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ADVANCE DIRECTIVES IN ROMANIA AND LITHUANIA

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ABSTRACT. Advance directives, a set of written instructions that a person gives that specify what actions should be taken for their health if they are no longer able to make decisions due to illness or incapacity, are a well-implemented tool in America, but few European countries have specific provisions about them in the law. Significant differences exist regarding the way advance directives are regulated and implemented between countries. The authors analyze the attitudes of several professional categories in Romania and Lithuania towards the advance directive using data obtained by conducting several interviews in Lithuania and a focus group in Romania. Both Romania and Lithuania are post-communist, now European Union member countries. All respondents thought that advance directives should be introduced in the law, but their social acceptance is expected to be low in Lithuania.

Keywords: *Advance directive; Romania; Lithuania; law*

Introduction

Advance directives are medical and legal tools that allow a person to express preference towards a certain type of healthcare in advance, should he/she become incompetent from a decision making point of view at some moment in time. Among the advantages of the advance directive we could mention that it prevents medical treatments or gestures that the person would not want in case of a terminal illness, permanent unconscious state, severe mental disability or coma and it does not represent a form of euthanasia. It also reflects the cultural and

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religious values of a person, his or her views on life quality and represents a way of enforcing patient dignity and autonomy at the end of life. The main disadvantages world literature recognizes are the fact that a patient may change his mind about what he has written in the advance directive, but have no time to update it, the risk of misinterpretation, since no advance directive can cover all potential situations; also, discussing an advance directive can be stressful for anyone; furthermore, there remains the question on where to store advance directives, how to know if a person admitted in an intensive care unit has one and exactly what is specified in that document.

There are two forms of advance directives. The *living will* provides specific directives about the course of treatment that is to be followed by health care providers and caregivers. In some cases a living will may forbid the use of various kinds of burdensome medical treatment, life support (such as hydration, feeding or the use of ventilators) or lifesaving (cardiopulmonary resuscitation) measures[1].

The *healthcare proxy* consists of appointing a representative (a trusted person) who can make decisions on behalf of the patient when he/she becomes unable of doing so. The healthcare proxy can assist the physician in choosing the best treatment alternative according to provisions of the living will or can shed light over confusing provisions of the living will. The designated person must be well acquainted with the moral and religious values of the patient. The proxy is usually a family member or a friend.

These forms of advance directives may exist at the same time, as they complete each other. The advance directive may be modified at any point, if the patient is still competent to make decisions.

Although advance directives were first introduced the United States of America in 1969[2] and by 2007 41% of Americans had one[3], this tool still does not exist in some European countries.

The legislative situation of advance directive in Romania and Lithuania

Romania and Lithuania are both post communist countries. Romania joined NATO on March 29th, 2004 and the European Union on January 1st, 2007, whereas Lithuania became a full member of NATO and the European Union in the spring of 2004 and a member of the Schengen Agreement on December 21st, 2007.

After the fall of Ceaușescu regime in December 1989, Romania started a reform process in all areas, including healthcare. A similar process started in Lithuania in 1990, when the country gained its independence from the Soviet Union. Healthcare reforms included articulating patient and healthcare providers' rights and obligations. Both countries have ratified the Oviedo Convention, that states that "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account" (article 9), but have not enacted any specific laws or provisions on advance directives. This represents the legal ground on which advance directives laws or law provisions should be built on. The Oviedo Convention also protects human autonomy by regulating informed consent and consent by proxy for incapable persons (articles 5-8)[4].

In both Romania and Lithuania there are no laws or official statements directly related to advance directive.

In Romania, the law no. 46/2003 regarding the patient's rights, stipulates that the patient has the right to refuse or to stop a medical intervention by assuming responsibility in writing, but the doctor must make sure to explain the consequences of such an action to a competent, conscious patient. Mentally disabled persons, if able, are also asked for consent to treatment; if unable to give consent, informed consent is required from the family (Mental Health Law 487/2002, republished in 2012)[5]. Law 95/2006 and the Medical Deontology Code also protect human autonomy and consent, but state nothing about advance directives.

In emergency situations, if the medical personnel is aware of previously expressed wishes of the patient, those must be taken into consideration. In case such information is unavailable for an incompetent patient in an emergency situation, the consent of the family or medical representative is no longer necessary. In non-emergency situations involving incompetent patients, the consent of the medical representative is sought, but the patient must also be involved in the decision making process to the extent of his understanding capability. This also applies to children, whose assent must be sought, and whose opinions must be taken into consideration in medical care.

In case healthcare suppliers and medical representatives cannot reach common ground, the decision is made by an arbitrage committee, consisting of three doctors for patients admitted in hospitals and two doctors for ambulatory patients.

All patients are entitled to terminal medical care in order to die with dignity[6].

