



Special Article

COPD. A Model for Using Advance Directives and Care Planning

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ABSTRACT

Decision-making in COPD is complicated by the lack of clear prognostic factors. In this clinical situation it is also necessary to include the desires, values and choices of patients. The problem is more complex in the critical episodes, where the patients are incapable to make decisions. The instruments that allow incapable patients to represent themselves, the kind of patients who could benefit from its use, and the Spanish legislation on the matter, are presented in the first part of the work. The paper goes on to explain how to apply advance directives to the case of COPD. The article concludes that the appropriate use of advance directives and advanced care planning increases the quality of decisions at the end of the life of the patients with COPD."

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La EPOC: un paradigma para el uso de directivas previas y la planificación anticipada de decisiones

RESUMEN

La toma de decisiones en la EPOC es compleja por la ausencia de indicadores pronósticos claros. En estas situaciones clínicas es aún más necesaria la introducción de los deseos, valores y elecciones de los pacientes. El problema es aún más complejo en los episodios críticos intercurrentes, en los que el paciente no suele ser capaz de hecho. En la primera parte del artículo se definen los instrumentos que permiten que un paciente incapaz se represente a sí mismo, el tipo de pacientes que más se pueden beneficiar de su uso, y la legislación española al respecto. En la segunda se aplica al caso de la EPOC. El artículo concluye que el uso adecuado de las directivas previas y la planificación anticipada de decisiones incrementa la calidad y el fundamento en la toma de decisiones al final de la vida de los pacientes con EPOC.

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Introduction

Ever since Law 41/2002, which provided basic regulation of patient autonomy and rights and obligations regarding clinical information and documentation,¹ was effected on November 14, 2002, Spain has had a framework that clarifies the rights and duties of both patients and health professionals in terms of clinical relationship. While the law can be seen as a development of the rights contained in Article 10 of the General Health Act, it went further by introducing significant developments, including the right of patient access to their medical history and the granting of ownership of the right to patient information to the patient's family (or not, as the case may be), and the development of a new instrument for decision-making in situations of patient incapacitation and advance directive.

An advance directive is an instrument by which a patient drives and defines the actions of health professionals and sets limits for medical intervention and action by indicating how far they want the treatment for their pathology to go. This decision-making process with a capable patient is called the informed consent process. When a possible future incapacitation of the patient is predicted, the patient has the right to perform a declaration of advance vital directive and to have it respected in case the need arises. Law 41/2002, or the basic law of patient autonomy, gives legal force to the expression of the person's will for treatments they want to receive (or not) when they are incapable of expressing their preferences.

While practitioners in Spain started to become aware of these developments, the idea spread that this actually affects terminally ill patients much more than other types of patients such as the critically ill or those with chronic diseases. In North America, something similar happened with the *Natural Death Acts*, also known as living wills, which since 1976 have been adopted in various states so that people could express their wishes about how they wanted to die and what treatments they accept or reject. Originally, living wills could only be applied to the terminally ill and those in an irreversible coma. However, in the following two decades there were important changes.

The first development extended the possibility of decision-making to any pathology, although the most common area for rejection or limitation of treatment is when conditions meet the criteria of being serious, irreversible and advanced. The second one is the possibility for the patient to designate a representative, a negotiator able to speak to the practitioners on the patient's behalf when they are no longer capable of doing so, and to help interpret the patient's will, to specify their values, and apply the advanced directive to the actual clinical situation, something that almost always requires interpretation that goes beyond the written word.

