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Advance directives and psychology in palliative care: a scoping review

Thaís Chaves Rosendo Rocha[1], *Glenda Ramos Ebert de Mello*[1], *Louizia Pinto Lima*[1], *Carla Nogueira Sampaio*[1], *Ivan de Paula Fialho*[1]

1. Centro Universitário de Valença, Valença/RJ, Brasil.

Abstract

This scoping review aimed to understand advance directives in the context of palliative care from the perspective of psychology. Based on the available literature, the review was conducted using the PRISMA-ScR method. Eighteen articles were selected from SciELO, LILACS, and PePSIC databases for the final review. Duplicate studies, non-scientific articles, and studies that did not address the study topic or the Brazilian context were excluded. Advance directives, besides being closely related to the reduction of anxiety and depression symptoms, play an important role in promoting patient autonomy. We concluded that psychologists contribute to the implementation of advance directives, help with communication and family acceptance, and help with grief. Finally, future studies should expand the discussion on this topic, especially in psychology, a field with a lack of studies.

Keywords: Advance directive. Palliative care. Psychology, medical.

Resumo

Diretivas antecipadas de vontade e psicologia em contexto paliativo: revisão de escopo

Esta revisão de escopo teve por objetivo compreender, sob a ótica da psicologia, as diretivas antecipadas de vontade no âmbito dos cuidados paliativos. A partir da literatura disponível, realizou-se a revisão por meio do método Prisma-ScR. Com busca nas bases de dados SciELO, Lilacs e PePsic, 18 artigos foram selecionados para a revisão final. Foram excluídos estudos duplicados, os que não se configuraram como artigos científicos e aqueles que estavam fora do tema e/ou não discorriam sobre o contexto brasileiro. Observou-se que, além de estarem intimamente relacionadas à diminuição de sintomas ansiosos e depressivos, as diretivas antecipadas de vontade exercem papel importante na promoção da autonomia do paciente. Concluiu-se que o psicólogo contribui na implementação das diretivas antecipadas de vontade, auxilia na comunicação e na aceitação da família e na elaboração dos lutos. Por fim, ressalta-se a importância de ampliar as discussões a respeito do tema em pesquisas futuras, sobretudo na psicologia, na qual se evidenciou escassez literária.

Palavras-chave: Diretivas antecipadas. Cuidados paliativos. Psicologia médica.

Resumen

Directivas anticipadas de voluntad y psicología en el contexto paliativo: revisión de alcance

El objetivo de esta revisión de alcance fue comprender, desde la perspectiva de la psicología, las directivas anticipadas de voluntad en el contexto de los cuidados paliativos. A partir de la literatura disponible, la revisión se llevó a cabo utilizando el método PRISMA-ScR. Mediante búsquedas en las bases de datos SciELO, LILACS y PePSIC, se seleccionaron 18 artículos para la revisión final. Se excluyeron los estudios duplicados, los que no estaban configurados como artículos científicos y los que no correspondían al tema o no discutían el contexto brasileño. Se observó que, además de estar estrechamente relacionadas con la disminución de los síntomas ansiosos y depresivos, las directivas anticipadas de voluntad desempeñan un papel importante en la promoción de la autonomía del paciente. Se concluyó que el psicólogo contribuye a la implementación de las directivas anticipadas de voluntad, ayuda en la comunicación y en la aceptación por parte de la familia y en la elaboración del duelo. Por último, se resalta la importancia de ampliar las discusiones acerca del tema en futuras investigaciones, especialmente en psicología, donde hay escasez literaria.

Palabras clave: Directivas anticipadas. Cuidados paliativos. Psicología médica.

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Death is still a taboo topic and, according to Kovács [1], it is permeated by silence and considered a failure, and everything is done to prevent it, extending the patient's life as much as possible. Technology can postpone death, but it does not guarantee that the patient will have a good quality of life.

The conspiracy of silence, that is, remaining silent about a subject—in this case, death and grief—is observed among families of patients at the end of their lives and among health professionals, not to mention its impact on society as a whole. The frustration of loss increases with the current paradigm of hidden death. The denial of death makes it impossible to discuss a patient's end of life with dignity and handle different types of grief, especially in elderly patients.

Therefore, talking about these issues involves the idea that the end of life is a sensitive topic that causes distressing sensations and feelings. Consequently, ethical dilemmas are seen at the moment of death, especially in the hospital setting [2], when physicians, patients, and family members are in bioethical conflicts related to death and dying [3].

