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Advance directives in a hospital emergency department

Paula Azambuja Gomes[1], *José Roberto Goldim*[1]

1. Universidade Federal do Rio Grande do Sul, Porto Alegre/RS, Brasil.

Abstract

Patient participation in planning their health care means respecting the patient's right to self-determination. In this sense, this study aimed to examine the position of doctors working in the Hospital Emergency Service of the Hospital de Clínicas de Porto Alegre regarding patient advance directives. This is a cross-sectional study conducted with 32 physicians. Most participants (81.3%) declared to have knowledge about advance directives, but only 6.3% declared having sufficient knowledge; 87.5% were in favor of their use and the patient's will was considered decisive in three of the four scenarios presented; and 84.4% considered that specific legislation on the matter is necessary in addition to Resolution 1995/2012 of the Federal Council of Medicine. Our results allowed us to conclude that most physicians had prior knowledge about advance directives and were in favor of using this type of document in hospital emergency care.

Keywords: Decision making. Advance directives. Emergency medical services. Bioethics.

Resumo

Diretivas antecipadas de vontade em unidade de emergência hospitalar

A participação do paciente no planejamento de seus cuidados de saúde respeita seu direito à autodeterminação. Com isso, esta pesquisa teve como objetivo avaliar o posicionamento de médicos que atuam no Serviço de Emergência Hospitalar do Hospital de Clínicas de Porto Alegre em relação às diretivas antecipadas de vontade de pacientes. Trata-se de estudo transversal com 32 médicos. A maioria dos participantes (81,3%) afirmou conhecer as diretivas antecipadas de vontade, mas apenas 6,3% tinham conhecimento suficiente; 87,5% foram favoráveis à sua utilização e a vontade do paciente foi considerada determinante em três dos quatro cenários apresentados; e 84,4% consideraram necessária legislação específica além da Resolução 1.995/2012 do Conselho Federal de Medicina. Ao final do estudo foi concluído que a maioria dos médicos tinha conhecimento prévio sobre diretivas antecipadas de vontade e se posicionara a favor da utilização deste tipo de documento em emergência hospitalar.

Palavras-chave: Tomada de decisões. Diretivas antecipadas. Serviços médicos de emergência. Bioética.

Resumen

Directivas anticipadas de voluntad en una unidad de emergencia hospitalaria

La participación del paciente en la planificación de su atención médica respeta su derecho a la autodeterminación. Así, esta investigación tuvo como objetivo evaluar el posicionamiento de médicos que actúan en el servicio de emergencia hospitalaria del Hospital de Clínicas de Porto Alegre en relación a las directivas anticipadas de voluntad de los pacientes. Se trata de un estudio transversal con 32 médicos. La mayoría de los participantes (81,3%) afirmó conocer las directivas anticipadas de voluntad, pero solo el 6,3% tenía conocimiento suficiente; el 87,5% se mostró a favor de su uso y la voluntad del paciente fue considerada determinante en tres de los cuatro escenarios presentados; y el 84,4% consideró necesaria una legislación específica además de la Resolución 1995/2012 del Consejo Federal de Medicina. Al final del estudio se concluyó que la mayoría de los médicos tenían conocimiento previo sobre directivas anticipadas de voluntad y se habían posicionado a favor de la utilización de este tipo de documentos en emergencias hospitalarias.

Palabras clave: Toma de decisiones. Directivas anticipadas. Servicios médicos de urgencia. Bioética.

Research

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Achieving greater longevity is a major challenge for human health sciences. This search has often been associated with an attempt to delay death and change the natural course of diseases, as well as with an increasing incidence of multiple comorbidities. Greater longevity can sometimes only prolong existence while resulting in poor quality of life [1,2].

Similarly, the last decades have seen a significant advance in recognizing patients' autonomy and right to self-determination. This has posed further challenges for healthcare providers in how to adequately provide information to allow patients to decide about their treatment, exercising their freedom to authorize or refuse a procedure or therapy [1].

One current healthcare goal is to ensure that high quality care is associated with respect for patient autonomy. This has been especially challenging in hospital emergency care [2], in which health conditions imply an imminent risk of death or intense suffering. These conditions require quick decision-making to allow adequate and fast medical treatment [3]. Such scenario can even seem to justify a form of paternalism, in cases in which the patient is unable to participate in the decision-making process.

