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AN AGING EUROPE: HARMONIZING THE PROTECTION OF DEMENTIA PATIENTS' SELF-DETERMINATION IN HEALTH CARE DECISION-MAKING

Bachelor Thesis

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I hereby declare that I am the sole author
of this Bachelor Thesis and it has
not been presented to any other
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Abbreviations

CPA	Continuing Power of Attorney
CoE	Council of Europe
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
MCA	Mental Capacity Act
LPA	Lasting Power of Attorney
ACP	Advance Care Planning

Introduction

> *"I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men's, acts of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were, from outside. I wish to be somebody, not nobody; a doer – deciding, not being decided for (...) I wish, above all, to be a conscious of myself as a thinking, willing, active being, bearing responsibility for my choices and able to explain them by references to my own ideas and purposes."*[1]

Self-determination denotes free choice of one's acts without external manipulation or coercion. Every competent individual is entitled to decide on his affairs and how to live his life. Besides people are free to pursue themselves, they are entitled to enjoy protection to enforce this right.[2] Although the right to self-determination is not included in the Human Rights treaties as such, it forms the basis for many fundamental and human rights. The idea of the right of an individual to make own independent choices and decisions forms one of the cornerstones of the Western moral thinking. In health care decision-making, self-determination is implemented through the exercise of free and informed consent. People shall decide which treatment they wish to receive or not to receive. Respect for self-determination, regardless medical condition, is crucial in modern medical ethics and law. However, the law requires that any individual making decisions must have the capacity to do that.[3]

What about those who lack the capacity? An aging Europe results in a growing number of diseases, which weaken the capacity. The most widespread disease brought along by older age groups is dementia since approximately 10 million Europeans live with the condition.[4] Although any preventative or curative treatment for dementia has not been found, progress in health care, such as technological and medical developments, enable life to be prolonged and may allow physical survival for years. Sometimes those life-sustaining technologies are no longer for the real benefit of the patient but rather futile, and this is where self-determination plays a vital, but a sometimes controversial role. Due to different stages and gradual progression of dementia, it is

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1 Berlin, I. Four Essays on Liberty. Oxford University Press 1969, p 131

2 Launis, V. Itsemääräämisoikeus ja paternalismi terveydenhuollossa. Sosiaalilääketieteellinen Aikakauslehti 2010, p 136

3 McLeod, I. Legal Theory. Palgrave McMillan Law Masters 6th edition 2012, p 19

4 World Alzheimer Report 2015: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf (August 2015).

sometimes hard to determine to what extent a demented patient can make decisions. People should be able to express their wishes, values, and preferences even though the capacity to make decisions is lost due to mental or physical incapacity.[5] Advance directives and continuing powers of attorney (CPA) provide a solution to this problem. These written documents allow competent people to express their wishes and appoint someone to make health care decisions on their behalf for the future when they might lack the capacity.

Changes to promote self-determination have occurred in Europe since the turn of the millennium, and it is still one of the current concerns of the Council of Europe Member States. European countries share consensus, based on the European Convention on Human Rights and the Council of Europe Convention on Human Rights and Biomedicine, that "a capable adult patient must not be manipulated and that his or will, when clearly expressed, must prevail even if it signifies refusal of treatment. If a patient is not, at the time of the intervention, in a state to express his wishes, they shall be taken into account if they have been previously expressed".[6] Since then the legal status of these protective measures has begun to be recognized in both domestic law and international documents. When an advance directive is binding, a physician must comply with it, but when it is not, a physician must use it as a guide when determining patient's preferences and wishes. Despite the consensus, national approaches and legislations remain very diverse on this matter, and not all of them have recognized previously expressed wishes as legally binding.

First, the author provides an answer to the question: **How dementia patients' right to self-determination is protected and promoted in health care decision-making?** The author introduces two protective measures, which provide potential utility by enabling the expression of wishes in advance. For an advance directive and a CPA to be valid, it requires sufficient capacity from its creator. The author examines what kinds of factors are important to take into account in dementia patient's competence assessment. Moreover, it is a complex question whether a demented patient can be considered as the same person as before. Which wishes should prevail, past or present? What if the capacity is already lost and previous, competent wishes have not been expressed? Should the decision be made on the basis of a patient's presumed will or his best interests? Second, the author will try to answer the question **whether there is a need for**

[5] Goffin, T. Advance Directives as an Instrument in an Ageing Europe. European Journal of Health Law 2012, p 121

[6] Council of Europe Parliamentary Assembly, Social, Health and Family Affairs Committee. Draft Resolution and Recommendation on Protecting Human Rights and Dignity by Taking into Account Previously Expressed Wishes of Patients, Strasbourg 2011, p 1

new solutions for harmonized European standards to ensure dementia patients' self-determination in health care decision-making, and what these solutions could be. The answer will be provided with the help of analyzing the current situation on the European level and comparing the legal status of those protective measures in some European countries. The author explores whether it is possible to reach a deeper consensus among countries, and presents some proposals and ideas so that the exercise of patients' self-determination would be secured everywhere in Europe.

As the author reviews and compares the existing legislation, examines the present day situation and approaches to the treatment of incompetent elderly in law and aims to find the underlying reasoned answers to the topic in question, the legal-scientific treatment of the topics, and comparative and qualitative research methods are used. For the qualitative research, the author will use relevant legal literature and peer reviewed articles and journals to examine and analyze the topic. Comparative overview deals with regulation of protective measures in the United Kingdom, Spain, and Germany. These countries were chosen because they all have a strong legal status on protective measures. Thus, the author gives three examples from advanced, but slightly different approaches.

In the comprehensive introduction, the author provides background for the thesis topic and introduces research questions and methods as well. After that, this thesis is divided into five chapters. The first two, mostly descriptive chapters deal with the concept of self-determination in health care context, the protective measures promoting self-determination, and challenges to the exercise of dementia patients' self-determination, as well as proper ways to manage them. In the fourth chapter, the author reviews the legal background separately on the European level and national level in the UK, Spain, and Germany regarding the regulation of protective measures. After that, the national reports and also other approaches around Europe will be compared and analyzed together to get more perspective on the situation. The last two parts consist of shortcomings in the regulation of protective measures and recommendations for further developments for more consistent standards on this matter. This thesis ends with the conclusion. The topic was chosen because of its high relevance and the author's interest towards civil law and relationships between individuals. The author is especially eager to examine the treatment of mentally disabled people in legislation and how the law interacts with important things in life, such as love and caring for others, as well as human rights.

1. Self-Determination

1.1 Self-Determination in Health Care Context

Self-determination, or autonomy, has been known as a philosophical concept throughout times, but the cogitation of Immanuel Kant and John Stuart Mill open up more recent approach.[7] Kant interpreted autonomy as a rational person's rights to self-determination and self-governance, while Mill as an expression of our preferences.[8] Among others, self-determination consists of the right to competence, which refers to people's eligibility to act in society.[9] Competence requires mental, physical and social capabilities to think, act, state a choice, and collaborate independently.[10] Patient self-determination includes the right to bodily integrity and the right to make decisions regarding treatment.[11] In the UK case *Re T*, Lord Donaldson MR reaffirmed that every individual has a right to self-determination in respect of the medical treatment that they receive:[12]

"An adult patient who... suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered... This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."[13]

In the health care context, the exercise of self-determination is closely linked to the quality of life. The quality of life can be evaluated by considering the degree of autonomy that a person has, taking into account the socio-cultural background in which he lives.[14] Also, the human dignity is closely linked to the right to self-determination. The concept of dignity can be broadly interpreted, but it has been claimed that dignity consists of more than just respecting self-

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7 Saarenpää, A. Henkilö- ja persoonallisuusoikeus. Lapin yliopiston julkaisuja. Rovaniemi 2012, p 311

8 Walker, S. Autonomy or Preservation of Life – Advance Directives and Patients with Dementia. UCL Jurisprudence Review 2011, p 112

9 Saarenpää, A. (2012), *supra nota 7,* pp 311-312

10 Launis, V. (2010), *supra nota 2,* p 136

11 Edozien, L. Self-Determination in Health Care, A Property Approach to the Protection of Patients' Rights. Routledge 2016, p 24

12 *Ibid,* p 25

13 EWCA 30.7.1992, (1992) 4 All ER 649, *Re T (adult: refusal of treatment)*, paragraph 3

14 Burlá, C., Rego, G., Nunes, R. Alzheimer, dementia, and the living will: a proposal. Medicine, Health Care & Philosophy 2014, p 392

determination.[15] The core idea behind it is that one should be able to feel valued by other people.[16] Everyone deserves the same treatment as any other human being regardless of mental capabilities.[17] Taking properly into account the wishes and opinions of the principal in a patient-physician relationship is an important way to respect the human dignity.[18] Appointing a legal guardian is a way of supporting or replacing the use of person's competence in case of this person needs assistance or is unable to act on his own.[19]

1.2.1 Paternalism as the Opposite Principle

Paternalism can be seen as an opposite principle to the principle of self-determination. Anne Mäki-Petäjä-Leinonen sums up the definition of this principle well by stating that the main point of it is that "an individual has the right to receive protection against torts coming from outside or against losses caused by him."[20] Society has an obligation to protect incompetent patients from acts they might take if those acts are likely to be against their best interests.[21] In other words, a patient's autonomy is about to be limited for what is presumed to be his own good. Traditional basis for health care has been the assumption that doctor knows what is best for the patient, and therefore decisions about treatments were in the hands of the doctor. This tradition of medical paternalism has started to become outdated and replaced by a modern approach to patient-centred care.[22] An important consideration is that there always exists a legal presumption of capacity unless shown otherwise. No one shall be declared incompetent without a well-founded reason, and the priority shall be given to the decisions of a patient over the ones of other people as long as the patient is capable of making decisions.[23] However, legal approaches to decision-making in the health care of incompetent person are still based on the combination of respect for the patient's autonomy and protection of his welfare.[24]

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15 Herring, J. Losing it? Losing what? The law and dementia. Child and Family law Quarterly 2009, p 14

16 *Ibid,* p 14

17 *Ibid,* p 15

18 Antila, T. Edunvalvontavaltuutus. Talentum Media Oy 2007, p 4

19 Saarenpää, A. (2012), *supra nota 7,* p 313

20 Mäki-Petäjä-Leinonen, A. Ikääntymisen ennakointi: Vanhuuteen varautumisen keinot. Talentum Media Oy 2013, p 51

21 Mäki-Petäjä-Leinonen, A., Juva, K. Of Sound Mind? Dementia and Aspects of Assessing Legal Capacity. European Journal of Health Law 2015, p 15

22 Edozien, L. (2016), *supra nota 11*, p 14

23 *Ibid,* p 15

24 Lewis, P. Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems? European Journal of Health Law, the Netherlands 2006, p 219

2. Protecting and Promoting Self-Determination in Health Care Decision-Making and Challenges Relating to Dementia Patients Protection

2.1 Free and Informed Consent

The right to self-determination is implemented through the exercise of free and informed consent for any medical intervention.[25] The informed consent process is fundamental to treat and take care of patients properly.[26] It includes providing the patient with information about the procedure, its potential benefits, side effects, and risks, as well as other possible alternatives to the recommended procedure.[27] The patient should participate in the decision-making process and has a right to refuse or consent to certain treatments without being under unreasonable influence or coercion from a third party.[28] The patient may change his mind at any time. It is essential for the physician to provide information in an understandable manner and avoid using complex medical terms that a patient might not be familiar with.[29] This way a patient can make clear statements, which are easier to comply with, and thereby the autonomous choice remains respected, which indeed is the fundamental target.

