

# Advance planning of decisions in mental health: bioethical analysis

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## Abstract

Studies on advance planning of decisions are frequent in the health field and growing in the mental health field. As part of a proactive and ethical approach to decision-making, it is an ideal tool for providing dignified care and respect for the individual and their surroundings. This article presents a solid ethical approach that substantiates and vindicates such practices. To this end, a rigorous analysis of the ethical and care benefits is carried out, highlighting the barriers that hinder their incorporation and reflecting on the need for more research to overcome these barriers to provide more humanized care for patients with mental disorders. Furthermore, recommendations are proposed for healthcare professionals involved in the care of such people to implement this type of care relationship.

**Keywords:** Advance directives. Mental health. Bioethics. Autonomy.

## Resumen

### Planificación de decisiones anticipadas en salud mental: análisis bioético

La investigación sobre la planificación de decisiones anticipadas es una constante en el contexto sanitario y, cada vez más, en el ámbito de la salud mental. Como parte de un enfoque proactivo y ético hacia la toma de decisiones, constituye una herramienta idónea para proporcionar un cuidado digno y respeto por la persona y su entorno. Este artículo expone un marco ético sólido que fundamenta y reivindica esta práctica. Se lleva a cabo un análisis riguroso de los beneficios éticos y asistenciales, también se muestra las barreras que dificultan su incorporación y se reflexiona sobre la necesidad de haber más investigación para superar dichas barreras y lograr una atención más humanizada a los pacientes con trastornos mentales. Además, se proponen recomendaciones a los profesionales sanitarios que se dedican al cuidado de estas personas para poder implementar este tipo de relación asistencial.

**Palabras clave:** Directivas anticipadas. Salud mental. Bioética. Autonomía.

## Resumo

### Planejamento antecipado de decisões em saúde mental: análise bioética

Os estudos sobre planejamento antecipado de decisões são frequentes no âmbito da saúde e, cada vez mais, no campo da saúde mental. Como parte de uma abordagem proativa e ética para a tomada de decisões, é uma ferramenta ideal para fornecer um cuidado digno e respeito ao indivíduo e seu entorno. Este artigo apresenta uma abordagem ética sólida que fundamenta e reivindica tal prática. Para tanto, realiza-se uma análise rigorosa dos benefícios éticos e assistenciais, destacando as barreiras que dificultam sua incorporação e refletindo sobre a necessidade de mais pesquisas para superar essas barreiras a fim de proporcionar um cuidado mais humanizado aos pacientes com transtornos mentais. Além disso, propõem-se recomendações aos profissionais de saúde envolvidos no cuidado de tais pessoas para implementar esse tipo de relação assistencial.

**Palavras-chave:** Diretivas antecipadas. Saúde mental. Bioética. Autonomia.

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Respect for patients and their healthcare decisions is a fundamental pillar of the healthcare system. In this sense, informed decisions, which take the form of informed consent, are essential in the current health relationship paradigm. This consent can also be given in advance through an advance directive of will (AD) and/or advance decision planning (ADP), although we are increasingly talking about shared care planning<sup>1</sup>.

In Spain, advance directives are defined by Law 41/2002 as a document in which the individual *expresses their will in advance so that it is respected when they are faced with situations in which they are not able to express it personally regarding the care and treatment of their health or, once death has arrived, about the fate of their body or organs*<sup>2</sup>. Furthermore, it is possible to appoint a representative to check whether prior instructions are being respected.

ADP is a deliberative, voluntary, and structured process through which a person capable or assisted by their guardian/representative expresses their values and preferences and following them in collaboration with their care team (and with their relational environment if so they wish), formulates and plans the social and health care they would like to receive on occasions when they are not in a position to decide. This communicative and deliberative process must be formalized in a document called "PIIC" (individual and integrated care plan), which must be part of their clinical history.

In the field of mental health in Spain, there is not enough knowledge about ADP, perhaps due to the barriers to its introduction in the health field. This is why formulating proposals to introduce and state them in the social and health environment is needed<sup>3</sup>. It is necessary to better evaluate the entire care process generated by the ADP, as it contributes to more responsible decisions and closer and more welcoming assistance, promoting a culture of dignified care.

Furthermore, with ADP, patients with limited competence have increased opportunities for participation (with appropriate supports), and they better situate their decisions in the actual, rather than hypothetical, clinical context so that they can record decisions in advance with better quality. However, professional help, counseling,

and clinical advice can help them make more informed, scientifically based decisions. In any case, we consider that from a good ADP, good AD can emerge to further support the patient's wishes and preferences.

