Manifestation of patient's anticipated will as dysthanasia inhibiting factor

Camila Stolz
Géssica Gehlen
Elcio Luiz Bonamigo
Marcelo Carlos Bortoluzzi

Abstract

This study was conducted through interviews with physicians from the Association of Santa Catarina Midwestern Municipalities region (AMMOC). The objective was to evaluate if the patient's anticipated will are respected by doctors, when he is unable to communicate and whether this manifestation is considered a valid dysthanasia inhibiting instrument. The results indicated that physicians considered as a convenient record of patient's wishes by means of anticipated will statement and they would respect them, respectively, with a score of 7.68 and 8.26 on a scale of 0 to 10. It was also found that physicians consider them a useful tool for decision-making with evaluation of 7.57. These data allow for supposing that the ethical and legal regulation of anticipated will comprises a suitable measure to respect patient's autonomy and a relevant factor to inhibiting dysthanasia.

Key words: Bioethics. Advance directives. Personal autonomy. Terminally ill. Hospice care. Medical futility.

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Camila Stolz
Student at the fourth year of Medical school at the University of Western Santa Catarina (Unoesc), Joacaba, Santa Catarina, Brazil

The concern with dysthanasia exists since the origin of medicine. Plato[1], the philosopher, in the 4th century BC, observed in *The republic* that prolonging illnesses was not part of Asclepius' teachings. He specifically criticized a citizen called Herodicus, who prolonged to the utmost his illness life with medication and exercising, tormenting himself and the other people. In benefit of his utopian republic, those who needed treatment throughout their lives should not have their dying moment postponed.

Patients' rights evolved in the millennia that followed in the same proportion that human autonomy did, particularly during the past century when patient's will became increasingly valued. However, the decision–making on severely ill patients continues to be a complex task. When the real previous wishes of a terminal patient and incapable

Géssica Gehlen
Student of the fifth year of Medical school at the University of Western Santa Catarina (Unoesc), Joacaba, Santa Catarina, Brazil

Elcio Luiz Bonamigo
Ophthalmologist, doctor in Bioethics, councilor of the Regional Council of Medicine of Santa Catarina (Cremesc), professor and member of the Ethics in Research Committee and of the Bioethics Nucleus of the University of Western Santa Catarina (Unoesc), Joacaba, Santa Catarina, Brazil

to communicate and they are not clearly known, divergences arise between physicians and family members, difficult to equate both from a scientific point of view and from the ethical and legal [2].

In parallel, if patient clarified which were his wishes, not respect them hurts his autonomy. The respect for the patient's autonomy goes beyond his lucidity period. The individual has full right to make his own choices on the care about his health, which should be respected, if ethically acceptable, even if he is incapable to manifest them. However, the difficulty consists in predicting possible scenarios of his illness. The solution may be in the registry of a patient's scale of values that contemplate broadly his concept about independence, performance of functions, and quality of life [3].

From this considerable progress, the concept of anticipated directives originated in the 1960s in the United States [4], which turned into Federal Law in 1991, with the *Patient Self Determination Act* (PSDA), and its concept expanded throughout the world. Several countries, such as Spain, England, and Italy have legislation on anticipated directives. The directives were introduced in Spain with Law 41/2002, getting the denomination of '*instrucciones previas'*. According to Simon-Lorda [5], during 2007 and 2008 a total of 36,289 individuals registered their anticipated wishes, showing population's approval regarding their wish to manifest them.

Amidst this vigorous legislative expansion in the past two decades, the World Medical Association (WMA) [6] wrote a declaration about anticipated Will or vital testament, defining it as a *written and signed document* or *verbal statement in front of witnesses in which an individual expresses his will related to medical care that he desires or not getting if he is unconscious or if he is not able to express his will*.

Marcelo Carlos Bortoluzzi
Doctor in stomatology, coordinator of the Oral and Maxillofacial Surgery and Oral Pathology disciplines of the undergraduate Dental course of the University of Western Santa Catarina (Unoesc), Joacaba, Santa Catarina, Brazil

Although there is diversity in terminology, the term advanced directives, anticipated will and vital testament will be used as synonyms, even though there are small concept differences. The major one refers to the vital testament that does not include in its content the nomination of representative.