Although it is widely acknowledged that patients should be involved in the decision-making process, there is a lack of universal consensus on what that means in practice.[30] The final decision does not have necessarily to be made explicitly by the patient, but what is of high importance is respect for the extent to which a patient wishes to participate or not participate. This way, the final decision can be formulated in cooperation, and as long as the treatment is acceptable to the patient the right to self-determination is respected.[31]

2.2 Protective Measures

Advance directives are written or oral statements to govern health care decision-making drafted for both negative and positive decisions.[32] The ultimate idea behind them is respect for patient's right to self-determination by protecting precedent autonomy throughout the course of patient's

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[25] Andorno, R., Brauer, S., Biller-Andorno, N. Advande Health Care Directives: Towards a Coordinated European Policy? European Journal of Health Law 2009, p 207

[26] Farmer, L., Lundy, A. Informed Consent: Ethical and Legal Considerations for Advanced Practice Nurses. The Journal of Nurse Practitioners Volume 13 2017, p 124

[27] Coll, P. Legal and Ethical Issues at the End-of-Life: Dementia. Quinnipiac Probate Law Journal 2009, p 379

[28] *Ibid,* p 378-379

[29] *Ibid,* p 379

[30] Edozien, L. (2016), *supra nota 11*, p 28

[31] *Ibid,* p 29

[32] Goffin, T. (2012), *supra nota 5,* p 121

bodily existence regardless of his current cognitive and voluntarily capacities.[33] Through advance directives, people are given an opportunity to attain dignity and comfort over the unavoidable death and efforts unlikely to enhance the quality of end-of-life. However, advance directives can cover many other things as well, such as general wishes regarding daily care or donation of organs. A physician has an obligation in principle comply with these previously expressed wishes of the patient regardless whether they consider them reasonable or even in the patient's best interest.[34]

There are two potentially complementary types of advance directives: instruction directives, which are written documents designed to allow people to express their preferences and decisions regarding specific treatments, and proxy directives, which allow individual to appoint someone as a health care proxy to make health care decisions on his behalf once the ability to make them is lost. From a medico-legal perspective, the most desirable situation is to bring both types together to determine the wishes and decisions of the patient best possible way.[35] Instruction directives can be divided into negative advance directives, positive advance directives, and advance guidelines.[36] In general, these are referred to as advance directives, while proxy directive is separately called a health care proxy or a continuing power of attorney. To avoid confusion, terms in this thesis are used as mentioned above. Advance directives and CPAs are introduced as separate categories in the following subsections.

2.2.1 Advance Directives

Instruction directives are designed to give instructions as to which form of care or treatment a patient wishes to receive or not to receive. In general, advance directives can also cover end-of-life decisions, and therefore instruction directives can be very diverse.

In a negative advance directive, a patient refuses to receive medical treatment, which would be necessary at the moment when he is incompetent to decide. This is the most commonly mentioned type of instruction directive, and European countries share a broad consensus that they should be binding. Patient's decision must be respected even when it would be irrational, and failure to treat may lead the patient's death. Reasons for the physician to not follow the directive are the facts that there are reasons strong enough to believe that an incompetent patient

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33 *Ibid,* p 121

34 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 209

35 Veshi, D., Neitzke, G. Advance Directives in Some Western European Countries: A Legal Comparison between Spain, France, England and Germany. European Journal of Health Law 2015, pp 324-325

36 Goffin, T. (2012), *supra nota 5,* p 124

has changed his opinion, advance directive is not valid anymore, the medicine and technology have taken significant advances since completing the advance directive, or the treatment refusal will cause serious harm to the patient. The biggest problem with negative advance directives is the foreseeability of the situation. They apply only to foreseeable situations. Hypothetically, the life-sustaining treatment should be carried out in the case of a car accident in spite of the refusal in advance directive because it cannot be foreseen.[37] The most common statement in a negative advance directive states that "if I suffer an incurable, irreversible illness, disease, or condition and my attending physician determines that my condition is terminal, I direct that life-sustaining measures that would serve only to prolong my dying be withheld or discontinued."[38]

Positive advance directive states which treatment the patient wishes to receive. A physician may follow these instructions as long as the treatment is in the patient's best interest and accordance with professional standards. If a patient has been offered with sufficient information at the moment he concluded the advance directive, and if at the moment the advance directive is needed, the physician still believes that this is the best treatment for the patient and that the patient has not changed his opinion regarding this treatment, nothing indicates that the physician should not comply with this advance consent.[39]

Advance directives can play a crucial role as advance guidelines as well. A demented patient may be at a stage where he is not fully capable of deciding on his own but capable of participating in the decision-making process. Instead of finding a patient entirely incompetent is important to include a partially competent patient in the process as far as possible. In such a situation advance guidelines form an instrument to understand and guide the patient and let him better take part in the decision-making. For this purpose, it is better to include a health care proxy as well to better interpret the meaning of the patient and the advance directive.[40]

2.2.2 Continuing Powers of Attorney

The possibility to choose one's guardian plays a vital role in terms of patient autonomy. In addition to advance directives, individuals may appoint someone as a health care proxy to make health care-related decisions on their behalf once they lose the ability to consent themselves. The task of the health care proxy is to represent the patient, and he has an obligation to do so in such

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[37] *Ibid,* pp 125-126

[38] Hecht, M., Shiel, W. Advance Medical Directives (Living will, Power of Attorney, and Health Care Proxy): http://www.medicinenet.com/script/main/art.asp?articlekey=7814

[39] Goffin, T. (2012), *supra nota 5,* pp 127-128

[40] *Ibid,* pp 126-127

a way that the best interest of the patient is taken into account.[41] This legal institution, a CPA, is already implemented in many European countries as a part of the civil law, and it offers an opportunity to secure one's future in case of becoming incompetent due to illness, disturbed mental faculties, or impaired health.[42] It is based on the document made by the donor who is entitled to decide the affairs that authorization is about to concern. Those affairs can also include financial affairs and other welfare affairs, and it is possible to appoint more than one attorney and divide tasks among them.

To avoid confusion, this more recent term can be distinguished from other forms of guardianship. A CPA, as stated, is an opportunity for a competent person to designate someone to take care of his personal and financial affairs in advance if this person becomes incompetent somewhere in the future, while a legal guardian is appointed for an already incompetent person by a court or other guardianship authority. The titles and extent of duties of legal guardians vary from country to country. CPA is an alternative for the traditional form of guardianship and derived from the person's declaration of intent.[43] However, both seek to reliably take care of the affairs of an incompetent person and emphasize trust between the donor and donee.[44] The aim of the CPA is to provide more flexible and effortless possibility for people to take care of their family and close ones. People in need of a guardian, and, as a result, the workload of district courts and guardianship authorities, are significantly increasing. This alternative instrument also reduces the burden on society. Moreover, it can be seen as a strengthening instrument regarding self-determination encouraging many people of different ages to prepare for what may happen in the future. Anglo-American legal systems were the first ones introducing the CPAs.[45]

2.2.3 Hierarchy

An advance directive, either positive or negative, always has the priority, the proxy has to follow it even though the decision would appear to be irrational. If there is some ambiguity in the directive, a physician tries to interpret it. A proxy may give assistance by explaining what the patient would probably have wanted to express. When the capacity is already lost, and the decisions or wishes of the patient have not been expressed in advance, they have to be made on behalf of the patient either on the basis of the substituted judgment or best interests of the

41 *Ibid,* p 129
42 Antila, T (2007), *supra nota 18*, p 1
43 *Ibid,* p 1
44 Välimäki, P. Edunvalvontaoikeus. Talentum Media Oy 2013, p 232
45 *Ibid,* p 227

patient. The substituted judgment is based on respect for the autonomy interests as the decision is made on the basis what the incompetent individual would have decided in such a situation were he competent, which requires that there is clear evidence about the values and preferences of the patient available. The best interests test is based on the protection of the incompetent individual's welfare interests and can be used regardless of whether an individual was previously competent. This approach is justified by the principles of beneficence and non-maleficence.[46] If a physician has a reason to doubt the proxy's decision, it can be rejected. Thus, it is not possible for the proxy to make unreasonable decisions on behalf of the patient, such as refuse life-sustaining treatment.[47] However, the procedure, again, varies from country to country.

2.3 Challenges Relating to Dementia Patients' Protection

To achieve a somewhat deeper understanding of dementia, this subchapter first provides a brief overview what kind of disease it is. The wording originates from the Latin *de,* meaning without, and *ment,* meaning mind, which refers to a decline in mental functioning.[48] Dementia cannot be defined as a single disease, but rather "a clinical state where a decline in cognitive function, such as loss of memory, judgment, language, complex motor skills, and other intellectual functions, leads to a decline in normal independent daily function."[49] Dementia influences on activities of daily living, as well as on behavior and cognition.[50] The most common disease leading to dementia, Alzheimer's disease, is a neurodegenerative disease, which slowly and progressively destroys brain cells. It affects 60-65% of people who have dementia and is diagnosed most often in people over 65 years of age.[51] Other neurodegenerative diseases causing dementia syndromes are, among others, vascular dementia, Parkinson's disease-related dementia, dementia with Lewy bodies, frontotemporal dementia, and Huntington's disease.[52] Dementing illnesses are on the rise since the population is constantly aging all over the globe. Approximately 10 million Europeans live with dementia and speaking worldwide; the estimated number is about 47 million, which will almost double every 20 years.[53] Moreover, it is important to bear in mind that those prevalence rates are based on studies involving diagnosed cases of dementia. Thus, the actual

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46 Negri, S. Self-Determination, dignity and end-of-life care: Regulating advance directives in international and comparative perspective. Leiden, Brill 2012, p 80

47 Goffin, T. (2012), *supra nota 5,* p 129

48 Foster, C., Herring, J., Doron, I. The Law and Ethics of Dementia. Hart Publishing, Oregon 2014, p 37

49 *Ibid,* p 37

50 Schaffner, A. Understanding Dementia. Quinnipiac Probate Law Journal 2009, pp 373-374

51 Dementia, Alzheimer's disease: http://www.alzheimer-europe.org/Dementia/Alzheimer-s-disease (27.08.2015).

52 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 48

53 World Alzheimer Report 2015 (August 2015), *supra nota 4*

number is likely to be much higher since many people with dementia have not necessarily received a diagnosis. To ensure the effective planning of longterm care and social policy, it is essential to be aware of the present day and future prevalence of dementia,[54] and for legal and medical professionals to understand the condition, its manifestations, and impact on mental capacity and function.[55]

Dementia brings a variety of challenges for patients, their family members, health care providers, as well as lawyers. As stated before, only a person with sufficient capacity can make an advance directive or CPA. From the legal point of view, the primary concern relating to dementia is indeed the capacity.[56] Since dementia progresses gradually, it is sometimes hard to determine patient's decision-making ability, and whether he may draft an advance directive or appoint a proxy. Furthermore, physicians and lawyers may meet philosophical, personal identity problems with dementia patients, which are challenges to the law since physicians must evaluate whether to follow and advance directive or patient's current wishes if they state the opposite.

