance directives, both by health care professionals and citizens.
In the professional realm, remains of medical paternalism and lack of appropriate instruction. On the patient side, too passive attitudes and insufficient exercise of autonomy in health care decisions.
Imbalance between enactment of legal norms and changes in policies of health care institutions and health professionals training.

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3) State of debates on advance directives

a) What are the major issues and concerns?

- Developing a theoretical and practical (social, political and professional) debate
- Supporting the education of health care professionals and citizens on this topic.
- Scope of patient autonomy in end of life decisions.
- Appropriate understanding of advance directives and the other concepts concerning patients autonomy and end-of-life decisions.
- Understanding AD as a new tool in the broader advance care planning, and a way for improving health care relationships.

b) What are the hopes and expectations?

- Harmonisation of legal regulation
- Spreading an appropriate knowledge and use of advance directives as a tool for advance care planning.
- Developing of health care policies on AD.
-Supporting the training of health care professionals.
- Social and cultural development of the meaning and scope of the patient autonomy in health care decision-making, specially regarding the end of life.

c) Bibliography of literature and/or other sources of information

SIMÓN P, BARRIO I. Quién puede decidir por mí? Una revisión de la legislación española vigente sobre las decisiones de representación y las instrucciones previas. Rev Cal Asist 2004; 19: 460-472

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SEOANE JA. Derecho y planificación anticipada de la atención: panorama jurídico de las instrucciones previas en España. Derecho y Salud 2006; 14: 285-295

MARTÍNEZ K, Los documentos de voluntades anticipadas An. Sist. Sanit. Navar. 2007 Vol. 30, Supl. 3: 87-102.

4) Other remarks

It must be underlined the enormous and complex legal regulation. There are some current national laws and many regional laws and other legal norms (cfr. Appendix 1).

Regional laws usually develop and go into detail in accordance with the national regulation. However, in some matters they come into conflict.
It also must be noticed that AD are a relatively new event in Spanish health care. Therefore we might wait for a longer timescale.

SWITZERLAND

Peter Lack and Claude Regamey [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Due to the federal organization of Switzerland, there are no nationwide specific legal regulations on this issue. The range differs from some cantons with a strict binding law to cantons where the Living will is not even mentioned. There are no limitations in the scope of the living will.
The current law of guardianship is being revised and the final draft which has been discussed and accepted by both chambers of Swiss Parliament is introducing two new legal instruments, the Living Will (including a proxy decision-maker for medical issues) and the Proxy Directive (Durable Power of Attorney). The law is expected to come into effect in 2010. The living will will then be binding. If a doctor undertakes a treatment not in line with the stipulations of Living Will, his decision has to be substantiated and made a clear note of it in the Medical Records. There is no limitation provided for in the living will scope. The Living Will would be applicable in any situation where a patient has lost his power of judgement.

b) Possibility of appointing a proxy decision-maker

Cf. point 1a), same situation.

c) Right to patient self-determination and limits of patient autonomy

Cf. 1a) There is no federal patient-law in Switzerland. Some cantons have Patient Laws which usually confirm self-determination and patient autonomy. The expected new law of guardianship will regulate some patient-physician related issues as well as long term care issues (Nursing homes etc.).
The Swiss Academy of Medical Sciences has published Principles regarding the patients' right to self-determination. In this document, as well as in earlier documents, the living will has been acknowledged as an instrument for expressing the patients' will in advance. Therefore, it has to be followed. Currently, a new document of the Swiss Academy of Medical Sciences is being elaborated concerning the criteria for valid Living Wills and a draft will be published in 2008.

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d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Active euthanasia is prohibited by law. Assisted suicide without selfish interests is generally free from penalty, irrespective of the person helping to commit suicide being private or professional..

There are no legal restrictions to excluding or withdrawing artificial nutrition or hydration.

e) Bibliography

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Lack, P. Die Bedeutung der Werteanamnese als Grundlage für Patientenverfügungen. In: Lehrbuch Palliative Care; Hrsg. Knipping, Cornelia; Bern 2006, S. 588-596.

