Revista Bioética
ISSN: 1983-8042
ISSN: 1983-8034
Conselho Federal de Medicina

Oliveira, Ana Sarah Vilela de; Machado, Juliana Campos; Dadalto, Luciana
Cuidados paliativos e autonomia de idosos expostos à covid-19
Revista Bioética, vol. 28, no. 4, 2020, October-December, pp. 595-603
Conselho Federal de Medicina

DOI: https://doi.org/10.1590/1983-80422020284422

Available in: https://www.redalyc.org/articulo.oa?id=361570653003

Revista Bioética
Print version ISSN 1983-8042 On-line version ISSN 1983-8034
Rev. Bioét. vol.28 no.4 Brasília Oct./Dec. 2020
Doi: 10.1590/1983-80422020284422

UPDATE

Palliative care and autonomy of older adults exposed to Covid-19

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Abstract

This article aims to contextualize the Covid-19 pandemic regarding older adults in view of age-related criteria to allocate scarce healthcare resources imposed in some prevention protocols, evidencing discrimination against elderly people for disregarding their biography and values. The goal of this study is to defend autonomy in old age and highlight the need for access to palliative care, regardless of whether resources are available. To this end, it conducts a bibliographic and legal-dogmatic investigation with a qualitative approach. The research concludes that in a situation where collective interest should prevail, palliative care is crucial to respect the autonomy and dignity of the aged, granting them a better experience at the end of life.
Keywords: Aged. Palliative care. Bioethics. Personal autonomy.

Resumo

Cuidados paliativos e autonomia de idosos expostos à covid-19

Este artigo visa contextualizar o cenário da pandemia da covid-19 em relação aos idosos, tendo em vista a imposição de critérios etários em protocolos para alocação de recursos escassos, evidenciando um tipo de discriminação à pessoa idosa que desconsidera sua biografia e valores. Objetivou-se defender a autonomia na velhice, bem como ressaltar a necessidade de acesso aos cuidados paliativos, independentemente de haver ou não recursos. Para tanto, adotou-se como método a investigação bibliográfica e jurídico-dogmática, com enfoque qualitativo. Conclui-se que em cenário em que o interesse coletivo deve preponderar, os cuidados paliativos são cruciais para respeitar a autonomia e a dignidade do idoso, garantindo melhores experiências no fim de vida.
Palavras-chave: Idoso. Cuidados paliativos. Bioética. Autonomia pessoal.

Resumen

Cuidados paliativos y la autonomía de las personas mayores expuestas a la covid-19

Este artículo busca contextualizar el escenario de la pandemia de la covid-19 respecto a las personas mayores, teniendo en vista la imposición de criterios de edad en protocolos para determinar la asignación de recursos escasos, lo que pone de manifiesto un tipo de discriminación hacia las personas mayores que desprecia su biografía y valores. El objetivo es defender la autonomía en la vejez, así como resaltar la necesidad de acceso a los cuidados paliativos, independientemente de si hay recursos o no. Para ello se adoptó como método la investigación bibliográfica y legal-dogmática, con un enfoque cualitativo. Se concluye que, en un escenario en que el interés colectivo debe ser preponderante, los cuidados paliativos son cruciales para respetar la autonomía y la dignidad de las personas mayores, y garantizarles mejores experiencias al final de la vida.
Palabras clave: Anciano. Cuidados paliativos. Bioética. Autonomía personal.

The authors declare no conflict of interest.

The first case of Covid-19, caused by Sars-CoV-2, was recorded in Wuhan, province of Hubei, China, and soon the disease spread globally. The World Health Organization (WHO) declared the outbreak a pandemic on March 11, 2020 [1]. The speed with which the virus spread, the difficulty to contain it and the severe clinical manifestations were surprising, given that the six other human coronaviruses known are the second leading cause of the common cold in the world and in recent decades have rarely caused more serious diseases [1].

Like other coronaviruses, Sars-CoV-2 causes a potentially severe respiratory disease in some individuals [2]. Given its high transmission capacity and the lack of a specific vaccine and medication, government initiatives have been based on prevention practices, such as social distancing, wearing of face masks and hygiene habits (washing hands well, not touching eyes, nose and mouth until hands are clean, among others). Thus, it is up to both the government and the population to jointly act to mitigate contagion while more effective measures, such as vaccines, are not developed.