2.3.1 Competence Assessment

How then to assess the capacity of a demented patient? A common but false assumption is that a patient diagnosed with dementia automatically lacks capacity.[57] Some laws and literature, in general, tend to draw a strict line between capacity and incapacity and forget those demented patients on the borderlines of mental capacity. It is perfectly possible to live with dementia and still retain full capacity.[58] There is no one legal test of capacity since it is issue and time specific.[59] What is also important to note, is that legal capacity is heavily dependent on the complexity of the decision. Different issues, such as making a contract, managing financial affairs, or granting a health care proxy, need to be assessed separately since a person may have a capacity to make one decision but lack the capacity to make another.[60] In the assessment of the capacity to make medical decisions, determining factor is whether the person understands the meaning and consequences of the decision he is about to make. As long as the person is capable

54 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 58
55 Coll, P. (2010), *supra nota 27,* p 385
56 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 411
57 Herring, J. (2009) *supra nota 15,* p 4
58 *Ibid,* p 4
59 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 429
60 *Ibid,* p 429

of making valid decisions, those decisions have to be given priority over the opinion of others. A diagnosis of dementia does not prevent the patient from giving the informed consent.[61]

In health care decision-making it is essential to find a fair and right balance between self-determination and protection from harm. The right to self-determination should be followed as long as possible and hurt as little as possible, but to prevent something harmful from happening, sometimes it is necessary to protect the person even though he would not want a certain act to be carried out. Conflict with dementia patients is whether to let them make irrational decisions and take risks or to protect them from making possibly harmful decisions. Dementia patient's capacity is not an all-or-nothing issue, and it calls for a well thought-trough consideration.[62] In most countries, it is a physician who makes the decision about the patient's capacity. The Council of Europe's Guide has listed important aspects to take into account in the assessment of the person's ability to make decisions regarding medical treatment, which is the following:

- ability to understand essential information about the diagnosis and the related treatment and be capable of showing that they understand;
- ability to appraise the situation in which they find themselves, recognize the problem and evaluate the consequences of treatment in their own situation in relation to their own scale of values or view of things;
- ability to reason and compare options proposed and weigh up their risks and benefits (this skill depends on the ability to assimilate, analyze, and handle information rationally); and
- ability to state a choice, and express and substantiate it.[63]

2.3.2 Past versus Present Interests

Although in many cases the proposed treatment is in the best interests of the patient who also gives his consent to it, and there is nothing else in an advance directive or his past which would suggest any other treatment be given, some cases are not as simple as there might be a conflict between dementia patient's past wishes as expressed in an advance directive and their present, actual feelings and interests at that very moment. The much-debated question is whether to think a person as a demented person or a person who has become demented.[64] When the physician

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61 Coll, P. (2010), *supra nota 27,* p 379

62 Goffin, T. (2012), *supra nota 5,* p 130

63 Council of Europe. Guide on the decision-making process regarding medical treatment in end-of-life situations, 2014, pp 16-17

64 Herring, J. (2009) *supra nota 15*, p 17

complies with an advance directive of an incompetent dementia patient, is it the exercise of self-determination or perhaps illegal imposition of one person's autonomous choice on another person?

Ronald Dworkin makes a distinction between experiential and critical interests. Experiential interests are the current interests acquired as a demented person, while critical interests are acquired in the past going to the core of the person. Dworkin argues that critical interests are more important to autonomy because these things are at the heart of the person's plans for his life. According to his view, they critical interests should prevail experiential ones because the incompetent person lacks the necessary capacity for a fresh exercise of autonomy, and thus advance directives should be followed.[65] Contrarily, Rebecca Dresser argues that most important is to protect those who have lost the capacity and promote their best interests instead of things that they would have wanted earlier. The creator of an advance directive refusing treatment may be unaware of the threat to his future welfare if the directive is implemented. Even if the creator assessed his welfare interests in advance, the problem remains as the individual's previous assessment of his future welfare may be flawed. People may be mistaken about their future experiential interests as incompetent individuals.[66] Both Dworkin and Dresser's approaches are quite extreme. The division between critical and experiential interests is not necessarily possible as it is hard to determine at what point does a person's enjoyment becomes a critical interest.

Convinced by the compromise views, the solution should be the approach that the incompetent person is in some sense the same person as before and in other a different person. In some circumstances, current desires should be given greater weight than the prior wishes expressed before becoming incompetent. Dworkin's approach can be said to better apply in the context of life or death issues, while Dresser's approach outside that area. A demented patient should be allowed to perform activities he enjoys at present even though he would have refused them before if they do not cause any harm to him, but in case of a life prolonging treatment, which does not predict any recovery, it should not be carried out if refused before. Thus, an advance directive should be followed as long as the result will not cause serious harm, pain or terror to the patient.[67]

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65 *Ibid,* p 17-18
66 *Ibid*, p 21
67 *Ibid,* pp 22-23

3. Regulation of Protective Measures

3.1 European Level

While the debate about the scope, strengths, and shortcomings of advance health care decisions started over thirty years ago in the United States, it is still relatively recent in most European countries.[68] This topic is increasingly important for three reasons. First, because of the growing value attached to patient autonomy in health care decision-making, congruent with the rejection of the medical paternalism that dominated the doctor-patient relationship until the 1970's, second, the dramatic increase in the number of elderly and consequently dementia diagnoses, and third, extraordinary progression in clinical treatment and in life-sustaining technologies, which may allow physical survival for years, but may no longer be of real benefit for the patient.[69]

The Council of Europe (CoE), consisting of 47 European countries, is beyond doubt the most influential intergovernmental organization in the development of common European standards regarding patient autonomy. It was established after the Second World War to promote respect for and human rights and democratic values across Europe. The European Convention on Human Rights was adopted in 1950 to achieve this goal. Later, the CoE aimed to extend human rights law into the biomedical field and adopted the Convention on Human Rights and Biomedicine (Biomedicine Convention), which opened for signature in Oviedo on 4 April 1997.[70] In the following subsections, the author introduces these documents among others recognizing protective measures and the patient autonomy. Also, the author reviews the case law of the European Court of Human Rights since it can be seen as a crucial source for describing the legal status of advance directives in Europe.

3.1.1 The European Convention on Human Rights

The ECHR does not contain a direct provision concerning the right to self-determination nor advance directives. However, Article 8 of the ECHR is of high importance as it provides the right to respect for private and family life, home, and correspondence.[71] This right shall not be interfered by a public authority except when it is in accordance with the law and necessary in a

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68 Negri, S. (2012), *supra nota 46,* p 75

69 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 207

70 Negri, S. (2012) *supra nota 46,* p 74

71 Council of Europe. Convention for the Protection of Human Rights and Fundamental Freedoms (1950), Article 8

democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others. According to Article 5, "everyone has the right to liberty and security of person, and no one shall be deprived of his liberty save in the cases stated in the Article."[72]

Even though the right to self-determination is not included in the ECHR as such, it is regarded as a fundamental right, which forms a basis for several human rights. The European Court of Human Rights has affirmed the importance of these two provisions regardless the capacity.[73] The freedom of bodily integrity and movement must be protected even if the person's capacity to understand this is restricted.[74]

3.1.2 The European Convention on Human Rights and Biomedicine

The purpose of the Biomedicine Convention is to safeguard respect for human dignity and human rights regarding the applications of biology and medicine.[75] It contains several patient rights such as the right to information, to informed consent, and to privacy and is therefore also called patient rights convention.[76]

Article 5 of the Biomedicine Convention lays down the general rule by stating that " intervention in the health field may only be carried out after the person concerned has given free and informed consent to it." [77] It requires that people shall in advance be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks, and this consent may freely be withdrawn at any time. Article 6 protects adults who are not able to consent by stating that in such a situation the intervention may only be carried out with the authorisation of an incompetent adult's representative or an authority or a person or body provided by law, and that the individual concerned shall as far as possible take part in the authorisation procedure.[78] The authorisation may be withdrawn at any time in the best interests of the individual concerned. Article 9, in turn, is of high importance as it marks the first and only

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[72] *Ibid,* Article 5

[73] Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 416

[74] Herring, J. (2009), *supra nota 15,* p 15

[75] Negri, S. (2012), *supra nota 46,* p 77

[76] Goffin, T. (2012), *supra nota 5,* p 130

[77] Council of Europe. Convention fo the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Oviedo (1997), Article 5

[78] *Ibid,* Article 6

legal framework of the value of advance directives in a common European binding instrument.[79] According to it, ”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 wishes shall be taken into account”. However, European countries are not obliged under this Article to give legally binding force to advance directives, but at least recognize their advisory value.[80]

The Explanatory Report to the Biomedicine Convention gives a bit more information about the Articles by opening up the meaning of them. In the light of Article 6, the report opens up the assessment of capacity and best interest criteria. The incapacity to consent must be understood in the context of a given intervention. The report reminds about the diverse legal systems in Europe. It states that countries differ in that sense that in some of them ”the patient's capacity to consent must be verified for each intervention taken individually, while in others the system is based on the institution of legal incapacitation, whereby a person may be declared incapable of consenting to one or several types of act” and ”since the purpose of the Biomedicine Convention is not to introduce a single system for the whole Europe but to ensure the protection of those people who are not able to give their consent, it is for domestic law in each country to determine whether or not persons are capable of consenting to an intervention and taking account of the need to deprive persons of their capacity for autonomy only where it is necessary for their best interest.” [81] It is essential that the decision of a patient's incapacity to make decisions is not made too easily. Authorities should let the patient decide as far as possible, perhaps helped by the physician and the health care proxy, and thus to strike the right and fair balance in the capacity assessment. Advance directives and CPAs help to extend this period when the patient is able to participate. When an adult has lost the capacity, a health care proxy must follow the best interest criteria, which states that the patient must benefit from the intervention, the physician, and the health care proxy must involve the patient as far as possible, and the decision of the health care proxy can be overruled if not in the patient's best interest.

In regard to the Article 9, the report explains that it covers situations where individuals have foreseen that they might lack the capacity to give their valid consent, for instance in the case of dementia. It also remarks that taking previously expressed wishes into account does not stipulate that they must be followed. Not following them may happen in situations where the wishes were

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79 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 210

80 Negri, S. (2012), *supra nota 46,* p 76

81 Explanatory Report to 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. Oviedo 04.04.1997, Article 6, paragraph 42

expressed a long time ago, and science has since advanced a lot. The physician should as far as possible follow the wishes of the patient and keep them valid, but take into account particularly technical progress in medicine.[82]

3.1.3 Recommendations No. R (99)4 and CM/Rec(2009)11

Recommendation (99)4 of the Committee of Ministers to the Member States on principles concerning the legal protection of incapable adults included the basics of the new trend of European guardianship for elderly.[83] The key principles presented in the Recommendation aimed to give a new perspective for drafting more specific and protective provisions of this branch of the law. Among other things, recommendation suggested that the advantage and welfare of the principal play the crucial role in the establishment or implementation of a measure of protection.

According to the principle of necessity, no measure of protection should be established unless it is necessary. The legal capacity of a person must retain as wide as possible and must be restricted only to that extent which is necessary to protect the person. Subsidiarity can be regarded as a sub-principle of the principle of necessity, which means that the guardianship should not be an option when the affairs can be reliable looked after by the person's family or other close ones.[84] The principle or proportionality implies that the protective measures should be determined flexibly and tailored to the individual need of a specific situation, rather than being general protection. This is also known as the principle of the least restrictive alternative, meaning that the measure should restrict the legal capacity, right and freedoms of the person in question as little as possible to achieve the purpose of intervention.[85]

Recommendation (2009)11 of the Committee of Ministers to the Member States on principles concerning continuing powers of attorney and advance directives for incapacity build further on Biomedicine Convention and Recommendation (99)4, which continues to be of great relevance and remains entirely up-to-date. Recommendation (2009)11 suggested mainly that governments of Member States should promote self-determination for capable adults by introducing legislation on continuing powers of attorney and advance directives or by amending existing law and implementing the principles stated in the recommendation covering the content, form, appointment, termination, role and supervision of attorney, as well as the content, form, effect

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[82] *Ibid,* Article 9, paragraph 62

[83] Council of Europe Committee of Ministers. Recommendation No. R (99) 4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults. 23.2.1999.

[84] *Ibid*, Principle 5

[85] *Ibid,* Principle 6

and revocation of advance directives.[86] It also stipulates that "States should decide to what extent advance directives should have binding effect" and points out that "advance directives which do not have a binding effect should be treated as statements if wishes to be given due respect".[87] The scope of the recommendation includes much more than health care as it also states that advance directives should cover welfare and personal matters as well as economic and financial ones, and an appointment of a guardian.