The principle of respect for autonomy is associated with the personal right to free choice with as little external influence as possible. Respect for self-determination – being able to express one's wishes and actively participate in one's health care planning – has been progressively ensured and incorporated into the practice of healthcare providers [4]. We must differentiate between autonomy, understood as the ability to decide, and self-determination, an exercise of the decision-making ability [5].

Brazil has several provisions in place to guarantee one's right to participation. Freedom is a fundamental right assured by article 5 of the Federal Constitution [6]. In its article 15, the Brazilian Civil Code [7] grants citizens the right to actively participate in decisions involving medical treatments and procedures. Article 17 of Law 10,741/2003 [8] establishes additional protection for older adults to guarantee them this right to participation, providing that if the patient is unable to decide, decision-making must fall to their caretaker, if any, their family or even their physician, in life-threatening situations.

But not everyone is able to fully exercise their autonomy. Psychological-moral development takes place throughout life and may be hindered by numerous physical and mental factors, thus fully or partially impairing their ability to exercise self-determination due to physical or mental impairment, or other circumstances severely restricting their freedom to decide [9]. Furthermore, patients treated in hospital emergencies may often be unable to exercise self-determination, and their family members may make decisions which disagree with their wishes. This can be avoided with the use of advance directives (AD) or by previously defining a representative to make decisions in their place in case of incapacitation [10,11].

In Brazil, this possibility is guaranteed by Resolution 1,995/2012 [12] of the Federal Council of Medicine (CFM), which established conditions and procedures to ensure that patients' wishes are considered even when they are unable to actively participate in healthcare decisions. Resolution 1,995/2012 [12] established that patients' wishes regarding AD, registered in their medical records by the medical team, prevail over decisions made by their family members. The appointment of a representative, who should also be identified in the medical record, guarantees that this person will be the patient's proxy interlocutor with the healthcare team. Only the patients themselves can amend the AD. According to this same resolution [12], care teams must consider AD in any decision involving a patient who is unable to participate in this process. Advance directives, however, are guidelines, not obligations [12].

Some studies show that health professionals have doubts about AD, and this lack of knowledge is compounded by fears arising from a lack of specific legislation on the subject in Brazil [13]. Despite the recognized absence of specific AD laws, current legislation allows for this possibility in Federal Constitution [6], the Civil Code [7] and the Statute of the Elderly [8] articles. CFM Resolution 1,995/2012 [12] explicitly establishes AD and the possibility of appointing a representative for health care decision-making. All these legal instruments combined attest to the legal and deontological adequacy of AD [12].

Emergency care particularities add other factors that may hinder the proper use of AD. One such factor is the lack of prior knowledge of the patient, their needs, and their preferences. In patients with chronic-degenerative diseases,

the worsening of the illness may raise important ethical questions regarding the adequacy of the treatments to be offered. This situation becomes even more difficult when these patients lack any therapeutic possibility of cure. Patients, family members, and healthcare teams do not always agree on this assessment [14].

In cases of patients with incurable diseases or in end-of-life situations, some treatments provided in emergency health care services may be considered as therapeutic obstinacy [15]. This type of care may result in impacts on the patient in terms of physical discomfort and loss of quality of life. For family members, this kind of treatment can lead to false expectations and high incurred costs. For society, they may represent a futile consumption of resources [16].

However, the situation is often unclear. Doctors working in emergency units are often faced with cases involving difficult decisions, associated with a high degree of uncertainty and requiring rapid intervention. Psychological and moral development directly influences how these circumstances are approached. It is this development which allows for better quality care throughout the process, due to the complexity of the multiple interests involved [17].

The lack of knowledge and uncertainty associated with emergency situations make decision-making even more complex. There may be conflicting expectations, especially regarding the conduct and procedures to be adopted. The patient, even at the end of life, when taken to emergency care, expects to have their life preserved. The act of seeking emergency care may be understood as a cry for help. The professional-patient-family relationship is fundamental in these cases [18].