The third change was a radical shift in the concept of this instrument. This change had much to do with the *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment* (SUPPORT) conducted in North America to describe how decisions are made at the end of life, the influence of the values and preferences of the patients and their families (descriptive phase), and to evaluate whether various strategies such as enhanced communication or the completion of advance directives (intervention phase) improved outcomes.² These changes were not the expected ones and started people thinking that decision-making at the end of life should not depend exclusively on written forms but on a much broader and more inclusive perspective.³ This means putting aside forms in order to focus on communication processes between physicians, patients and families concerning end of life processes. This is what is called

advanced care planning (ACP), a way of focusing the decisions that require active citizen participation, and practitioners capable of overcoming the bureaucratic model based exclusively on forms.^{4,5}

Something similar is happening in Spain. Many practitioners believe that these documents are aimed towards the terminally ill patients. There has also been an extension of the concept that there is "one more form" for the patient that must be taken into account. This situation leads to "legalism" and to a bureaucracy that threatens the clinical relationship by filling it with documents instead of allowing it to handle the clinical and ethical considerations that are required for appropriate planning of end of life decisions. It seems that Spanish law recognises more rights than those exercised and respected by the patients and the health professionals in clinical practice.⁶

The basic law of patient autonomy and later administrative regulations have developed the procedures that give validity to these documents. For practical purposes, we can classify citizens who decide to register their advance directives into two types. The first type are those who, using the standard format for their autonomous region, have gone directly to the registry or to the location stipulated by law for this purpose, and have completed the procedure in accordance with the requirements of the law. The majority of these people tend to be healthy individuals who, probably due to having had a sick family member or perhaps through knowing cases in the news where frequent conflicts at end of life are settled, make the decision to perform and register their advance care directives.

These citizens do not, in general, go through the "clinical path". When the time comes that they are affected by a disease and do not have the ability to make decisions, the clinician will have to take this directive into account in order to respect it and make it effective. It is therefore important for the autonomous communities to work towards creating well-designed formats where the various clinical situations are spelled out, where the various life support methods are accepted or rejected, and where the values and criteria that the patient wishes to be taken into account are laid out. In addition, it would also be very helpful to have a designated representative for the patient who could talk to the practitioners, interpret the patient's values and apply them to the clinical situation.

The second type of citizen is those that are currently patients, i.e. those who are in a clinical relationship due to their disease. The care and monitoring of the disease process should lead the practitioner to start an ACP with these individuals and carefully record it in the medical history. If both the doctor and patient think it necessary, such planning can also lead to an advance directive document, although this is not essential. As a result, the clinicians will have to explicitly make this possibility available to patients by talking with the chronically ill and showing them its usefulness for future decision-making.

This means that, as happens with informed consent, the paper should not be confused with the process. An advance directive is not just a form but is the result of several factors: a patient with a serious illness, a clinical relationship with good communication, and a process of personal, family and professional reflection with the patient, leading them to record their express wishes and personal choices concerning the extent of treatment for their pathology. Oncology patients can benefit from this process, as can those with neurodegenerative diseases and those with dementia. A common mistake is to believe that chronic diseases that occur with intermittent critical episodes that have no clear prognostic indicators cannot benefit from these instruments. Chronic obstructive pulmonary

disease (COPD) is an example of this type of pathology. We will attempt to explain why it is a clinical pattern whose features make both tools, the ACP and advance directives, significantly useful in the decision making process.

COPD and Decision Making at the End of Life

Decision making in Medicine has always been based on clinical criteria, and only the recent emergence of autonomy as a value to be considered in the clinical setting has substantially changed this model. These criteria, dispensed in the form of comprehensible information for the patient, should lead to joint decision making with the practitioners. The objective is to make decision making a shared process where practitioners provide knowledge, experience, perspective on the various treatments, and recommendations and patients provide their objectives and values, which probably will be affected by the various courses of treatment, leading to a comparative evaluation of the therapeutic possibilities or the rejection of them. This is what is known as the informed consent process in which two rights become effective; the right to information and the right to decide, both of which reside in the capable adult patient.

