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Advance care planning: a practical guide

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Abstract

Advance care planning is a process of discussion between healthcare professionals and patients that enables shared decision-making on current and/or future healthcare goals, based on patients' desires and values and technical care issues. Advance care is considered essential in the provision of quality terminal care, allowing healthcare professionals to align the care provided with what is most important to the patient. Despite its benefits, it is still underused in clinical practice, especially in Brazil. Considering the need for practical guides for advance care planning adapted to the Brazilian reality, drawing on empathetic communication strategies, this study is a guide proposal based on an integrative literature review (PubMed and SciELO), with recommendations of current evidence, including instruments validated for Portuguese (Brazil), to facilitate its implementation in clinical practice.

Keywords: Advance care planning. Shared decision-making. Communication. Terminal care.

Resumo

Planejamento antecipado de cuidados: guia prático

O planejamento antecipado de cuidados é um processo de discussões entre profissionais de saúde e pacientes que permite a tomada de decisão compartilhada quanto a objetivos de cuidados de saúde, atuais e/ou futuros, com base nos desejos e valores do paciente e em questões técnicas do cuidado. É considerado fundamental na prestação de cuidados de excelência em fim de vida, permitindo que profissionais de saúde alinhem os cuidados prestados com o que é mais importante para o paciente. Apesar de seus benefícios, ainda é muito pouco realizado na prática clínica, especialmente no Brasil. Considerando a necessidade de guias práticos de planejamento antecipado de cuidados adaptados à realidade brasileira, pautados em estratégias de comunicação empática, este estudo é uma proposta de guia baseada em revisão integrativa da literatura (PubMed e SciELO), com recomendações de evidências atuais, incluindo instrumentos validados para o português (Brasil), para facilitar sua implementação na prática clínica.

Palavras-chave: Planejamento antecipado de cuidados. Tomada de decisão compartilhada. Comunicação. Cuidados de fim de vida.

Resumen

Planificación anticipada de atención: una guía práctica

La planificación anticipada de atención es un proceso de discusión entre los profesionales de la salud y los pacientes que permite la toma de decisiones relacionadas a los objetivos de atención médica actuales y/o futuros, basadas en los deseos y valores del paciente y en cuestiones técnicas de la atención. Resulta ser una apropiada atención terminal, ya que estos profesionales pueden adecuar la atención con los deseos del paciente. Pese a sus beneficios, es poco realizada en la práctica clínica, especialmente en Brasil. Dada la necesidad de guías prácticas para la planificación anticipada de atención, adaptadas a la realidad brasileña y basadas en estrategias comunicativas empáticas, este estudio propone una guía a partir de una revisión integradora de la literatura (PubMed y SciELO), con recomendaciones de evidencia actual, incluidos instrumentos validados para el portugués brasileño para facilitar su aplicación en la práctica clínica.

Palabras-clave: Planificación Anticipada de Atención. Toma de decisiones conjunta. Comunicación. Cuidado Terminal.

The authors declare no conflict of interest.

Few people talk to their family, friends and/or healthcare professionals about their future care preferences in the case of a severe and advanced illness. Although most individuals desire care that prioritizes quality of life and relief of suffering at the end of their lives, the health system tends to offer interventions to maintain life, often without improving quality of life. In the absence of conversations about prognosis, goals and treatment expectations, patients do not have the opportunity to inform their values and preferences, which leads physicians to decide for additional interventions that are generally incompatible with patients' priorities and desires^{1,2}.

Most people consider this a very important issue and wish to discuss with their doctors their health conditions and the care options that best fit their personal desires and values, but such discussions are still infrequent in clinical practice³.

Advance care planning (ACP) is a process of discussions between healthcare professionals and patients that enables shared decision-making on current and/or future healthcare goals, based on the patient's desires and values and on technical issues of care. For patients, discussions about care goals, treatment options and prognosis are important and most desire to have this kind of conversation with their physicians. However, although many physicians agree on the importance of this discussion, fewer than 20% report having it with patients on a regular basis^{4,5}.

Thus, ACP is justified for being an instrument that makes it possible to respect the patient's autonomy^{6,7} by means of a continuous and dynamic process in which preferences and care goals must be reviewed and discussed throughout the course of the disease. Each complication or hospitalization is considered, as well as the prognosis, which should be discussed whenever there is a change in the clinical course of the disease. Its content can be changed and other aspects can be added at any time^{3,6}.

The following is included within the scope of ACP⁸:

1. Understanding of diagnosis and prognosis by patients;
2. Identification of their desires, preferences, priorities and concerns;

3. Discussion of the best available treatment options suited to patients' needs and values;
4. Preparing an advance directive (AD) in the form of a living will or appointment of a health care proxy.