Schweizerische Akademie der Medizinischen Wissenschaften. Umgang mit urteilsunfähigen Patientinnen und Patienten – Medizinethische Grundsätze. Basel, 2005.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

There are no “official” data, but it probably is between 5% and a maximum of 10% of the population.
A social non-denominational organization in Basel specializing in Living Wills (GGG Voluntas) is counselling about 200 persons per year, and Living Wills and Proxy Directives of approx. 1000 persons have been deposited. The population of Basel is about 200’000. The percentage of people seeking advice is therefore less than 1%.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

No data is available on this issue in Switzerland. My perception is that the willingness of doctors to act in accordance with a Living Will is growing. National Standards of medical ethics (cf. 1c) call for the observance of an existing Living Will. This is getting more and more accepted in practice.

c) How high is the acceptance of advance directives by physicians and other care takers?

Cf 2b). It is growing, partially due to changing views on Patient self-determination in the public, the Standards of the Swiss Medical and the coming (or in some cantons existing) law.

d) What are the 3 main practical problems in writing and/or applying advance directives?

- Informed Consent: Accurate Information of a person when writing a Living Will
- Lack of a federal legal regulation (until now)
- Lack of Procedures in clinical institutions (Hospitals, Nursing homes etc.)

e) Bibliography of empirical studies and /or other sources of information:

Federspiel, B.: Patientenverfügung zur Auftragsklärung am Lebensende. Schweiz. Gesellschaft für Gesundheitspolitik, Zürich 2004.

3) State of debates on advance directives

a) What are the major issues and concerns?

- Protection of the patient's self-determination
- Changes of the personal will regarding life-sustaining treatments; changes in personal attitudes towards (chronic) illness and dying.
- Information of the population on the Living will and related Issues
- Help in establishing a Living will
- Information about an existing Living Will: relation of rights and duties, especially patient – medical profession.
- Depositing a Living will, guaranteeing instant availability of the document
- Protection of the medical profession when following a Living Will
- The danger of Living Will as an instrument for limiting health care

b) What are the hopes and expectations?

- Legal regulation which is comprehensible and can be followed
- Ensuring the patients self-determination
- Pactical help for members of the medical professions, especially physicians.

c) Bibliography of literature and / or other sources of information

The New Law of Guardianship: http://www.admin.ch/ch/d/ff/2006/7139.pdf

TURKEY

Tolga Guven (*)

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

The situation of advance directives is not directly addressed in any part of the health legislation of Turkey. Article 9 of Oviedo Convention, which is also binding for Turkey, states that "previously expressed wishes….should be taken into account." However, this is a vague statement which does not clarify the bindingness of such wishes and unfortunately, a more detailed or clear provision that corresponds to this Article's content does not exist in Turkish law as of this moment and Professional Code of Ethics of Turkish Physician's Association does not address the issue. The closest process to an advance directive in Turkish medical practice is perhaps the one defined in Article 14 of Law on Organ Transplantation, which allows the individual to donate his organs via a written will or in the presence of two witnesses.

b) Possibility of appointing a proxy decision-maker

The concept of a proxy decision maker is implied in Article 19 of Patient Rights Regulation. The article implies that under conditions where information is withheld from the patient, this information may be disclosed to someone else determined beforehand. However, the Regulation does not elaborate on how such process is to be handled. In addition, while the status of legal representatives in the decision making process is addressed in the Regulation, whether such decision makers can be appointed via an advance directive is not mentioned.

c) Right to patient self-determination and limits of patient autonomy

The right to bodily integrity for any individual has been recognized in Article 17 of the 1982 Constitution of Turkish Republic. In addition, Regulation on Patient Rights emphasizes the importance of patient consent in health care service. However, certain procedures, on the basis of protecting public benefit and health, may be performed without the individual's consent, as implied in the Common Health Law and Law on the Eradication of Malaria. These laws address certain health care services, regarding communicable/infectious diseases, including mandatory treatment for such conditions.
The limits of patient autonomy is perhaps most clearly defined in the provisions of Patient Rights Regulation regarding the refusal of treatment.

