

## Advance directives in the perception of Medical students

*Diretivas antecipadas de vontade na percepção de estudantes de Medicina*

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### ABSTRACT

**Introduction:** The patient's autonomy in making decisions about their life and about diagnostic and therapeutic approaches related to their health has been the object of growing social value. Then advanced directives appear to express the patient's last will, safeguarding the Principle of Autonomy. During the undergraduate learning process, students are committed to life, and all of their training is based on technical aspects. Only a small part of the curriculum covers specific contents focused on terminal illness, when present. Medicine has evolved with important technological advances that resulted in quality-of-life improvement, but also brought a questionable extension of life, with often unjustifiable treatments and a therapeutic obstinacy to maintain life at any cost.

**Objective:** The aim of this study is to analyze the perception of medical students about end-of-life directives.

**Method:** A descriptive qualitative research was carried out through an individual and semi-structured interview, applied through Google forms. Due to the period of pandemic caused by the SARS-CoV-2, the survey was carried out remotely, in accordance with current national legislation. After the target was attained through sample exhaustion, the responses of 13 students were analyzed.

**Results:** In accordance with the elements, steps and methodological criteria, the obtained information was classified and arranged into two categories: Human Dignity and Patient Autonomy; Knowledge of Advance Will Directives.

**Conclusion:** This qualitative analysis brought to light important topics such as the regulation that guides advance will directives and principles that involve bioethics, to consolidate the respect, autonomy and dignity of the patient who is, or will be, undergoing the terminality of life.

**Keywords:** Terminal care, Advance Directives, Palliative care.

### RESUMO

**Introdução:** A autonomia do paciente na tomada de decisões a respeito da sua vida e das condutas diagnósticas e terapêuticas na sua saúde tem sido objeto de valorização social crescente. As diretivas antecipadas de vontade surgem, então, como um meio de o paciente expressar sua última vontade, salvaguardando o princípio da autonomia. No processo de aprendizagem acadêmica, na maioria das escolas médicas, o acadêmico se compromete com a vida, e toda a sua capacitação é fundamentada em aspectos técnicos, e apenas uma pequena parte do currículo, quando presente, abrange conteúdo específico voltado para a terminalidade da vida. A medicina evoluiu com importantes avanços tecnológicos que resultaram em melhorias na qualidade de vida, porém também trouxeram um prolongamento questionável da vida, com tratamentos muitas vezes injustificáveis e com a obstinação terapêutica de manter a vida a qualquer custo.

**Objetivo:** Este estudo teve como objetivo analisar a percepção de estudantes de Medicina sobre as diretivas antecipadas de vontade.

**Método:** O instrumento de pesquisa foi elaborado com uma entrevista individual e semiestruturada, aplicada pela plataforma de pesquisa Google Forms. Por causa do período de pandemia pelo Sars-CoV-2, a pesquisa foi realizada de forma não presencial em conformidade com a legislação vigente nacional. Após fechamento da amostra por exaustão, analisaram-se as respostas de 13 estudantes.

**Resultado:** Em conformidade aos elementos, passos e critérios metodológicos, as informações obtidas foram classificadas e dispostas em duas categorias: dignidade da pessoa humana e autonomia do paciente; e conhecimento sobre diretivas antecipadas de vontade.

**Conclusão:** Essa análise qualitativa trouxe à tona importantes temas, como a regulamentação que norteia as diretivas antecipadas de vontade e os princípios que envolvem a bioética, a fim de consolidar o respeito, a autonomia e a dignidade do paciente que está, ou estará, passando pela terminalidade da vida.

**Palavras-chave:** Cuidados Paliativos na Terminalidade da Vida; Diretivas Antecipadas; Cuidados Paliativos.

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Chief Editor: Rosiane Viana Zuza Diniz.  
Associate Editor: Cristiane Barelli.

Received on 10/26/22; Accepted on 03/21/23.

Evaluated by double blind review process.