In Lithuania the recommendations on advance directives are only provided by Lithuanian Association of Physicians, which adopted (translated and published) The World Medical Association Statement on Advance Directives ("Living Wills") by the WMA General Assembly, Helsinki 2003. However, the advance directives are not officially integrated into the medical decision-making process in this country[7].

The right of patient self-determination and its limits are regulated by the Law on Patients rights and the Law of Mental Health.

In Lithuania, the competent patient's consent is also needed in non-emergency situations. On the other hand, the patient's consent is not needed if he/she is unconscious or if his/her will cannot be known for another reason and a serious threat is being posed to his life or health. In this case, emergency medical assistance is offered without the patient's or his/her legal representative's consent.

In cases where there is a disagreement between the doctor and the medical representative, the medical ethics commission of the health care institution or the Committee for Medical Ethics of Lithuania has the right to give consent for the treatment that is considered to be in the best interest of the patient. The administration of the health care institution or the treating physician have the right to appeal to this commission or committee.

A minor patient must be informed about the treatment and, with his age and level of development permitting a correct appraisal of the status of his health and proposed course of treatment (the treating physician shall decide this), the minor may not be treated against his will, unless provided otherwise by the Republic of Lithuania laws. The physician shall select the methods of treatment which would best suit the interests of the minor[7].

Methodology

We have conducted a qualitative research in Romania and Lithuania aiming to assess the opinions of different categories of professionals regarding the relevance of the advance directives and the need for such an instrument in the two countries.

In Romania we organized a focus group with 10 specialists in bioethics, theology, psychology, medicine and law in Cluj, at the Center of Bioethics of Babes-Bolyai University.

In Lithuania we conducted 12 interviews with Lithuanian bioethicists in Vilnius and Kaunas Universities.

A semi-structured interview guide was used to ensure consistency across participants.

The interview and focus group guide included open-ended questions grouped in the following topics:

- Views on the usefulness and advantages of the advance directive
- Views on the risks associated with the advance directive
- Views on how to draft and implement a law introducing advance directives in Romania and Lithuania
- Views on the probability of the population to consider such a tool adequate in the current socio-economic and cultural environment of Romania and Lithuania.

The interviews and the focus group were tape-recorded, typed and reviewed for accuracy. Transcripts of the interviews were compiled and then the phenomenological analysis was applied, aiming to identify the common views of the respondents, but also specific features.

Results and discussions

The results are partly presented as condensed descriptions of data, partly by quotations that are considered illustrative.

Both Romanian and Lithuanian professionals had all heard before participating in the focus group about the advance directive, but most of them only knew about them in the limited form of do-not-resuscitate orders.

The utility of such a document was clear to all Romanian participants. Physicians and lawyers were most in favor of this tool and their opinion was that it would help to solve many "borderline" cases:

> "I say it would be good from all points of view! Not for the quality of life, but for the dignity [of the patient], that cannot be measured, and each of us defines it by his own cultural system. It would be good for the health system itself, for the social system as well." (doctor, Cluj focus group)

All the interviewed Lithuanian experts also agreed that the advance directive is a useful tool:

> "I think advance directives is one of the best tools to protect a person's dignity in such situations." (bioethicist, Vilnius University)

Our results are in line with other studies which have shown almost uniformly positive opinions among patients and physicians regarding the *concept* of advance directives (Emanuel[8], Joos[9]) but the opinions of other professional categories were not as widely investigated.

The advantages of the advance directives that were highlighted by Romanian participants were: "reducing the physician's psychological stress", less conflicts between the family and the physician and placing the decision in each patient's hands. However, some of the specialists suggested that not all members of the Romanian society seem to be ready to take matters into their own hands.

> "We live in a society that does not teach us to live in a system and to be independent. We are educated to live in families where the man makes every decision and the woman does not work and is totally dependent until old age, where children are not taught to make decisions and to be on their own by the time they turn fourteen". (social worker, Cluj focus group)

This is also the situation in Lithuania, where the fear of responsibility among the patients is acknowledged:

> -"Many people don't want to know about their diagnosis, their treatment; they just want to be healthy and ok.
> -So they don't want to take responsibility for their own life?
> -Yes." (bioethicist, Vilnius University)

Lithuanian experts identified several advantages of advance directives: they provide "legal clarity":

> "When a patient's will is not known and family members sometimes are in disagreement how to treat such a patient, sometimes it leads to the legal cases". (lawyer and bioethicist, Vilnius)

Second,

> "relatives do not need to make very difficult decisions in very difficult situations" (nurse, bioethicist, Vilnius). Third, "if you base your views on autonomy, it's the way to implement autonomous decision making". (doctor, bioethicist, Vilnius)

The economical factor also came up in one interview:

> "For patients who would not agree to have this artificial ventilation or other stuff... the money would be saved and could be used to help other patients".(doctor, bioethicist, Kaunas)

Yet literature describes cases where patient decisions are not always made autonomously even in the process of drafting advance directives. Klessig[19] and others found that the preeminence of patient autonomy is far from universal. Considerations such as religious beliefs, suspicions about the medical establishment, familial obligations, and respect for authority all entered the patients' preferences.