In this situation, healthcare teams and government agencies face difficulties to fight the virus with little scientific evidence. What is already known is that Sars-CoV-2 causes respiratory and intestinal infections that may result in complications, such as severe acute respiratory syndrome, heart damage and secondary infection [3]. All of these complications lead to a high hospitalization rate, with the potential to overwhelm health systems and cause their collapse.

The largest risk group consists of older adults and patients with chronic diseases [1], as the deficient immune system of this population increases the incidence of infectious diseases [2]. In this context, older adults become doubly vulnerable, as the changes in the organism that reduce the capacity of the immune system, natural to the aging process, are added to the severity of Covid-19 symptoms, further weakening its physiology.

However, the scarcity of resources caused by the extraordinary demand for care, inputs, technologies and human resources has challenged healthcare institutions, which have been forced to choose how to distribute risks and benefits among patients. The age criterion has sometimes been adopted, as in the case of the Italian Society of Anesthesia, Analgesia, Resuscitation and Intensive Care (Siaarti) [4] and the Brazilian Society of Intensive Care (Amib) [5], which reviewed its first recommendation after careful analysis, considering the discriminatory manner in which this criterion was being used [6]. Thus, in some countries, including Italy [7], the older population has been suffering age discrimination by being denied priority care, in a kind of social segregation that disregards the patient's history and dignity.

It is important to view old age as a natural and inevitable process. In Brazil, this is essential for effective compliance with the guidelines of both the Federal Constitution of 1988 [8] and of the Statute of the Elderly [9]. However, it requires an environment conducive to healthy aging and duly based on respect for the life and values of older adults, ensuring them the autonomy to enjoy their final years in the best way possible.

In view of the uncertainties caused by the Covid-19 pandemic, it is essential to evaluate the best behaviors to respect the aged, considering the bioethical principles of beneficence, non-maleficence, justice and autonomy. WHO [10] plays a crucial role in this context as it has not only defined the concept of palliative care – which will be addressed during the study – but also released the guide *Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises* [11].

This guide is part of a series of WHO documents on palliative care and aims to direct its integration with pain relief in health systems. Although they are not the answer to scarce resources, these precautions are in accordance with bioethical precepts and essential in the current situation. When medical technology alone is no longer capable of ensuring life extension, end-of-life care can relieve suffering and offer patients physical, psychological, social, moral and spiritual assistance.

Sophie's choice in times of Covid-19

According to Leitão Júnior and Mousinho [12], the term "Sophie's choice" comes from an American movie of the same name released in 1982, based on the novel by William Styron. The drama tells the story of Sophie, a Polish immigrant and daughter of an anti-Semitic father, who was interned in Auschwitz during World War II on charges of smuggling. The choice alluded to in the title occurs in the concentration camp, where the character is forced to save only one of her two children from execution, otherwise they will both die. The expression, therefore, refers to decision-making under conditions of enormous pressure

 Rev. bioét. (Impr.). 2020; 28 (4): 595-603 http://dx.doi.org/10.1590/1983-80422020284422

and sacrifice, and can be translated in the legal and bioethical sphere as "difficult choices" or, in practice, as "tragic choices" [12].

The choice addressed in this article relates to who will benefit from scarce healthcare resources. For example, in a hypothetical situation in which we have two patients with Covid-19 – an 80-year-old who respected the lockdown rules and a 25-year-old who did not – and only one bed in the intensive care unit (ICU), who should benefit from the resource? [13] Thinking rationally, the answer is almost instinctive: the patient who is most likely to survive. However, the issue is complex and has been faced in practice in several places around the world.

It is true that in catastrophe situations some patients may not receive all the assistance they need, but they should never be left without any care, even if it is merely palliative, aiming to relieve their pain. On the other hand, in a pandemic situation it is unavoidable to consider severity of clinical conditions and likelihood of survival as criteria to allocate resources. Thus, it is essential to develop protocols with clear and objective scores that justify not meeting the ascertained needs of patients.