In recent years, several studies have confirmed the applicability of ADP in patients with cancer<sup>4</sup>, dementia<sup>5</sup>, intellectual disability<sup>6</sup>, severe mental disorders such as schizophrenia or bipolar disorder<sup>7</sup>, or those with suicidal behavior<sup>8</sup>, among others.

Regarding advance directives in mental health, psychiatric patients prefer alternatives to hospitalization, such as receiving professional home care<sup>9</sup>. The most frequent aspects of therapeutic choices are rejections and/or choices of specific pharmacological treatments or even specific denials of electroconvulsive therapies<sup>10,11</sup>. Thus, anticipating decisions would allow them to express preferences about visits during hospitalization, formulate specific requirements about the food they want, and indicate a person to care for their family members and pets<sup>9</sup>.

Given that ADP can play a crucial role in establishing a caring relationship of dignified care for these patients, this article aims to present an ethical framework to support and justify this type of decision-making process, as well as an analysis of the ethical benefits and assistance that derive from its establishment in the field of mental health. Finally, based on our professional experience in applying the ADP to patients with mental illnesses, we will propose some recommendations for professionals dedicated to caring for this population.

## Ethical foundation of ADP in mental health

Healthcare professionals can recognize episodes of high vulnerability in patients with mental illnesses, such as psychotic episodes, depressive phases, manic states, pharmacological treatments that were not well tolerated, and negative experiences in health centers, among others, in which these patients will not be in a position to decide fully. Given this scenario, it is advisable to anticipate, without rushing, to provide respectful care for the person, their family (if the

patient so wishes), and their values. This process includes essential ethical aspects.

Caring for a person means recognizing they are in greater vulnerability, as vulnerability is an inherent characteristic of all human beings<sup>12</sup>. However, it takes on different forms and dimensions, influenced by economic, sociocultural, political, regional, educational, intellectual, and physical factors<sup>13</sup>. Likewise, not all people with mental health problems are vulnerable in the same way or to the same degree, which is why it is necessary to individually assess the type and intensity of care for each case.

Vulnerability has a direct impact on people's autonomy. The principle of autonomy is usually analyzed from a liberal conception, based on the fact that each individual makes decisions thanks to their principles, values, and preferences. However, another perspective, relational autonomy, recognizes that interpersonal and family relationships influence people's decisions. This perspective emphasizes that our identity, values, and preferences are in a specific context where multiple people interact.

ADP is associated with relational autonomy rather than liberal autonomy. In the context of mental health, the perspective of autonomy allows us to comprehensively consider each individual's life story in their particular context and at a given moment, considering the different spheres that make up their life. From this perspective, the care provided to patients must be individualized and focused on their values and preferences, and unwanted medical interventions or those that may harm their well-being must be detected.

Thus, if these decisions are anticipated, minimizing risks and increasing benefits is possible. In the ADP process, we shape, adapt, and evaluate which situations really bring benefits or harm<sup>14</sup>.

By weighing the harms and benefits in their autonomous decisions, people genuinely seek to achieve well-being, live autonomously, and have meaningful personal relationships, personal achievements, understanding, aesthetic enrichment, physical and mental functioning, and pleasure<sup>15</sup>. To this end, dialogue between the patient and professionals is essential to ensure the patient's decisions are consistent with their values,

desires, and interests. Thus, respect for the dignity and autonomy of people is promoted towards a dignified life.

Kant<sup>16</sup> states that people are not mere objects but subjects of rights. People have dignity and not price, a quality inherent in all humans. Manuel Atienza<sup>17</sup> states that the core of this principle lies in the right and obligation of each individual to develop as a person and, at the same time, in the obligation of others to contribute to their free (and equal) development. Dignity, affirms Atienza, *consists of treating everyone with the same consideration and respect*<sup>17</sup>.

This approach requires non-discrimination and respect for individuals' freedom, thus ensuring an environment of non-interference. We coincide with Adela Cortina<sup>18</sup> in her thesis: dignity does not only consist of not instrumentalizing or harming people but also requires empowering them to carry out their self-realization projects and life projects as long as they do not harm others. That is what the ADP aims to do: encourage the patient to develop as a person so that they can exercise their autonomy and decide about their body and their life path.

This demand for dignity articulates the principle of recognition. In his theory of recognition, Axel Honneth<sup>19</sup> proposes ways of valuing and appreciating people's dignity and equal status. Honneth divides recognition into three spheres: love, law, and social recognition.

The first refers to intimate personal relationships (family and close friends), which are based on the need for affection and care and establish the basis for developing solid self-confidence.

