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Abstract

Giving value to the wishes of the terminal patients regarding the treatment at the end of their life, the use of the advance directive, as an extension of their autonomy when the patients are incompetent, represents a mean to respect and promote their dignity. The authors present and discuss the results of their research that analysed the attitude of Romanians toward the use of the advance directive to identify the usefulness of implementing such a document in the Romanian social cultural context.

The target group in this research is general population over 18 years old, speaking Romanian and without psychological illnesses. The representative random sample lot included 828 persons from Iasi County. The data were recorded based on a transversal descriptive study, using the method of questionnaire enquiry.

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The persons participating in the study admitted the importance of respecting the patient's dignity and autonomy with reference to decisions concerning the treatment at the end of life. For the subjects agreeing with legalizing the advance directive, the main advantages of such a document are firstly the respect of the patient's right to decide and secondly the improvement of the medical treatment.

The study showed that young, healthy and better educated individuals are interested in the advance directive and are in favour of introducing it in the current medical practice. The results of our research suggest that educational and informative programmes are needed in Romania regarding the role and usefulness of the advance directive, as well as the way to implement it, in order to encourage the implication of all adult persons in planning their own medical treatment in general and in particular in the medical decisions concerning the end of life.

Keywords: *medical decision, end of life, advance directive, ethics*

Introduction

Respecting human dignity is a social and moral scope, more so in the case of medical assistance and health politics. For the patients, dignity represents an important element of the psychological emotional balance and, sometimes, their last "possession".

Respecting the dignity implies essentially a psychological spiritual connection that requires empathy, compassion and, not last, communication (Sandman, 2005).

The use of medical procedures to sustain life is often a problem when the patients are no longer competent to take part in making decisions concerning their care. Because in these cases the treatment decisions are loaded with profound moral significance, but also expensive, contested and sometimes in contradiction with the patient's wishes, the use the advance directive as an extension of the autonomy when they become incompetent represents a way to respect and promote their dignity.

The advance directive is a written statement in which a person decides on the use or absence of a certain treatment, in case the patient, during the evolution of a terminal disease, no longer has the capacity of making competent decisions.

The advance directive can be expressed in the course of life, by any competent person, either by drawing a legal document (living will),

either by giving another person a durable power of attorney delegating to make these decisions in case the patient reaches decisional incompetence (Emanuel, Barry, Stoeckle, Ettelson and Emanuel, 1991).

This document, backed up by proper legislation, could represent a mechanism in solving the conflicts generated by the requests of the patient's family to "do everything" or to "stop any treatment" when the attending physician considers that cannot ethically agree with these decisions. The conflicts between the medical team and the caregivers are placed on a continuum; at one end there is the dilemma generated by the concept of "medical futility" or the situation when the physician is asked to "do everything" when in his/her opinion terminating the treatment or initiating it is the most adequate solution to the clinic state of the patient and at the other end there is the dilemmas caused by the family asking to terminate the vital support of the patient in order to ensure the patient's "right to die", as a reflection of the compassion toward human sufferance, when the medical team wants to carry on with the treatment (Winkler, Reiter-Theil, Lange-Riess, Schmahl-Menges and Hiddemann, 2009). Advance directive solves these issues in the patient-physician relationship, valorising the terminal patient's wishes with respect to the end of life and relieving to a certain degree the physicians and caregivers from the "moral responsibility of failure" due to medical human and technical limitations (Tillyard, 2007; Kish, Martin, Shaw and Price, 2001).

This paper presents the results of a study that analysed the attitude of the Romanian people toward the advance directive, in order to identify the utility of implementing such a document, considering the Romanian social cultural specifics.

Advance directive - short description

The positioning of the patient's autonomy in the centre of the medical practice and the developments in medical technology in the last 50 years are major events that lead to the recognition of the medical decisions made at the end of life as a real ethical challenge: in a specific case, not all that is technically possible is necessary or not all that is possible must be carried out. But... who decides? This dilemma was the base of numerous researches for the identification of different ways in which the patients can exercise their right to autonomy and self

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determination, including at the end of life, one of these solutions being the advance directive (Winkler, Hiddemann and Marckmann, 2011).

