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Contributions from the values history to the right to die with dignity

Aportes de la historia de valores al derecho a morir con dignidad

Ana Milena Álvarez Acuña^{a-c} ; Boris Julián Pinto Bustamante^{c-g} ^a Anesthesiology and Resuscitation, Universidad Industrial de Santander. Bucaramanga, Colombia.^b Pain and Palliative Care, Fundación Universitaria de Ciencias de la Salud. Bogotá, Colombia.^c Department of Bioethics, Universidad El Bosque. Bogotá, Colombia.^d School of Medicine and Health Sciences, Universidad del Rosario. Bogotá, Colombia.^e Master in Medical Law, Universidad Externado de Colombia. Bogotá, Colombia.^f Bioethics, ONG Paliativos Sin Fronteras del País Vasco. País Vasco, Spain.^g Advisory Committee of Regional 1, Organ and Tissue Donation and Transplant Network.**Correspondence:** Carrera 43A N1 SUR 100. Anestesiar. Edificio Sudameris. Medellín, Colombia.**Email:** amalvarez_23@yahoo.es**How to cite this article::** Álvarez Acuña AM, Pinto Bustamante BJ. Contributions from the values history to the right to die with dignity. Case report. Colombian Journal of Anesthesiology. 2026;54:e1163.

Abstract

The values history (VH) is a valuable tool of the advance care planning (ACP) process for all patients – regardless of health status – and may ultimately lead to the drafting of a document. This article outlines the benefits of VH as a process of personal reflection and as a document—either standalone or attached to an advance directives document (ADD)—to guide surrogate decision-making. The implementation of VH is advocated within ACP programs and the right to die with dignity. Likewise, the article supports establishing ACP as a standard practice for every individual and in every healthcare institution, regardless of the level of care complexity, with the aim of integrating the set of rights or legal powers that enable the right to die with dignity in Colombia.

Key words

Values history; Advance directives document; Advance care planning; Right to die; End-of-life care; Dementia; Alzheimer's disease.

Resumen

La historia de valores (HV) es una herramienta valiosa dentro del proceso de planificación de decisiones anticipadas (PDA) en cualquier paciente, en condiciones de salud o de enfermedad, que puede culminar en la elaboración del documento. Este artículo expone los beneficios de la HV como proceso de reflexión personal y como documento solo o adjunto al documento de voluntades anticipadas (DVA) para orientar la toma de decisiones subrogadas. Se defiende la implementación de la HV en los programas de PDA y el derecho a morir con dignidad; de igual manera, crear la práctica asistencial de una PDA para toda persona y en toda institución de salud independiente de la complejidad en la atención, con la finalidad de integrar el conjunto de derechos o facultades que posibilitan el derecho a morir con dignidad en Colombia.

Palabras clave

Historia de valores; Documento de voluntades anticipadas; Planificación de decisiones anticipadas; Derecho a morir; Atención final de la vida; Demencia; Enfermedad de Alzheimer.

INTRODUCTION

Advance care planning (ACP) is a deliberative, relational, and person-centered process that takes place within the context of the physician–patient relationship. Its purpose is to allow individuals to identify and express their treatment preferences and expectations regarding their current situation and a future clinical scenario in which they may lack decision-making capacity. (1) ACP may or may not result in the drafting of an advance directives document (ADD) as the final and tangible expression of this process. (1,2)

This article stems from a reflection on the fundamental role of the values history (VH) in ACP. It highlights the importance of recognizing ACP as a process, the first step of which is to know and understand the patient as a person—through the identification of their values, expectations, attitudes, and beliefs shaped by their life story—referred to as VH, in order to understand the possible decisions the person may make at the end of life.

This is the foundation for the individual to establish his/her preferences and decisions regarding future clinical care, which may be formalized in an ADD. Although the dialogue between physician and patient is the central element of this process, the drafting of a VH document and an ADD should not be overlooked. Accordingly, the creation of a VH or ADD document should be considered the result of an ACP process and should never be just a simple self-completed form, as it usually happens in some healthcare settings.

Values History

In the late 1980s, Doukas and McCullough introduced the Values History (VH) as an “ethically justified clinical tool” designed to explore and acknowledge patients’ personal values within the context of advance care planning (ACP). (3) Although VH represents a process of personal reflection, it can be facilitated during the physician-patient encounter using a form

Table 1. Examples of values or questions from values history scales or questionnaires.