3.1.4 Draft Resolution and Recommendation on Protecting Human Rights and Dignity by Taking Previously Expressed Wishes of Patients into Account

In 2012, the Social, Health and Family Affairs Committee of the Parliamentary Assembly of the Council of Europe accepted a draft resolution and recommendation which refers to the European Convention on Human Rights and Biomedicine and Recommendation (2009)11 on principles concerning advance directives and CPAs. To conclude the aim of the draft resolution and recommendation, the target was to get the Member States sign, ratify and fully implement the Convention on Human Rights and Biomedicine, apply Recommendation (2009)11 and review, if necessary, their relevant legislation with a view to possibly improving it.[88]

It considers that rapid progress made in this area is essential to ensure that people's human rights and dignity are guaranteed across the whole continent. Thus, all Member States should put in place and implement legislation in this field based on the Council of Europe *acquis* and principles outlined in the draft resolution.[89] According to the Principle 6.1, self-determination for capable adults in the event of their future incapacity, using advance directives, living wills, and CPAs, should be promoted and given priority over other measures of protection.[90]

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86 Council of Europe Committee of Ministers. Recommendation CM/Rec(2009)11 of the Committee of Ministers to Member States on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity. 9.12.2009.

87 *Ibid,* Principle 15

88 Council of Europe Parliamentary Assembly, Social, Health and Family Affairs Committee (2011), *supra nota 6,* p 2

89 Goffin, T. (2012), *supra nota 5,* p 132

90 Council of Europe Parliamentary Assembly, Social, Health and Family Affairs Committee (2011), *supra nota 6*, p 2

3.1.5 Charter of Fundamental Rights of the EU

Since the Lisbon Treaty came into force on 1 January 2009, the Charter of Fundamental Rights of the EU became a legally binding document even though its legal status remains still rather limited. A basis for advance directives can be found in Article 3 and 25, even though the Charter does not regulate them directly. Article 3 aims to protect the right to physical and mental integrity of the person in the fields of medicine and biology and consequently the right to free and informed consent,[91] while Article 25 protects the rights of the elderly to lead o life of dignity and independence and to participate in social and cultural life.[92]

3.1.6 The Implementation Report on the Commission Communication

In addition to previously mentioned documents, the following Commission Communication and its Implementation Report are worth mentioning. Although they have no legal effect, they are relevant in that sense that they pointed out important facts and achieved significant effort on EU level regarding dementia patients' health care. The Commission presented its Communication on a European initiative on Alzheimer's disease and other dementias in July 2009, according to which, Alzheimer's disease remains under-diagnosed in the EU. At that time, the available epidemiological data showed that only half of those people who suffer from the disease were identified.[93] To summarize the overall target of the Communication, the goal was to "set out actions providing support to the Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for Alzheimer's disease and other dementias in Europe".[94] The strategy included four main objectives in which the EU and Member State should take more action and cooperation. It suggested that early diagnosis could guarantee interventions at the time when they are most effective. The awareness of the importance of acting early and people's possibility to help to prevent dementia needs to be raised. The reason for the lack of awareness is a low level of understanding of dementias. To fix this issue, there should be more information available by offering sufficient epidemiological knowledge and coordination research about such common, widespread diseases. As potential practices concerning diagnosis, treatment, and financing of therapies occur in some EU countries, they

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91 European Union. The EU Charter of Fundamental Rights, 2000/C 364/5, 18.12.2000, Article 3

92 *Ibid,* Article 25

93 Europen Commission. Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias. Brussels, 22.7.2009, p 3

94 *Ibid,* 3

should be promoted and shared for the care of people suffering dementia throughout the Union. Finally, more attention should be paid to rights of people who suffer from a cognitive deficit.[95]

In 2014, the Implementation Report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias responded to the Commission's announcement by presenting the key activities that have taken place since 2009 and summarizing their main achievements. Most importantly, the Joint Action Alzheimer Cooperative Valuation in Europe (Joint Action ALCOVE), co-financed by the EU Health Programme 2008-2013 and the participating Member States, has raised existing information on dementia and promoted the exchange of it, in order to protect the health, quality of life, autonomy, and dignity of people living with dementia and their caregivers in EU Member States, through various actions, such as findings, recommendations and toolkits which provide concrete guidance for future actions in the field of dementia at EU Member States level. In 2009, when EU initiative was adopted, France was the only one who had a national plan on dementia while currently there are seven, including Finland and the United Kingdom.[96]

3.1.7 The European Court of Human Rights Case Law

The case law of the ECtHR forms a crucial source for describing the legal status of advance directives. Few of them will be briefly introduced in this subsection to understand the real life examples, which call for the need of advance directives.

In 2002 in the assisted suicide case of *Pretty v. the United Kingdom,* the European Court of Human Rights stated as the first case well-known case that the right to respect for one's private and family life in Article 8(1) includes a right to self-determination.[97] According to the Court, "... it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with lingering life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advance physical or mental decrepitude which conflict with strongly held ideas of self and personal identity."[98] ECtHR made a distinction between the right to autonomy and the right to privacy and stated that based on the

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[95] *Ibid,* pp 4-8

[96] Implementation Report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias. Brussels, 16.10.2014.

[97] Lewis, P. (2006), *supra nota 24,* pp 231-232

[98] ECtHR 29.04.2002, 2346/02, *Pretty v. United Kingdom*

ECHR in general and though the concept of human dignity, a right to autonomy could be deduced from the ECHR.[99]

X v. Finland concerned the continuation of the involuntary psychiatric confinement and medication. Plaintiff X was a criminal patient who has not been arrested due to her mental capabilities and after that set under involuntary treatment. X complained that her right to liberty had been breached as a result of her involuntary and unlawful confinement to a mental hospital against the Article 5. Relying on Article 8, X complained about having been forcibly injected with drugs, which interfered her physical integrity. The ECtHR held that there had been indeed a violation of these Articles.[100]

In 2010 *Jehovah's Witnesses of Moscow and Others v. Russia* offered more recent approach. The legal recognition of an entity of Jehovah's Witnesses was refused because they provoked their members to refuse lifesaving blood transfusions. The Court held that the decision to refuse the legal recognition was against the individual's right to autonomy by stating that "the very essence of the Convention is respect for human dignity and human freedom and the notions of self-determination and personal autonomy are important principles underlying the interpretation of its guarantees... The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy."[101]

Furthermore, the ECtHR made a concrete consideration about advance directives. Jehovah's Witnesses carry a "No Blood" Card with them, according to which, they do not want a blood transfusion under any circumstances. The Card can be considered as an advance directive, and therefore the ECtHR stated that "designed as an advance medical directive, the care merely certified the choice that the patient had already made for himself, namely, to refuse any transfusion of blood or its components. It did not delegate the right to make any other medical decision to anyone else, but designated the patient's legal representative who could ensure, in the case of the patient's unconsciousness or inability to communicate, that his choice of medical treatment is known to, and respected by, the medical personnel".[102] Hence, the ECtHR stated that advance directives should be legally binding as far as possible, and a health care proxy who is

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[99] Goffin, T. (2012), *supra nota 5,* p 133
[100] ECHR 03.07.2012, 34806/04, *X v. Finland,* p 1
[101] Goffin, T. (2012), *supra nota 5,* pp 133-134
[102] *Ibid,* pp 134-135

faced with an advance directive has to follow the directive and make decisions based on the substituted judgment, not in the best interests of the patient or any other basis.[103]

Berkovd v. Slovakia of 24 March 2009 and *Shtukaturov v. Russia* of 4 March 2010 emphasized the importance of a balanced and case-by-case decided competence assessment. Although neither case affects the medical-legal field as such, in both of the cases, the Court stated that "it is vital that the Member States do not jump too quickly to conclusions and declare a person incompetent."[104] Again, the role of advance directives as an instrument as advance guidelines was emphasized as an important part of the competence assessment.[105]

In 2015, the ECtHR lodged its judgment in the case of *Lambert v. France* concerning end-of-life decision-making on behalf of the persistently incompetent patient, who was in vegetative state and had to be artificially fed and hydrated through a gastric tube. The controversy arose when some of the patient's relatives wanted him to be kept fed and hydrated, while other relatives and the physician wanted the nutrition and hydration to be terminated, which would eventually result in the patient's death. Court held that the procedure established in France for terminating the medical treatment of persistently unconscious and incompetent patients does not violate Article 2 and Article 8 the ECHR. At the same time, the ECtHR emphasized that the case was not about euthanasia or assisted suicide, which involves the intentional termination of human life, so it does not approve those practices under the ECHR. To conclude, the ECtHR made a careful, but a very important step towards recognizing the protection of individual autonomy in end-of-life decision-making. If the state establishes the protection and appropriate safeguards around it, this does not constitute a violation of the ECHR.[106]

3.2 National Level

According to one of the pioneer studies of the legal status of advance directives,[107] countries can be divided into four groups:

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[103] *Ibid,* p 135

[104] *Ibid,* p 134

[105] *Ibid,* p 134

[106] From Therapeutic Abstention to the Right to Die? The Case of Lambert and Others v. France: https://strasbourgobservers.com/2015/07/06/from-therapeutic-abstention-to-the-right-to-die-the-case-of-lambert-and-others-v-france/ (06.07.2015)

[107] Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* pp 212-213

- countries having passed specific laws *prima facie* binding (the UK, Germany, Austria, Belgium, the Netherlands, Spain, Portugal, Estonia, Finland, Hungary, Georgia);
- countries having passed specific laws but assigning a merely advisory value (Denmark (binding in certain circumstances, advisory in others));
- countries with no specific legislation but immediate plans (Italy, Switzerland, Luxembourg, Ireland, Slovenia, Malta); and
- countries with no legislation nor any concrete plans (Norway, Greece, Serbia, Slovakia, Bulgaria, Lithuania, Turkey, Czech Republic, Poland)

The list includes the European countries from which there is information regarding advance directives and CPAs available, and is drafted according to as timely information as has been found. For a more detailed overview in the following subsections, legislation of three countries with strong legal status on advance directives will be brought up to present concrete and advanced, but slightly different examples how advance directives are put into practice (as it would be useless to go deeper in countries lacking specific legislation).

3.2.1 The United Kingdom

In English and Welsh law, respect for patient autonomy is a dominant principle as the right to self-determination is seen as a fundamental right.[108] Patient's ability to consent to treatment must be assessed each time treatment is necessary, and physicians have a common law duty to give treatment to an incapacitated person if this would improve or prevent a deterioration of the patient's health, providing that it is clear that it is in the patient's best interests.[109] In 2007, the major piece of legislation, the Mental Capacity Act 2005, entered into force providing best practices and common law principles concerning people who lack mental capacity and those who make decisions on their behalf. Lord Filkin stated that the aim of MCA was to maximize the capacity of those who lack the capacity to make certain decisions for themselves, prevent abuse and neglect, and guide families, informal carers, and professionals.[110]

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[108] Horn, R. "Why Should I Question a Patient's Wish?" A Comparative Study on Physicians' Perspectives on Their Duties to Respect Advance Directives. European Journal of Health Law 2016, p 5

[109] 2016: Decision making and legal capacity in dementia: United Kingdom (England). http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/United-Kingdom-England (09.02.2017)

[110] The Joint Committee on the Draft Mental Incapacity Bill Vol 1 HL Paper 189-I HV 1083-I. Authority of the House of Lords and the House of Commons London 2003, paragraph 34

Under the MCA, as at common law, capacity is determined on a functional and task-specific basis.[111] The Act provides clear guidelines for determining capacity as Section 2(1)[112] provides a decision specific test, which is not based solely on having a particular medical condition or diagnosis and Section 3(1)[113] sets out the criteria whether a person is unable to make a decision. According to it, a person is unable to make a decision if he in unable to understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision, or communicate his decision.