In this scenario, advance directives (AD) have emerged aiming to collect documents that confirm the patient's wishes regarding the health care that will be provided if communication becomes impossible. The documents collected include the living will (of a legal nature) and the health care power of attorney [4,5].

ADs help to humanize the patient's experience by offering choices. The philosophy of palliative care considers the patient as the protagonist of his/her illness process. According to the World Health Organization (WHO), palliative care comprises multiprofessional care provided by a multidisciplinary team to patients with a life-threatening illness, with a focus on comprehensive care, prevention and relief of suffering, treatment of pain and physical, psychological, social, and spiritual symptoms [6].

Palliative care promotes autonomy, respect, and a dignified end of life for patients. ADs are important in palliative care because they allow the patient, the family, and the healthcare team to determine the course of treatment while the patient is still lucid. Particularly for elderly patients suffering from various chronic diseases, ADs are an ally in humanized care, allowing the exclusion of treatments that make no sense to the patient [7].

ADs can also be a powerful resource, especially in Brazilian society, given that today more than 30 million Brazilians are over 60 years old [8]. With the inclusion of ADs in public policies, the older population of Brazil (not necessarily those with terminal illnesses) can have access to good quality health care, which is also concerned with the best ways to die, improving health care at all stages of life, from start to end.

Therefore, the proposal for this review is justified, since psychology, as a profession and a body of knowledge, can significantly contribute as a promoter of autonomy and psychological well-being in the experience of terminality and/or the aging process. In the hospital setting, respect for patient autonomy, reduction in conflicts between family members, and improved communication between team members are perceived benefits resulting from the incorporation of ADs.

The aspects mentioned above guide the work of psychologists in hospitals and, besides demonstrating their involvement in the issue of ADs (given that their work is based on the patient-family-healthcare team triad), they indicate the need to expand the debate and bring them to the sphere of psychology, including them in its practices [9]. Therefore, this study aims to understand ADs in the context of palliative care in the perspective of psychology in Brazil.

Method

This is a scoping review that seeks to answer broader questions of a field of knowledge, synthesizing the evidence available [10]. The method used in this review was PRISMA-ScR, which evaluates the literature and discusses the basic concepts of a particular field of study.

This type of study also aims to systematize knowledge so that it can contribute to and disseminate practices, policies and research;

identify gaps in the literature; and understand how research is conducted in this field[11].

The steps defined to conduct this study followed a rigorous process in which the objectives and the main study question were defined, and then the inclusion and exclusion criteria were determined, as well as the preparation for the search for evidence, and data selection, extraction, and presentation. Once the search for evidence was performed, it was carefully selected, followed by detailed extraction. A detailed analysis was performed and the results were then described[12].

The guiding question for the research was developed using the PCC strategy, that is, the following basic elements: P – population, C – concept, and C - context[12]. Then, P was defined as the health professionals; the first C represented the ADs, and the second C represented palliative care. After that, the following question was developed: How can health professionals contribute to ADs in palliative care?

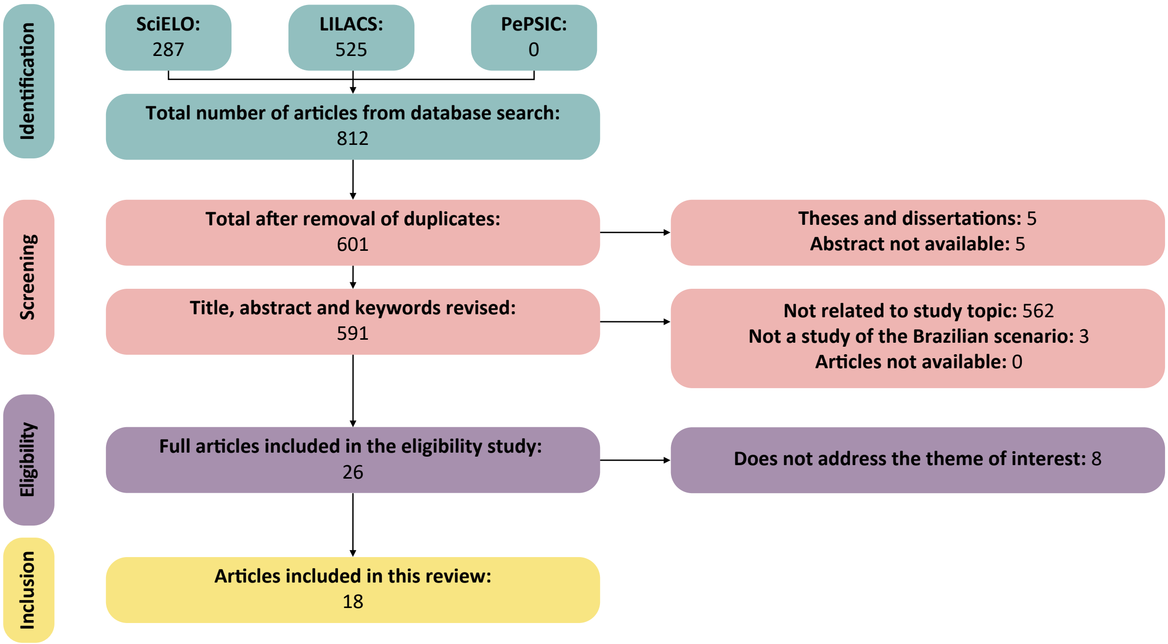
The databases analyzed in this review were SciELO, LILACS, and PePSIC, selected for their relevance to the fields of health and psychology. The descriptors were combined in the strategic equation, which aimed to match the PCC mnemonic.