In CFM Resolution 1.931/09 [7], which instituted the new Code of Medical Ethics (CME), there are some pertinent guidance to procedures limitations in terminal patients, revealing the Federal Council of Medicine's concern with the possibility of occurring dysthanasia in the country. In this regard, Article 35 of the current code kept the content of Article 60 of the previous one, which prohibits the physician to therapeutic complication or exceeding in medical procedures [7]. Nevertheless, the main innovation in the code about this issue was the insertion of Item XXII of the Fundamental Principle that brings specific guidance against dysthanasia with the following text: *In irreversible and terminal clinical situations, physicians will avoid to undertake unnecessary diagnosis and therapeutic procedures and he will provide to patients under care all appropriate palliative care* [7].

Later, this guidance reappears with greater emphasis in Article 41, single paragraph: *In cases of incurable and terminal diseases, the physician shall offer all available palliative care without undertaking useless diagnosis and therapeutic, or obstinacy actions, always considering patient's express will or, in his impossibility, of his legal representative* [7].

However, there is not, until now, specific regulation in Brazil on preparation of anticipated directives, guiding the registry of patient's will on medical procedures' acceptance or not. When patient is incapable of communicating, his family or nominated representative, along with the medical team will decide on conducts to be undertaken. This justifies the importance of carrying

out new studies on preparation of anticipated will aiming at informing the medical team on patient's previous wishes.

The research is also justified by the necessity to evaluate in what proportion patient's anticipated wishes Will influence medical team's conduct during decision-making on the medical procedures at the end of life and if dysthanasia could be inhibited through this manifestation, thus, justifying its regulation.

Methodological procedures

The descriptive and transversal study was developed with the application of questionnaire with Likert's items. The research population was composed by physicians working in the region delimited by the Mid-West Catarinense Municipalities Association (AMMOC), comprising the municipalities of Agua Doce, Capinzal, Catanduvas, Erval Velho, Herval d'Oeste, Ibicare, Joaçaba, Lacerdopolis, Luzerna, Ouro, Tangara, Treze Tilias , and Vargem Bonita.

According to data from the Joacaba Regional Office of the Regional Council of Medicine (Cremesc), 189 physicians were registered in these municipalities in 2010. From this total, 126 were invited to participate in the research and 63 were not located or were not available for approaching. A total of 100 (52.6%) physicians replied to the questionnaire. They all received previous information on the research and signed the free and clarified consent term (FCCT).

Data were collected in questionnaire comprising a header with socioeconomic variables (gender, age, work area, and type of service), two objective questions and ten with dichotomous variables having Likert's items (scale0-10). This questionnaire resulted from adaptation of model used by Pablo Simon-Lorda *el al* [5]. Collected data were transcribed to Microsoft Excel and analyzed by Stata 8.0® statistics Software. Later, the obtained results were organized in table format.

Anticipated will, anticipated directives, previous wishes and vital testament, for this research's purposes, were considered as synonyms expressions. The Project was approved by the Ethics in Research Committee of the University of Western Santa Catarina (Sisnep registration FR 375816), in October 27,.

Results

A total of 100 physicians (52.6%) accepted to participate in the study, 78% of which were males and 22% females, with age average of 43.07 years, varying between 24 (minimum) and 75 years (maximum). Physicians were divided into four groups: basic care, ICU, emergency, and expertise. It was found that 60% work exclusively in their expertise, 9% in basic care, 1% in ICU, and 7% in their expertise ICU. The remaining 17% work in association of these areas.

Regarding the feature of the service, 18% are in public service, 50% are in the private service, and 32% in both. The relation

between social variable (gender and age) and expertise or place of work (basic care, ICU, emergency) were statistically analyzed. Nevertheless, significant differences between the averages in replies were not found. For that reason, these results were not inserted in Table 1. Additionally, some areas did not have sufficient number of professionals that allowed for analysis undertaking. The remaining results may be seen in Table 1.