The sphere of law alludes to the rights and obligations of citizens and the legal norms of society, which seek to guarantee equal recognition before the law, regardless of personal relationships. In this way, the foundations of self-respect are laid.

The sphere of social recognition involves a person's value for a community. It values personal qualities that contribute to a specific community's objectives and social values with which projects are shared, promoting solidarity and individual well-being. This is how the foundations of self-esteem are established.

In ADP, there is a desire for recognition so patients can freely exercise their rights. There is also a genuine interest in having their life project, well-being, and autonomy respected and promoted, in addition to encouraging them to be considered moral agents capable of actively participating in decision-making.

ADP allows family or close friends to participate, too. This reflects an authentic culture of care committed to everyone affected by the decision and consensual decision-making on social and health issues.

Joan Tronto<sup>20</sup> considers that care (clearly relational) has a series of dimensions:

- *Caring about*, in which the process really begins, becoming interested in a situation;
- *Caring for*, in which someone must take care of this situation and assume the responsibility that this implies;
- *Care-giving*, in which a specific activity is carried out to satisfy the detected need and which requires skills on the part of the person providing care;
- *Care-receiving*, the ideal space where those who are cared for are included;
- *Caring with*, which refers to the context where the caregiver and the one cared for trust each other, creating a reciprocal and conscious recognition of vulnerability and interdependence.

For Jurgen Habermas<sup>21</sup>, fair political and legal decisions must go through a dialogical and deliberative process among the affected citizens. This implies including all those affected in decision-making, even those with compromised interlocutory capacity, allowing them to express/justify their points of view through consensual decisions. A commitment is required from interlocutors to respect people, their ways of life, and their rights, listen to different views and maintain cordial recognition from others<sup>18</sup>.

This cordial recognition is another advantage of the ADP, as it is supported by this form of decision-making, which is achieved by agreeing on decisions thanks to dialogues between the patient, healthcare professionals, and family and community environments.

As we can see, there are sufficient ethical grounds to justify the introduction of ADP in the field of mental health. They are all based on the need to provide more dignified care to these people. Not only are there ethical reasons to justify its need, but we also find ethical and welfare benefits.

## Ethical and care benefits of ADP

In recent decades, there has been an increase in research on planning decisions (both ADP and AD) in mental health. Several studies have concluded that there has been a substantial improvement in clinical, care, and ethical aspects<sup>10,22-24</sup>

One study revealed that patients who completed AD felt more protected and satisfied because, instead of relying exclusively on the medical team, they could make decisions in vulnerable situations<sup>25</sup>. Another study found that respecting the patient's wishes reduces the feeling of involuntariness in treatment and facilitates collaboration in the process<sup>26</sup>. On the other hand, when the patient's autonomy in decision-making is not respected, they experience feelings of exclusion and injustice, which could reduce adherence to recommended treatment<sup>10,27-29</sup>

Choosing the treatment, knowing its contraindications and the importance of monitoring it increases therapeutic adherence and, therefore, reduces the likelihood of recurrence. Therefore, helping to decide and respecting the patient's decision can positively affect their well-being and health<sup>30,31</sup>.

ADP could also improve continuity of care and long-term health outcomes. Promoting this type of care relationship was shown to enable the prevention of involuntary hospitalizations and reduce the risk of problems with the criminal justice system<sup>32</sup>.

There is no systematic analysis of this issue in Spain, which results in a lack of knowledge between professionals and patients<sup>33</sup>. If we really want a people-centered model to create a culture of care for these patients and their relatives, we must publicize this issue among professionals.

It is crucial to detect barriers that may hinder its application to achieve this.

## Barriers

The literature has highlighted several barriers that make it difficult for patients to make advance decisions about their health<sup>34</sup>. Barriers also exist among professionals, such as concerns about legal responsibilities due to compliance or non-compliance with patient preferences, lack of resources and time, and little importance given to advance directives in clinical practice<sup>35</sup>. There is concern that these advance decisions may interfere with clinical aspects. Likewise, the true meaning and implications of planning decisions are not known.

Other studies have shown that the possibility of patients changing their minds during crises causes doubts among professionals about advance decisions<sup>36</sup>. On the other hand, there is a deep-rooted belief that people with mental illnesses do not have the competence to make responsible decisions about their own lives<sup>37</sup>.

Furthermore, the stigma associated with mental illnesses, communication difficulties between patients and professionals, lack of knowledge of patient's rights, and possibly resistance to change to move from a paternalistic paradigm to one based on autonomy generate obstacles that hinder the introduction of ADP in the field of mental health.