Advance directives have a strong legal status in the UK since the MCA came into force in 2007 allowing every competent adult to make advance decisions related to medical treatment.[114] Advance directives must be clear, unambiguous and relevant so that physicians can comply with them. It is physician's legal and ethical obligation to act in the best interests of the patient, which, among clinical factors, requires past and present wishes of the patient to be taken into consideration. According to the law, advance refusal is considered legally binding if it applies the situation that has arisen and was issued voluntarily by over 18-year-old person who had sufficient capacity to do it.[115] On the contrary, advance requests for treatment are not binding, but they may help physicians to determine what is in the best interests of the patient. An advance directive can cover treatment of medical and psychiatric conditions, care and welfare decisions, life-supporting and –saving treatment, the appointment of a health care proxy, and research. The refusal can cover artificial nutrition and hydration but not basic or essential care, such as warmth, shelter, hygiene measures and offer of oral food and drink. Also, euthanasia and assisted suicide are illegal in the UK.[116] Advance directives can be either written or oral form, and no registration process is required, except in a case of refusal of life-sustaining treatment which must be in writing, witnessed and signed, and include an explicit, signed statement indicating that the refusal applies even if life is at risk.[117] They can be amended or canceled at any time when the person has the capacity to do so, and they do not need to be in writing.[118]

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111 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 420
112 Mental Capacity Act (2005), Section 2 §1
113 *Ibid,* Section 3 §1
114 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 213
115 MCA (2005), *supra nota 112,* Section 24 §1
116 2016: Decision making and legal capacity in dementia: United Kingdom (England), *supra nota 108*
117 MCA (2005), *supra nota 112,* Section 25 §5
118 *Ibid,* Section 24 §4-5

The MCA also introduced a welfare lasting power of attorney (LPA), under which a mentally capable adult, a doner, may confer on one or more donee the authority to make health care decisions in circumstances where the doner no longer has the capacity.[119] The donee is a trusted and willing person who has reached the age of 18 and is.[120] In the case of more than one donee, it must be stated in the document whether they act jointly, jointly and severally, or jointly in respect of some matters and jointly and severally in respect of others.[121] Donees may not appoint substitutes but the donor may put it into the document that in the case of death, bankruptcy, rupture of a marriage or civil partnership or incapacity, some other person shall replace the previous donee.[122] The authority is created by an instrument made and registered with the Public Guardian in compliance with sections 9 or 10 or Schedule 1 of the MCA.[123]

When there is doubt concerning an advance directive or person has not expressed his will, the MCA provides the best interest standard, which most importantly requires that in determining what is in a person's best interests, the person making the determination:

- must not make it merely on the basis of the person's age, appearance, a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests;
- must, so far as reasonably practicable, permit and encourage the person to participate, or improve his ability to participate, as fully as possible in any act done for him and any decision affecting him;
- must consider, so far as is reasonably ascertainable, the person's past and present wishes, feelings, beliefs and values that would be likely to influence his decisions if he had the capacity, and the other factors that he would be likely to consider if he were able to do so;
- and take into account, if it is practicable and appropriate to consult them, the views of any other person who could contribute as to what would be in the person's best interests and, in particular, as to the matters mentioned above in the previous section.[124]

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[119] Samanta J. Lasting Power of Attorneys for Healthcare undet Mental Capacity Act 2005: Enchanced Prospective Self-Determination for Future Incapacity or a Simulacrum? Medical Law Review 2009, p 378

[120] MCA (2005), *supra nota 112,* Section10 §1

[121] *Ibid,* Section 10 §4

[122] *Ibid,* Section 10 §8

[123] *Ibid,* Section 9 §2-3

[124] *Ibid*, Section 4

3.2.2 Spain

Nowadays, ethical and legal recognition of patient autonomy and rights is reality also in Spain. However, despite the fact that Spain is probably the most prolific producer of legislation concerning advance directives, the medical paternalism has roots deep in its history and continues to flourish even today.[125]

In Spain, everyone is presumed to have capacity unless shown otherwise using a legal procedure and declared by a court. Causes for incapacitation include those illnesses or permanent deficiencies of a physical or psychiatric nature, which prevent the person from managing his affairs. Anyone can commence an incompetence proceeding by informing the Department of Public Prosecutions. Alternatively, the person with presumed incompetency, first or second degree relatives, the authorities or public officers must inform the Department of Public Prosecutions if they are aware of any grounds for incompetence.[126]

The Law 41/2002 for the Regulation of Patient Autonomy, Rights and Obligations with Regards to Medical Information and Documentation, which entered into force on 16 May 2003,[127] provides a legal framework for advance directives on the entire Spanish territory.[128] This State law takes priority over the regulations of all the 17 Autonomous Regions in Spain, and they must abide by its stipulations.[129] The law follows all the principles of the Convention on Human Rights and Biomedicine.[130] Article 11 forms the basic and common regulation of advance directives by providing that health care services must establish adequate procedures to guarantee that the previous instructions are complied with.

Advance directives have a broad legal content. First of all, they cover treatments refusals and consents including the withholding and withdrawal of life-sustaining treatments, a decision on palliative treatment, sedation, comfort and other measures. The designation of a health care proxy can be included in an advance directive. The proxy should be a trustworthy person who is aware of the values and wishes of the patient, and he is appointed to act together with health care

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125 Simon-Lorda, P., Tamayo-Velázquez, M-I., Barrio-Cantalejo, I-M. Advance Directives in Spain. Perspectives from a Medical Bioethicist Approach. Bioethics, Volume 22, Number 6, 2008, p 346

126 2016: Decision making and legal capacity in dementia: Spain. http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/Spain (09.02.2017)

127 Ley 41/2002, se 14 noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de informacíon y documentacíon clínica 15.11.2002.

128 Veshi, D., Neitzke, G. (2015), *supra nota 35,* p 336

129 Simon-Lorda, P., Tamayo-Velázquez, M-I., Barrio-Cantalejo, I-M. (2008), *supra nota 125,* p 349

130 Veshi, D., Neitzke, G. (2015), *supra nota 35,* p 336

professionals as an interlocutor. The so-called "values history" including personal values, preferences, objectives and life-prospects is desirable to state in an advance directive and communicate to the physician, family and other close ones for better interpretation of patient's wishes. Additionally, a patient can state whether he wants to donate his body for research, training future health care professionals, or use of a reproductive material. An advance directive can be used to prevent the deceased patient's biological samples from being obtained and analyzed after his death.[131]

Section 3 restricts the patient autonomy as it states three limits for applying advance directives. According to it, "advance directives which are contrary to the norms of the legal order or the *lex artis* (good medical practices) shall not be applied nor those, which do not correspond with the previous statement of the interested party at the time of issuing them." A reasoned record of the notes related to these considerations must be included in the patient's clinical history.[132] Some Autonomous Regions has introduced two additional limits: professional or medical ethics and conscientious objection.[133]

Requirements for drafting an advance directive are the same as in the UK and Germany: a person must be of full age, free from pressure, and have the necessary capacity to do it. Additionally, advance directives must always be in a written form. They must be issued before a notary or before three fully competent, over 18 years old witnesses, from which at least two cannot be on the second level of lineal consanguinity of affinity nor be linked by patrimonial relations. Some regions have added a third issuing procedure before the civil servant or member of the Registry of advance directives or the corresponding Administration. The special feature in Spanish law, the creation of a National Registry and Autonomous Communities' Registries for advance directives, guarantees the nationwide efficacy of these documents by following its functioning principles: coordination, interconnection, security and confidentiality.[134]

When all the aforementioned requirements are met, an advance directive can be considered as valid, and it enters into force at the time the patient becomes incompetent. Until then, current wishes of the patient prevail. The law does not demand renewal or ratification of advance directives, and they can be revoked at any time provided that the person has the necessary

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131 Seoane JA. Advance care planning in Spain. A short national report. Part II. Department of Philosophy of Law, School of Law, University of A Coruña, Spain. Prog Health Sci Vol 5 No 1 2015, p 170

132 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 215

133 Seoane JA. (2015), *supra nota 131,* p 170

134 *Ibid,* p 170

capacity to do so, and this must be done in writing.[135] Health care professionals have a *prima facie*, not "all things considered" duty to comply with the content of advance directives. Like legal field, medical field requires prudential reasoning which leads to the respect of the patient's autonomy but not to the blind or unconditional obedience of every autonomous decision. Since future situations are humanly impossible to accurately and completely forecast, they need to be interpreted by the health care professionals with the help of values history and health care proxy.[136]

Two types of power of attorney are highlighted in Spanish Civil Code. First one takes effect when incapacity occurs and second immediately even in the case of competence. The doner must be competent at the time of the appointment. The donee's tasks may vary from patrimonial matters to personal ones. [137]

3.2.3 Germany

The right to make medical decisions in advance for the future incapacity is recognized by the German jurisprudence and by legal scholars as an expression of the right to self-determination regarding one's body which can be derived from various provisions of the Constitution.[138] The Professional Rules fo German doctoral state that in all medical treatment, human dignity must be ensured and the personality, will, and rights of the patients, in particular, the right to self-determination must be respected, and to provide treatment, a doctor requires the consent of the patient. Whether a person is capable of consent is not based on legal criteria but rather on whether a person can understand the consequences of an intervention or treatment for his body, profession, and private life.[139]

Germany has followed many of its neighbor countries and introduced a new law on advance directives in 2009.[140] The law is integrated into Book 4 of the German Civil Code. An advance directive can cover medical investigations, treatment, and medical interventions. It has to refer to specific treatment or situation and cannot include anything illegal, such as assisted suicide. A person of full age and able to consent may authorize a written advance directive for the event of

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135 2016: Decision making and legal capacity in dementia: Spain, *supra nota 126*

136 Seoane JA. (2015), *supra nota 131,* p 172

137 *Ibid,* p 173

138 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 218

139 2016: Decision making and legal capacity in dementia: Germany. http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/Spain (08.02.2017)

140 Drittes Gesetz zur Änderung des Betreuungsrechts (2009)

future incompetence, and it can be revoked at any time.[141] The law states that only written advance directives signed by hand are valid, but it still grants legal value also for oral statements. In determining patient's will, an oral statement is recognized either as an expression of preferred treatment, when referring directly to a specific treatment in question or as a clear sign of the presumed will of the patient.[142] There is no registration procedure nor any time limit for advance directives. The law does not state that a person must have full capacity to do that. The binding directive must be respected in any decision concerning medical treatment, regardless of the nature and stage of any illness.[143]

In the absence of advance directive, the treatment preferences or the patient's presumed will must be determined based on concrete evidence, such as previous oral or written statements, ethical or religious convictions and know personal values.[144] The procedure must be carried out, irrespective of the stage or type of illness, through communication between the physician and the patient's surrogate, whereas the physician has to determine the medical indication in advance.[145] Approval by the adult guardianship court is not necessary if the physician and the surrogate agree on the patient's will in a concrete situation.[146]

3.2.4 Comparative Analysis

This comparative overview analyzes the findings within the national level, to be more specific, the similarities and differences as well as the advances and problems concerning the regulation of protective measures in the UK, Spain, and Germany.

What can be stated at first, Spain has the most paternalistic approach and Germany the most liberal one, while the UK has achieved a golden mean between these two. The UK has implemented a separate law for those who lack capacity, and those who make the decision on behalf of them, while Spain has regulated advance directives by one Article and Germany has integrated its law concerning advance directives into Civil Code. All national parliaments of these countries have recognized the patients' right to self-determination.[147] In the UK and

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141 German Civil Code BGB §1901a.1

142 Wiesing, U., Jox, R., Heibler, H-J., Borasio, G. A new law on advance directives in Germany. Journal of Medical Ethics Vol 36, No. 12 2010, p 780

143 German Civil Code BGB (1896), §1901a.3

144 *Ibid,* §1901a.2

145 *Ibid,* §1901b

146 *Ibid,* §1904

147 Veshi, D., Neitzke, G. (2015), *supra nota 35,* p 330

Germany, patient autonomy is considered fundamental. In the UK, it is protected by supporting those who lack capacity and in Germany rather by highlighting the patient's right to self-determination. Even though Spain has recognized patient autonomy, a physician's opinion is often of higher importance.[148] All of these countries also established the significance of a health care proxy as a surrogate decision-maker although the terms and duties of them vary to some extent. The general rule is that every legally competent adult can be nominated. In the absence of a health care proxy, the UK supports best interests test, while in Germany a presumed will of the patient prevails.