Efficient and affectionate communication between doctors, patients, and family members is a key element of patient-centered care. However, in emergency care, time for interaction is restricted or even nonexistent. AD can be an important communication and decision-making factor in this situation, as it involves not only life but also the patient's living experience. Most of the time, however, patients' wishes, expectations, and desires regarding their future life are disregarded, unavailable or even unknown [4]. Thus, this article aims to examine the views of doctors working in a hospital emergency service about patients' AD regarding their awareness, appreciation, and ethical-legal basis.

Method

This is a cross-sectional study conducted with doctors working in the Adult Emergency Service of the *Hospital de Clínicas de Porto Alegre* (HCPA). All 43 doctors who performed clinical activities at the hospital were invited to participate. Data collection took place at participants' own workplace.

Participants' sociodemographic and professional data were collected, including age, sex, and length of time working in emergency care. Participants were asked questions about their degree of personal knowledge about AD, their opinion regarding its use and, if applicable, their justifications for its use. Their views on the need for specific legislation were also assessed. Another question sought to verify whether, in their perception, doctors understood that there are ethical differences between withholding and withdrawing futile treatment. Moreover, 11 different aspects that could be associated with the use of AD were presented. To assess participants' attitude to decision-making, four different scenarios were presented, each with six alternatives: the patient plays a determining role; the patient influences physicians' decision; the patient and his family influence physicians' decision; only family members influence physicians' decision; legal basis is lacking; or legal risk is involved.

Participants' levels of psychological and moral development was assessed using a previously validated instrument [19]. This tool asks participants to select nine sentences among 30 different options associated with different stages of psychological and moral development: impulsive, opportunistic, conformist, conscientious, autonomous, and integrated. A person is considered capable of making decisions in their best interest when they are classified into the conformist, conscientious, autonomous, and integrated stages. Participants were classified into one of these stages based on their individual selection of sentences.

The data collected were analyzed using mixed methodologies. Descriptive and inferential

statistical techniques were used. Associations were obtained using Fisher's exact test, considering the size of the study sample. The significance level was set to 5% (p<0.05). The SPSS system, version 18, was used in these procedures, and qualitative data were evaluated using content analysis [20].

This research project was approved by the HCPA Research Ethics Committee in accordance with Resolution 466/2012 of the Brazilian National Health Council [21]. All participants authorized the use of their data by signing an informed consent form.

Results

This study used a convenience sample of 32 doctors, representing 74.4% of the 43 professionals working at the HCPA Emergency Service who were invited to participate in the study. Participants' age ranged from 32 to 58 years. Sample distribution by sex was balanced since 50% of the participants were women and 50%, men. The shortest length of time working in emergency care was six months and the longest, 25 years, with a mean and median of 10 years.

The assessment of psychological and moral development showed that results for all participants were compatible with the ability to make adequate decisions, as all fell into the conformist, conscientious, autonomous, and integrated stages. Most participants fell into the autonomous stage (n=20; 62.5%), and the conscientious one was the second most common (n=10, 31.3%). The conformist and integrated stages had only one physician (3.1%) classified into each.

In total, 26 (81.3%) participants stated having knowledge of AD, of which only two (6.3%) claimed having sufficient knowledge. Of the others, 12 (37.5%) declared having average knowledge and the other 12 (37.5), little knowledge on the subject. Regarding AD use, most participants (n=28; 87.5%) were in favor, two (6.3%) claimed they might use them, one (3.1%) would refuse to use them, and another (3.1%) failed to respond.

Overall, 25 participants (78.1%) explained their reasons for AD use, which we could group into four different categories: two related to the patient – their autonomy (50%) and prior and adequate information (6.3%) – and two related to the physician – to facilitate decision-making (15.6%) and to prevent the use of futile treatment (6.3%). Regarding legislation, 27 (84.4%) participants considered specific legislation on AD use, in addition to CFM Resolution 1,995/2012 [12]. If specific legislation was already in place, 28 (87.5%) physicians claimed they would accept AD, and the remaining four (12.5%) stated that they might consider them in their decisions.

Only one (3.1%) of the 32 participants failed to respond to questions involving the four decision-making scenarios. In their answers, no participant chose the alternatives referring to "lack of legal basis" or "legal risk." All participants chose alternatives engaging the patient or family members in the decision-making process (Table 1).