The advance directive offers the patient the possibility to express his/her wishes regarding the treatments at the end of life when, due to the extremely serious clinical condition the patient is incompetent decision wise and incapable to communicate with the medical staff (terminal state of a disease that can no longer be treated, irreversible coma or permanent vegetative state). The term "terminal patient" refers to the patient that cannot be cured or treated adequately with the existing medical resources, with a life expectancy of 6 month or less. In general, the notion of terminal disease/affection includes progressive affections such as cancer and chronic diseases in advanced state with vital prognosis, especially neurological, as well as trauma severe and irreversible neurological damage (Royal College of Physicians, 2003; Center for Bioethics University of Minnesota, 2005). From the 60s, the advance directive became an answer to the capacity of modern medicine to postpone death, including for patients with severe clinical state and incompetent decision wise, through different medical technologies such as mechanical ventilation, artificial nutrition and hydration. The increasing possibilities to medically sustain life, many times of low quality, lead to the need to create procedures and methodologies for physicians, patients and caregivers with regard to the decisions to use these technologies, especially in the case of comatose terminal patients (Silveira, DiPiero, Gerrity and Feudtner, 2000; Koch, 2000).

The advance directive, as a reflection of the individual autonomy and a variant of the "informed consent", stipulates that when given complete and accurate medical information, the patients, and not their physicians, are responsible for the decisions concerning the type of medical treatment they want for the end of life. This vision regarding responsibility is based on the principles of autonomy and self determination that recognise the right of individuals to control their own body by giving in advance instructions for the moment when they will no longer be competent. This way, the advance directive surpasses the paternalistic model of the physician-patient relationship and allows the active involvement of the patient in the planning of his/her medical care (LoBuono, 2000; Post, 2004).

Still, the advance directive is not a simple act of exercising the right to autonomy and self determination, but it reflects a decision based on the personal perception of what really matters, using the individual's spirituality, experiences and views on life and death, according to which sometimes the will to live doesn't necessarily means to be kept alive at all costs.

Materials and methods

The data was collected in a transversal descriptive study, using the questionnaire method, based on the questionnaire guide, respectively the questionnaire with mixed questions. The questionnaire included a number of 16 questions and was pretested on 10% of the total amount of subjects and then validated (see Annexe).

The target group of the research was the population over 18 years old from the Iasi County, speaking Romanian and without psychological affections. The randomised representative sample included 828 persons. The error margin was $\pm 3.4\%$, for a 95% level of confidence.

The subjects participated in the study voluntarily, under no constraints and no remuneration, each subject signing an informed the questionnaire before filling the questionnaire. The data was processed by classification, series, codification, tabulation and statistical calculus using SPSS 16.0.

The research was conducted respecting the amendments of Law 206/27.05.2004 regarding good practice in research, technological development and innovation, as well as the national and international ethical regulations concerning the research on human subjects. The study was carried out with the notification from the Commission of Ethics in Research of the "Grigore T. Popa" University in Iasi.

Results and discussions

The sample population included 828 persons, 45.3% male and 54.7% female, the structure of the lot being relatively balanced. The average age was 43 years, with a small trend toward younger ages - between 18 and 23 years of age. The average age did not differ statistically for man - 43.30 years and women - 42.75 years old (Mann-

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Whitney test, $p=0.405$). According to their level of education and profession, over one third of the subjects were high school graduates (297 persons representing 35.9%). With respect to religious beliefs, most of the subjects (73.7%) declared themselves as pertaining to different religious cults, observant or not. A part of the subjects (37.9%) considered themselves as "healthy enough"; 294 subjects (53.5%) declared to have "some health problems", while 104 persons (12.6%) considered to have excellent health. In the case of chronic diseases (172 subjects), the most frequent were cardiovascular diseases (6.2%), diabetes (5.0%), asthma, cancer and hepatitis, each with 1.3% weight.

The percentage of subjects "unsatisfied with the medical services" in the hospitals in Iasi is double than the percentage of those "satisfied" (17.9% versus 8.1%); the percentages of the subjects with an undecided attitude toward medical services were approximately equal (30.1% of the subjects declared to be "rather satisfied", while 33.1% considered themselves "rather unsatisfied"), their sum representing the majority of the participants in the study (523 subjects). From the total of 828 participants, 51.8% declared that they had the opportunity to come into contact and/or communicate with at least one person with cancer.