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While the right to refuse treatment is clearly defined in Article 25 of this Regulation, Article 24 states that a patient can withdraw his consent for an already initiated on condition that no medical drawbacks will occur as a result of such an action. Opinions of authors in Turkish legal doctrine about the implications of these two articles differ dramatically. However, while Article 25 necessitate written documentation of refusal, the Regulation does not refer to any process regarding the use of advance directives for refusing a treatment. Therefore, the status of a written refusal of treatment prepared before hand by the patient is unclear, particularly if such refusal will result with an obvious harm to the individual.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

End-of-life decisions are addressed specifically in a Turkish document, but Turkish legal doctrine defends that the right to life is indefeasible and inalienable and even the individual himself/herself is not entitled to restrict its limits. Therefore, terminating a patient's life to put an end to his suffering on his demand is forbidden in Turkish law. The individual's consent will not justify the unlawful status of such an act. In addition, it is observed that such interventions have been clearly prohibited in certain legislations. Medical Deontology Regulation's Article 13, paragraph 3 states that the physician is not allowed to perform interventions on patient's demand when such interventions have no diagnostic or therapeutic purpose and will harm the physical and mental health of the patient. The Regulation on Patients Rights also clearly prohibits euthanasia and declares that individuals can not waive the right to life due to medical or other reasons. However, the Regulation does not include a definition of euthanasia and does not elaborate which type of euthanasia this provision applies to.
There are no articles in Turkish law that directly or specifically regulates the provision of artificial nutrition and hydration procedures. However, the framework relating to refusal of treatment defined and the limits on patient autonomy in Section c above would also apply to these issues.
On the basis of the data above, the possible status of an advance directive expressing a demand for euthanasia or withdrawing life support/nutrition/hydration could be defined as problematic at best.

e) Bibliography

B. Erman, Tıbbi Müdahalenin Hukuka Uygunluğu (*Lawfulness of the Medical Intervention*), Seçkin Yayınları, Ankara, 2003.

G. Sert, Hasta Hakları –Uluslararası Bildirgeler ve Tıp Etiği Açısından- (*Patient Rights From the Perspective of International Documents and Medical Ethics*) Babil Yayınları, İstanbul, 2004.

G. Sert, T. Guven, S. Gorkey. Medical Law- Turkey Monograph. International Encyclopaedia of Laws – Medical Law, Suplement 52. General Editor R. Blanpain, Editor Herman Nys. Kluwer Law International, The Netherlands, 2007.

K. Bayraktar, Hekimin Tedavi Nedeni ile Cezai Sorumluluğu (*Criminal Liability of the Physician for Treatment*). İ.Ü. Yayınları, Sermet Matbaası, İstanbul, 1972.

S. İnceoğlu, Ötanazi. Ölme hakkı (*Euthanasia. The right to die*). Ayrıntı Yayınları, İstanbul, 1999.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

There is no data pertaining to the use of advance directives. Advance directives are not a part of routine heath care service practice in Turkey and the term probably does not correspond to any theoretical or practical framework for the average health care professional.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?
Please see 2/a above.

c) How high is the acceptance of advance directives by physicians and other care takers?
Please see 2/a above.

d) What are the 3 main practical problems in writing and/or applying advance directives?
The lack of a clear legal and ethical framework for the use such directives is possibly the biggest problem. In addition, medical paternalism is very common in Turkey and the individual/patient autonomy is not adequately realized in the decision-making process despite a rather detailed legal framework defined in the Regulation of Patient Rights. If the main concept behind the use of such directives (i.e., respect for patient autonomy) is not adequately understood, preparation of advance directives can easily be evaluated as another formality or extra paper work with no obvious practical result in such a setting.

e) Bibliography of empirical studies and/or other sources of information:

N/A, please see 2/a above.

3) State of debates on advance directives

a) What are the major issues and concerns?

Unfortunately, in Turkey the use of advance directives in health care is not debated adequately in any of the platforms listed in parenthesis above. The subject is most likely come up in medical ethic lectures in Turkey as a theoretical concept.

b) What are the hopes and expectations?

Health care professionals in Turkey experience ethical issues during the health care service of patients that lack decision-making capacity. Although they may not be aware of the concept of advance directives in general, they

do expect to be provided a clear legal and ethical framework to deal with such situations.

c) Bibliography of literature and / or other sources of information
N/A. Please See 3/a above and the following.