Concerning knowledge about legal regulation of anticipated will in Brazil, 12% stated that there is regulation, 54% replied no and 34% replied they did not know. Questioned if they had read any document on anticipated will, 46% of professionals stated that they had read and 54%, no.

The results presented next refer to questions that explored interviewed physicians' opinions regarding anticipated will. Likert's scale was used in these evaluations, with values ranging from 0 to 10, representing minimum and maximum, respectively.

When questioned about the grade that they would give to their knowledge about the anticipated Will, the average reply was 5.88 (standard deviation: 2.8), while the mode is 5, with 22% of replies. Questioned if the believed as convenient that citizens should make plans about their health wishes leaving them in writing in the anticipated will declaration, the average reply obtained was 8.18 (standard deviation: 2,7) and mode was 10, with 49% of results.

Regarding the anticipated will as useful instrument for health professionals at decision time about a patient, the average obtained was 8.37 (standard deviation: 2.5) and mode was 10, with 54% of replies. Concerning their opinion about anticipated will as been also useful for family members at decision time, the average obtained was 8.09 (standard deviation: 2.7) and mode was 10, with 45% of replies.

On the value of nominating a representative by patient in his anticipated Will, in order to facilitated health professionals' decisions when patient is incapable, the evaluation average of interviewed physicians was 7.57 (standard deviation: 3,1) and mode was, 10 (40% das of replies).

Questioned whether, as professionals, physicians would recommend their patients to prepare anticipated will, the average grade was 7.68 (standard deviation: 3.0), while mode was 10, with 43% of replies. In this same sense, with average grade of 7.88 (standard deviation: 3.0), physicians would like that their family member prepare their anticipated will declaration, the mode was 10, with 48% of replies.

Questioned whether they would respect the wishes expressed by a patient in anticipated will declaration, interviewees' average grade was 8.26 (standard deviation: 2.3) and mode was 10, with 52% of results.

Concerning filling in their own anticipated will document as potential patients, the average grade obtained was 8.09 (standard deviation: 3.2), and mode was 10, with 59% of replies. In parallel, when questioned whether they would fill in their anticipated Will in the coming year, the average reply fell to 4,17 (standard deviation: 3.9) and mode was 0, with 35% of replies.

Table 1. Overall results of replies to questionnaire on anticipated will (AW)

Question	Minimum	Maximum	Average	Mode	Standard deviation
Knowledge on AW **Very bad 0 1 2 3 2 3 6 7 8 9 10 Excelent**	0.00	10.00	5.8800	5.00	2.80072
Is it advisable for patients to plan and write their health will **Not all convenient 0 1 2 3 2 3 6 7 8 9 10 Very convenient**	0.00	10.00	8.1800	10.00	2.72430
Is it an useful instrument for professionals **Not all useful 0 1 2 3 2 3 6 7 8 9 10 Very useful**	0.00	10.00	8.3700	10.00	2.54517
Is it an useful instrument for family members **Not all useful 0 1 2 3 2 3 6 7 8 9 10 Very useful**	0.00	10.00	8.0900	10.00	2.70464
The representative facilitates professionals' decision-making **Not all useful 0 1 2 3 2 3 6 7 8 9 10 Very useful**	0.00	10.00	7.5700	10.00	3.16947
Would you recommend your patients in preparing AW **Never 0 1 2 3 2 3 6 7 8 9 10 Always**	0.00	10.00	7.6800	10.00	3.02475
Would you like that your family member made their AW **Wouldn't like 0 1 2 3 2 3 6 7 8 9 10 Would like**	0.00	10,00	7.8800	10.00	3.03275
Would you fill in the AW document **Less likely 0 1 2 3 2 3 6 7 8 9 10 Very likely**	0.00	10.00	8.0900	10.00	3.20068
Would you respect a patient AW **Never 0 1 2 3 2 3 6 7 8 9 10 Always**	0.00	10.00	8.2600	10.00	2.39368
Would you do your WA in the coming year **Less likely 0 1 2 3 2 3 6 7 8 9 10 Very likely**	0.00	10.00	4.1700	0.00	3.95953

Discussion

Due to the fact that this study has been undertaken with application of questionnaire to physicians from AMMOC region, it is worth stressing its possible limitations concerning generalization of data obtained beyond researched population. Another aspect to be noticed is that questionnaire refers to hypothetic situations, since there is not, currently, legal or ethical regulation in force in Brazil about preparation of anticipated directives or will.