The treatment decisions discussed in the ACP may be recorded in the AD, which is part of care planning but not always mandatory, despite its great value. The living will is a written record of patients with preserved decision-making capacity about treatment and/or care decisions to which they wish to be submitted or not, in the event of advanced and irreversible disease, to be used when the patient loses his capacity for decision-making and communication⁹.

The decision-making process can be more difficult when the disease progresses and patients lose the ability to express themselves. In such cases, the health care proxy (generally a family member) must intervene to make decisions that he considers in the best interest of the patient according to their previously expressed desires. ACP also serves to guide the choice of substitutes, if this is the patient's preference, to represent them when they can no longer make decisions and express themselves, and to prepare this substitute to make decisions on behalf of the patient.

This can minimize the difficulty for family members to make decisions during complications, as they are often emotionally vulnerable and unable to respond for their loved one. That is why ACP should be done as soon as possible, while the patient's cognitive capacity allows them to determine what is important to them. It is worth remembering that anyone, even without a chronic or serious illness, can share with their doctors or those closest to them their preferences and priorities related to end-of-life provisions^{7,10}.

In addition to ensuring that patients receive treatment that is consistent with their preferences, reducing the decision-making burden on the family and the significant emotional burden related to decisions involving end-of-life care, studies indicate other benefits of ACP, such as: reduced moral distress for healthcare professionals; higher rates of AD; greater likelihood of physicians and family members understanding and complying with the patient's wishes; fewer extraordinary treatments at end of life, with greater follow-up

by palliative care teams; greater likelihood of the patient dying in a place of their preference; greater satisfaction with quality of care; lower risk of anxiety and depression among family members when grieving¹¹⁻¹⁵.

Despite the abundant evidence of the benefits of ACP, this important resource, which aims to guarantee the patient's autonomy until the end of their life, is still underused in clinical practice in Brazil. Therefore, this article aims to outline communication strategies to stimulate, initiate and better conduct ACP.

When to do it?

Conversations about care goals commonly happen too late, at times of greater criticality—exacerbation of the underlying disease, for example—which demand more urgent decisions related to treatment when the patient no longer has capacity to decide. In these circumstances, healthcare staff and family members end up making decisions that do not always represent the patient's values and priorities. Therefore, the conversation about care goals should be started gradually and as early as possible, based on the prognosis^{4,14,16}.

This planning is a complex process and should not be accomplished in a single conversation. It takes time to establish a trusting doctor-patient relationship that makes it possible to explore information about what is most important to the patient. This discussion can be started at any time over the course of the illness, but ideally the patient should be clinically and emotionally stable so that he can fully reflect and express their preferences.

The planning content may vary according to the patient's health condition: from a context of absence of symptoms, through the initial phase of the disease, up to a situation of terminality. Moreover, the content should be regularly reviewed, especially when there is a change in clinical condition—after the patient is admitted to hospital, for example—to check whether there have been changes in care preferences or to add new information^{6,17}.

Some characteristics related to the prognosis indicate the need for discussion about care goals, including^{18,19}:

- Surprise question: “Would you be surprised if this patient died in the next year?”;
- Functional decline due to underlying disease: Palliative Performance Scale (PPS) or Karnofsky Performance Scale (KPS) ≤ 50 ;
- Lack of response to initial treatment or uncertainty about the therapeutic response;
- Second or third-line chemotherapy;
- Recurring hospital admissions;
- Disease exacerbations despite optimal treatment;
- Characteristics related to the prognosis of the underlying disease²⁰.

All patients with palliative care needs must have their ACP, which is currently recognized as a good indicator of quality palliative care^{6,7}. Some people may have more difficulties to engage in this conversation, especially if they are not well informed about their diagnosis and prognosis.

Evidence suggests that certain demographic characteristics, such as advanced age and low level of education—which is still common in Brazil—may influence healthcare decision-making, making these individuals more likely to trust their physicians with such decisions. In these cases, it is up to health professionals to explore the patient's values and priorities, considering their life history, to define care based on the patient's best interest^{21,22}.

How to do it?

Despite the growing interest in the subject and the various studies and guides proposed in the international literature for preparing ACP, to date there is no systematized content for this instrument, which can be divided into the steps described below²:

- Preparation: this precedes the conversation with the patient, including a thorough review of medical history, prognosis and treatment options. In addition, information on psychosocial aspects and family dynamics can be accessed in the discussion with other members of the health team.
- Introduction: step in which the purpose of the conversation is explained. It is the moment to establish a relationship of trust between doctor and patient, aiming at a more effective conversation.