## INTRODUCTION

The patient's autonomy in making decisions about their life and their therapeutic process has been the object of growing social appreciation. In Latin America, countries such as Puerto Rico<sup>1</sup>, Argentina<sup>2</sup> and Uruguay<sup>3</sup> already have legislation granting this autonomy to patients.

In Brazil, there is no legislation on the subject, only class council resolutions. Resolution number 1,805/2006, of November 28, 2006<sup>4</sup>, allowed the physician to limit or abort treatments that prolong the life of terminally-ill patients<sup>4</sup>. As for Resolution number 1995/2012, of August 31, 2012<sup>5</sup>, it maintained the previously established provisions and more fully regulated advance directives (AD)<sup>5</sup>. In this context, ADs emerge as a way for the patient to express their last will, safeguarding the Principle of Autonomy<sup>6</sup>.

Students in most medical schools are committed to life, and their training is based on technical aspects. Only a small part of the curriculum includes contents focused on the terminality of life, but nonetheless, they are insufficient to deal with end-of-life scenarios. Considering this scarcity of reflections on the terminality of life from the medical student's context, it is necessary to understand how familiar the students are with the subject<sup>7</sup>.

It is important to assess knowledge and attitudes towards these issues among medical students, as it is known that this is a scenario of lack of knowledge and insecurity, aiming to identify possible gaps in medical curricula and work on fundamental ethical issues for care<sup>7</sup>. Therefore, this research was carried out with the objective of analyzing the knowledge about the understanding that medical students from a Higher Education Institution (HEI) have about Advance Directives.

## METHOD

The present study is a descriptive research with a qualitative approach, aiming to analyze values and meanings that do not fit the quantitative approach. This methodology was chosen due to the need for more in-depth studies on the subject and the population under this methodological view<sup>8</sup>.

The guiding question of the study, "How much knowledge do undergraduate medical students have about advance directives?" had its answers analyzed according to Minayo's theoretical framework, which allows the approach of human expressions in relationships, subjects and representations<sup>9</sup>.

The focus of the qualitative methodology is on the increase of understanding; it seeks to explain the reason for things, producing in-depth and illustrative information. Therefore, there is no widespread concern with numerical representativeness<sup>9</sup>.

To structure the qualitative research, Minayo defends the existence of four terms: experimentation, experience, common sense and action<sup>10</sup>. Based on this, the analysis is performed through understanding, interpretation and dialecticization<sup>10</sup>. Understanding acts as the basis of the methodology used in the present study, being exercised by the act of putting oneself in the other's place; it is noteworthy that all understanding is partial and unfinished, both by the interviewee and by the researcher - we are limited in what we understand and interpret<sup>10</sup>.

Regarding the context in which the research was carried out, the proposal for data collection through semi-structured interviews was initially developed with the simulation of a realistic scenario. During the data collection period, the SARS-CoV-2 pandemic emerged and, due to the need for social isolation, face-to-face interviews became unfeasible. In view of the unexpected scenario, the alternative of carrying out data collection through a digital platform was found. A questionnaire was prepared using Google Forms, with dissemination through digital platforms (WhatsApp and E-mail).

The invitation for the survey was sent to a total of 608 medical students duly enrolled at the HEI. After several attempts in the months of April to July 2020, when the pandemic was in its ascending phase, 14 responses were obtained. One of them was excluded because the student already had a previous degree. After 90 days of waiting and fruitless searching for new participants, the authors decided to close the sample due to exhaustion<sup>11</sup>.

To analyze the qualitative material, Minayo defends the existence of three modalities: content analysis, discourse analysis and hermeneutic-dialectical analysis<sup>9</sup>. We chose to use discourse analysis for the present study, which involves historical materialism, linguistics and discourse theory<sup>9</sup>.

The first stage of the analysis consists of the pre-analytical disposition of the data, in which the literal transcription of the interviews is carried out. Subsequently, it is possible to organize a classification according to keywords and core meanings evident in the interviewees' speeches<sup>12</sup>.

In the second stage, also called the final pre-analytical stage, the thematic organization starts, based on the central ideas of the responses and the most relevant identified topics<sup>13</sup>.