In the case of COPD, a few refinements to the above described model should be made, since they complicate the decision-making process. The first one is that this is a pathology in which it is difficult to identify prognostic factors.^{7,8} For decades, forced expiratory volume in one second (FEV₁), the most relevant parameter of pulmonary function and the one that best reflects airflow limitations, has been used as a prognostic indicator. Its baseline value has been considered as a major predictor of mortality and morbidity. A conceptual change is occurring at present that sees COPD in a broader sense, as a multi-dimensional chronic inflammatory disease with systematic connotations, some of which have prognostic implications. Exercise tolerance, pulmonary hyperinflation, systemic manifestations in the cardiovascular area, and exacerbations of the pathology have emerged as powerful predictors of death in recent years.⁹ They predict mortality independently of pulmonary function and are better predictors than even FEV₁.^{10,11}

Predictive factors for hospital readmission are also being identified in episodes of re-exacerbation.¹² Additionally, the understanding of COPD from its systemic manifestations and not just from its airflow

limitation has led to the development of multi-dimensional indexes that integrate those currently considered prognostic determinants. An example is the BODE index that integrates BMI (the B in body mass index), FEV₁ (O for airflow obstruction), dyspnea (D) and exercise capacity (E) information.¹³

All of this entails additional difficulty in decision making at the end of life, difficulties that do not exist in other pathologies that have highly reliable indicators and prognostic scales. Perhaps for this reason it is even more important than in other areas of medicine to introduce the second element in decision making: patient perspective, the assessment by the patient of their situation, the possible treatments, the alternatives, etc. This is already being done through health-related quality of life (HRQoL) questionnaires given to patients with COPD that, although important, add the problem that these measures have other objectives.

HRQoL explores how patients feel in relation to the disease and to the limitation and impact that it causes in their daily life.^{14,15} There are specific questionnaires for respiratory diseases, some even validated for Spanish culture.¹⁶ The objectives of this evaluation in chronic patients is twofold: extending life and improving its quality, the second being more desirable than the first. This improvement in quality is related to individual response to treatment, so it makes no sense to carry out HRQoL studies when there are more objective measures. For example, in the treatment of pneumonia there are sufficient objective tests for evaluating treatment response.¹⁷

The application of HRQoL measurements is useful for making decisions on treatments that are not very effective from the point of view of traditional measurements and on treatments that are effective but that exhibit little subjective response to treatment. An example of these last two can be found in the correction of hypoxemia with home-based oxygen therapy, a process that does not substantially affect patient HRQoL¹⁸ or the assessment of noninvasive ventilation.¹⁹

Without the data that HRQoL provides, we can not make wise decisions; however, we must bear in mind that we are still talking about data that allows us to make professional decisions without yet taking the patient perspective into account. In other words, it is a step forward to make the patient's "subjective response" to treatment "an objective", but there is still another step: introducing the patient's

Table 1
Advance Care Planning. Perspective of the practitioners versus the perspective of the patients

Objectives of Advance Care Planning of Decisions ^a	Characteristics that the process and documents must have ^b
1. Prepare decision making for the moment in which the patient is incapable of doing so himself *Preparing for death is also a part of the central goal of ACP	<ul style="list-style-type: none"> The <i>forms</i> (advance directives) are educational instruments that help the process: requires the structuring of discussions; the clarifying of concepts about the disease, the end of life and death; the defining of values, objectives and preferences; and facilitating the discussion with others It is recommended that advance directives be <i>specific</i> and not generic, since they help physicians apply the values, objectives and preferences articulated by the patient and should be validated as much as possible In the process of <i>advanced decision planning</i>, the practitioner must clarify with the patient what their preferences are in order to apply them to the clinical situation, identify information that the patient needs, ensure that the representative is involved in the process, and review the entire process The <i>evaluation</i> of the process is focused on achieving the goals that are important to the patient rather than the filling in of forms, which patients do not consider necessary
2. The principle of autonomy and the exercise of control over decision making constitute the foundation *It also involves helping the patient's family in decision making and relieving them of a major emotional burden	
3. The most important point is to ensure that the patient completes an advance directive *This is a social relationship process that helps us face the concepts of the disease and death with the family and the completion of an advance directive is not necessary nor is it an objective of that process	
4. The process takes place within the doctor-patient relationship. *It also has to involve loved ones	

^a Patient perspective.

^aSinger P, Martin D, Lavery J, Thiel E, Kelner M, Mendelssohn D. Reconceptualizing Advance Care Planning From the Patient's Perspective. Arch Inter Med 1998; 158: 879-894.