The UK has used the laws of other English-speaking countries as a model when drafting the MCA of 2005, which was also adopted by the Welsh Parliament in 2007. Scotland has the Adult Incapacity Act of 2000 and Ireland the Assisted Decision-Making (Capacity) Bill 2013 both of which share the same principles as the MCA. One study has shown that English physicians were not afraid to discuss diagnosis and prognosis with patients and emphasized the importance of open communication. On the other hand, they hesitated to discuss explicitly advance directives, which results in a low implementation of these documents.[149] It has been suggested that more focus should but on discussions with patients rather than on criteria that limit the validity of advance directives.[150] Thus, the physicians' doubts about the credibility of advance directives could be decreased.

One problem related to Spanish law is, first of all, the fact that disparity also continues in the country itself as Regional laws and terminology differ from each other, which confuses the public and tend to hinder attempts to spread the use of advance directives. Moreover, drafting an advance directive is not made as easy as it could be because of the excessive legal impediments.[151] One study showed that in 2008, 43,668 people had filled in and registered an advance directive in Spain, which means approximately 50 people per 100,00 inhabitants.[152] It seems to be, that cultural traditions have not step aside in Spain even today. Death is a taboo and people hesitate to discuss it openly, which is probably derived from the Catholic morality, according to which life belongs to God and should not be limited in any way.[153] Spain has bee suggested to harmonize the national and regional legal norms and correct the ambiguities and

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148 *Ibid,* p 328

149 Horn, R. (2016), *supra nota 108,* p 7

150 *Ibid,* p 15

151 Simon-Lorda, P., Tamayo-Velázquez, M-I., Barrio-Cantalejo, I-M. (2008), *supra nota 125,* p 350

152 *Ibid,* p 351

153 *Ibid,* p 352

vagueness related to terminology. Health care professionals should trust more in law as an improving instrument regarding advance care planning.[154]

In the international context, the German law is very liberal since it does not set many requirements for advance directives to be legally binding. German law does not trust only physicians' decisions but gives the power to medically-neutral persons, which is derived from the past where physicians were criticized for undue paternalism.[155] Nowadays, physicians have a strong duty to comply with the law on advance directives. What is controversial, despite this strong duty, the law does not require physicians explicitly to discuss advance directives with patients. One study has shown that even though the importance of patient-physician communication is acknowledged among German physicians, they do not often start these conversations and consequently do not know whether the patient has written an advance directive or not.[156] However, German appears to be the country with the highest level of awareness of advance directives as 93% of its population is aware of such documents.[157]

Although patient autonomy has been recognized, disadvantages of the implementation of advance directives have also been emphasized in the Romance-speaking countries, such as France, Italy, Spain, and Portugal. The paternalistic and physician-centred approach is usual as the general principle is to safeguard patients. Spain was the first one to regulate advance directives adopting the most precise rules, and at the same time, the most liberal approach. Spanish model was also used as a model for the Portuguese law of 2012. France has directly recognized the advisory power of advance directives for a long time, and the only one that has modified its public health code adopting such a paternalistic approach. However, France adopted a new law in 2016 confirming the binding value of advance directives, and time will show the change.[158] Italy has no specific laws probably because of the most radical approach. All in all, in the family-oriented Mediterranean area, patients' family is typically given more information than patients themselves, and therefore the majority of informal caregivers are relatives of the patient. As Germany, also Austria and Switzerland have integrated norms regarding advance directives in their civil codes. What comes to Northern Europe and the Baltic States, the regulation of advance directives is far from coherent as they recognize totally different levels of protection.

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154 Seoane JA. (2015), *supra nota 130,* p 173
155 Veshi, D., Neitzke, G. (2015), *supra nota 35,* p 345
156 Horn, R. (2016), *supra nota 108,* p 16
157 *Ibid,* p 11
158 *Ibid,* p 16

To conclude this comparative analysis, the legal status of advance directives remains very diverse in the national legislation regardless the consensus and developments on a European level. European countries began to recognize the potential utility of advance directives and to regulate them only during the last decades,[159] and today they have been recognized in the majority of them. Although health is considered a constitutional right throughout Europe, the extent of its protection varies from country to country.[160] These different policies emphasize different values and cultures. However, the more dominant part states that advance directives should be binding.[161] They agree that advance directives, with necessary safeguards, have at least the potential to play a positive role in health care practice, for instance, to prevent futile or disproportionate treatments. The decision power should lie on physician only when there exist reasons strong enough to state that an incompetent patient has changed his opinion.[162] Differences in advance refusals in the European countries concern form and scope rather than the validity of the general principle. The central much-argued question is if an advance directive shall include refusal to life-prolonging treatment or not. For instance, in the UK quite general terms are accepted. Otherwise, a wide consensus has been achieved among European countries regarding the fact that giving medical treatment to a competent adult is unlawful if this person has given an effective refusal of consent to that treatment.[163] Written advance directives are strongly encouraged by non-legal organizations, most dominantly Alzheimer Europe,[164] which is the main organization above all national Alzheimer's patient organizations.

159 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 212

160 Veshi, D., Neitzke, G. (2015), *supra nota 35,* p 326

161 Goffin, T. (2012), *supra nota 5,* p 122

162 *Ibid,* p 122

163 *Ibid,* p 125

164 Lötjönen, S. Medical Research on Patients with Dementia – the Role of Advance Directives in European Legal Instruments. European Journal of Health Law 2006, p 241

4. Shortcomings in the Regulation of Protective Measures

4.1 Introduction

Regarding advance health care planning little development have emerged in Europe, which is congruent with the low development of advance directives. The situation can be explained by the disparity between the different countries. Even though advance directives are recognized in many countries, there are significant differences between these legal standards, and also countries without legal standards at all. This chapter gathers together shortcomings that have occurred in the regulation of advance directives and CPAs in Europe.

4.2 Ambiguity of the Biomedicine Convention and Recommendation (2009)11

First, the attention should be paid to the ambiguity of the Biomedicine Convention, which provides the starting point for regulation of advance directives. Despite the significant effort the Convention has achieved, there has been found few shortcomings. To begin with, the Convention has been drafted only in respect of one form of advance directives, a living will, but a possibility to make a CPA has been totally ignored. Secondly, the meaning of the main provision in Article 9 remains quite problematic. According to it, previously expressed wishes "shall be taken into account". This tends to indicate that advance directives should not necessarily have a legal status but at least advisory effect. It has been claimed that this provision is too ambiguous and can be interpreted in very different ways,[165] which appears to be true when looking at the national legislations diversity. A better way to balance the conflicting views of European countries would be drafting more clear guidance as to what extent and under what conditions patients' previously expressed wishes must be complied with. The Article uses term "previously expressed wishes" instead of "advance directives", which can be interpreted as less binding nature of such documents.[166] Furthermore, the pioneer study on advance directives suggests that patient's "wishes" are not enough but a broader terminology should be adopted covering also patient's "goals" and "values."[167]

The Explanatory to the Convention does not serve any solution to the ambiguity of the Article 9 but explicitly states that previously expressed wishes should not necessarily be followed in certain circumstances, such as when the wishes were expressed a long time ago, and science has

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165 Negri, S. (2012), *supra nota 46,* p 78

166 *Ibid*.

167 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 224

since progressed.[168] Of course, this is because of the obligation to protect patients from possible harm, and physicians have to have good reasons not to comply with the previously expressed wishes. The problem itself is that the minimal requirements for the validity of advance directives and legal effect of them have not been stated explicitly in the Article, which leaves it ambiguous and hard to obey in a proper manner. To conclude, controversial is that the Convention has not given the binding effect to written advance directives, but it treats them like documents, which should only be taken into account by the legal and medical representatives in their decision-making.

Recommendation (2009)11 has aimed to fill these gaps. While the Convention mentions advance directives only in their narrow sense, the Recommendation provides CPAs as a separate category. Also, the Recommendation perhaps gives more weight to advance directives as it states that they should be given "due respect". The main target of the Recommendation is explicitly strengthening the principle of self-determination by giving priority to the advance directives and CPAs over other protective measures. The further reason besides strengthening self-determination was the prevention of sometimes costly and burdensome judicial and administrative proceedings.[169] However, the Recommendation has its shortcomings as some overlaps can be detected. First, it does not serve guidance clear enough on what basis the proxies should make the decision. While they are required to act according to the best interests of the patient, they must also take into account as far as possible the wishes and feelings of the patient and given them due respect. In this regard, the MCA provides probably the best model for the best interests test. Among other things, it highlights the fact that the proxy shall not be motivated by a desire to make a decision which brings about patient's death. As it has been suggested, the general principle should that the best interests of the patient always guide the proxy's decision, but when determining the best interests, wishes and feeling of the patient must be taken into account. Second, the double terminology is used regarding advance directives. Principle 2.3 defines advance directives as "instructions given or wishes made by a capable adult". While instructions refer to the legally binding documents, wishes sound only advisory. This ambiguity itself explains the great disparity between the states as it let them decide about the bindingness. Therefore, the aim to fill the gaps in Biomedicine Convention was not successful enough.

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[168] Explanatory Report to the Convention on Human Rights and Biomedicine, paragraph 62

[169] Negri, S. (2012), *supra nota 46,* p 81

4.3 Other Issues

Naturally, ambiguity in international legislation leads to the differences in national legislations. In the absence of common European standards, countries will remain in their positions derived from cultural and historical reasons. Communication training for health care professionals seems to be almost non-existent, which means that patients are not aware of such possibilities as making an advance directive or appointing a health care proxy. These things are routine in none of them, and consequently, a good way promote patient autonomy, reduce the burden from worried family and uncertain health care staff, and avoid costly, often futile medical interventions, and court proceedings, is not utilized as far as it would be possible.

5. Recommendations for Harmonised European Standards Ensuring the Protection of Dementia Patients' Self-Determination in Health care Decision-Making

5.1 Recognizing Legally Binding Effect on Protective Measures

For further solutions for those shortcomings faced in the previous chapter, the author suggests that to better protect patients' right to self-determination in the health care field, each European country should legally recognize advance directives and grant them binding effect, if they have not done it yet. First, countries must sign, ratify and implement the Biomedicine Convention. Next, countries with weak or advisory legal status of advance directives should clarify and amend their legislation to strengthen them. Countries with no specific laws but immediate plans should take actions and put them in place, and countries without any concrete plans should introduce such and start to legislate them. To start with the European level, common standards should be clarified first to get national governments to take actions in this field. What needs to be clarified, is the requirements for the validity of advance directive and the legal effect of it. For instance, Article 9 of the Biomedicine Convention could state the following:

> "The previously expressed wishes and values stated in an advance directive, relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his wishes shall be complied with, save in the following cases:
> a) it is contrary to the law;
> b) it is not applicable to the circumstances and proposed treatment that have arisen;
> c) current, competent wishes state other than previously expressed wishes;
> d) there are sufficient reasons to believe that a patient has changed his opinion regarding the circumstances and proposed treatment that have arisen; or
> e) science has taken significant advancements since the wishes have been expressed."