Then the following terms were used in the search: (profissional da saúde) OR (profissionais da saúde) AND (diretivas antecipadas de vontade) OR (diretiva antecipada de vontade) OR (diretivas antecipadas) OR (diretiva antecipada) OR (DAV) OR (DAV's) OR (ética) OR (bioética) AND (cuidados paliativos) OR (cuidado paliativo).

Database searches were performed independently by two researchers between August 21 and 30, 2023. A total of 812 results were found in the three databases, of which 211 were duplicates and were removed at the screening stage (after reading the title, abstract, and keywords). Of these, five were excluded because they were theses and dissertations, and five were excluded because they had no abstract.

Of the remaining 591 articles, 562 did not address the study topic and three were not about the geographic context defined for this review (Brazil), and were also excluded. At the eligibility stage (after reading the full text), eight articles were removed, leaving 18 articles for the scoping review. Figure 1 shows the flowchart of the article selection process.

Figure 1. Flowchart of the article selection process.



Two independent researchers analyzed the studies to determine whether they were relevant for data extraction. In cases where there was disagreement regarding the screening and eligibility stage, the studies were analyzed by a third researcher. Data were entered into an Excel spreadsheet and then transferred to SPSS statistical software. The degree of agreement between the analysis of researchers (inter-rater agreement) is represented by the κ coefficient (kappa coefficient)[13].

According to Fleiss, Cohen and Everitt[14], the maximum value of κ is 1, which represents absolute agreement between the raters. However, the closer the value of κ is to zero, the lower the level of agreement. With κ=0.839 (screening stage) and κ=0.821 (eligibility stage), according to Fleiss[15], this study presents an excellent level of agreement between the raters (where κ>0.75 means a ≥95.3% agreement).

Results

Chart 1 shows the studies found about ADs and palliative care in Brazil.

Chart 1. Studies about ADs and palliative care in Brazil.

Authors/Year	Title	Objective
Fusculim and collaborators; 2022[3]	"Advance directives of will: bioethical support for ethical health issues"	Analyze the current context of implementation of advance directives of will in Brazil in the perception of medicine and nursing professionals and the main contribution of bioethics to such implementation.
Lima and collaborators; 2022[4]	"Advance directives: patient autonomy and professional safety"	Propose a review of bioethics in the sense of safely promoting and ensuring the patients' dignity, respectful of their decision making, following regulations and protocols that help fulfill this will and bring safety to the care team.
Lampert and collaborators; 2022[16]	"Therapeutic adequacy: presentation of a hospital protocol"	Present a protocol on therapeutic adequacy implemented in a university hospital.
Hassegawa and collaborators; 2019[17]	"Approaches and reflections on advance healthcare directives in Brazil"	Explain the approaches and discussions about the Advance Directives spread among health professionals, lawyers and society.
Peruzzo; 2017[18]	"Autonomy, care and respect: the debate on assisted extension of life"	Discuss concepts of assisted extension of life.
Salles; 2014[19]	"Bioethics and religious processes among terminally ill patients in Brazil"	Show the diversification of Brazilian patients' needs regarding the spiritual wellbeing at the end of life.
Guirro and collaborators; 2022[20]	"Knowledge regarding advance directives in a teaching hospital"	Evaluate the knowledge of health professionals and patients regarding advance directives in a Brazilian teaching hospital.
Chaves and collaborators; 2021[21]	"Palliative care: knowledge of cancer patients and their caregivers"	Assess the perception of palliative care, advance directives and do-not-resuscitate order of patients and their caregivers, as well as their relationship with health professionals.
Nunes, Anjos; 2014[22]	"Advance directives: benefits, obstacles and limits"	Discuss the benefits, obstacles and limits of advance directives in the clinical practice.
Maingué and collaborators; 2020[23]	"Bioethical discussion on end of life patient care"	Identify factors that influence the decision-making process of health professionals regarding patients in intensive care units.

continues...