The opinion regarding the usefulness of the advance directive

From the experimental results, 51.4% of the subjects consider the advance directive a useful document for the decisions concerning the end of life. In this group, 54.7% are women and 45.3% men, without these differences to be statistically significant (test $\chi^2 = 1.792$, DF = 2, $p = 0.408$).

The perception of the advance directive as a useful document is also not statistically different from the age point of view (test $\chi^2 = 4.229$, DF = 4, $p = 0.376$). Still, it can be observed that from the total subjects with a positive answer, the highest percentage corresponded to the persons less than 40 years (49.6%).

The level of education seems to be the (test $\chi^2 = 25.956$, DF = 14, $p = 0.026$). The trend to see this document as useful is for better educated subjects - persons that graduated from high school, professional postgraduates school or universities (Spearman coefficient = - 0.108, $p = 0.002$).

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The health state of the subjects does not represent a differentiating criteria with respect to the perception of the advance directive as useful (test $\chi^2 = 6.105$, DF = 10, $p = 0.806$). Still, it can be observed that among the ones considering the advance directive useful, the subjects with multiple serious diseases have the smallest weight (4.5%).

With reference to the degree of to which the medical services are satisfactory, without being a trend (Spearman coefficient = - 0.096, $p = 0.006$), the percentage of subjects less satisfied by these services that know about the advance directive and its usefulness is higher than the ones who don't know (test $\chi^2 = 17.084$, DF = 8, $p = 0.029$).

The religious factor does not influence the perception of the usefulness of the advance directive (test $\chi^2 = 2.604$, DF = 4, $p = 0.626$).

The subjects that had in their family a cancer patient are the ones that know the most about the advance directive and represent the highest percentage (59.4%) from the ones that consider the usefulness of such a document at the end of life (coefficient Spearman = 0.194, $p = 0.000$).

From the justification of the affirmative answer regarding the necessity of the advance directive, it resulted that the highest percentage of subjects considered that such a document respects the patient's right to decide about his/her life (11,6%), followed by the subjects that consider it the patient's wish (8.9%) and respectively that is good for the patient (6.0%). The gender and the age factors had no influence on these opinions (test $\chi^2 = 21.866$, DF = 29, $p = 0.826$, respectively for the age test $\chi^2 = 58.630$, DF = 58, $p = 0.452$).

The motivations of the subjects that considered the advance directive as unnecessary include: the fact that such a document wouldn't be used by the patient (7.70%), the opinion that a person has no right to take his/her own life (6.40%) or that such a decision does not correspond to religious norms (3.20%). Gender is a factor that doesn't affect the perception of the advance directive as not useful (test $\chi^2 = 20.951$, DF = 18, $p = 0.282$), the age being also a statistically insignificant influence factor (test $\chi^2 = 31,356$, DF = 36, $p = 0.689$).

Opinions regarding the regulation of the advance directive

The regulation of a document with respect to in advance medical decisions a person wishes to be executed at the end of his/her life if this person is no longer competent represents for 43.4% of the subjects (359 subjects) a normal procedure meant to respect human dignity. On the other hand, 29.15% of the subjects (208 participants) do not see the regulation of such a document as appropriate.

Gender and age factors do not affect the option regarding the regulation of the advance directive (for the gender factor test $\chi^2 = 4.864$, $DF = 2$, $p = 0.008$ and for the age factor test $\chi^2 = 0.704$, $DF = 4$, $p = 0.951$)

There is a weak trend for the better educated persons (high school, university) to agree with the regulation of the advance directive (Spearman coefficient = - 0.082, $p = 0.019$), but the level of education determines significant differences in the perception of the utility of regulating such a document (test $\chi^2 = 24.187$, $DF = 14$, $p = 0.043$).