Books

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Articles

Ersoy N. Gundogmus, U. A Study of the Ethical Sensitivity of Physicians in Turkey. Nurs Ethics. 2003 Sep;10(5):472-84.

Oguz, NY. Miles SH. Buken N and Civaner M. End-of-Life Care in Turkey.

Camb Q Healthc Ethics. 2003 Summer;12(3):279-84.

UK

Richard Huxtable and Anne Slowther [*]

[Please note that the following information relates to the specific legal position in the jurisdiction of England and Wales]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

Advance directives (which refuse specified treatments) have long been respected in English common law. However, since 1 October 2007 such decisions are governed by statute, specifically the Mental Capacity Act 2005. Under this Act, an advance decision refusing treatment can take any form, unless life-sustaining treatment is refused, in which case the decision-maker must verify that it applies to a treatment even if "life is at risk" and the directive must be written, signed and witnessed. Life-sustaining treatment "means treatment, which, in the view of the person providing healthcare, is necessary to sustain life". However, basic care (including the offer of oral food and water, warmth and hygiene measures) may not be refused by an advance decision.
More generally, an advance decision will only be binding if it:

- Amounts to a clear refusal of treatment (advance requests *for* treatment are not strictly binding, although they may help guide health professionals in determining what is in the best interests of the patient);
- Was made by an adult (i.e. someone aged 18 years or over) who is now incompetent, who issued the decision at a time when s/he was competent;
- Has not been (competently) withdrawn either explicitly or through behaviour that is inconsistent with the directive;
- Has not been superseded by the appointment of a lasting power of attorney;
- Applies to the situation that has now arisen – where there are no reasonable grounds for believing that circumstances have arisen that the person did not expect and that would have affected his decision had he expected them.

Failure to respect a valid advance directive will in theory give rise to legal actions in trespass to the person (a civil wrong, for which financial compensation might be awarded) and/or assault or battery (criminal wrongs, subject to penalties like imprisonment).

b) Possibility of appointing a proxy decision-maker

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The Mental Capacity Act 2005 allows (for the first time in English law) for the appointment of a health care proxy, known as a "lasting power of attorney". This appointment can be made by a competent adult (i.e. someone aged 18 years or over who is mentally capable) and it must comply with various formal requirements e.g. made in writing, witnessed, lodged with the Office of the Public Guardian. In health care matters, the donee's authority can be general or limited to specific matters, but it does not authorise the attorney to consent to or refuse life-sustaining treatment (which in the view of the person providing healthcare is necessary to sustain life) unless there is express provision to this effect in the formal document. The attorney's consent should be sought as if s/he was the (competent) patient, although the attorney is required to make their decisions in the best interests of the patient.

c) Right to patient self-determination and limits of patient autonomy

Patient autonomy is a governing principle in English medical law, which extends to permit the right to consent to and refuse treatment, even if this is necessary to prolong life. The right to consent to treatment applies to both competent adults and competent minors, although the (legal) right to refuse is effectively limited to adults. Many statutory provisions in the realm of health care rest on respect for autonomy (e.g. provisions on organ donation, fertility treatment and research). Critics note that the main limit placed on respect for autonomy in health care relates to the prohibition on (voluntary) euthanasia and assisted suicide.
The Mental Capacity Act places some limit on autonomy in advance refusals of treatment. It is not permissible to make an advance refusal of basic care (food, warmth). Also an advance refusal of treatment for a mental illness can be overridden if the patient is being treated under the provision of the Mental Health Act 1983.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Generally speaking, life-sustaining treatment (including artificially provided nutrition and hydration) may be withdrawn where:

- The patient is incompetent and continued treatment is no longer in their best interests; and/or
- The patient is competent and refuses to consent to treatment.