The time limit for an advance directive to stay valid would not necessarily be needed in case of dementia patients since they may live long after the diagnosis during which medical interventions may occur a lot. The time limit is used in only in few states. A competent person of full age who is not manipulated by others should be able to draft a valid advance directive. The scope of advance directives should be wide and cover refusal and consent to treatment, also concerning life-sustaining and –saving care, requests concerning generall care and preferences, an appointment of a health care proxy, participation in research. Refusal of basic care and

necessary pain relief should not be covered. For advance directive to be valid, it should be clear and unambiguous for best possible future interpretation and prevention of misunderstandings. Furthermore, advance directives should be in clear form free from costs, and easily obtainable for all people of full legal age. For these purposes, the importance of appointing a health care proxy besides the advance directive should be emphasized. The Draft Resolution and Recommendation has already advised the States to carry out many of these recommendations, but not enough has happened since the year of 2011. Convinced by the idea of a new Additional Protocol to the Biomedicine Convention,[170] the clarification about the scope and legal effect of advance directives could be given more weight through such an amendment.

Advance directives may not be only for so-called patients' self-interests, but also a possibility to state a choice to participate research or donate organs or tissue. They can be used as a helpful tool to provide an opportunity to do something constructive to help others with the similar condition and be part of the development of science. To raise awareness and make early diagnosis possible, research about the topic is necessary. The possibility of using advance directives to prospectively to research participation in the event of dementia remains largely unexplored in Europe and unclear in its documents on medical research. As advance directives are achieving greater legal status in health care decision-making, they should do the same in regards to medical research.[171] This is probably because medical research is rarely in the very best interests of the participating individual because of the unknown risks and the trial designs involved, and consent to participation may not be the first think in patient's mind when drafting an advance directive.[172]

5.2 Advance Care Planning Practices

One way to start promoting common standards could also be introducing advance care planning (ACP) practices, which require hospitals and physicians to ask every patient whether they have completed an advance directive or a CPA or both and, if so, to bring a copy to them. If the patient does not have an advance directive but would like more information about these documents, hospitals must also provide the information. To take an example from the Unites States of America, the Congress passed in 1991 the Patient Self-Determination Act, which requires those things exactly. According to it, most hospitals, nursing homes, home health

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170 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 212

171 Lötjönen, S. (2006), *supra nota 164,* p 235

172 *Ibid,* p 257

agencies, health maintenance organizations and other health care institutions are obliged to provide information on advance directives. They, except individual physicians, must at the time of the admission give a written summary of health care decision-making rights and the facility's policies on recognizing advance directives. They are required to ask if a patient already has an advance directive and, if so, to document that fact in the medical record. Moreover, education must be provided for the staff and community about advance directives. Discrimination against patients based on whether or not they have an advance directive is prohibited. It is always up to the patient whether he is willing to have one.[173]At present, all 50 states of the US also have specific laws recognizing the use of advance directives[174] and often provide a model document that may, or in some states must be followed. Another good model is Canadian ACP, which is is a process of reflection and communication enabling patients to reflect their values and wishes and let people know what kind of health and personal care they would want in the future if they were unable to speak for themselves. It may include having discussions and writing down wishes with family, health care providers and financial or legal professionals.[175]

Adopting, for instance, a common code of conduct protecting explicitly the right to self-determination might help to strengthen the legal status of advance directives and CPAs up to the binding one. This code of conduct would include a set of rules requiring, among other things, health care providers routinely to provide a procedure where an advance health care plan would be tailored individually for each patient. Patients should be informed about the existence and scope of advance directives, and the issue should be discussed as soon as possible after the diagnosis since it requires sufficient competence from the patient. ACP should be available also for other people willing to prepare for the future. The optimum time for ACP would be in a period of relative wellness, and it could be a part of a routine care initiated automatically at a certain age threshold.[176] The provisions of this code of conduct should be consistent with applicable European standards on this matter. Furthermore, open discussion where the family or other close ones should also be welcomed may prevent possible conflicts arising between people around the patient. Speaking on the EU level, it could take more action in this regard by

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[173]Law for Older Americans: http://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html

[174] Institute of Biomedcial Ethics University of Zurich. Country Reports on Advance Directives: Lehmann, L. USA. Switzerland 2008, p 103

[175]What Is Advance Care Planning? http://www.advancecareplanning.ca/what-is-advance-care-planning/

[176] Aw, D., Hayhoe, B., Smajdor, A., Bowker, L.K., Conroy, S.P. Advance care planning and the older patient. QJM: An International Journal of Medicine, Volume 105 (3), 2012, p 226

considering an adoption of the directive on ACP for elderly to achieve more significant, binding changes. The directive could similarly require countries to incorporate ACP into their health care systems and promote the creation of a network so that advance directives and the CPAs would be free and immediately available online for everyone. Countries would be obliged to take immediate actions, but the methods to carry them out would be left to them. Member States could also consider national registries for advance directives if they have not done it yet. Few patients are aware of the existence of ACP as a method of documenting wishes in advance for the future loss of capacity even though advance directives and CPAs would be recognized by law in their country. However, when informed about this opportunity, many are eager to make such a plan not just for their benefit but also for their families as they feel that it reduces their burden in the future. ACP enables families and physicians to feel confident that they are acting on explicitly expressed wishes of the patient. It offers a clear assistance for physicians to act correctly and eases especially complex situations related to end-of-life decisions. Also burdensome, futile and unwelcomed intervention can be avoided by using ACP. If the wishes of the patient are unknown, prolongation of life may lead to expensive procedures, which would not even have wanted to receive by the patient.[177]

The importance of written advance directive alongside the nomination of a health care proxy and discussion with health care professionals should be emphasized for the best possible outcome. It is important to note that although it is desirable to appoint also a health care proxy at the same time when drafting an advance directives, it is also perfectly possible to make only a CPA. For this purpose, the best way to guarantee decisions to match the patient's autonomous ones is to appoint someone who deeply knows the values and beliefs embraced by the patient. The most desirable person for this position is likely to be a spouse, child, other family member, relative, or a close friend who has known the patient for a long time. It might sometimes seem that dementia patients do not care what people decide on behalf of them or they do not have any opinion of their own. This is a false assumption in that sense that they should be respected as individuals as they have lived their lives and follow those values and wishes they had back in the day. Dementia is a harsh disease, which does not necessarily reveal these values and preferences anymore even though they still live inside those patients. It is often important for the close relatives to see that their elderly are treated as they have wished and in accordance with their values. It is also essential to take into account that not everyone is willing to make an advance directive or grant a health care proxy. Some people may be okay with that that decisions are

[177] *Ibid,* p 226

made on behalf of them, which should be respected and let them participate the decision-making to the extent they want. Many studies have shown the positive impact of advance care planning on the implementation of advance directives. Furthermore, one research showed that "a coordinated, systematic model of patient centred advance care planning using non-medical advance care planning facilitators assists in identifying and respecting patient's wishes about end of life care, improves such care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives".[178]

5.3 Informal Representative as a Surrogate Decision-Maker

Informal or unofficial representative refers to a person who is not appointed by the court or the patient himself, but who makes health care related decisions on behalf of the patient in case the patient lacks the capacity.[179] Like any other form of representation, informal representation should never deprive the patient of his legal capacity and therefore should be used only in case of real incapacity.[180] However, an informal approach to surrogate decision-making should always go in parallel with sufficient protection of the incompetent patient, including procedural safeguards concerning the decision that the patient is incompetent, limits to the decision-making power of informal representatives and effective forms of conflict resolution. It is a valuable and lawful complement to the main forms of formal surrogate decision-making, court or self-appointed proxies, at least when the law provides for the necessary safeguards.[181] Countries whose laws do not recognize informal representatives besides other forms of protection should consider adopting such provisions. According to the principle of necessity enshrined in the Recommendation R (99), no measure of protection should be established unless it is necessary. When the court considers appointing a legal guardian for a person in the absence of a CPA, more practical and less burdensome and more practical way would be granting only the necessary and situation specific power for an informal representative. This would reduce the burden from societies and enable a person close to the patient to take care of him.

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178 Detering, K., Hancock, A., Reade, M., Silvester, W. BMJ Research: The impact of advance care planning on end of life care in elderly patients: randomised controlled trial 2009. http://www.bmj.com/content/bmj/340/bmj.c1345.full.pdf

179 Gevers, S., Dute, J., Nys, H. Surrogate Decision-making for Incompetent Elderly Patients: The Role of Inromal Representatives. European Journal of Health Law 2012, p 61

180 *Ibid*, p 67

181 *Ibid*, p 68

Conclusion

This thesis has dealt with the right to self-determination as the most remarkable principle regarding patients' health care decision-making. The author has put a special focus on dementia because it is the most widespread disease among aging European population bringing challenges to the exercise of self-determination. Special attention and deliberation are needed when assessing dementia patients' decision-making capacity.

In answer to the first research question, the author has concluded that dementia patients' right to self-determination in health care decision-making is protected by the exercise of free and informed consent and proper, case-by-case competence assessment, where the patient's complex and continuously changing capacity is taken into account. In addition to these, the author has found advance directives and CPAs as great tools to promote the right to self-determination since they enable previously expressed wishes to be documented and followed later on when the capacity is lost. These protective measures provide a good foundation for ensuring the realization of self-determination in health care decision-making for dementia patients, and so on to other people in case of future incompetence. The author suggests that where there is clear evidence available about the values and wishes of the patient, the decisions on behalf of him could be done on the basis of the substituted judgment. Another case, the person making the decision on behalf of the patient should rely on the best interests test. When there is a conflict between a dementia patient's past and present wishes, the present wishes should be complied with as long as they do not cause any serious harm or pain to the patient, so that he may feel autonomous in his present situation. An exception is an end-of-life situation, which is reasonable to carry out as the patient has expressed before.

Based on the studied materials and knowledge gained during this process, the author finds the second research question positive. There is a need for new solutions for harmonized European standards to ensure dementia patients' right to self-determination in health care decision-making because the current legislations regarding protective measures in the European countries are very diverse and not legally binding everywhere. The author has suggested several solutions to this issue. The starting point is to raise the position of protective measures by granting legally binding effect on them and spreading awareness by advance care planning practices. Proper patient-physician communication is a cornerstone of any medical intervention where important, as well as more trivial, decisions are to be made.

The CoE has achieved two important milestones in the promotion of patient's self-determination regarding medical care to be implemented in the event of future decisional capacity: the Biomedicine Convention and the Recommendation (2009)11. The clear statutory basis for legally binding advance directives and especially refusals of treatment would encourage people to take the responsibility of arranging their lives for the future and get physicians to follow them without the need to worry about the consequences they are afraid of. Families can feel more relaxed when they know that their elderly are taken care of in the way they always have wanted and avoid managing futile, expensive treatments, which the patients would not even have wanted to receive. Although many European countries have already recognized legally binding advance directives the use of them remain low. Lack of information and communication between legal and health care professionals and patients is one reason to this. Writing an advance directive or a CPA does not seem to happen routinely. The Draft Resolution and Recommendation in 2011 has already advised the Member States to take actions in this field. However, as time passes and there is still much to do, further actions would be advisable. A common code of conduct on a European level would help national governments to integrate these practices into their health care systems. The law should provide concrete tools to carry out self-determination in health care decision-making and not left it on the shoulders of physicians because, in that case, the actions usually remain minor. Proper communication training required by law could result in further developments.

As many studies on advance directives were made approximately ten years ago, it would be time for a new comprehensive study, which would include legal, medical and ethical professional since these aspects are closely intertwined in the examination of self-determination in heath care decision-making. Proofs are needed regarding the development occurred in Europe since the last remarkable study of the University of Zurich in 2008. Many countries have taken steps forward since then, but as many have not. Debates and plans are going on all the time, but nothing concrete happens in this regard. There are many countries with strong legal status on advance directives, and those should be used as a model for the weaker ones. The starting point is that advance directives should be complied with.