^bMartin D, Emanuel L, Singer P. Planning for the end of life. Lancet 2000;356:1672-76.

values, preferences and wishes in the decision-making process in a structured and professional manner. This is what allows for ACP and what we are developing below.

Advance Care Planning and COPD

The “clinical path” of a patient with COPD is complex and even more in our health system’s structure where, among other issues, the interconnection between levels of care is still pending. Primary care, internal medicine and pulmonology are the specialties that manage this pathology from the time of diagnosis. Intensive care intervenes in crisis situations that may require ventilatory support, intubation, or other means of life support. Palliative care is provided in advanced stages of the disease in which worsening of systems (dyspnea), side effects of an immobilised patient who receives high doses of corticoids and antibiotics (pain from vertebral compression, nausea, anorexia, constipation), and associated psychological symptoms (anxiety, distress, fear of death, depression, sleep disorders) generate much suffering in the patient and their family and require practitioners capable of addressing all these aspects at the same time. It makes no sense to talk of ACP without taking into account the complexity of this process as well as the diversity of practitioners involved.

It is illuminating to dwell on the specific literature published on this topic of planning and communication with these types of patients. The Heffner group in Phoenix, Arizona, carried out a descriptive study on 105 patients in pulmonary rehabilitation programs in order to identify their attitudes towards advance directives and the factors that determine them. Although 94% of the patients already had an opinion on intubation, only 42% had formalised a directive about it. Eight-nine percent wanted specific information about advance directives and about life-sustaining treatments. Ninety-nine percent wanted the health professionals to inform them and talk with them about this subject but only 19% had received this information. The conclusion was that this type of patient wanted much more information about the end of life than was being provided by their doctors.²⁰

In addition to this problem, many directives are focused on two situations, endotracheal intubation and cardiopulmonary resuscitation. Although specific rather than generic directives are recommended for use in cases of COPD,²¹ it often happens that these actions and procedures are performed during crisis situations and are carried out by intensive care practitioners who generally do not know the patient and have not participated in the creation of these documents. These practitioners may or may not apply the directives, or may interpret the patient’s wishes quite differently from how they or their families would.²³ Hence the need for broader and more integrated planning of an adequate ACP that is much more than the editing of up-to-date documents for specific actions.²⁴

Since the late 90s, medical literature has had excellent articles about ACP that are the result of various studies performed using qualitative methodology on patients in haemodialysis and HIV-positive patients.^{25,26} They are an excellent guide for further research with other types of patients, such as those with COPD, in addition to having succeeded in changing theories, and a few academic ideas about the objectives and fundamentals of ACP and pointing out what is really important to patients (table 1).

To apply all of this to the CPOD patient requires the designing of simple proposals for the progressive introduction of these issues in conversations with the patient. Primary care pulmonologists, internists, and practitioners deal with the process at its most chronic stage and, consequently, they are the most indicated for guiding the ACP process. Although intensivists are the recipients of both the documents and the ACP process and must have them at hand when making decisions, they may also be the initiators of the process at the time of admission to the unit or through associations of patients admitted to the ICU.^{27,28}

Although there are few empirical studies with Spanish citizens on this subject, none of them are disappointing. In a cross-sectional study conducted on 132 users to understand outpatient attitudes on the advance directives document, 97% were interested in the document and 39% said they would formalise it. For those that wanted to, 88.8% wanted to talk to their family about it and 73.8% wanted to talk to their family doctor.²⁹ If the participants were clearly in favor of