Finally, the final analysis is carried out, which interprets the contents organized in the first two phases. As a result, new questions must always be generated, respecting the spiral process of the Research Cycle - it starts from the empirical and once again returns to the empirical<sup>9</sup>.

Regarding the ethical aspects, the research was carried out based on Resolution n. 466/12 and 510/16. The project was submitted to and approved by the Research Ethics Committee, under CAAE number 26695919.7.0000.5580. Data

collection was started only after the approval for the research was obtained.

The risk of direct embarrassment ceased to exist in the new data collection format, but the risk of loss of the participants' anonymity, loss of confidentiality of collected information and risk of triggering feelings when asking questions of a sensitive nature remained.

As a way to minimize risks, the answers were removed from the digital environment, the participants' confidentiality and anonymity were maintained by the researcher and direct access to the researcher was made available through personal e-mail for all participants.

The study's benefit comprises the possibility of the analysis and understanding of students about the advance directives of will.

The simulations used for data collection were recorded in the institution's simulation laboratory, with the participation of members of the Palliative Care Undergraduate Research Group.

These simulations included a virtual patient with a terminal illness who reports to their attending physician that they have doubts about the treatment continuation and the quality of life that this treatment has brought them. In a second moment, the virtual patient informs their attending physician during an outpatient consultation that they no longer want to maintain their treatment. And the third part of this simulation takes place in an emergency care environment, with the virtual patient showing evident suffering, reporting their desire for palliative care and the family member requesting that every possible effort be made for the patient's survival.

## RESULTS

The analysis of the information collected during the interviews with the 13 participants was carried out after a detailed and careful reading of all the material, transcribed in its entirety. This allowed highlighting the contents that answered the initial research questions.

After the material was read, it was organized into categories. According to the previously mentioned elements, steps and methodological criteria, the obtained information was classified and arranged into two categories and eight subcategories. The first concerns the *Dignity of the Human Person* and the *Patient's Autonomy*, involving terms that are frequently used in the answers, such as respect for professional ethical values, palliative care, quality of life, orthothanasia. The second category, *Knowledge about Advance Directives*, concerns the periodicity of the terms of terminality of life, quality of life, patient's rights and choices, and therapeutic decision.

Therefore, it was possible to subdivide the categories

into subcategories according to the key terms based on the students' responses. Based on the students' responses, the most frequently observed contents were highlighted, namely:

Related to Category 1 – Dignity of the human person and the patient's autonomy, with the following citations being selected, which allowed the identification of the subcategories cited in parentheses:

*Student K - "That the patient made the therapeutic decision that would mostly grant them peace. Regardless of their choice, my role as a physician is to offer comfort and relief in the form of palliative care. If the patient's decision is to abstain from treatment, it is still my duty to provide the best quality of life, the best palliative care, even in this situation." (Ethical and professional values).*

*Student E - "Seeking to know about the case of another patient with the said physician is the referral service in which they were followed! Ask to have a conversation with the family member in a peaceful environment, ask what they understand about palliative care, about their perception of their mother's illness! Ask if they have heard of advance directives of will and explain that for the patient this whole process can be much more painful than for the family, who wants to keep them alive for a longer period of time! And always respect the patient's will, because it is their right!" (Palliative care)*

*Student A - "For me, I would define it as freedom of choice and quality of life. The patient, aware of their terminality of life, has complete freedom to choose what they want for themselves, and it is up to us to accept this decision. The patient chooses the quality of life that they miss so much, and, therefore, is up to us to offer support to them to regain that. After that, the patient's choice, at first I would confirm with the patient if that was what they wanted, whether they would not like some help from other services, such as Psychology. If this is what they really want, I would accept it and try to provide all the quality of life that the patient wants. Allow them to do what they want, with adequate arrangements. Freedom of choice for the patient; however, with all the necessary guidelines." (Quality of life)*

*Student F - "First I would admit the patient and refer them to be medicated for pain. During that time, I would try to find out more about the patient's medical history and talk to their family member, explaining the disease condition and whether or not there is a possibility of cure, respecting the patient's desire to no longer undergo treatment." (Orthothanasia)*