To this end, the Brazilian Society of Bioethics (SBB) published Recommendation 1/2020 [14], which addresses fundamental and ethical aspects to face the Covid-19 pandemic in Brazil, dealing with the allocation of resources and the equal use of health technologies. The document advocates protecting those who are most vulnerable and highlights the key role of the Brazilian Unified Health System (SUS). It is also advocated the right of everyone to the best treatment possible and equal access to ICU beds, whether public or private, going so far as to recommend drawing on the principles of the *Universal Declaration on Bioethics and Human Rights* (UDBHR) [15] to define criteria in case of insufficient beds.

The SBB recommendation [14] is based on Article 5 of the Brazilian Constitution [8] and on the International Covenant on Economic, Social and Cultural Rights, adopted by the United Nations in 1966, which provides in Article 12, paragraph 1, recognition of *the right of everyone to the enjoyment of the highest attainable standard of physical and mental health* [16]. Also considered are the rights advocated in Article 6 of the Brazilian Constitution and the provisions of Article 25 of the *Universal Declaration of Human Rights*: *Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control* [17].

In Italy, Siaarti stated that if the age criteria were not adopted, resources would be applied according to the process most commonly used in ICU care worldwide: admitting patients by order of arrival and not treating patients when there are no more beds available [4]. In addition, the institution's specialists pointed out that when there is a large patient flow and a hospitalized person does not respond to treatment, the decision to place them under palliative care should not be postponed [4].

The bioethics working group of the Spanish Society of Intensive and Critical Care Medicine and Coronary Units (Semicyuc), endorsed by the Spanish Society of Internal Medicine, published ethical recommendations for making decisions in ICUs amid the exceptional situation of the pandemic [18]. The guidelines prioritize those who will benefit most from care, establishing specific priority scores (ranging from 1 to 4). The institution argues that this type of planning is essential to ensure the proper use of resources and respect for life, noting, however, that screening criteria are only justified after all efforts to increase the availability of resources have been made. Semicyuc emphasizes justice, duty to care and manage resources, transparency, consistency, proportionality and responsibility as key principles in managing the crisis.

In Brazil, Amib, together with the Brazilian Association of Emergency Medicine, published recommendations on the allocation of scarce resources during the pandemic [5]. The document is based on a screening protocol proposed by Biddison and collaborators [19] and is similar to the model of White and collaborators [20,21], presenting three goals: to save the largest number of people; to save the greatest number of life years; and to afford different individuals equal opportunity to go through the life cycles. In the models proposed by Biddison and collaborators [19] and White and collaborators [20,21], this last goal is achieved by allocating more points (the higher the score, the lower the chances of survival) as the patient's age range increases. This criterion is used as part of the main model in White and collaborators in the 2009 version [20] and as a tiebreaker in the model of Biddison and collaborators [19] and White and collaborators in the 2020 version [21].

However, following consultation with bioethics experts, healthcare professionals and lawyers,

a new recommendation to use scarce resources was published [6], given that the age criteria of the first version of the document violated Brazilian legislation and the patient's dignity. In the most recent protocol, the entities, supported by the Brazilian Society of Geriatrics and Gerontology and the National Academy of Palliative Care, suggest two tiebreaking scores, in this order: 1) total score of sequential organ failure assessment (rather than the score associated with the quartile used in the overall score, considering all criteria established in the final protocol); and 2) clinical judgment by the screening team [6]. Thus, the screening model proposed by Amib started using an alternative criterion to age, which, without any kind of discriminatory bias, acknowledges that the severity of organic disorders, the presence of comorbidities and the reduction of the patient's physiological reserve are associated with worse outcomes, such as hospital mortality and long-term mortality [6].

One notes that age is a widespread principle in resource allocation models. In Brazil, concern with this criterion is increased due to the diversity of protocols, since no standard has been established and different institutions have made individual choices. Therefore, it is understood that the government's main challenge, given the dichotomy between individual and collective rights, is to improve the health and justice systems, which requires planning strategies that respect the dignity of each individual and provide fair and ethical parameters.

The right of older adults to autonomy

In choosing the dignity of the human person as the guiding thread for the entire legal order, the Federal Constitution of 1988 [8] recognized plurality and, consequently, the protection of personality and freedom for its development [22]. However, as stated by Teixeira, *it is impossible to build an a priori and universal concept of dignity because, in a plural world, everyone has the right to build their own idea of dignity and live according to it* [23]. Thus, each person develops their ideal values based on their conception of life and history, and no concept can be defined to address such complexity.