Table 2
Scope of decision making

On what can be decided	Patients with COPD
Life goals and personal values <ul style="list-style-type: none"> • To assist in interpretation of wills and to guide decision making • The expression of life goals, -quality of life and personal expectations, as well as personal choices in moral, cultural and religious issues 	<ul style="list-style-type: none"> • Ability to communicate and relate to others • Ability to maintain a minimum cognitive, memory and abstraction ability • Ability to maintain minimum functional independence in daily living activities • To not suffer severe dyspnea • To not suffer severe and disabling pain • Preference for not extending life for its own sake in situations of grave prognosis if minimums have not been given for the above issues.
Healthcare situations <ul style="list-style-type: none"> • Clinical scenarios • Instructions for medical interventions that the patient wishes to receive and those they do not wish to receive for each scenario. 	<ul style="list-style-type: none"> • Event of serious infection and bronchospasm • Severe dyspnea episode • Cardiorespiratory arrest • Vertebral compression secondary to corticoids
Prolongation of life <ul style="list-style-type: none"> • Do not artificially prolong life by disproportionate technologies and treatments • No life-support treatment, or discontinuing that already initiated when ineffective for maintaining an adequate <i>quality of life according to the criteria and values given by the patient</i> 	<ul style="list-style-type: none"> • Mechanical ventilation • Intubation • Cardiopulmonary resuscitation • Other means of life support • Non-invasive mechanical ventilation (BIPAP, CPAP)
Palliation and pain control <ul style="list-style-type: none"> • Avoidance of suffering with palliative measures even when they shorten life • The application of sedation procedures 	<ul style="list-style-type: none"> • Control of physical symptoms (benzodiazepines, opiates, etc.) • Sedation for refractory anxiety

these type of documents and if thinking about them did not make them uncomfortable, one must ask why five years later in 2008 only 50 out of every 100,000 people (43,668 individuals) have registered their living wills. Many factors are probably responsible, but this is also an incentive to continue down the path of ACP and stop focusing exclusively on the registration of advance directives. This path requires both the education of practitioners and patients as well as the development of particular proposals for the clinical setting.

What Can a Patient with COPD Decide and How Can They Go About Deciding

Article 11.1 of the basic law of patient autonomy indicates that the advance instructions document acts as a statement of the citizen's will for "the care and treatment of their health or, once death has occurred, the destination of their body and organs." This is a very

general statement since the care and treatment of their health can encompass many specific aspects and decisions. The subsequent emergence of legislation in Spain's autonomous communities has expanded this subject that is of great interest to the clinician in determining what a citizen can decide³⁰ (table 2).

The patient may indicate their *life values and personal goals*, those that outline and provide meaning to the decisions that will be made later. This point is particularly important because the values and goals of a person's life are the best and most targeted criteria for interpreting a person's will. Hence, it is important to spend time with the patient to identify the criteria that enable the patient's values to be applied. For example, if a patient believes that autonomy and personal independence (value) is essential to their life, they may see dependence on others for their most intimate of activities as unacceptable (specific action criteria to keep in mind). However, a different patient with great family and social support throughout

Table 3
Stages and contents of advance care planning

Advance care planning with patients with COPD*

1. Introducing the topic in conversations with the patient

- Define the stage of the pathology. It is advisable to do so in phases that are not too late and that are clinically stable
- Start discussing. Ask if they have thought about the evolution of their disease and if they know something about advance directives
- Detect and evaluate the patient's emotional response
- Gradually introduce the possibility of talking about these issues with family members
- Establish the importance of selecting a representative

2. Structured dialogue around the issue

- Identify the *clinical situations* with the patient that can result in uncertainty, some of which may have been experienced earlier (e.g. a serious respiratory infection)
- Clarify patient *values*
 - Learn how they have dealt with previous disease situations
 - Encourage them to think of what they would do in each of the described clinical scenarios
 - Help them identify their preferences in each scenario
 - Define their preferences when faced with clinical decisions that may arise
 - Clarify their preferences as to the use of life support measures and other clinical actions:
 - a) mechanical ventilation
 - b) intubation
 - c) cardiopulmonary resuscitation
 - d) other means of life support
 - e) pulmonary rehabilitation programs
 - f) non-invasive mechanical ventilation
 - g) control of symptoms
- Identify whether they prefer to die at home or in the hospital
- Clarify patient's *quality of life criteria*:
 - ability to communicate and relate to others
 - ability to maintain a minimum cognitive, memory and abstraction ability
 - ability to maintain minimum functional independence in daily living activities
 - to not suffer severe dyspnea
 - their preference for maintaining a good quality of life even though it might mean shortening life
- Work with the *patient* and the *representative*, clarifying their role, and jointly identifying the patient's values that are important for decision making
- Elaborate with the patient and the representative the benefits, risks and prognosis of each clinical scenario