A more apparent than actual barrier is the perception of some professionals that individualized intervention plans appearing in the clinical history, as a result of an ADP, lack legal value. The fact that the concept of ADP does not appear textually in Law 41/2002<sup>2</sup> does not imply that it does not respond to the true spirit of that norm and the conceptual core of informed consent. All care planning recorded in the medical record (whether in the PIIC or not) must be respected, with the professional who does not respect it bearing the burden of proof in the event of a conflict.

Patients also face barriers, such as a lack of understanding and knowledge about planning decisions, low trust in the healthcare team and the

healthcare system in general, and concern about the revocability and legal enforceability of the decisions themselves. Van Dorn and collaborators<sup>38</sup> also observed these uncertainties in advance directives, noting a lack of knowledge about their content and registration procedures.

Other barriers point to the difficulties in finding someone trustworthy to act as a representative in case of inability to decide and even problems finding a trustworthy professional to support the process.

Despite all these barriers, we should not forget that people with serious mental disorders are interested in ADP<sup>39</sup>, although very few have had the opportunity to put it into practice. It is important to remember that these people can express their values and preferences, and even their propositions seem reasonable. This should motivate professionals to introduce it as an essential care axis<sup>39</sup>.

In Spain, implementing the principle of autonomy through ADP or AD did not reach the desired level of success<sup>33</sup>. A public awareness process was not carried out to educate patients and professionals in this area, as, despite the efforts and advances achieved, a paternalistic culture still prevails in the Spanish healthcare system<sup>33</sup>. In mental health, it is even more worrying, as both tools are practically unknown among professionals and patients. Likely, the paternalistic and stigmatizing model is still firmly rooted among many healthcare professionals.

Regardless, these barriers can be overcome with accurate information and specialized training<sup>38,40</sup>. Thus, the discussion raised in this study can contribute to promoting the introduction of ADP in the health system, which is why we propose the recommendations below to encourage professionals to put it into practice with their patients with mental illnesses.

## Implementation of ADP in mental health

### Practical recommendations

The transdisciplinary paradigm requires mutual integration of the team's disciplines, dissolving



each specialty's divisions and limits to achieve common objectives, fully respecting specific competencies<sup>41</sup>. Nursing competencies focused on biopsychosocial and spiritual assessment allow the creation of care plans that merge with the mental health team's individual and comprehensive approach.

The role of nursing specialized in mental health in multidisciplinary and transdisciplinary work acquires vital relevance to strengthen ADP implementation<sup>42,43</sup>.

The helping relationship is used by nurses specializing in mental health to generate respect and trust to establish a therapeutic bond. This type of relationship in the approach to advance directives implies the adoption of a professional attitude and adequate management of emotions, i.e., adequate management of the professional's involvement, especially when it comes to sensitive issues related to values such as freedom, safety, autonomy or contexts such as physical care, palliative care, or end-of-life situations.

Lenagh-Glue and collaborators<sup>29</sup> highlight the suitability of nursing in guiding and monitoring the execution of advance directives, given its training in understanding and meeting the patient's physical, emotional, social, and ethical needs.

The companion provided throughout the care process provides higher quality care. Empathy and active listening, common in nursing practice, favor the understanding of the patient's values and preferences, which facilitates the identification of potential patients who benefit from advance directives, as well as the appropriate reception and approach to their demands, the beginning of relevant conversations with them and their families, and the exhaustive documentation of the entire process.

Once the candidates have been identified, the initial phase is preparation, in which the available information about the person is analyzed. After the first contact with the individual, an offer to participate is made. This is followed by the dialogical and reflective phases that make up the content of the ADP. Finally, validation and registration complete the process.

Piers and collaborators<sup>44</sup> offer 32 recommendations for carrying out ADP in people

with dementia. Among them, and so that they can be applied to patients with mental illness in general, we intend to highlight the following:

- Assess the patient's decision-making competence;
- Recognize the role and importance of loved ones in the ADP process;
- Identify the patient's values and preferences;
- Check the patient's care objectives;
- Check the medical and non-medical treatments the patient wants or does not want to receive.

To this end, the effective application of advance directives requires a series of skills<sup>43</sup>. The essential skills are related to the need to carry out active and empathetic listening. It is essential to provide adequate time and space, avoid rushes or forced visits, plan each session's content, and establish objectives for each meeting to achieve this.

Indeed, when ADP is implemented in mental health, there are more extended deadlines to address certain aspects of planning. This allows people to adapt to the conversation, achieving a balance between a directive approach and more open questions. This flexibility allows them to meet non-verbal or implicit demands.