Concerning the questionings that sought identifying level of physicians' knowledge on anticipated will, results obtained showed that, on a scale from 0 to 10, physicians marked an average grade of 5.88 for their knowledge, 46% stated having read some document on the topic. Regarding regulation, 12% replied they believe that anticipated Will are already regulated by Law in Brazil, while 54% mentioned that it is not, and 34% could not inform.

In Andaluzia, Spain, a study was undertaken [5], in 2008, with 307 basic care and specialized physicians in which the average grade on knowledge on anticipated will was 5,29, while 69.6% knew that anticipated will was regulated by law in Spain, and 37.6% stated they had already read some document on anticipated will. Therefore, regarding the knowledge level on anticipated will, there were replies, which were very close among physicians researched in Brazil and in Spain, with results average of 5.88 and 5.29, respectively. The replies about having read some document about anticipated will were also convergent: respectively, 46% and 37.6% manifested positively. Concerning knowledge on existence or not of legislation on anticipated will in their country, replies were less coincident: 54% of physicians in Brazil, and 69.6% of physicians in Spain replied correctly.

Study published by Sánchez [8] in 2008, encompassing 113 physicians, interns and nurses in Santa Cruz de Tenerife, in Spain revealed that 68% of interviewees replied on anticipated will. In the other hand, in another study carried out with physicians from Mallorca, 82.5% stated having scarce or no knowledge about the topic [9]. However, in a research carried out in 1991[10], 97% of physicians from North Carolina replied that they knew the document already. Thus, there is major variation between data previously indicated in Spain and in Brazil related to this result found in the United States, where there was already a federal legislation since that year, in addition to other factors that may have collaborated toward the difference in the outcomes.

Concerning the reference to citizens registering their own health wishes through anticipated will declaration, physicians researched in this study replied that it is a convenient measure, with grade of 8.18.

A total of 75% marked their grades between 8, 9, and 10 in the scale; 49% marked 10, making clear their favorable stand. According to study carried out by Bravo [11], which compared opinions from 15 physicians with 13 individuals from the population at large, 92% of physicians manifested positive attitudes in face of anticipated will, while 81% from the population at large revealed as favorable to its use, showing convergence of opinions.

The anticipated will declaration has shown as useful instrument for health Professional at decision time about a patient, with average of replies of 8.37; 77% of physicians marked their grade between 8, 9 and 10. The physicians believe, inclusively, that anticipated will declaration constitutes an useful instrument for patients' family members as well, with grade average of 8.09.

In Sánchez' study [8] shows also that anticipated will declarations are considered very useful tools for health professionals when facing conflicting decisions that emerge at the end of life. A fact that stresses the relevance of these opinions and that, at the instance of making medical decisions referring at the end of life, around 95% of patients are incapable to communicate; as consequence, decisions are made by physicians and patients' family members [2].

Another aspect refers to the nomination of patient's representative. With grade average of 7.57, physicians replied that, if patient nominated a representative in their anticipated will, such measure would ease the decision making at the moment when they are not able to express themselves. In Simon-Lorda's study [5] a very similar result was obtained, with grade average of 7,66. This similarity of results allows to state that physicians from both countries equally acknowledge the importance of nominating a representative to participate in decision-making replacing a patient who is on incapacity status.