3. Document their preferences

- Gradually introduce ACP into the medical history.
- Help the patient, if he/she wishes, to formalise an advance directive that will be added to the medical history
- If the patient wishes to register their living will, help them adapting the standard format of each autonomous community to their clinical situation
- Explain the importance to the patient that their family know about the advance directive and their representative
- Adjust treatment to the values and preferences specified by the patient

4. Review and update periodically

- Periodically review the directive
- If significant changes in the patient's preferences, values or choices are observed, suggest a meeting to review the document

5. Apply them to the clinical situation

- Evaluate the patient's current capacity, so as to understand when they cannot intervene in the decision making
- Locate the representative and extrapolate from them what the patient would want in that situation
- If decisions have to be made about a situation that was not specifically contemplated, do so on the basis of the values and criteria of quality of life expressed by the patient

* Modified from: Barrio IM, Simón P, Júdez J. De las voluntades anticipadas o instrucciones previas a la planificación anticipada de las decisiones. Nure Investigation 2004;5: 1-9.

their life may identify their social group as a primary value, and is perhaps less worried about functional dependence (criteria) in terms of incapacitation.

Another possibility that complements the previous one is the identification of predictable *clinical scenarios* in the evolution of the pathology and the concomitant health care practices. The patient needs to weigh their choices if placed in the scenarios and whether they would accept or reject the use of means that could reverse the processes. Mechanical intubation and ventilation in advanced stages of CPOD is an example. The choice of where (hospital or home) and how (active treatment versus palliative approach) they wish these future episodes to be treated is another.

These issues can be included in the ACP process, which must be guided by practitioners who care for the patient and who have established a meaningful relationship with them (table 3). For practical purposes we can distinguish three stages: initial phases and diagnosis, development of the chronicity and progressive increase in severity of symptoms, and final or advanced phase. It is appropriate to start the dialogue in the second phase and to steadily clarify values and objectives as the subjective experience of the disease advances. This means that by the advanced stage the path has already been taken towards facilitating decision making at the patient's end of life. Although some decisions may be very specific (resuscitate or do not resuscitate, intubate or do not intubate), it is impossible to make them with only a minimum basis if the advance process has not been worked through with the patient.³¹

Studies usually show that these patients wish to maintain communication about that end, but that only a few do so.^{32,33} Important patient issues have been identified that have not been taken into account by the physicians, such as talking about the prognosis, death, religious values and spiritual needs of the patients.³⁴ Knowing the barriers and facilitators to communication that doctors and patients create will help identify those that every practitioner encounters or generates with their patients.³⁵ Communication skills are, without any doubt, essential tools for carrying out the ACP process.

Finally, there is the rejection of treatment. This can take place in the context of a worsening crisis or in the context of palliative care that every patient with COPD should receive.³⁶ When this happens, decision making is much more complicated than with other types of patients, such as cancer patients (although CPOD and lung cancer often occur at the same time³⁷) since there is always place in COPD for drug-intensive treatments and ventilation that may provide some improvement.³⁸ In addition, the desire to refuse treatment may change over time, motivated by the changing intensity and severity of the symptoms, it is therefore difficult to be sure of the consistency of these choices.

In practice, this opinion must be kept in mind when it is maintained over time and is not changed after treatment with antidepressants, morphine or anti-anxiety medications, or with the company and support of practitioners and family members. Advance planning provides a better framework for handling these situations and builds a more solid consistency, stability and authenticity to these types of decisions.

Decision making at the end of life for patients with COPD is complex. The recommendations of the Spanish Society of Pulmonology and Surgery (SEPAR) insist that given the difficulty in anticipating the prognosis of the final stages, it is essential to anticipate them and that the advance directive can be of help.³⁹ What we wanted to demonstrate was that what needs to be handled is a process and not just a document and that this process should be directly based on the clinical reality of these patients.

Conflicts of Interest

The authors affirm that they have no conflicts of interest.

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