In this context, respect for autonomy is the basis of dignity, which guarantees equal freedom for individuals to position themselves in society. However, the term "autonomy" has no univocal definition either, which requires in-depth studies and spurs various debates. Moreover, one can say that the most influential theories are based on two important principals: the liberty and the quality of the agent [24].

Beauchamp and Childress [24] use the term to examine healthcare decision-making, suggesting that autonomy presupposes self-governance. However, we must assess not a person's ability to be autonomous, but whether a particular act was autonomous. With this, the agent must act intentionally, independently and with understanding, which presupposes rational actions. However, such criteria are not absolute, given that any citizen may suffer external influences, whether for affective or moral reasons. Furthermore, usually the ability to make decisions is only contested when the action opposes dominant values, and given the complexity of the topic, it is necessary to guarantee a considerable degree of understanding and liberty, considering autonomy in concrete cases [24].

Within this perspective, Teixeira [22] understands that autonomy manifests subjectivity, allowing individuals to conceive the laws that will guide their own life, as long as they do not clash with outside rules dictated by the state. Therefore, the concept refers to the *recognition of free, rational and unforced individual decision about personal interests whenever it does not affect third parties* [25], since the multiplicity of values of a given society holds subjects accountable for the choices they make. Accordingly, Article 5 of UDBHR [15] states that personal autonomy to make decisions must be respected as long as responsibility for them is taken and the autonomy of others is respected.

Philosopher and jurist Ronald Dworkin [26] emphasizes that everyone has the right to make important and defining decisions regarding their own life. Reflecting on the theme, the author notes an obvious but often overlooked fact: not all individuals are equally competent to perform the same activities, but everyone can change their mind, whether regarding a new preference or to correct a mistake. That is autonomy: the right to decide, learn and take responsibility for one's actions. In Dworkin's words, *autonomy requires us to allow someone to run his own life even when he behaves in a way he himself would accept as not at all in his interests. The value of autonomy derives from the capacity it protects: the capacity to express one's own character – values, commitments, convictions, and critical as well as experiential interests – in the life one leads* [27].

However, advances in science and biotechnology have provided humans with ways to

 http://dx.doi.org/10.1590/1983-80422020284422

deal with the body's weaknesses and even deceive them. In the medicalized society, extending life is seen as a perpetual goal, even though such a view is contradicted in a pandemic by setting limits to life based on age.

The fact is that the individuality of older adults is disregarded and their autonomy disrespected. The lack of a conception of dignified death presupposes the hierarchy of lives: the older a person, the more expendable they are. Such prejudice and discrimination against the elderly is called "ageism" and its roots can be found in the very structure of Brazilian society [28]. Thus, the division of life into chronological stages – childhood, adolescence, adulthood and old age – establishes stereotypes that are justified economically, culturally and socially.

Individuals are valued for their usefulness and supposed contribution to society. In classifying a person as "productive" or "non-productive," this view ends up denying their dignity and preventing the full exercise of autonomy [28]. It is important to understand that although vulnerability is natural to aging, disability is not [28], and that old age is felt in different ways. Means must be found to develop skills in older adults that will keep them actively healthy. Furthermore, it makes no sense to benefit the young at the expense of the older to ensure the former's right to grow old.

The Statute of the Elderly [9], in Article 3, determines that family, community, society and government must ensure the full protection of older adults. Thus, as provided in Article 8 of the same document, aging is a strictly personal right and must be protected by setting priorities in care. Accordingly, even though many motor skills decrease with age, making it difficult to perform certain daily life activities, one must keep dignified aging in mind and invest in it, valuing the ideals and life story of individuals. This ensures compliance with Article 10 of the Statute, which provides that *the state and society must ensure freedom, respect and dignity to older adults* [9].

These provisions are based on Article 3 of the Brazilian Constitution, which determines that the fundamental objectives of the Republic are *to build a free, just and solidary society;* (…) *to guarantee national development;* (…) *to eradicate poverty and substandard living conditions and to reduce social and regional inequalities;* (…) *to promote the well-being of all, without prejudice as to origin, race, sex, color, age and any other forms of discrimination* [8]. Like the Statute of the Elderly [9], Article 230 of the Constitution provides that it is *the duty of the family, society and the State to assist the elderly, ensuring their participation in the community, defending their dignity and well-being and guaranteeing their right to life* [8].