Angel-Lopez-Rey' study [12], carried out with 395 individuals from the population at large from Toledo, Spain, published in 2008, investigated whom researched subjects would like to have as representative. The majority (34.44%) expressed that a close family member would be, basically, the spouse. In this same study, 76.9% of individuals replied that they would maintain the anticipated will declaration once written, but 49.3% would change it at their family's request, while males were more susceptible to this change. It was also noticed that 46.6% would change the declaration after talking with their physician.

These data show that patients are a little more susceptible to their families' opinions than to their physicians. Another information that strongly confirms this fact is that, in this same study, 82% of patients,

who were questioned, stated that they would like to deal their anticipated Will with their family, and only 26.1% with their assisting physician.

When questioned whether, as professionals, physicians would recommend that their patients prepared their anticipated will, the grade average was 7.68 and 43% replied that they would certainly recommend it, grading 10 in the scale. In this aspect, according to Sanchez's study [8], 60.7% of physicians feel bothered in approaching the topic with patient, finding difficulties to talk about death, as well as explaining their circumstances and capable measures.

Regarding this fact, 75.6% of interviewees consider that patient should take the initiative to talk about their anticipated will. One datum that confronts Sanchez's research was noticed in Markson's study [13], published in the United States (USA) in 1997, with 1,050 interns and basic care physicians, in which 82% of professionals stated that being the physician the one who is responsible to start the conversation about anticipated directives with his patient.

In 2010, Detering [14] carried out a clinical study with patients over 80 years old hospitalized in an university hospital in Australia, in which the intervention group was comprised by 125 patients who received information and support to undertake the anticipated will. The control group counted on 154 patients and they did get any information. Results were surprising: in the intervention group, a total of 86% of the individuals expressed their anticipated will, 56% of them in writing. From those, 86% had their will known and respected. Nevertheless, only with 30% of those who died in the control group the same occurred. Such difference in result allows supposing that when patients get information related to anticipated Will and manifest them, there is higher probability that they are respected by health professionals at the opportune moment.

In this study, with grade average of 7.88, physician would like that their family would prepare their own anticipated will declaration medicos. In Simon-Lorda's [5] study, the grade average was 7.95, showing that physicians, from both studies, have similar views on this topic, in spite of been form different countries and cultures.

A highly relevant datum found in this study and that, when questioned whether they would respect the wishes expressed by a patient on a anticipated will declaration, 52% replied that they would certainly respect it, and 30% replied that they most likely would respect it. The grade average was very high: 8.26. This result reinforces the premise that the anticipated will declaration is a major factor for dysthanasia inhibition.

In accordance with this result, another research indicated that approximately

90% of physicians would meet patient's anticipated Will when he is found incapable to participate in this decision [15]. According to Angel-Lopez-Rey's [12] study, 85.4% of the interviewed individuals would be calmer if they knew that their will would be met when they would become incapable to decide, against 13.8% who did not bother with this. These conclusions are basic in relation to dysthanasia, which may be inhibited if patient's anticipated Will were prepared and known.

Alvarezude's[16] Spanish article, published in 2011, reports the application of questionnaire in 2,481 healthy individuals. Eight out of ten individuals stated to oppose a physician's punishment who puts a painless end in a terminal patient's life, if he repeatedly and consciously requests for it. The majority of participants in this study were in favor of a legislation allowing a physician to help a patient in terminal and in great suffering to get closer to death, if he requests freely.

When questioned whether, as potential patients, they would fill in the anticipated will document, 59% of the physicians replied that they would certainly do it, with grade average of 8.09. In parallel, paradoxically, physicians think very likely they would do their own anticipated will declaration in the coming year, with average of reply of 4.17. Nevertheless, it was noticed a greater trend among older physicians writing their anticipated will document than among the younger ones. This outcome is in accordance with Simon-Lorda's study, which observed that there is a theoretical contradiction in filling the anticipate will document and the real possibility to do it.

Final considerations

This study allowed identifying interviewed physicians' stand regarding the value of patients' anticipated Will and its importance as inhibiting factor of dysthanasia.