Regarding Category 2 - Knowledge about Advance Directives of Will, the following citations were selected:

*Student A - "(...). The patient, aware of their terminality of life, has complete freedom to choose what they want*

for themselves, and it is up to us to accept this decision. The patient chooses the quality of life that they miss so much, and, therefore, it is up to us to support them to regain that. After that, the patient's choice, at first I would confirm with the patient whether it was what they wanted, whether they would not like some help from other services, such as Psychology. If this is what they really want, I would accept it and try to provide all the quality of life that the patient wants. Allow them to do what they want, with due prudence. Freedom of choice for the patient; however, with all the necessary guidelines." (Terminality of Life)

Student K - "For me, the patient's decision must be respected, they recognize one's end of life, it is not up to me to make judgments and decisions for them, such as forcing them to undergo a very invasive treatment that only decreases their quality of life and make the end of their life troubled and filled with suffering; thus, I would present palliative care, explaining how it works, what the objectives are and the proximity that can take place with the family." (Termination of Life)

Student L - "Yes! When they decided that they didn't want to continue with the chemotherapy, or dialysis, or hospitalization, or resuscitation." (Quality of life)

Student C - "I would explain to the patient's family member that it is their mother's right and about their mother's autonomy over the decision regarding the conduct; I would explain about the terms that the patient could establish about their wishes and administer the medication for pain relief." (Patient's right and choices)

Student D - "I respect the patient's decision. And I explain to the family member that their decision must be respected, however sad it may be for the family." (Patient's right and choices)

Student F - "I know it is a difficult situation, but I would talk to the family about psychological treatment, to convince the family member and about a palliative care approach (because they also need this care) and I would try to comply with the patient's wishes, because I understand that it is the right of any patient while they are still conscious" (Patient's right and choices)

Student E - "Seeking to know about the case of another patient with the said doctor is the referral service in which they were followed. Ask for a conversation with the family member in a quiet environment, ask what they understand about palliative care, about their perception of their mother's illness! Ask whether they have heard of advance directives of will and explain that for the patient this whole process can be much more painful than for the family, who wants to keep them alive for a longer period of time! And always respect the patient's will, because it is their right!" (Patient's right and choices)

Student L - "Yes! When they decided they didn't want to continue with the chemotherapy, or dialysis, or

hospitalization, or resuscitation." (Patient's right and choices)

Student B - "I would talk to the family trying to demonstrate that the patient is in perfect mental health and this choice can only be made by them. I would try again to show the positive sides of the treatment and the negative ones. I would find therapy that, according to their health status, would allow the reduction of pain without causing other problems" (Therapeutic decision)

Student D - "I would treat the pain with medication and I would respect the patient's choice, I would talk to the family member about their mother's decision and that the support of the whole family at this moment is very important." (Therapeutic decision)

## DISCUSSION

### Human Dignity and Palliative Care

From a conceptual perspective, according to Bonavides et al., (2009)<sup>14</sup> human dignity is a broad and complex concept, "[...] it is a set of social, economic, cultural and political conditions". A concept that is difficult to understand, but of easy assertion. Historically, the principle of human dignity had its origins in the American and French Revolutions, in the 18<sup>th</sup> century, and the basis of these revolutions was the search for the triad encompassing happiness, freedom and equality<sup>15</sup>.

In Brazil, the principle of human dignity is embedded in the Federal Constitution of Brazil<sup>16</sup>, in art. 1, III, under title I "Of fundamental principles", as the foundation of the Democratic State of Law of the Federative Republic of Brazil, alongside sovereignty, citizenship, social values of work and free initiative, and political pluralism. Moraes (2015)<sup>17</sup>, in turn, states that the dignity of the human person is a principle that "grants unity to fundamental rights and guarantees, being inherent to human personalities". Dignity would be, according to him, "a spiritual and moral value inherent to the person", manifested in the "conscious and responsible self-determination of one's own life"<sup>17</sup>.