Values-oriented questions	Authors
Do you wish to live as long as possible, regardless of quality of life? Or would you prefer to maintain a good quality of life, even if that shortens your life?	David Doukas and Laurence McCullough (3).
What activities do you enjoy? Do you feel life is worth living? Are you happy to be alive? How satisfied are you with your life achievements?	Pam Lambert, Joan McIver Gibson and Paul Nathanson (8).
What is important to you? · Thinking clearly · Communicating with others · Making my own healthcare decisions · Being a financial burden to my family · Being a physical burden to my family	David Doukas and D. W. Gorenflo (12).
· First, think about what is most important to you in your life. What makes life meaningful or good for you now? · Some people feel there could come a time when life would no longer be worth living. Can you imagine a circumstance in which life would be so unbearable that you would not want medical treatments to keep you alive? · Is there anyone in particular whom you would NOT want involved in making healthcare decisions on your behalf?	M. J. Karel, J. Powell and M. D. Cantor (13).
What is important to you? · Enjoying simple pleasures (e.g., music, television, even if ill) · Ability to think clearly · Quality versus length of life · Accepting help for personal needs · Ability to continue communicating with others · Ability to continue making decisions for myself Can you imagine a circumstance in which you would prefer to die rather than continue living?	M. J. Karel, J. Moye, A., Bank and A. R. Azar (11).

Note: Each author can be consulted in the references for more details on the specific values history scale or questionnaire.

Source: Authors.

with open-ended questions that encourage introspection to unveil one’s own values, preferences, quality of life, and attitudes toward death. The goal is to construct the individual traits that guide beliefs and relevant decisions regarding future clinical care or end-of-life care.

VH explores patients’ perspectives on personal relationships, independence, quality of life, moral, religious, and cultural convictions regarding illness, dying, and death, as well as activities that provide joy and a sense of purpose, among others (Table 1). Through VH, patients may

experience less distress and fear, as they are not forced to identify a single response to hypothetical clinical decision-making scenarios, as is often the case with standard treatment directives or advance directives (ADD). (4)

Some treatment directives or advance directives (ADs) may be ambiguous—for example: “Do you want cardiopulmonary resuscitation?”—and should be replaced with questions that focus on the patient’s overall goals. In this way, values-based directives—such as “Under what conditions

would life be unacceptable to you?”—are more useful than treatment-based ADs or standard ADDs. (4,5) The VH is modifiable and revocable as long as the person is able to express his/her preferences and values. It is important to clarify that these documents may be lengthy and present some challenges in interpretation when surrogate or proxy decisions must be made. (6)

The information collected may not relate directly to specific medical treatments in clinical situations, but it is essential in contexts where the physician needs to understand the patient as a person (4) in order to appropriately guide surrogate decision-making. (7,8) Shared decision-making—by the legal representative, family, and healthcare team—can benefit from the explicit declaration of values to guide and support concrete treatment decisions, rather than inferring a patient's values from the ADs recorded in the ADD. (9)

In clinical practice, VH can contribute to medical decision-making and clinical care in the absence of an ADD or in clinical scenarios beyond the scope of the ADD. (10) In this sense, VH complements treatment directives rather than replacing them. (7) VH also plays a fundamental role in promoting person-centered care, facilitating dialogue between the patient and their family regarding care preferences in serious illness or end-of-life situations. Additionally, it helps improve communication with the healthcare team and reduces the emotional burden on surrogates. (9)

The holistic and comprehensive approach of palliative care (PC) practice emphasizes the importance of assessing patients' spiritual and existential concerns during the course of serious illness or at the end of life. In this regard, VH emerges as one of the possible interventions to help patients address and accept mortality, understand their attitudes toward death, reflect on the meaning and purpose of life, quality of life, and dignity, among others. This process, carried out in advance throughout illness or aging, can contribute

to psychological and emotional preparation in coping with the end of life journey.

VH has been promoted by various authors since the early 1990s (3,4,8,10-13) and has been incorporated into strategies for promoting patient rights and person-centered quality care during serious illness and end-of-life care, with the support of practical experience and research studies. However, the reproducibility and/or clinical effectiveness of these tools or questionnaires in healthcare settings has not been explored. (11) In the Colombian context, although VH has been addressed in academic settings, it is necessary to advance its characterization and implementation in clinical environments.

The right to die with dignity in Colombia

The right to die with dignity (RDD) refers to the set of rights that enable individuals to face the end of their life with dignity and to make free and informed decisions about their health and end-of-life care. In 2020, the Ministry of Health and Social Protection (14) declared RDD a multidimensional right—that is, a set of rights translated into healthcare practices that enable patients to decide how to cope with the dying process. Thanks to the diversity of available practices (e.g., palliative care, treatment refusal, euthanasia, ADD, etc.), each person may choose among them according to his/her preferences.

Although the ADD is based on solid ethical foundations, its implementation often overlooks exploring and acknowledging individual values with regards to treatment preferences. (7) In line with this, a national study by Álvarez et al. showed that some ethical dimensions are not sufficiently represented in ADD forms. Specifically, the forms lacked a VH and did not explicitly inquire about the patient's concept of quality of life. (15) These findings highlight gaps in the understanding of the significance and practical value of VH in clinical end-of-life care.