Treatment that carries a risk of shortening life (e.g. sedative use in severely compromised, terminally ill patients) may be lawfully administered, in accordance with responsible medical practice and so long as there is no intention to cause death (but rather an intention to relieve symptoms).
Despite (failed) legislative proposals and recent legal challenges, euthanasia and assisted suicide remain prohibited – they constitute homicide offences. However, it is worth noting a recent ruling which indicated that competent citizens are free to travel to other jurisdictions (specifically, Switzerland) to obtain assistance in dying.

e) Bibliography

- Mental Capacity Act 2005: http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1
- Mental Capacity Act: Code of Practice: http://www.dca.gov.uk/menincap/legis.htm#codeofpractice

- Department of Health guidance on the Mental Capacity Act 2005: http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/index.htm
- Johnston and Liddle, "The Mental Capacity Act 2005: A new framework for healthcare decision making" *Journal of Medical Ethics* 2007; 33: 94-97
- General Medical Council, *Withholding and withdrawing life-prolonging treatments: Good practice in decision-making*: http://www.gmc-uk.org/guidance/current/library/witholding_lifeprolonging_guidance.asp#13

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Advance directives would appear to be rarely encountered in clinical practice, which implies that few people make such "living wills" (indeed, it has been remarked that few people even make wills).

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

Relevant findings include the following:

Schiff et al (2000):
Questionnaire survey of 74 participants, aged 65 years and over. Findings to note include: "Sixty one participants (82%; 95% confidence interval 72% to 90%) had not heard of living wills, advance directives, or advance statements"; "Fifty participants (74%) expressed interest in writing a living will, most commonly because their views would be known (25; 34%) and to relieve the burden of decisions on their family (22; 30%).Women and men were equally interested in writing a living will"

Schiff et al (2006)
Postal questionnaire survey of 1, 426 physicians who were members of the British Geriatric Society. Of 811 geriatricians 56% had cared for someone with a living will and of the 280 who had cared for a patient at the time that the living will had come into effect 39% had changed treatment because of the living will and 78% ofthose had found the decision easier to make because of the living will.. However only 16% of respondents were aware of a Trust (hospital) policy on living wills. 92% saw advantages of older people using living wills.

Seale (2006):
A postal survey questionnaire of 857 UK medical practioners and comparison with data from other countries including those permissive and non permissive of medical involvement in actively hastening death. UK doctors are relatively cautious in shortening life by more than a few days. Willingness to discuss end of life decisions with patients and relatives is relatively high in the UK, but not as high as in permissive countries. UK doctors are highly likely to discuss end of life decisions with colleagues, and are more likely to do this than doctors in other countries.

c) How high is the acceptance of advance directives by physicians and other care takers?

This is difficult to gauge, but a qualitative study by Thompson et al (2003), which was based on a hypothetical directive and vignette, reveals that there can be significant differences of opinion in practice as to whether or not a directive is binding: 6 of the 12 participants were against treatment, 5 were for it, and 1 was unclear. The study by Schiff (2006) cited above suggests in elderly medicine about half of doctors would alter treatment based on an advance decision, but a higher percentage thought that there were some advantages to advance directives.

d) What are the 3 main practical problems in writing and/or applying advance directives?

- Ensuring that patients know about their rights in this area
- Ensuring that the directive is valid, and especially that it applies to the situation that has arisen: Thompson et al (2003) demonstrate the ambiguities of applying such directives in practice
- Consistency in policies and practices surrounding advance directives: Diggory & Judd (2000) have noted inconsistency between NHS hospitals

e) Bibliography of empirical studies and /or other sources of information:

- Diggory and Judd, "Advance directives: questionnaire survey of NHS trusts" *British Medical Journal* 2000; 320: 24-25
- Seale, "Characteristics of end-of-life decisions: survey of UK medical practitioners" *Palliative Medicine* 2006b; 20: 653-659
- Schiff, Raikumar and Bulpitt, "Views of elderly people on living wills: interview study" *British Medical Journal* 2000; 320: 1640-1641
- Schiff R, Sacares P, Snook J, Rajkumar C, Bulpitt CJ.Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians Age Ageing. 2006 Mar;35(2):116-21
- Thompson, Barbour and Schwartz, "Adherence to advance directives in critical care decision making: vignette study" *British Medical Journal* 2003; 327: 1011

[More references available on request]

3) State of debates on advance directives

a) What are the major issues and concerns?