The duty to care for older adults and guarantee their autonomy is based on the rights and principles that govern the Brazilian legal order. Therefore, in times of scarce resources and poor infrastructure, despite the challenge to safeguard the human person, especially the aged, it is crucial to provide effective protection. Moreover, society and the State must be required to view the vulnerabilities that emerge in this context with greater humanity and attention.

Bioethics as guarantee of respect for older adults

Bioethics, or ethics applied to life, is a recent branch that emerged in the United States in the 1970s [29]. The word was first used by oncologist Van Rensselaer Potter [29] who, according to Reich, defined it as *the systematic study of human behavior in the life sciences and healthcare, examining such behavior in light of moral values and principles* [30]. The author proposed a new field of knowledge which could help people reflect on the possible consequences, positive or negative, of scientific advances for human life or, more broadly, for all living beings. He suggested linking two cultures, scientific and humanistic, guided by the idea that not everything that is scientifically possible is also ethically acceptable [29].

Potter conceived bioethics as interdisciplinary when he stated that *science is knowledge, but it is not wisdom. Wisdom is knowledge on how to use science and how to balance it with other kinds of knowledge* [31]. Therefore, the study of bioethics is conducted by professionals from different areas who, based on their points of view and on methods, languages and personal experiences, debate in order to reach consensus. Decision-making in this field seeks to solve conflicts of values in a world marked by biomedical intervention [32].

The most commonly used model of analysis in Latin American bioethics is "principlism," introduced by Beauchamp and Childress [24] in the 1980s and based on three principles: beneficence (non-maleficence), autonomy and justice. According to Drummond, this so-called *bioethical triad* (…) *rests on the physician (for beneficence* [*and*

non-maleficence]*), on the patient (for autonomy) and on society (for justice)* [33]. As to the subject of this study, these principles afford healthcare professionals a form of dialogue with older adults.

The principle of beneficence considers that promoting well-being in the elderly is the duty of professionals and family members, addressing not only biological aspects, but also patients' psychological and spiritual health, with a view to improving their quality of life. Non-maleficence, on the other hand, establishes that any professional intervention should avoid or minimize risks and damages, which implies never doing any harm, whatever the case may be. Although Beauchamp and Childress [24] see it as a development of beneficence, non-maleficence is commonly considered an autonomous bioethical principle and a fundamental concept of the Hippocratic tradition, which advocates the habit of helping someone or at least not causing harm.

The principle of justice concerns the coherent and adequate distribution of social duties and benefits, emphasizing equity, according to which identical situations should be treated equally and divergent situations differently [34]. Healthcare professionals should therefore recognize the differences of each patient and tailor care to their needs, giving more attention to those who need it most. According to Kottow, *every individual is equally exposed and therefore should enjoy indiscriminate and equal access to protection that grants fundamental rights, for this reason called universal* [35]. Indeed, human rights aim to reduce risks arising from life in society, and are based on the search for justice as the moral and legal right of every citizen, as well as in the exercise of protection.

When resources are scarce, exclusionary decisions threaten the most vulnerable. Therefore, no action based on a universal principle can be considered ethical without considering equity. Protection must be inspired by justice, which is universal, but at the same time applied to the specific needs of the vulnerable [36].

As seen, autonomy relates to freedom to act. Autonomous people are able to deliberate and act according to their own desires, provided it does not result in harm to others (which requires maturity and consciousness when making choices) [37]. Respect for autonomy in old age, constantly discussed by bioethics, involves not only the decisions of each patient regarding care, but also the inevitable influence of family members and social factors in the therapeutic processes. Respecting the autonomy of the elderly is a complex task that requires reviewing expectations, understanding the patient's position in relation to the disease and identifying the limitations of the disorder to adapt to them.

However, in an emergency situation of great severity such as the current pandemic, respect for autonomy may create dilemmas between collective and individual interest. The State must respect people's right to health while preserving a balance between intent and resources so as not to privilege the individual over the community. A situation of scarce resources requires determining which healthcare actions and services will be privileged, without losing sight of the constitutional principles of existential minimum and reserve of the possible.