- Identification of the patient's perception: step in which the patient's perspectives and capacity for coping with the disease are accessed, involving finitude, feelings (fears and concerns, hope) and practical issues related to end of life. It is the main part of the conversation.
- Action: this involves recording information of the discussion, which can be done in the following ways:
 - a. Inserting what was discussed in the medical record (which is considered a legal document);
 - b. Preparing an AD, for example, by means of a separate document in which the patient describes their desires and preferences for care, with proper guidance by the health professional who knows and provides care for them;
 - c. Appointment of the patient's health care proxy when they are no longer able to express themselves (durable power);
 - d. Strategies for the patient to share the ACP content with people close to them and of their choice, so that they are aware of their care preferences;
 - e. Guidance on legal issues.

Chart 1 provides some practical recommendations on each of these steps of the ACP discussion, based on current guidelines on the subject^{2,4,7,23}.

The discussion about ACP may include orders related to specific medical treatment—for example, no resuscitation or no enteral feeding—reflecting the individual's treatment preferences and current medical condition. These medical treatment orders should be properly drafted and standardized so that they are readily understood by healthcare professionals during an emergency or in any form of care⁷.

Chart 1. Advance care planning steps

Steps	Goals	Examples
Preparation		
	Be sure of the details of diagnosis, prognosis and available treatment options before talking to the patient.	
Introduction		
Permission/check autonomy	The patient should be asked whether he wants to be involved in decision-making or if he prefers the team to talk to a family member.	<i>"Would you like to talk about this alone or are there other people you would like to include in the conversation?"</i>
Establish a rapport with the patient	Build a trusting relationship so that the patient feels comfortable talking about their desires and fears.	<i>"Despite your condition, there are still many things related to care that we can do. I'd like you to feel free to talk so I can help you. Whatever may happen, you will not be alone."</i> <i>"As your doctor, I want to make sure I'm doing the things that can help you."</i>
Invite the patient to talk and understand the expectations for the future.	Invite the patient to discuss their current condition and wishes regarding future medical care. Patients with decompensation symptoms should have the conversation after symptoms improve.	<i>"Would you like to talk about what might happen ahead and how we can make sure your preferences are respected?"</i> <i>"To align treatment options with your wants and needs, we need to know your preferences in some aspects. Do you wish to talk about them now?"</i> <i>"Do you think a lot about the future? What worries you? What are your expectations?"</i>

continues...

Chart 1. Continuation

Steps	Goals	Examples
Identification of patient's perception of the disease, their values and desires		
Establish a starting point	Check the understanding of patient and family about the diagnosis and prognosis and standardize the information so that everyone understands the current moment.	"What do you understand about your illness?" "What have your doctors told you about the disease and possible treatments?"
Explore life values and goals	Understand the patient's concept of having a good life and their expectations regarding the treatment.	"What is most important to you right now?" "What worries you most about your situation?" "What has your life been like in the past year coping with the disease? What do you expect from the treatment?" "If your health situation gets worse, what are your most important goals?"
Talk about possible dilemmas and care preferences	Introduce a conversation about treatment preferences, especially invasive ones: ask the patient if he has ever thought about how he would like to be taken care of and what types of treatment he would not like to undergo. Some people have previous experiences from relatives or acquaintances with resuscitation and intubation, and this may be a way to introduce the subject. Explain the risks and benefits of different treatment options. Clarify when invasive and artificial life support measures are beneficial and when they cease to be technically beneficial to become futile.	"Has anyone close to you ever been through situations and/or treatments during the course of a serious and advanced illness that made you think about your end of life, in the sense of not wanting to undergo certain interventions, such as breathing through machines or being fed through tubes? These procedures cannot reverse the underlying disease, but there are comfort measures to relieve shortness of breath or other symptoms as an alternative." "It would be important to know what types of care you would like to have. How and where do you imagine yourself spending your final days, weeks and months? You can already express your desires about this. In a more serious complication, you may be assisted in the emergency room by staff that does not know you well and may not know the details of your illness. If your family are not well informed about your care preferences, they will have more difficulties in deciding with the staff what would be best for you."
Decision-making and care planning	Outline the care plan by aligning the available therapeutic options with the patient's preferences and priorities	"Given your goals and priorities and what we know about your illness at this time, it would be recommended to..." "You said that if your illness worsens, you would rather let nature take its course, unsupported by invasive measures such as cardiopulmonary resuscitation, mechanical ventilation and admission to an intensive care unit. I recommend comfort measures to control symptoms as a priority. Am I correctly stating your preferences?" "Unfortunately, targeted treatment for cancer has not proven to be more beneficial. Proceeding with more chemotherapy at this time may bring you more risks than benefits and is not recommended. Likewise, other invasive support measures, such as cardiopulmonary resuscitation, are not associated with improved quality of life in a worsening condition, with cardiorespiratory arrest. I recommend comfort measures as a priority. What is your opinion about that?"

continues...