The health state of the subjects appears to have no statistical influence on accepting the regulation of this document. Regardless of their health, the percentage of affirmative answers is higher than the negative ones. Still, one must observe that out of the 359 persons that would accept the regulation of the advance directive, the highest percentage - 73% represents individuals without serious health problems ("reasonably healthy" and "with some health issues", each with 36.5%) (test $\chi^2 = 7.308$, $DF = 10$, $p = 0.696$).

Also, the degree of satisfaction with respect to medical services and the religious believes are not making a difference in the perception of the regulation of the advance directive. There are no differences between the percentage of those in favour and those against this document when considering the degree of satisfaction (test $\chi^2 = 10.374$, $DF = 8$, $p = 0.240$) and religion (test $\chi^2 = 1.432$, $DF = 4$, $p = 0.839$).

A percentage of 56.5% of the subjects that had a relative with cancer (429 persons) agree with the regulation of this document, in comparison with the amount of persons that had not known a cancer patient and gave an affirmative answer (39%, corresponding to 361 persons). The differences are statically significant (test $\chi^2 = 34.263$, $DF = 4$, $p = 0.000$). It is evident the trend between the subjects who have been involved with a cancer patient, even a terminal patient, to agree with

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regulating such an act like the advance directive that certifies the respect of the patient's dignity, including at the end of life, by respecting his/her wishes regarding the medical treatment (Spearman coefficient = 0.138, $p = 0.000$).

From the point of view of those in favour to the regulation of the advance directive (359 subjects), most of them (17.3%) consider that such a document helps the patients, allowing them to express unequivocally their wishes regarding the medical care at the end of their lives. Gender has no significant influence on the acceptance of regulation (test $\chi^2 = 25.260$, $DF = 19$, $p = 0.152$), nor does the age of the subjects (test $\chi^2 = 40.544$, $DF = 38$, $p = 0.359$).

From the point of view of the subjects who were against the regulation of the advance directive (208 persons), most of them (11.1%) considers such a document to contradict religious believes. The differences determined by the gender factor are not statistically significant (test $\chi^2 = 9.093$, $DF = 13$, $p = 0.766$), the same thing for age (test $\chi^2 = 24.348$, $DF = 26$, $p = 0.556$).

In general, the results of this study are similar to the ones reported by previous studies. It was observed that most of the subjects that consider necessary and agree with the regulation of such a document like the advance directive are better educated (high school, professional school, postgraduate school, university). These results are also similar to previous ones that demonstrated that a higher level of education is associated with an attitude open to communication and discussions regarding the care at the end of life (Martin, Emanuel and Singer, 2000; Nolan and Mock, 2004). Furthermore, younger subjects (under 40 years old), as well as the ones without serious health know about the advance directive and consider its regulation as useful. These findings probably reflect the difference between generations, seen from the point of view of spirituality influenced by education and globalization or from the pragmatic angle of the life's quality perception and correspond to the results published in the literature (Emanuel et al., 1991).

The results of the present study suggest that the subjects from the target group recognise the importance of respecting the patient's dignity and autonomy when making decisions concerning medical care at the end of life. Considering that the malignancies represent the highest percentage of the affections with an unfavourable evolution, most of the

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subjects with a cancer patient in their family consider useful a document concerning the decisions at the end of life. For the subjects in favour of regulating the advance directive, the main advantages of such a document are respecting the patient's right to decide and secondly an improvement of the treatment. From the point of view of those who are against the regulation of the advance directive, the main disadvantages/risks of such a document are the premature death of the patient and secondly his/her sufferance, mentioning in order the conflicts that can appear between the patient and the family, as well as different legal disputes (e.g. partition of the inheritance, collecting a life insurance).