It is unreasonable to withdraw scarce resources from the State and direct them to a few individuals at the expense of the community, since health is a constitutional right of every citizen, directly linked to the dignity of the human person and social rights. On the other hand, it is vital to understand each specific case, considering the subject's values and biography, factors that can directly assist in difficult decision-making by healthcare teams.

Palliative care in older adults exposed to Covid-19

WHO defines palliative care as *an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual* [38]. This type of assistance affirms life and considers death a normal process, with no intention to postpone or rush it. Psychological and spiritual aspects are integrated to allow the patient to live as actively as possible until death, as well as to help family members deal with illness and grief. Palliative care can be used over the entire course of the disease alongside other life-extension therapies in an interdisciplinary approach [10].

In line with WHO [10], the Brazilian National Academy of Palliative Care defines end-of-life care as an approach *directed to symptom control, comfort and quality of life. It should be offered alongside the standard treatment of any disease that threatens the continuity of life, and should never be associated with omission or exclusion (therapy abandonment), even during a pandemic* [39]. Thus, this type of

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assistance should be present whenever the situation is serious rather than only when curative care is no longer possible, given that care is more effective when both approaches are used simultaneously, regardless of the patient's age [40].

The current pandemic compromises continuity of life and causes physical, emotional, spiritual, social and psychological suffering not only in individuals infected by the virus and their families, but also in healthcare staffs, who must make urgent decisions without enough scientific evidence. This corroborates the need to administer supportive care, a low-tech but affection-based approach [41] that can improve the quality of assistance, reduce costs and provide more humane and ethical treatment [40]. But such care must be administered properly and not simply to avoid responsibility.

Ensuring patient comfort is one of the main purposes of end-of-life care. Integrating physical, psychological and spiritual aspects contributes to this goal by allowing patients to also come to terms with facing death [41]. Pain is a complex and dynamic interaction of feelings, cognitions, behaviors and emotions, and symptoms other than physical that contribute to aggravate suffering must be understood and treated [42]. Understanding finitude as a natural and inevitable stage is key to improving the end-of-life experience, even more so in the case of older adults facing Covid-19.

Thus, the proposal to restrict the elderly's access to healthcare, in addition to being discriminatory, can be considered a death sentence, insofar as it denies essential care to such individuals [28]. In this sense, the proposal to integrate palliative care should not be viewed as an answer to scarce resources or as a mere alternative to the undeniable discrimination. The defense of this approach aims to ensure that individuals exposed to the virus – and especially the most vulnerable – have access to adequate treatment capable of providing better quality of life, since, as previously mentioned, pain does not result from physical factors only [42].

According to Prata [41], quality of life is a subjective notion that influences therapy choice as, despite the existence of protocols, there is no single treatment that is suitable for all cases. Thus, palliative care requires personalized assistance that respects the life, values and personality of each individual [41]. Respect for autonomy is essential, and even in critical moments such as a pandemic, when social interest must prevail, healthcare staffs must be guided by truly adapted and dynamic communication, reassuring patients about the care they are receiving. The humanist approach views the actual subject as the reason of all efforts and care, treating *the patient as a person within his own system of values* [43] and providing comfort and treatment of symptoms.

Final considerations

Since there are no recent historical precedents for the dynamics of care in a pandemic, healthcare professionals dealing with the situation are forced to choose who to assist. Bioethics plays an important role in this context by determining potential practices and protocols for decision-making based on the principles of beneficence, non-maleficence, autonomy and justice. According to these principles, even in a situation of scarce health resources, setting a limit on life based on age is discriminatory.

Reinterpreting the position of older adults in the pandemic is not easy, since common sense views them as invalid persons who are close to death. It is essential, however, to consider them as subjects of values, with rights supported by the legal order. In this context, palliative care should be offered not as a solution to scarce resources, but as a need, since this type of assistance aims to guarantee peoples' dignity and autonomy and respect for their values. When medical technologies are insufficient to ensure a cure, dealing with death is indispensable. Therefore, ensuring better experiences at such a time, in agreement with the patient's view of "quality of life," is paramount to respect autonomy in situations in which social interest prevails.

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Received: 5.28.2020
Revised: 8.27.2020
Approved: 9.14.2020

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