Chart 1. Continuation

Steps	Goals	Examples
Action/ACP recording		
Document the decisions	Always record preferences in the medical record so that the entire team responsible for the patient has access to what has been discussed. Encourage and guide the patient to write their advance directive*	<i>"These are important decisions about your possible treatments in the future. We must be sure about them, preferably by documenting them in writing, so that there are no doubts."</i>
Identify the patient's healthcare proxy, if any	If you feel it is appropriate, encourage the patient to talk to family members about their care preferences and choose a person to represent them when they cannot express themselves. If he does not want to choose a representative, he should be encouraged to share their preferences with persons of their trust who are close. Note: If the patient names various people, try to establish a main proxy.	<i>"If you were unable to tell your doctors what kind of treatment you would like to receive, who would you name to represent you, talking about your wishes to help in decision-making with the health team?"</i> <i>"It would be important for people you trust to know your wishes and desires for the future."</i>
Review the ACP	This is the occasion to validate what has been discussed and offer the patient the possibility of reviewing the care plan at any time.	<i>"Would you like to review your care plan? Have any decisions changed after this last hospitalization? You can add or change information at any time."</i>

*Recommendations for the preparation of advance directive²⁴

Advance planning

Instruments for advance directives

Several instruments are available to facilitate the conversation about end-of-life care preferences and help prepare an AD, but few have already been validated and adapted to the Brazilian reality, as most relate to other languages and cultures,

especially the US. It is important to emphasize that such instruments reinforce rather than exclude the role of physicians in the conversation about these care goals. It is essential to guide healthcare professionals in this process, including talking about the disease and prognosis.

Chart 2 features some examples of instruments validated for Brazilian Portuguese, which can be used as resources to prepare ACP.

Chart 2. Instruments to help prepare advance care planning

Instruments	Goals	Target audience
<i>Cards on the table</i> ²⁵ – card game	To encourage and facilitate the conversation about your care preferences in a simple and playful-based way. It can be played in pairs with your health care proxy.	Patients and family
<i>My wishes</i> ²⁶ – smartphone application	To reflect on care preferences and then share them with your physician and people you trust. Consider choosing a health care proxy.	Patients
<i>Physician Orders for Life-Sustaining Treatment (POLST)</i> ²⁷	To translate end-of-life patient care values and preferences into a medical prescription in order to facilitate the provision of care that is consistent with those values and preferences.	Physicians

continues...

Chart 2. Continuation

Instruments	Goals	Target audience
<i>The conversation project</i> ¹⁶	Initial conversation guide to help people talk about their end-of-life care desires.	Patients and family
<i>Voicing my choices</i> ²⁸	To introduce discussions about ACP. Validated only with young adults with cancer.	Patients

Legal aspects

Caring for patients is a challenging task that requires not only a holistic view of individuals, but also an understanding of the family, social, legal, economic and institutional circumstances surrounding them, especially as they approach end of life. Unfortunately, there are a lot of myths and misconceptions about legal aspects in this matter. In the US and in some European countries (Portugal, France, United Kingdom and Spain, for example), ADs are already considered legal documents that guide treatment decision-making.

In Brazil, there is no specific legislation on AD yet. However, Resolution 1,995/2012²⁹, of the Federal Council of Medicine (CFM), provides that every doctor must consider patients' advance directives in decisions about care and treatment when they are unable to communicate or freely and independently express their desires. It also provides that physicians must record the DAs communicated to them by the patient in their medical record^{7,29}.

This resolution aims to ensure that the patient's autonomy is respected, based on orthothanasia—with no relation to euthanasia—recognizing the patient's right to refuse extraordinary treatment, understood as treatment aimed solely to prolong life, without guaranteeing quality of life or benefits from the patient's perspective. Thus, what has been determined in the DA prevails over any other

decision by third parties, provided that it complies with the ethical and legal precepts²⁹.

Conclusions

Aligning patients' values with the best treatment alternatives available requires communication skills to understand their needs and priorities and set care goals based on what has been shared. There is no one-size-fits-all plan for a specific clinical context and such flexibility requires a certain degree of practice.

This article features suggestions and recommendations of current evidence to facilitate ACP in clinical practice, which should be based on empathic communication, ranging from diagnosis and prognosis information—essential for patients to identify their priorities—through active listening to explore what is important for the patient, to actual decision-making and subsequent sharing of information and recording of the care plan.

There is sufficient evidence to validate ACP as a key process for improving end-of-life care, and therefore it should be routinely integrated into clinical practice by all physicians treating patients with chronic and potentially serious illnesses. The earlier these discussions are started, the greater the chances of patients receiving treatment consistent with their desires and values, resulting in better quality of life, less emotional burden for family members and reduced costs with disproportionate interventions.

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Laiane Moraes Dias and Francisca Rego designed the study and prepared the initial manuscript. Mirella Rebello Bezerra and Williams Fernandes Barra collected the data and helped prepare and draft the guide. Rui Nunes and Francisca Rego contributed to the critical review. All authors reviewed the manuscript.

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