Table 1. Answers given by 31 physicians working in emergency care about four different scenarios of patient and family participation in the decision-making process

Treatment refusal	Patient's will is decisive	Patient's will influences	Patient's and family's will	Family's will
Competent patient with therapeutic possibility of cure	25 (80.6%)	2 (6.5%)	4 (12.9%)	–
Competent patient without therapeutic possibility of cure	28 (90.3%)	1 (3.2%)	2 (6.5%)	–
Patient no longer competent and without therapeutic possibility of cure left advance directives	26 (83.9%)	1 (3.2%)	4 (12.9%)	–
Patient no longer competent and without therapeutic possibility of cure expressed his will to a family member	14 (45.2%)	4 (12.9%)	12 (38.7%)	1 (3.2%)

Note: n(rf); X^2=19.09; p=0.003 (S).

Research

The first scenario asked the physician's position regarding a fully competent patient with therapeutic possibility of cure who refused treatment. Most respondents (n=25; 80.6%) indicated that the patient's will would be decisive in decision-making; four (12.9%) participants indicated that the patient and family members would participate in decision-making; and only two (6.5%) responded that the patient's will would influence their decision.

The second scenario involved a patient considered fully competent, but without therapeutic possibility of cure, who refused to authorize treatment. Its distribution pattern was similar to that of the previous scenario, but with a few more participants characterizing the patient's will as decisive (n=28; 90.3%). The involvement of the patient and family members was indicated by two (6.5%) participants; and only one (3.2%) indicated that the patient would influence their decision.

The third scenario also presented a patient without therapeutic possibility of cure, but who had an AD registered in their medical record expressing treatment refusal. Responses showed a distribution similar to that of the first and second scenarios, with 26 (83.9%) participants indicating that the patient's will is decisive; four (12.9%) observing the patient's and family's will; and one (3, 2%) indicating that patient's will would only influence decision-making.

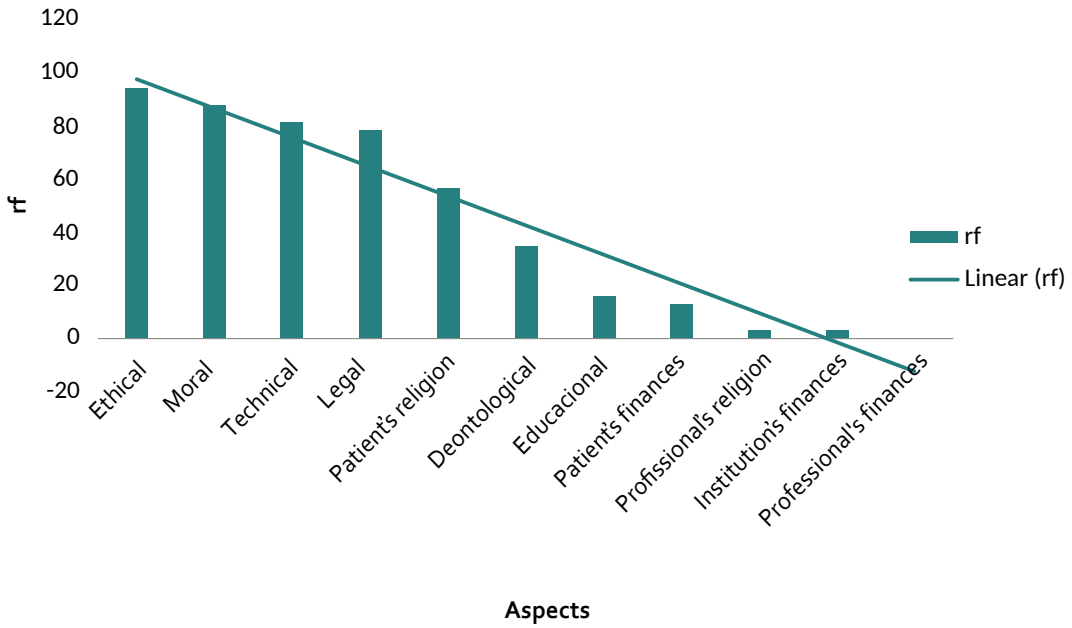
The fourth and last scenario presented a patient without therapeutic possibility of cure who was unable to participate in decision-making and only verbally expressed their treatment refusal to a family member. The pattern of responses changed for this scenario. The patient's will was considered decisive by 14 (45.2%) participants, followed by the observance of the patient's and family's will (n=12; 38.7%). The alternative in which the patient only influences the physician's decision was chosen by four (12.9%) respondents; and only one (3.2%) indicated that they would consider the family's will.