Chart 1. Continuation

Authors/Year	Title	Objective
Pirôpo and collaborators; 2018[24]	"Correlation of living will, bioethics, professional activity and patient autonomy"	Analyze the correlation between living will and bioethical aspects, professional performance and patient autonomy.
Santana, Câmara; 2022[25]	"Perception and expectations of cancer patients about the anticipated directives of will"	Assess the perception and expectations of cancer patients about the concept and applicability of the advance directives of will.
Dias and collaborators; 2022[26]	"Advance care planning: a practical guide"	Develop communication strategies to encourage, start, and better manage an advance care planning.
Lima, Rego, Siqueira-Batista; 2015[27]	"Decision-making process in end-of-life care"	Discuss ethical issues related to decisions about end-of-life care.
Moreira and collaborators; 2017[28]	"Physician's perceptions to include living will in medical practice"	Promote a better understanding of physicians' point of view when dealing with the last moments of their patients' lives.
Chehuen and collaborators; 2015[29]	"Living will: What do healthcare professionals think about it?"	Assess the knowledge of healthcare professionals about living will.
Medeiros and collaborators; 2020[30]	"Bioethical conflicts in end-of-life care"	Identify the main conflicts between patients in end-of-life care, family, and healthcare team in the perspective of the principlism.
Vidal and collaborators; 2022[31]	"Position statement of ANCP and SBGG on shared decision-making in palliative care"	Present the official position of the National Academy of Palliative Care (ANCP) and the Brazilian Society of Geriatrics and Gerontology (SBGG) on shared decision-making in palliative care.

All 18 articles were published between 2014 and 2022, with 2022 being the most significant year in terms of number of publications. The most researched topics sought to understand and reflect on ADs in a broad context, and assess the knowledge of patients and professionals about this topic. The target audience of the articles was physicians and nurses, with a few articles focused on multidisciplinary teams. Other audiences were also found, such as technicians, nursing assistants, medical and law students, lawyers, patients (mainly cancer patients), and caregivers.

After a full reading and critical analysis, the categories of this study were created by grouping data that were theoretically similar: *principles of bioethics*, *concepts of palliative care and advance directives: legislation, autonomy, and psychological aspects*.

Principles of bioethics

Bioethics is a field of knowledge that combines ethics and biotechnology, promotes discussions about life and death[17], and seeks to reflect on ethical dilemmas, with a focus on respect for freedom and quality of life. In the hospital setting, it involves medicine and psychology, strengthening the biopsychosocial view of the patient. Its four main ethical principles are beneficence, non-maleficence, autonomy, and justice[19,30].

Beneficence refers to the pursuit of benefit while minimizing harm to patients and respecting their autonomy. Then, professionals must always do good for the patient, regardless of their individual beliefs. The principle of nonmaleficence seeks to do no intentional harm to patients. Autonomy means ensuring the decisions of patients are respected and that they are involved in the decision-making process. The principles of bioethics seek to help and support the healthcare team and patients in end-of-life care. In the articles selected for this review, the principle of justice was mentioned without a conceptual definition[17-19,30].

Concepts of palliative care

Palliative care is a multidisciplinary approach to patients with life-threatening illness that promotes relief and prevention of suffering and pain, as well as measures of comfort and well-being. The palliative care patient does not receive unnecessary procedures, contrary to therapeutic obstinacy and its goal of extending life. This care can be provided after diagnosis and is not exclusively an end-of-life measure. Bioethics and palliative care share humanization in the dying process and complement each other in practice, with bioethics guiding palliative care [16,18].

Orthothanasia, a practice used in palliative care and guaranteed by the healthcare team, aims to ensure a good death, without speeding it up or delaying it, providing comfort and peace of mind to the patient at the end of life [4,28]. It differs from euthanasia, a practice that causes death, and from dysthanasia, the extension of life by unnecessary technological means that can increase the pain and suffering of the patient and family members [4,17].