Concerning patients' anticipated will, the absolute majority of interviewed physicians replied that they would certainly or probably respect it, confirming the value of preparing the document. In accordance with this reply, the larger portion of physicians' also explained that patients should plan and write their wishes on health and that this instrument would be useful instrument for the researched professionals' decision-making. Likewise, physicians were widely favorable to preparation of anticipated Will by patients and their families.

Concerning personally preparing their own anticipated will in the coming years, few physicians manifested their intention in doing it. This low adhesion allows supposing that it is a reflection on the lack of information about regulation on this issue in our country.

In summary, the answers given by a wide majority of researched physicians allows concluding that patients' anticipated wishes will be respected when he is incapable to communicate and, if this is his wish, disproportional measures shall not be adopted that are configured as practice of dysthanasia.

The wide acceptance by researched physicians allows proposing that the anticipated will, also, denominated anticipated directives are regulated both from the ethical standpoint and legal as it is an useful instrument for respect to patient's autonomy and, consequently, an important inhibiting factor of dysthanasia. Bearing in mind the regional feature of the sample, new researches shall be carried out to confirm the found results.

Resumo

Este estudo foi realizado por meio de entrevistas com médicos da região da Associação dos Municípios do Meio Oeste Catarinense (AMMOC). O objetivo foi avaliar se as vontades antecipadas de um paciente serão respeitadas pelos médicos no momento em que estiver incapacitado de se comunicar e se essa manifestação constitui um instrumento válido de inibição da distanásia. Entre os resultados encontrou-se que os médicos consideram conveniente o registro dos desejos do paciente por meio da declaração de vontade antecipada e as respeitariam, respectivamente, com pontuação de 7,68 e 8,26 em escala de 0 a 10. E também que os médicos consideram esse instrumento útil para a tomada de decisões, com avaliação de 7,57. Esses dados permitem supor que a regulamentação ética e legal das vontades antecipadas compreende medida favorável para o respeito a autonomia do paciente e relevante fator de inibição a distanásia.

Palavras-chave: Bioética. Diretivas antecipadas. Autonomia pessoal. Paciente terminal. Cuidados paliativos. Futilidade médica.

Resumen

Manifestación de las voluntades anticipadas como factor de inhibición de la distanasia

Este estudio se llevó a cabo a través de entrevistas con médicos de la región de la Asociación de Municipios del Medio Oeste Catarinense (AMMOC). El objetivo fue evaluar si las voluntades anticipadas de un paciente serán respetadas por los médicos en el momento en que se encuentre incapacitado de comunicarse y si esa manifestación es un instrumento válido de inhibición de la distanasia. Entre los resultados se encontró que los médicos consideran conveniente el registro de los deseos del paciente por medio de la declaración de voluntad anticipada y los respetarían, respectivamente, con una puntuación de 7,68 y 8.26 en una escala de 0 a 10. Se encontró también que los médicos consideran ese instrumento útil para la toma de decisiones con evaluación de 7.57. Estos datos permiten suponer que la reglamentación ética y legal de las voluntades anticipadas constituye una medida favorable para el respeto de la autonomía del paciente y un importante factor de inhibición a la distanasia.

Palabras-clave: Bioética. Directivas anticipadas. Autonomía personal. Enfermo terminal. Cuidados paliativos. Inutilidad médica.

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Contacts

Camila Stolz - *kah_stolz@hotmail.com*
Géssica Gehlen – *gessicagehlen@hotmail.com*
Elcio Luiz Bonamigo – *elcio.bonamigo@unoesc.edu.br*
Marcelo Carlos Bortoluzzi – *marcelo.bortoluzzi@unoesc.edu.br*

Elcio Luiz Bonamigo - Rua Francisco Lindner, 310 CEP 8960-000. Joaçaba/SC, Brasil.

Authors' participation in article

Camila Stolz and Gessica Gehlen participated in the designing, project assembly, data collection and writing of article. Elcio Luiz Bonamigo participated in the designing, assembly, guidance, and writing of article. Marcelo Carlos Bortoluzzi participated in Project assembly and data statistics evaluation.