ANALYSIS

The VH puts the “Who is the person?” question at the core. Only by answering this question can truly person-centered care be achieved; this means aligning clinical care to patient's values to ensure high-quality end-of-life care. It is important to clarify that under the Colombian law, VH is not recognized as a legal document and therefore lacks binding legal force; however, this does not impair its ethical legitimacy or clinical value—both of which healthcare professionals are called to uphold. VH is a useful tool with a dual clinical purpose: first, as a process of personal reflection and self-understanding, and as a guiding framework to initiate dialogue between physician and patient during ACP; and second, the end result may be the drafting of a VH document and/or the signing of an ADD. VH not only broadens the concept of ACP but also extends its scope. While ACP primarily focuses on “defining preferences for future treatments and medical care” (1)—that is, treatment directives—VH encompasses a broader spectrum of decisions that are often overlooked but equally relevant, including personal values, attitudes, and life goals, in order to understand the foundations that will guide surrogate decisions. Thus, VH strengthens patient autonomy in a way that treatment directives alone cannot: by affirming the patient's personal identity and increasing the likelihood that medical interventions align with their identity. (6)

According to Article 4 of Resolution 2665 of 2018, the ADD must express treatment preferences in a “specific, clear, explicit, and unequivocal manner regarding their preferences for future healthcare and physical integrity, as well as concrete indications for their care and preferences at the end of life”. (16) Based on this premise, for some individuals, VH “may be more acceptable than a standard ADD”. (10) Considering that clinical scenarios are complex and ever-changing, it becomes increasingly challenging to anticipate “concrete” treatment preferences for all possible clinical situations in an ADD. For

this reason, it is recommended to include VH in the deliberative process of ACP and in the clinical practices associated with RDD in Colombia.

The scientific literature has focused on legitimizing ACP and the drafting of an ADD for patients with early-stage Alzheimer's disease (AD). (2,11,17–20) Unlike other serious illnesses, the specific challenge for patients with AD is the progressive loss of their ability to make decisions about their future. Therefore, the premise “it's now or never—postponing is not an option” becomes highly relevant. (20) In this regard, Porteri recommends attaching a VH to an ADD to help guide difficult medical decisions and ensure an accurate reflection of the patient's values, beliefs, and priorities. (17) Within the framework of this reflection and analysis, a question arises regarding patients with advanced-stage AD or unconscious patients in the intensive care unit (ICU) who have not drafted an ADD: Is it possible to implement ACP for patients who lack the capacity to decide or communicate? The answer is yes. To support this answer, let's refer to the work by Scheunemann et al., suggesting an approach aimed at high-quality surrogate decision-making for any patient lacking capacity: the facilitated values history (FVH) (21).

The FVH suggests a structured approach for healthcare teams to support families and surrogates in identifying, analyzing, and understanding the relevant—and sometimes conflicting—values of disabled individuals at the end of life. Through this process, healthcare professionals can formulate treatment recommendations that respect and align with those values. (21) This approach is achieved through dialogue between the healthcare team and the family during ACP. Based on this rationale, a patient with early-stage AD may participate in a physician–patient meeting and draft a VH and/or an ADD; in contrast, for a patient with documented disability, the recommendation is to draft a FVH

between the healthcare team and the surrogate decision-maker.

The Palliative Care Law in Colombia (Law 1733 of 2014) (22) establishes the right to sign an ADD. However, the enactment of a law or the recognition of a right is not sufficient to ensure its promotion and effective implementation in clinical practice. It is important to clarify that both participation in ACP and the drafting of an ADD can take place at any stage of life, regardless of whether the person is healthy or ill. (16,19) In line with this, ACP and ADD should not be considered healthcare activities exclusive to physicians in palliative care services. In the clinical setting—without neglecting any regulatory progress—it is essential to integrate ACP with the rights that constitute RDD in Colombia, which should be promoted starting from primary healthcare (PHC).

Along these lines, the Patient Self-Determination Act in the United States (18) provides a notable legal precedent that raises two important questions: Should a regulatory framework be established requiring healthcare institutions to inform and provide ACP to all hospitalized patients, regardless of the level of clinical care complexity? Likewise, should ACP and support for drafting an ADD be considered a separate and billable healthcare service? In accordance with this model, some bioethics advisory services have been established in healthcare institutions in Colombia. One remarkable example is the Humanism and Bioethics Service at the Fundación Santa Fe de Bogotá University Hospital, which promotes “compassionate, person-centered care”. (23) Among its various activities, the service includes an ACP focused consultation space. In this way, the organization of institutional bioethics and humanization consulting services that support patients, families, and healthcare professionals in clinical practice may constitute an effective

strategy to help guarantee RDD in Colombia.

CONCLUSION

The values history (VH) is a valuable tool with a dual clinical purpose: on one hand, it serves as a guide to facilitate dialogue between physician and patient during advance care planning (ACP); on the other, it may result in the drafting of a formal VH document that can help guide future surrogate decision-making or the signing of an advance directives document (ADD). The development of a VH or ADD should be the result of a structured and deliberative ACP process and should never be limited to self-completed forms by individuals. Having access to an institutional ACP program may contribute to ensuring the set of powers that constitute the right to die with dignity (RDD) in Colombia.

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Author contributions

AMÁA: Original idea.

AMÁA and BJPB: Contributions to the manuscript and critical review.

Authors have read and approved the final manuscript.

Conflicts of interest

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Availability of supplementary material

The dataset supporting the analysis and results of this study is available in the

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