In this sense, dignity is intrinsically involved with caring for the patient at the end-of-the-life stage, through palliative care that preserves human dignity. The concept of palliative care is defined by the National Academy of Palliative Care as an approach that improves the quality of life, with early and correct identification of pain, in addition to the management of other psychological, social and spiritual problems of the patient<sup>18</sup>.

In order to guarantee one's quality of life, well-being, comfort and human dignity, palliative care must be based on the person's care, valuing the patient's needs so that they can receive adequate and culturally appropriate information about their health status and their role in the decision-making regarding their treatment<sup>19</sup>.

## Therapeutic Decision and Patient Autonomy

Regarding the therapeutic decision, there is no obligation by the medical professional to prolong the life of the patient whose prospects for a cure have already been exhausted, and it is up to the patient or their legal representative to decide on treatment continuation, after receiving all the available information on therapeutic alternatives. Thus managing to preserve the patient's individual autonomy and dignity, who will receive the necessary care to alleviate their suffering. There is even the possibility of requesting hospital discharge for the patient, who will be able to undergo the death process with more dignity and humanity, alongside the people they love the most<sup>19,20</sup>.

The therapeutic decision is only validated after exhaustive information about the patient's health status, and possibilities of cure or death. It can be observed in the students' responses that the therapeutic choice is a way of respecting the patient's autonomy of choice.

The historically known Hippocratic concept was based on the principles of pain relief, reduction the pathology damage and renouncing treatments when Medicine is no longer capable of collaborating to reverse the condition. Currently, Resolution number 1995/2012 was published by the Federal Council of Medicine (CFM, *Conselho Federal de Medicina*), which recognizes the validity of advance directives of will and supports the physician who follows their determinations<sup>5</sup>. Such resolution, despite the fact that it has normative strength, whose non-compliance with the established acts violates the Code of Medical Ethics<sup>21</sup>, does not find regulation in the Civil Code<sup>22</sup>.

It is essential to maintain a balance between scientific and humanistic knowledge, recovering the dignity of life and the quality of death. Given that death is a gradual evolution of the vital process, from a philosophical and even ontological point of view, there are several concepts that have a complex impact on the field of Ethics and Law.

## Advance Directives of Will and the Patient's Rights of Choice

With the aim of reinforcing the importance of patient autonomy at the end of life, the Advance Directives are mentioned, which in Resolution number 1995/2012 of the CFM<sup>5</sup>, define them as the intentions declared by the patient regarding the decision of treatments that they want to be submitted or not, especially when unable to express oneself, in addition to clarifying borderline issues, including the hypothesis of manifestation by the patient's designated representative<sup>5</sup>.

Through this same resolution, it should be noted that it is not a doctor's prerogative to choose whether to follow it or not. If they do not comply with the provisions, they will be held responsible at least administratively, since the resolutions

are acts issued by the plenary sessions of the Federal Council of Medicine and some of the Regional Councils of Medicine that regulate matters of exclusive competence of these entities in their areas of scope, as the supervising, normalizing, disciplining, inspecting and judging bodies of medical professional activity throughout the national territory<sup>23</sup>.

In response to the behaviors adopted by the medical students in the simulation, in response to the simulated patient's request, much is observed of the preservation of the patient's right to make decisions through the process of convincing of and acceptance by the family member. It is very common in medical practice for the patient to request that fruitless invasive measures be avoided, but the family members refuse or do not accept it. One can observe the maturity in the students' responses regarding the bioethical principle of autonomy, and the constitutional rights of dignity and freedom of choice, without neglecting the care needs.

Thus, it is also the physician's responsibility to inform the patient, a responsibility guaranteed by the Federal Constitution/1988<sup>16</sup>, in its 5<sup>th</sup> article. XIV which quotes: "Access to information is guaranteed to all and the source confidentiality is safeguarded, when necessary for professional practice"<sup>16</sup>. This responsibility related to information is also provided in the Code of Medical Ethics itself, which states in its article 34 that it is prohibited for the physician to "fail to inform the patient of the diagnosis, prognosis, risks and objectives of the treatment, except when direct communication can cause them harm, and in that case, the legal representative must be notified"; it is clear, then, that the physician has a duty to inform the patient about the treatment to which they are to be submitted<sup>21</sup>.