Lithuanian participants also identified certain disadvantages of this document:

> "In case the family has certain interests… like inheriting something… I wonder if such legislation would not make such situations easier for that family" (doctor, bioethicist, Vilnius).

Concerns were also expressed about being able to modify the document at some point by the patient, should he change his mind and about "reducing medical care to simple technical aspects". (doctor, Cluj focus group)

The Romanian specialists mentioned also that another disadvantage of advance directive would be imposing limitations to the doctor's professional autonomy:

> "A risk would be limiting the doctor's professional autonomy, in case he wants to act" (lawyer, Cluj focus group).

In Lithuania people do not seem to have a lot of trust in the healthcare system, therefore one expert's opinion was that people might fear completing this document:

> "I think a lot of people don't trust the healthcare system. I can't say exactly why, because the reasons are very complex. Maybe it is because of this post-communist countries situation… nobody trusts other people… it's a problem." (philosopher, bioethicist, Vilnius)

This line of thought was taken even further:

> "Also there are some people who are very conservative and who associate advance directives with euthanasia, and especially those who follow catholic traditions. Because… it depends on how you define euthanasia. I think there can be some kind of misconception between these two… advance directives and euthanasia". (doctor, bioethicist, Vilnius)

Outdated provisions of the advance directive were seen as risky in both countries:

> "To what extent a decision already made can be modified... that needs to be discussed" (doctor, Cluj focus group).
>
> "Sometimes technologies develop and if you have this advance directive signed like… very long ago, you could already have some new treatment options available."(doctor, bioethicist, Vilnius), "And, of course, sometimes there can be the risk that patient's mind has changed. And he didn't update it". (doctor, bioethicist, Kaunas)

The risk of misinterpretation was acknowledged by all the participants:

> "I think sometimes doctors can interpret advance directives differently if they are not very precise and having in mind that many clinical situations can be different…" (nurse, bioethicist, Vilnius).

In Romania the risk of misinterpretation was discussed while talking about what the actual form should look like:

> "I think classical situations should be included, like... where would you like to be cared for, at home, or in the hospital...
> -So it would be best to adopt the western check- box type?
> -Yes, standard type. Because otherwise it could be interpretable and it may lead to abuse. It should have a formal structure, it should be standard, but it should also include the possibility to add something personal" (doctor, Cluj focus group)

One Lithuanian expert said that advance directives should only be allowed in terminal situations, or else "you can imagine some vicious scenarios." (doctor, bioethicist, Vilnius)

The disadvantages mentioned by the Romanian and Lithuanian specialists are also discussed in the literature. However, many other important disadvantages of advance directives such as the difficulty of their implementation, due to the complexity of the documents[11,12] , the failure of physicians to initiate discussions[13], the difficulty in understanding discussions[14], the perceived ill-effects on patients of having such discussions[15], and logistical issues such as the optimal time to initiate discussions about advance care planning[16,17] were not acknowledged by the participants in our study, showing either their incomplete knowledge about this issue or their opinion that the above mentiones issues are not a real problem.

Romanian experts agreed that Romanians would accept to have advance directives stipulated in the law, but probably few would actually complete one, because "In a normal family, it is out of the question. The patient places his life in the hands of family members"(priest, Cluj focus group).

The situation was different in Lithuania:

> "In Lithuania it would be very problematic to legislate this because we are a catholic country and in the field of bioethics the church has the impact on making decisions." (lawyer, bioethicist, Vilnius)

Another expert stated that many people in Lithuania would probably like to have such an institute of advance directive, because it is an expression of their autonomy, "but also there are some people who are very conservative and who associate advance directives with euthanasia, and especially those who follow catholic traditions."(doctor, bioethicist, Vilnius)

Experts in both countries identified a common fear:

> "Anyways, in Romania, patient's biggest fear is that, when they are admitted into hospitals, they are not treated enough, not that they are over treated". (doctor, Cluj focus group)

One expert in Lithuania followed the same line of thought:

> "Now the question is how much this over treatment decisions are prevalent in a country which is not very rich so I think that would be an interesting question to see how would the advance directives be applied to different scenarios in, let's say, transition country and the wealthiest state where everything is done up to the very last intervention available". (doctor, bioethicist, Vilnius)

Conclusions

Experts in Romania and Lithuania were all in favor of introducing legal provisions on advance directive, which it is considered an extensions of the patient' autonomy. The risk of misinterpretation was identified by all respondents, but the advantages of this legal tool surpass the risks. Lithuanian experts consider the very conservative nature of their culture and the strong involvement of the Church in the decisions as limiting factors for acceptance of the advance directives, which seem to be associated by the public at large with euthanasia. Romanian experts, in turn, saw written advance directives futile in normally functioning families, where patients can easily choose a proxy to talk to, but thought that society would agree to have a law regulating them.

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