The study by Chaves and collaborators [21] with cancer patients and their caregivers analyzed palliative care and showed a lack of knowledge about the term and its meaning, reflecting a lack of preparation and training of health professionals on the subject. Fusculim and collaborators [3] show that professionals with more knowledge about palliative care are more likely to use ADs.

Legislation, autonomy, and psychological aspects

As already explained, ADs are understood as wishes expressed by patients about the care and treatment they will receive in the absence of their ability to communicate freely and autonomously. Today, there is no specific legislation on this issue, which is so relevant in the hospital setting. However, there is a regulation—the Resolution of the Federal Council of Medicine (CFM) [32]—that describes the conduct that should be performed at the end of life and the health care that will be provided to patients [16,17,20,21,24,25,29].

ADs include a living will, a document that can be registered at a notary's office, and a health care power of attorney, which designates a representative responsible for making decisions. Despite the possibility to notarize the living will, the Brazilian Federal Council of Medicine recommends that ADs should also be included in medical records, considering it as sufficient, as long as it is written clearly and carefully and takes into account the patient's current state of health and the therapeutic measures that should or should not be performed [4,16,17,20,24,29].

With regard to ethical and legal standards, a fear of using ADs was identified, implying civil liability for physicians. However, the Code of Medical Ethics and CFM Resolution 1,995/2012 are important guidelines for clinical practice, which should be respected [17]. Despite the increased adherence to AD use, the lack of regulation and dissemination of this knowledge in the field of bioethics can generate wishes in all those involved. These issues can lead to a poor dialogue between the health team, patients, and their families [3,21].

It should be noted that ADs promote patient autonomy, as patients are able to align their choices with their values. Patients who are informed about the risks and benefits of ADs can agree or disagree with the therapeutic measures offered, fulfilling their wishes in the face of their terminal illness. This discussion can raise awareness of death and finitude among those involved and provide an understanding of the patient's real health status, and of what may happen as the diseases develops, avoiding therapeutic obstinacy, promoting well-being, and encouraging dialogue between patients, family members, and the healthcare team [18,20,22,25].

Many authors also emphasize the intense and profound nature of the decisions involved in ADs, indicating that, at the time of writing the document or declaring their wishes, the patient must be in a state of preserved emotional and behavioral capacity. The, in order to ensure greater safety, the participation of a psychologist and/or psychiatrist is recommended to confirm the necessary conditions [26,28]. The studies show a connection between the fields of medicine, psychology, and bioethics, based on an understanding of the human being according to the biopsychosocial model and comprehensive health care. It develops respect for aspects such as autonomy and spirituality in terminal patients, and the development of communication skills and empathy in healthcare professionals [19,28].

A study conducted with cancer patients showed that, given the security of their autonomy and the possibility of communicating with the healthcare team, they had lower rates of anxiety and depression symptoms when expressing their opinions for their own ADs. Therefore, pain and suffering in health care should be understood that they are not only manifested through physiological aspects [25,28], but also through psychological aspects.

Discussion

According to Dias and collaborators [26], a sign of excellence in the provision of palliative care services is the implementation of an advanced care planning (ACP) for all patients in this context. This process involves communication between health care professionals and patients in order to make shared decisions. It is possible, but not mandatory, to document the decisions in the ACP using an AD. According to the authors, the ACP should be developed as early as possible, while the patient is emotionally stable, and gradually progress in the complexity of the decisions.

Using the ACP 'protocol' ensures that patients receive treatments according to their preferences, reduces the burden of these decisions on the family and the suffering of the professionals involved, and encourages the production of more ADs in the hospital setting. Another benefit highlighted by the authors is the reduced risk of depression and anxiety among family members at the moment of grief [26].

The ACP has a number of stages that facilitate communication and address the psychological aspects of the patient at this difficult time, which are: preparation (reviewing the clinical history, prognosis, and treatment options); introduction (establishing the purpose of the conversation and doctor-patient trust); identification of patient perception (talking about coping with the disease and topics such as emotions, finitude and other practical end-of-life issues); and action (recording the information provided by the patient). The last stage refers to an AD medical record, designation of a legal proxy and/or sharing of the information with close people and family members [26].

The National Academy of Palliative Care (ANCP) Palliative Care Handbook [33] emphasizes the need to focus on communication, noting that good communication between health care professionals and their patients represents care and increases hope in difficult times. For this reason, communication skills must be improved. Some suggestions for how to proceed, especially in the palliative care context, include understanding the patient's main fears and expectations, providing true information, knowing the patient's cultural values, respecting and promoting autonomy, and considering the family's needs.