- The extent to which, in law, advance decisions are and will be respected; this essentially amounts to a concern that respect for patient autonomy is really only paid lip service, since patient choices can be reasonably easily deemed invalid
- The extent to which advance directives might be said to amount to "euthanasia" (this was a concern that was dominant in some of the media and public debates around the statutory reforms)
- The extent to which present wishes or choices are consistent with future wishes when a person can no longer make a competent decision about treatment. Does the experience of illness change our perception of what we would want to happen? Should present non competent choices outweigh previous competent ones?

b) What are the hopes and expectations?

- It is hoped that the statutory authority now granted to advance decisions (and, indeed, to proxies) will enhance respect for patient autonomy

c) Bibliography of literature and / or other sources of information

- Maclean, "Advance directives and the rocky waters of anticipatory decision-making" *Medical Law Review* 2008; 16: 1-22
- Michalowski, "Advance refusals of life-sustaining medical treatment: The relativity of an absolute right" *Modern Law Review* 2005; 68: 958-982
- Morgan, "Odysseus and the binding directive: only a cautionary tale?" *Legal Studies* 1994; 14: 411-442
- Stern, "Advance directives" *Medical Law Review* 1994; 2: 57-76

USA

Lisa Lehmann [*]

1) Regulatory situation of advance directives and beyond

a) Bindingness and scope of living will

In the vast majority of states in the United States advance directives are binding. However, there is variation state by state in the type of advance directive (living will or healthcare proxy) that is binding and each state regulates the use of advance directives differently. In 1976 California became the first state to legally sanction a living will. In 1990 the United States Congress passed the the Patient Self-Determination Act (PSDA) which is a federal law that acknowledges a patient's right to either refuse or accept medical treatment, empowers patients by safeguarding their autonomy and preserving self-determination, and protects physicians from litigation in end-of-life decision making. By 1992 all 50 states had passed some legislation on advance directives.

In 1999 Texas developed an Advance Directives Act, also known as the Texas Futile Care Law, that allow allows a health care facility to discontinue life-sustaining treatment against the wishes of the patient or guardian ten days after giving written notice if the continuation of life-sustaining treatment is considered medically inappropriate by the treating medical team. The law outlines a process that must be followed which includes giving the family information on ethics consultation, an invitation to participate in the ethics consultation process, 48 hours notice, and the option of transferring the patient to another institution. If after 10 days no institution can be found the hospital and physician may unilaterally withhold or withdraw treatment that is determined to be futile. A person who disagrees with this decision may appeal to a state court and request an extension of time before treatment is withdrawn.

b) Possibility of appointing a proxy decision-maker

Many states allow the appointment of a health care proxy. This is done by completing a form noting the person who is being designated to make decisions and by signing the document in front of two witnesses. The health care proxy becomes effective only when the patient is unable to make decisions, as determined by a physician. It can be revoked orally, and patients always have the right, while competent, to sign a new health care proxy.

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c) Right to patient self-determination and limits of patient autonomy

Advance directives are a way of respecting patient autonomy when patients do not have the capacity to make decisions for themselves. It is critical that this respect for self-determination occur within a context of advance care planning in which patients and their families receive information about a patient's clinical condition and consider the patient's values and goals in order to guide clinical decisions. Ideally advance directives should be revisited at critical junctures in the patient's care, when prognosis changes and when a request for a change is made by patients and proxies. Competent adult patients and health care proxies can refuse all medical treatment, including life sustaining treatment.

d) Options of end-of-life-decisions (e.g. active / passive euthanasia, regulations for provision of artificial nutrition and hydration)

Competent patients may refuse all life sustaining treatment including artificial nutrition and hydration. In the United States euthanasia is not ethically or legally sanctioned. In 1997 Oregon enacted the Death with Dignity Act which allows terminally-ill patients to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose. In 2007 physicians in Oregon wrote 85 prescriptions for a lethal drug dose requested by a terminally ill patient.

e) Bibliography

A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. *JAMA.* Nov 22-29, 1995;274(20):1591-1598.