The analysis of the responses for the four scenarios shows the same pattern of considering patients' will as decisive when they directly expressed it to physicians or byan AD, regardless of the existence or absence of a therapeutic possibility of cure. This pattern only showed a significant change (X^2=19.09; p=0.003) when patients' will was indirectly expressed via a family member. In this situation, responses were distributed between the patient's will being decisive and the involvement of both the patient and family (Table 1). Considered in isolation, the patient having or not the therapeutic possibility of cure was an insignificant factor for considering their will as decisive (X^2=0.3583; p=0.549 NS). On the other hand, when this association involves a patient expressing their will directly or by an AD, in comparison with a family member expressing their will without associated documentation, it becomes very significant (X^2=17.5627; p=0.00001).

Participants were almost unanimous (n=29; 90.6%) in declaring that there was no ethical difference between withholding and withdrawing therapeutic measures considered futile. The remaining participants (n= 3; 9.4%) stated that it is justifiable to withhold futile measures.

Overall, we presented 11 different aspects which could influence AD use in decisions involving patients treated in hospital emergency services. Each participant could select the aspects they considered relevant. Ethical aspects were the most selected (93.8%), followed by moral (87.5%), technical (81.2%), and legal ones (78.1%), those involving the patient's religion (56.2%), deontological (34.3%) ones, those involving the patient's financial situation (12.5%), educational ones (15.6%), those involving the professional's religion (3.1%), and those involving the institutional financial situation (3.1%). Only the alternative referring to professionals' financial situation was not selected by any participant (Figure 1).

Figure 1. Relative frequency of responses associated with aspects physicians believe influence the use of advance directives in hospital emergency care (n=32)



rf: relative frequency

Discussion

Study participants had ample experience in emergency care as more than 50% of the sample had worked in the area for more than 10 years. All participants showed sufficient psychological and moral development for adequate decision-making, with the majority (65.6%) classified into the autonomous or integrated stages. In these two stages, the person already perceives incorporated rules, allowing for independent decision-making free of external constraints [22].

However, in addition to the necessary level of psychological and moral development, decision-making capacity encompasses several other skills, such as the ability to get involved with a subject, understanding and evaluating alternatives, and communicating their preferences [23]. In emergency care environments, lack of acquaintance can impair the relationship and communication between physicians and patients. AD can remedy, at least in part, this lack of information about patients' desires and preferences.

Most participants in this study (81.3%) declared having knowledge of AD, even if superficial, as only a small group reported having ample knowledge (6.3%). Several studies [24-26] conducted in Brazil in the last years found poor knowledge on AD among medical students, even among those familiar with CFM Resolution 1,995/2012 [12].

Most physicians participating in the study (87.5%) were in favor of using AD to document patients' desires and preferences. A point of interest is the association between respecting patients' wishes and having a good knowledge about ADs. The two participants who indicated that patients could only influence but not define their decision declared having little or medium knowledge about ADs. The only physician who indicated that he would not consider patients' will in his decision had no knowledge of ADs.

Most respondents (87.5%) also mentioned the need for specific legislation on the subject in addition to CFM Resolution 1,995/2012 [12]. The percentage of participants who declared they would use AD if there was a specific legal basis remained the same (87.5%), that is, the existence of specific legislation could better support decisions but would fail to change physicians' willingness to consider ADs. Another study also corroborated this result, emphasizing that physicians could feel safer in their decisions if there were specific legislation on AD [27].

The use of AD has legal basis in article 5 of the Brazilian Federal Constitution [6] and article 15 of the Civil Code [7]. The former establishes autonomy as a fundamental right, and the latter, patients' right to participation and the possibility of consenting or not to medical treatments. Likewise, the Statute of the Elderly, Law 10,741/2003 [8], applicable to people aged 60 years and older, reiterates the right to participation in medical care decisions. CFM Resolution 1,995/2012 [12] establishes the ethically appropriate way of engaging patients in decision-making, even if incapacity is expected.