Choosing the appropriate time to perform the ADP is conditioned by the circumstances in which the need arises, based on the person's clinical and emotional state. It is advisable to postpone fundamental decisions or reflections until the patient feels a deeper connection with their own values and preferences.

What also facilitates communication is adapting the language and message to the individual characteristics of the person served, thus respecting their dignity, promoting autonomy, and increasing their empowerment in decision-making. In this sense, the information must be clear and personalized, aligned with the planning objectives. Therefore, it is a decision-making support, establishing shared objectives agreed upon with the patient.

It is essential to recognize that in the communication process, we must not take things for granted and that it is crucial always to demonstrate active listening. Using empathic understanding facilitators to validate the expression of emotions before continuing to ask

can provide more information and encourage the expression of emotions that have not yet surfaced. Phrases such as “I understand that what we are going to discuss is complicated...,” “I understand that this causes discomfort, but...” can be helpful<sup>45</sup>.

We must be able to detect situations that may cause discomfort (traumatic topics, unpleasant experiences, and intimacy-related issues) and approach them with prudence, offering our presence and waiting for the right moment to address the topic in question.

As information is collected and recorded, it is essential to review it, dialogue with it, and reach a consensus to facilitate its validation. This reinforces the person’s trust, transparency, and participation. We must be aware that this interaction with the patient and their surroundings (if they so desire) is enriching, as much information is obtained. Therefore, we must remain alert. Furthermore, it represents an opportunity for personal growth, as the topics covered tend to transcend needs and challenge us in our life purpose.

In summary, the nurse specializing in mental health, thanks to constant and direct access to patients, can simplify the introduction and development of the ADP. Their holistic and integral understanding of patients and solid training can provide a solid basis for making biopsychosocial decisions. Continuous support throughout the care process provides more dignified care for the people served. For these reasons, it is essential to strengthen the role of the mental health specialist nurse concerning advance decisions.

## Final considerations

This article focused on exploring the importance of ADP and considering its impact on mental health. It also highlighted its relevance as a suitable tool for providing dignified, person-centered care and empowering patients to make decisions.

Through our proposed ethical framework to substantiate and claim the ADP, weighty reasons were provided to justify and promote ethically appropriate treatment for these patients. ADP in mental health has been proposed to address the

inherent vulnerability of patients facing psychotic episodes, depressive phases, etc., which also affects their ability to make decisions. Anticipating scenarios and respecting their autonomy, even in moments of vulnerability, is essential to provide respectful care focused on the person and their family.

Thus, PDA is nourished from the perspective of relational autonomy, considering the full context of each individual and their interpersonal and family relationships to promote their well-being and ensure that their decisions are consistent with their preferences. Likewise, dignity and recognition are essential ethical foundations that enhance the inherent respect for dignity and one’s life project. This way of reaching consensus and anticipating decisions requires the creation of dialogical and deliberative processes, including those affected in decision-making and respecting their points of view.

Thanks to this, ethical and care benefits are obtained, ensuring more respectful care for patients with this problem. Sufficient evidence stood out, demonstrating that ADP empowers people and increases their satisfaction and feeling of protection. Likewise, it improves treatment adherence and reduces the perception of exclusion and injustice. Its implementation could also improve continuity of care and long-term results, avoiding involuntary hospitalizations.

Unfortunately, it has become clear that in Spain, there is still a considerable lack of knowledge about ADP in mental health, possibly due to several barriers that hinder its full incorporation, which constitutes a significant challenge for professionals and patients. In this context, the stigma associated with mental illness and a lack of understanding about ADP constitutes additional obstacles to practical implementation. This is even more worrying when people with mental disorders are interested in participating in the ADP and expressing their preferences.

Therefore, overcoming these barriers requires providing precise information and specialized training for patients and healthcare professionals. Such overcoming requires detailed research to identify the existing obstacles to promoting more humanized and respectful care.

For all these reasons, it is crucial to address this issue to move toward more humanized and person-centered healthcare since promotion and information about ADP will allow patients to exercise their autonomy and receive care consistent with their values and desires. This is why we highlight recommendations from nursing aimed at healthcare professionals who wish to implement the ADP with their patients and families.

We hope this article will increase knowledge about ADP in mental health, positively impacting the scientific community and clinical practice. Therefore, ADP emerges as a topic of growing interest in medical and nursing ethics, in which healthcare professionals and patients could benefit from a more humane care relationship committed to people's values and respect for their dignity.

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