The results of the present study have also shown that, when the patients make a decision regarding the end of life, they see the implication of the family useful. According to the subjects, the advance directive as a document influencing the decisions at the end of life according to the patient's wishes should clearly stipulate the treatment and should include not only the patient's agreement, but also the one of the family. These results correspond to the literature that culture and religious believes have a major impact on the medical decisions at the end of life. (Searight and Gafford, 2005; McDonald, Deloge, Joslin, Retow, Severson, Votino, Shea, Drenga, Brennan, Moran and Del Signore, 2003; Kahana, Dan, Kahana and Kercher, 2004). For example, the Americans prefer to ask for life sustaining methods, while Asian and Hispanic people concentrate more on what is best for the family as a whole, having the tendency to consider the opinions of their relatives more than their own opinions. These cultural differences can be the cause of the deficient communication between the patients and their families and the medical staff, deficiencies that can lead to misunderstandings and prejudices with respect to documents like the advance directive (Kwak and Haley, 2005). Improving the communication with the medical staff leads to understand the idea of the advance directive and how it works as a legal document, as well as the elimination of the patients' anxiety and doubt, helping them to make rational judgements (Winkler et al., 2009). Still, even if they have sufficient medical information, patients' judgements regarding the end of life can be different from the ones made by physicians, according to

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social, cultural religious particularities, and not the least the absolutely personal valorisation of life and death (Sandman, 2005).

Conclusions

Our study has shown that young healthy persons, with higher levels of education have a higher interest in the advance directive, considering it necessary and being in favour of its regulation. For the Romanians agreeing with regulating the advance directive, the main advantages of such a document are respecting the patient's right to decide and improving the treatment, while the ones who do not agree with regulating such a document see as main risk the premature death of the patient. Furthermore, most persons that had a cancer patient in their family consider a document concerning the decisions at the end of life, like the advance directive as useful in respecting the patient's dignity and autonomy.

The results also suggest that in Romania is necessary to start educational and informative programmes regarding the role and the usefulness of the advance directive in encouraging the active involvement of all adults in planning the medical care for their own person in general and for the medical decisions at the end of life in particular. There is also a need to improve and adapt to the social and cultural specifics the communication between patients and the medical staff concerning the medical decisions. Considering the profound moral significance, together with the financial implications of the medical care at the end of life, future studies are recommended to identify the attitude of the providers of medical services in Romania with respect to the advance directive, in comparison with the attitude of the patients and the medical staff.

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Annexe – Questionnaire

Q. Did you personally hear about the *ADVANCE DIRECTIVE*?

1. Yes 2. No
99. Don't know/Don't answer/Never heard of

Q. Do you consider that such a document could be useful?

1. Yes. Justify your answer: _____
99. 99. Don't know/Don't answer
 2. No. Justify your answer: _____
 99. Don't know/Don't answer

Q. Do you think that Romanians would accept the regulation of such a document?

1. Yes. Justify your answer: _____
99. 99. Don't know/Don't answer
 2. No. Justify your answer: _____
99. 99. Don't know/Don't answer

Q. What are the advantages of such a document?

- 1 _____ 2 _____

Q. What are the risks of such a document?

- 1 _____ 2 _____

Q. In your opinion, name two important things that should be mentioned in such a document?

- 1 _____ 2 _____

Q. Who should regulate such a document in the first place? (a single possible answer)

1. Parliament
 2. Health Ministry
 3. College of Physicians
 4. Patients associations
 5. Complex teams made of lawyers, physicians, patients, psychologists, sociologists
 99. Don't know/Cannot say

SUBJECT'S SOCIAL-DEMOGRAPHIC DATA:

SD1. Sex: Male/Female

SD2. Age:.....

SD3. Last form of education:

1. No education
 2. Elementary school
 3. Secondary School
 4. 10th grade
 5. Professional School

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- 6. High school
- 7. Postgraduate school
- 8. University

SD4. Currently, your main occupation is: _____

SD5. How do you describe your own state of health:

- 1. I am very healthy
- 2. I am reasonably healthy
- 3. I have some health problems
- 4. I have a serious disease
- 5. I have more serious diseases
- 99. Don't know/Cannot say

SD6. Do you have chronic diseases? If so, which one _____

SD7. How satisfied are you about the medical services in the hospitals from Iasi County:

- 1. Very satisfied
- 2. Rather satisfied
- 3. Rather unsatisfied
- 4. Very unsatisfied
- 99. Don't know/Cannot say

SD8. Do you consider yourself a religious person?

- 1. Yes
- 2. No
- 99. Don't know/Don't answer

SD9. Did you have/met in your family or among acquaintances a person with cancer?

- 1. Yes
- 2. No
- 99. Don't know/Don't answer

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