Contrary to the understanding of some authors [28], CFM can establish appropriate routines and procedures for the practice of medicine. This already occurs, for example, in assisted reproduction via CFM Resolution 2,168/2017 [29], and in the establishment of criteria for the diagnosis of brain death via CFM Resolution 2,173/2017 [30]. CFM is legally responsible for ethically regulating the practice of medicine, according to Law 3,268/1957 [31].

Several studies [24,26,32] involving different physician and medical student samples also showed results favoring following patients' guidelines established in AD. A study aimed at identifying factors which influence physicians to implement AD and assessing its impact on end-of-life care showed similar results [32]. Physicians tended to respect their patients' wishes and agree that advance directives helped in decision-making while also considering other factors, especially prognoses and irreversibility.

The reasons physicians gave for properly considering ADs included patients and professionals' perspectives. From patients' perspective, the justifications given involved two central issues for an adequate decision: the need to be properly informed and the respect for patients' autonomy. From physicians' perspective, advance directives facilitate decision-making by giving visibility to patients' desires and expectations and supporting the decision to refuse using therapeutic measures characterized as futile, that is, that which fails to benefit patients [32].

An additional issue refers to the difference between withholding and withdrawing a therapeutic measure considered futile. For most participants in our study (90.6%), both actions would be equivalent. The other participants (9.4%) stated that only withholding would be appropriate. These decisions always generate some degree of discomfort. From an ethical point of view, withdrawing and withholding a futile therapeutic measure are equivalent decisions [33] but some physicians may consider it inappropriate to withdraw measures considered futile due to the psychological impact associated with the consequences of this action.

Medical decisions made in emergency care settings are always sensitive. Deciding not to resuscitate patients or not implementing invasive treatments is always difficult for care teams. The scarce research on the subject, the lack of clarity in recognizing nuances in these situations, and the different attitudes and personal values professionals, family members, and patients have are elements which make this process even more difficult [16,34].

The analysis of the responses to the four scenarios presented in our study showed the same response pattern for three of them, with only one standing out. In scenarios where patients' wishes were known, either expressed directly to the care team or by advance directives, and regardless of whether or not the patient had a therapeutic possibility of cure, patients' will were decisive. However, when patients' wishes were communicated only through a family member, physicians considered this indirect and undocumented expression of will but with less determination.

Responses to the four scenarios clearly showed the importance of physicians in hospital emergency care engaging patients' family members in the decision-making process. This becomes even more necessary in cases lacking AD. In this situation, families participate in the process to inform health professionals about the preferences, desires, and wishes patients expressed to them [35].

AD-related aspects highlighted by physicians in our study could be classified based on their relative frequencies. A larger number of responses addressed patients' ethical, moral, technical, legal, and religious aspects. On the other hand, the financial situation of the patient, the institution, and the professional, as well as the deontological and religious aspects related to the professional, were less mentioned. These results show a rather comprehensive decision-making process on the part of physicians.

The above shows that decision-making in health care must consider the technical adequacy

of medical indications, patients' preferences and quality of life, and the context of care, which includes the associated legal framework [36]. All these aspects coincide with the answers given by the physicians participating in the study. The study data are also similar to that of a prior study conducted with intensive care physicians from five different Brazilian hospitals [37].

Final considerations

The information obtained from the physicians working in hospital emergency services included in the study sample allowed us to identify a need to enhance the dissemination of the ethical and legal bases of AD. Nevertheless, most participants showed their willingness to comply with the wishes expressed by patients in this type of instrument. The justifications for its use highlighted the importance of the participation of patients and physicians in the decision-making process, and the ethical, legal, and technical aspects were the most highlighted by the professionals included in the study. Our study data reinforce the need to promote educational actions to reassure physicians working in emergency services regarding the respect for patients' wishes and preferences expressed in AD.

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Paula Azambuja Gomes – Master – psicologapaulagomes@gmail.com
0000-0002-9663-8134

José Roberto Goldim – PhD – jrgoldim@gmail.com
0000-0003-2127-6594

Correspondence
Paula Azambuja Gomes – Rua Luiz Fontoura Júnior, 230, apt. 803B CEP 91215-095. Porto Alegre/RS, Brasil.

Participation of the authors
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