## Orthothanasia

Orthothanasia is defined as "death at the right time", which refers to the renunciation of futile and unnecessary treatments and procedures, thus avoiding dysthanasia, being possible to choose or not for palliative treatment methods, allowing pain control and quality of life. This reflection was already acknowledged in antiquity by Hippocrates, when he declared that the physician should "cure sometimes, relieve often, to comfort always"; in other words, when there is nothing else to do in terms of healing<sup>24</sup>.

Orthothanasia is a procedure envisioned as an ethical-medical procedure, on account of Resolution 1805 of the Federal Council of Medicine (CFM), of November 9, 2006<sup>4</sup>. In it, the CFM allowed the physician to intervene in the procedure that would prolong the life of the patient at the end of life, respecting their will or that of their legal representative<sup>4</sup>.

Therefore, when considering the possibility or not of the patient's cure and the need to medicate for the pain regardless

of the subsequent conduct, the student, when watching the simulation, demonstrated basic notions related to the concept of orthothanasia.

### Terminality and Quality of Life

The need to understand the terminality of life, a process resulting from the exhaustion of efforts to restore the patient's health, which brings to light imminent, inevitable and predicted death, is a crucial one, especially considering that, in current times, technology and invasive methods have not only increased longevity, but also delayed the death process and prolonged one's existence, although without ensuring quality of life<sup>25</sup>.

The terminality of life comes with considerable discomfort and anxiety, especially in oncological patients and victims of degenerative neurovascular diseases or accidents. Therefore, special ethical dilemmas are brought up, which depend on the cultural environment and religious convictions in which one lives, as well as the economic and social means destined to health<sup>26</sup>.

Therefore, approaching the patient in terminality aiming to maintain life at any cost is insufficient, exaggerated, unnecessary and ignores the suffering of the patient and their family. The simulated scenario, although it was a fictitious circumstance, showed how hard it is for the family to have to recognize the terminality of their loved one's life, being necessary for the health professional to explain that sometimes the patient is kept alive on account of treatments that bring more pain than relief and comfort. And from the bioethical point of view, these observations would not be a disapproval of technological medicine, but a stimulus to reflect on the conduct to be taken in the presence of inevitable human mortality<sup>26</sup>.

Within the cultural concept that it is the physician's duty to preserve life at any cost, the responsibility of providing information should not be overlooked, explaining to the patient and family members the real scope of a certain therapy, without hurting the patient's dignity, whose cure is no longer viable, and that palliative care is the choice for providing comfort to a body that is already very compromised. Thus, after the patient is duly informed and clarified, it is up to them to choose limiting or suspending the ineffective treatment, with the support of constitutional guarantees, which cannot be disregarded, since they are a guarantee, and not an optionality<sup>25</sup>.

### CONCLUSIONS

Due to the lack of legislation on advance directives of will, a lot of insecurity and lack of knowledge are generated, both in patients and physicians.

The interviews carried out with the students show that many already have knowledge about AD, but some of

them show insecurity in accepting the patient's decision, when contrary to that of the patient's family. One should not praise the survivor, nor use terms such "lost" or "won" a battle. Physicians are not at war with disease, there is no failure when someone dies.

This issue should be discussed in several areas and different moments, together with diverse topics and situations. The student should be allowed to feel the pain when giving news of illness or death. Thus, these professionals will be trained to be more empathetic and aware of their role by showing that they are not dealing only with the biological body of the patient, but with a life, full of stories, and that at a given moment they, as physicians, will be also part of that story.

### AUTHORS' CONTRIBUTION

Tatiana Rosa Ogata Nakagawa: researcher and editor of the study. Andressa Luciani Pereira Rodrigues, Valéria Carolina Armas Villegas, Laura Block Gurtat and Gabriela Ribeiro de Castro: collected the data and formatted the study. Márcio José de Almeida: advisor and reviewer of the study.

### CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

### SOURCES OF FUNDING

The authors declare no sources of funding.

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