Also about the family nucleus, there is a constant search for balance and organization, which occurs in a dynamic and interactive manner. Faced with stressors and deep changes, such as life-threatening situations, everyone involved may experience a sense of imbalance, conceptualized as a crisis. In this context, one or more family members may be involved. A broader network than the family should also be considered, such as friends and partners, who are also affected by the patient's illness and may collaborate to his/her care. These types of relationships have different implications for the patient's experience [34,35].

In addition to the crisis situation, feelings of denial, abandonment and confusion may arise among the patient's family and friends, who feel a moral responsibility for the patient's care. During the crisis period, they may experience changes in sleep and diet, make use of smoking, alcohol and medication, increase interpersonal interactions, seek moments of spirituality, and show feelings of guilt or anger. In view of the above, some strategies may help those involved, such as flexible visiting hours, interventions in moments of crisis, and support groups. Emotional support is very important in these circumstances [34,35].

Psychologists have an important role in this context. The ANCP Handbook [33] discusses the role of this professional in palliative care. Their work should be based on the patient-family-healthcare team triad, providing qualified listening and ensuring that the needs of the patient, family, and medical team are heard and met. The handbook recommends articulating the healthcare team, since palliative care uses the concept of total pain, that is, a holistic view of patients that considers their physical, psychological, spiritual, and social suffering. Psychologists must help patients and their families with their experience of illness, validate the concerns of family members, and provide a safe place for them to talk about their fear and pain [33].

Psychologists, or psychiatrists, must ensure that patients are lucid, in a state of normality, when formulating their ADs or living wills. It increases the guarantee of the document and ensures that it is not the result of a decision made in a moment of deep pain or grief. For this reason, psychologists are important actors in the process of AD formulation [28].

As highlighted in the studies by Kovác [36], the purpose of ADs is not to support suicide or to neglect help, but to value the patient autonomy in the face of their own death. Also, the importance of this issue should be disseminated and patients and their families should be familiarized with it, as well as health care team of hospitals. This way, ADs are a process also mediated by psychologists in different settings, mainly in hospital, which facilitates communication, the preparation for grief, the re-signification of human existence, and the possibility of experiencing a more dignified death. According to the author, patients who had the opportunity to talk about the end of their lives went through this process with dignity and a better control and peace. In addition, their families were better prepared to handle grief.

Final considerations

When analyzing the results of this review, the concepts of bioethics and palliative care are guiding principles for multiprofessional practice related to ADs, and clear and objective communication is a fundamental attitude towards the patient. ADs support a good death and orthothanasia, promoting autonomy and freedom for patients in their dying process, and are necessary to reduce dysthanasia and therapeutic obstinacy. It is the duty of healthcare professionals who provide palliative care and ADs to act according to the principles of bioethics, which guarantees a humanized view of the patient, taking into account the concept of total pain and enabling dignity and acceptance of death as a natural process.

This study reviewed the recent literature on ADs and their psychological impact on patients. It found that involving patients in the decision-making process strengthened their autonomy in the disease process and had a positive impact. It is important to broaden the discussion on ADs in future studies, especially in psychology, since this review found few studies in this field of knowledge. Psychologists have a lot to contribute to the implementation of ADs, helping patients communicate their wishes, supporting family acceptance and how they handle grief. The discussion about the contributions of psychology to the adoption of ADs has been broadened, supporting future studies.

Finally, we would like to highlight the need for legislation on ADs to support health professionals and provide greater security in their practice, as well as the dissemination of knowledge about them in all the fields in which care services are involved. The lack of legal support affects professionals and has a direct impact on the adoption of ADs. Healthcare teams, patients, and family members would all benefit from the implementation of a law that promotes the dissemination of this issue and its positive impact.

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Thaís Chaves Rosendo Rocha – Undergraduate student – chavesthais06@gmail.com
0009-0007-7704-5759

Glenda Ramos Ebert de Mello – Undergraduate student – glenda_ebert@live.com
0000-0002-7956-9341

Louizia Pinto Lima – Undergraduate student – louizialima@hotmail.com
0000-0002-9056-1586

Carla Nogueira Sampaio – Graduate (specialist) – carlanogueira14@gmail.com
0009-0000-0966-7635

Ivan de Paula Fialho – Master – ivan_fialho@hotmail.com
0000-0001-5819-8214

Correspondence

Thaís Chaves Rosendo Rocha – Rua Vito Pentagna, 637, Benfica CEP 27601-580. Valença/RJ, Brasil.

Participation of authors

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