Directive on Cross-Border Healthcare, which entered into force in 2013 in the EU, allows EU citizens to choose and be reimbursed for medical treatment anywhere in the EU, no matter where they live.[182] If there was a consensus on the scope and legal effect of advance directives, the Directive could also include an obligation to comply with them anywhere in the EU, no matter where they were issued. Inspired by the idea of the common European network of registries on advance directives, self-determination could also be secured for traveling people who may not be able to make health care decisions in other countries than the one in which they reside.[183] Moreover, elderly are part of the increased cross-border movement in the EU as more and more are willing to spend their retirement days abroad. Regarding the private international law, advance directives raise similar issues to those raised by other new institutions, such as same-sex marriage, where national legislations differ greatly in view of the social, moral, religious and philosophical values. In other words, legal problems posed by advance directives are similar to the ones posed by other personal status matters in a globalized World.[184] When at least the minimal consensus on the requirements and validity of advance directives and consequently on their legally binding effect would have been achieved, it was possible to start to follow an advance directive issued in one country also in another.

The law must address issues raised by dementia on their own terms and not simply as a subset of a broader capacity or incapacity agenda.[185] Perhaps, drafting special advance directives tailored for dementia patients could be taken into consideration. Proactive law from *ex ante* perspective needs to be exploited when seeking new solutions for aging and anticipation. It is important to focus on positive aspects of the regulations instead of deciding too quickly that from a legal point of view nothing can be said since the theories remain too vague, and that advance directives thus have a very little legal effect.[186] The question is not necessarily that the society does not know what should be done, but does the society work as well as it should. Implementation of fundamental and human rights is part of solidarity, which belongs to all institutional and professional actors in their field of practice. If the barrier to start to make amendments to the most influential European document in this regard, Biomedicine Convention, is too high, at least Article 6 and 9 could be reinterpreted in the light of ECtHR case law so that

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182 The cross-border healthcare directive enters into force:
http://ec.europa.eu/health/newsletter/117/focus_newsletter_en.htm (9.12.2016)
183 Andorno, R., Brauer, S., Biller-Andorno, N. (2009), *supra nota 25,* p 225
184 Negri, S. (2012), *supra nota 46,* pp 139-140
185 Foster, C., Herring, J., Doron, I. (2014), *supra nota 48,* p 425
186 Goffin, T. (2012), *supra nota 5,* p 139

they could serve as a basis for advance directives today and in the future with more positive impact.[187]

Even though the emphasis often turns to advance directives, the CPAs should not be forgotten. They might serve a less controversial tool for taking care of the interests of the elderly. Many do not know about this flexible and effortless opportunity to guarantee the affairs management of incompetent people. Each competent adult can prepare for the future at any time by drafting an advance directive and a CPA. Since this requires sufficient capacity from the creator, early diagnosis of dementia is necessary. Dementia is not easy, and the patient and his close ones may deny the diagnosis at first, but when thinking about the future, preparing for it as early as possible will turn out to be of benefit to everyone. This is also why advance directives for consent to research should be given more weight as it enables the scientifical development and thus, these early diagnoses. Paying attention to the elderly and their treatment makes immediately much more sense when one imagines oneself as old and incapable to take care oneself. One does not want to put his spouse or child in the position of having to make a decision like this alone but simply tell in advance what one may choose. All in all, capacity loss may occur at any time, not just in the old days. Barack Obama was the first US President who publicly announced that he and Michelle Obama have living wills. Obama thought that it is sensible to have one and encouraged others to do the same.[188]

All in all, in today's modern society, individuality and respect towards autonomous, uncontrolled choices are commonplace. This cogitation should be properly integrated into the medical field as well, and positive and present-day interpretation of protective measures put in place. As there is such a broad consensus about these facts, should not the right to self-determination itself deserve more protection? Strengthening the status of the right to self-determination by recognizing it as a separate legal right, perhaps even as an independent human right, might be worth taken into consideration. At least these facts together could protect patients' self-determination in they health care decision-making and justify them to live the life as they wish even in the old, incapable days.

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187 *Ibid*.

188 Advance Health Care Directive: http://johnsonestateplanning.com/data/advance-directive/

List of sources

Science books:

1. Antila, T. Edunvalvontavaltuutus, Talentum Media Oy 2007.

2. Berlin, I. Four Essays on Liberty. Oxford University Press 1969.

3. Edozien, L. Self-determination in Health Care: A Property Approach to the Protection of Patients' Rights. Routledge 2016.

4. Foster, C., Herring, J., Doron, I. The Law and Ethics of Dementia. Hart Publishing, Oregon 2014.

5. McLeod, I. Legal Theory. Palgrave McMillan Law Masters 6th edition 2012.

6. Mäki-Petäjä-Leinonen, A. Ikääntymisen ennakointi: Vanhuuteen varautumisen keinot, Talentum Media Oy 2013.

7. Negri, S. Self-Determination, Dignity and End-of-Life Care: Regulating Advance Directives in International and Comparative Perspective. Martinus Nijhoff Publishers 2012.

8. Välimäki, P. Edunvalvontaoikeus. Talentum Media Oy 2013.

Science articles:

9. Andorno, R., Brauer, S., Biller-Andorno, N. Advance Health Care Directives: Towards a Coordinated European Policy? European Journal of Health Law 2009. pp 207-22

10. Burlá, C., Rego, G., Nunes, R. Alzheimer, dementia, and the living will: a proposal. Medicine, Health Care & Philosophy 2014. p 392

11. Coll, P. Legal and Ethical Issues at the End-of-Life: Dementia. Quinnipiac Probate Law Journal, Vol. 23, Issue 4 2010. pp 378-385

12. Farmer, L., Lundy, A. Informed Consent: Ethical and Legal Considerations for Advanced Pratice Nurses. The Journal of Nurse Practitioners, Volume 13 2017. p 124

13. Goffin, T. Advance Directives as an Instrument in an Aging Europe. European Journal of Health Law 2012. pp 121-134

14. Herring, J. Losing it? Losing what? The law and Dementia. Child and Family Law Quarterly, Vol 21, No 1, 2009. pp 4-18

15. Horn, R. "Why Should I Question a Patient's Wish?" A Comparative Study on Physicians' Perspectives on Their Duties to Respect Advance Directives. European Journal of Health Law 2016, pp 11-16

16. Launis, V. Itsemääräämisoikeus ja paternalismi terveydenhuollossa. Sosiaalilääketieteellinen Aikakauslehti 2010. p 136

17. Lewis, P. Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems? European Journal of Health Law, Netherlands 2006. pp 219-232

18. Lötjönen, S. Medical Research on Patients with Dementia – the Role of Advance Directives in European Legal Instruments. European Journal of Health Law 2006. pp 241-257

19. Mäki-Petäjä-Leinonen, A., Juva, K. Of Sound Mind? Dementia and Aspects of Assessing Legal Capacity. European Journal of Health Law 2015. p 15

20. Saarenpää, A. Henkilö- ja persoonallisuusoikeus. Lapin yliopiston julkaisuja. Rovaniemi 2012. pp 311-313

21. Samanta, J. Lasting Power of Attorney for Healthcare Under the Mental Capacity Act 2005: Enhanced Prospective Self-Determination for Future Incapacity or a Simulacrum? Medical Law Review 17 2009. p 378

22. Schaffner, A. Understanding Dementia. Quinnipiac Probate Law Journal, Vol. 23, Issue 4, 2010. pp 373-374

23. Seoane JA. Advance care planning in Spain. A short national report. Part II. Department of Philosophy of Law, School of Law, University of A Coruña, A Coruña, Spain. Prog Health Sci Vol 5 No 1 2015, pp 170-173

24. Simon-Lorda, P., Tamauo-Velázquez, M-I., Barrion-Cantalejo, I-M. Advance Directives in Spain. Perspective from a Medical Bioethicist Approach. Bioethics Volume 22 Number 6 2008. pp 346-350

25. Veshi, D., Neitzke, G. Advance Directives in Some Western European Countries: A Legal Comparison between Spain, France, England, and Germany. European Journal of Health Law 2015. pp 324-336

26. Walker, S. Autonomy or Preservation of Life – Advance Directives and Patients with Dementia. UCL Jurisprudence Review, 2011. p 112

27. Wiesing, U., Jox, R., Heibler, H-J., Borasio, G. A New Law on Advance Directives in Germany. Journal of Medical Ethics Vol. 36, No. 12 2010. p 780

International and EU legal acts:

28. Council of Europe. Convention for the Protection of Human Rights and Fundamental Freedoms, 1950.

29. Council of Europe. Convention fo the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Oviedo 1997.

30. European Union. The EU Charter of Fundamental Rights, C 364/1, 18.12.2000.

National legal acts of the states:

31. The Mental Capacity Act 2005 (England and Wales) 07.04.2005.

32. Ley 41/2002, se 14 noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de informacíon y documentacíon clínica 15.11.2002.

33. Drittes Gesetz zur Änderung des Betreuungsrechts 29.07.2009.

34. German Civil Code BGB 18.08.1896.

Case law:

35. EWCA 30.7.1992, (1992) 4 All ER 649, *Re T (adult: refusal of treatment)*

36. ECHR , 29.04.2002, 2346/02, *Pretty v. the UK*

37. ECHR , 03.07.2012 4806/04, *X v. Finland*

Other sources:

38. Explanatory Report to 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, Oviedo 04.04.1997.

39. Recommendation No. R (99) 4 of the Committee of Ministers to member states on principles concerning the legal protection of incapable adults, 23.02.1999.

40. Recommendation CM/Rec(2009)11 of the Committee of Ministers to Member States on principles concerning continuing powers of attorney and advance directives for incapacity, 2009.

41. Parliamentary Assembly, Social, Health and Family Affirs Committee. Draft Resolution and Recommendation Protecting Human Rights and Dignity by Taking into Account Previously Expressed Wishes of Patients, 12.12.2011.

42. Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias, Brussels 22.7.2009.

43. Implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias, Brussels 16.10.2014.

44. Council of Europe. Guide on the decision-making process regarding medical treatment in end-of-life situations, 2014.

45. The Joint Committee on the Draft Mental Incapacity Bill Vol 1 HL Paper 189-I HV 1083-I. Authority of the House of Lords and the House of Commons, London 2003.

46. Institute of Biomedcial Ethics University of Zurich. Country Reports on Advance Directives: Lehmann, L. USA. Switzerland 2008.

47. Dementia, Alzheimer's disease: http://www.alzheimer-europe.org/Dementia/Alzheimer-s-disease. (27.08.2015).

48. World Alzheimer Report: https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf August 2015.

49. Hecht, M., Shiel, W. Advance Medical Directives (Living will, Power of Attorney, and Health Care Proxy): http://www.medicinenet.com/script/main/art.asp?articlekey=7814

50. From Therapeutic Abstention to the Right to Die? The Case of Lambert and Others v. France: https://strasbourgobservers.com/2015/07/06/from-therapeutic-abstention-to-the-right-to-die-the-case-of-lambert-and-others-v-france/ (06.07.2015).

51. 2016: Decision making and legal capacity in dementia: United Kingdom (England). http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/United-Kingdom-England (09.02.2017).

52. 2016: Decision making and legal capacity in dementia: Spain. http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/Spain (09.02.2017).

53. 2016: Decision making and legal capacity in dementia: Germany. http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2016-Decision-making-and-legal-capacity-in-dementia/Spain (08.02.2017).

54. Law for Older Americans: http://www.americanbar.org/groups/public_education/resources/law_issues_for_consumers/patient_self_determination_act.html

55. What Is Advance Care Planning? http://www.advancecareplanning.ca/what-is-advance-care-planning/

56. Detering, K., Hancock, A., Reade, M., Silvester, W. BMJ Research: The impact of advance care planning on end of life care in elderly patients: randomised controlled trial 2009. http://www.bmj.com/content/bmj/340/bmj.c1345.full.pdf

57. The cross-border healthcare directive enters into force: http://ec.europa.eu/health/newsletter/117/focus_newsletter_en.htm (9.12.2016).

58. Advance Health Care Directive: http://johnsonestateplanning.com/data/advance-directive/