Wilkinson A, et al. Literature Review on Advance Directives. US Department of Health and Human Services. June 2007. http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.htm

Galambos CM. Preserving end-of-life autonomy: the Patient Self-Determination Act and the Uniform Health Care Decisions Act. *Health Soc Work.* Nov 1998;23(4):275-281.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions.* Washington, DC: Government Printing Office; 1983.

2) Use of advance directives in health care practice

a) What percentage of people in your country has prepared advance directives?

Despite the existence of state and federal laws upholding advance directives many Americans do not have a completed advance directive. The literature suggests that between 18% and 30% of Americans have completed an

advance directive. Patients with chronic illnesses complete advance directives at rates only slightly higher than healthy individuals. For example, only 35% of dialysis patients and 32% of patients with COPD have completed an advance directive. Patients who are older, Caucasian, have a higher socio-economic status, and have a long-standing relationship with a primary care physician are more likely to complete an advance directive.

b) How often is medical decision-making based on an advance directive, or, at least, how often are advance directives a factor in medical decision-making?

It is difficult to assess how often medical decision-making is based on advance directives. We do know, however, that less than 50% of severely or terminally ill patients have an advance directive in their medical record. Furthermore, between 65% and 76% of physicians whose patients had an advance directive were unaware of its existence. The impact of advance directives in intensive care units is surprisingly weak. Some studies suggest that family awareness of patient preferences did influence decision making in an ICU setting while others show that it did not. The complexity of decision making in an intensive care unit frequently leads to confusion and disagreement between patients, families, and physicians.
Advance directives are completed more frequently in nursing homes than in other health care environments in the United States. Between 60-70% of nursing home residents have some form of advance directive, but most do not contain treatment decisions.

c) How high is the acceptance of advance directives by physicians and other care takers?

The majority of physicians in the United States recognize that advance directives have the potential to improve communication and trust, promote patient autonomy, and make treatment decisions easier. Studies of nurses also show that the majority have a positive attitude toward advance directives. While most physicians feel they should engage in a process of advance care planning that will result in the completion of advance directives, many do not because of both a lack of formal training in how to approach these conversations and because of a lack of time.

d) What are the 3 main practical problems in writing and/or applying advance directives?

1. Patient reluctance to discuss death and end-of-life care.
2. The designation of a health care proxy without discussion of the patient's preferences, goals and values.
3, The inability of a living will to capture the nuances of clinical situations which patients may experience.

e) Bibliography of empirical studies and /or other sources of information:

Collins LG, Parks SM, Winter L. The state of advance care planning: one decade after SUPPORT. *Am J Hosp Palliat Care.* Oct-Nov 2006;23(5):378-384.

Kass-Bartlemes BL, Hughes R, Rutherford MK, Boches J. *Research in Action Issue #12: Advance Care Planning: Preferences for Care at the End of Life.*

Rockville, MD: Agency for Healthcare Research and Quality (AHRQ); Mar 2003. AHRQ Pub No. 03-0018.

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3) State of debates on advance directives

a) What are the major issues and concerns?

1. How can we overcome the barriers to the completion of advance directives?
2. How can we ensure that advance directives accurately capture patient's preferences and are stable over time?
3. How can we mitigate differences in use of advance directives among racial and ethnic minorities?
4. What should be the role of advance directives for intellectually disabled persons?

b) What are the hopes and expectations?

The hope is that we will be able to develop creative ways to ensure that the preferences and goals of patients who lack the capacity to make decisions will be respected. Currently advance directives are only completed by a minority of the adult population and even when an advance directive has been completed it may not be available when needed clinically.

Possible approaches to enhancing the impact of advance directives may include the use of electronic medical record systems which could facilitate the completion and implementation of advance directives. Studies demonstrate that health information technology can increase the incidence of provider-initiated discussions of advance directives through computer-generated reminders as well as have an effect on the completion and documentation of advance directives in the electronic record. Another approach would be to develop systems to effect broad behavioral change. These could include providing education to providers and patients and implementing new laws/policies that induce behavior change. Additionally, there is a need for legislation to improve the portability of advance directives across state boundaries. The fact that advance directives created in one state may not be respected in another state is an obstacle to their implementation.

c) Bibliography of literature and / or other sources of information

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