Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Rev. Bioét. vol.29 no.2 Brasília Apr./Jun. 2021

# Bioethics, palliative care and liberation: a contribution to "dying well"

*Meiriany Arruda Lima* [1], *Camilo Manchola-Castillo* [1]

1. Universidade de Brasília, Brasília/DF, Brazil.

Update

## Abstract

Technological advances in the health field reinforce the importance of bioethics in guaranteeing fundamental rights related not only to life, but also to death. This article reflects on dying and the contributions that bioethics has made to the topic, either by the traditional principles of autonomy and dignity, or by the defense of a new category: liberation, proposed by intervention bioethics based on Paulo Freire. This qualitative research study, with a hermeneutic, reflective, sociocritical and analytical approach, aims to show that liberation can contribute to train more critical, committed and free professionals and patients, capable of facing a moment of such vulnerability as the moment of death is. The article argues that adopting the concept of liberation in the bioethical reflection on palliative care can contribute to the "dying well" process.

**Keywords:** Palliative Care. Personal Autonomy. Respect.

## Resumo

### Bioética, cuidados paliativos e libertação: contribuição ao "bem morrer"

Os avanços tecnológicos na área da saúde reforçam a importância da bioética na garantia de direitos fundamentais relativos não só à vida, mas também à morte. Este artigo apresenta uma reflexão sobre o morrer e as contribuições que a bioética tem dado ao assunto, seja por meio dos princípios tradicionais de autonomia e dignidade, seja por meio da defesa de uma nova categoria: a libertação, proposta pela bioética de intervenção com base em Paulo Freire. Trata-se de pesquisa qualitativa, de abordagem hermenêutica, reflexiva, sociocrítica e analítica, cujo objetivo é demonstrar que a libertação pode contribuir para formar profissionais e pacientes mais críticos, comprometidos e livres, capazes de enfrentar um momento de tanta vulnerabilidade como é o momento da morte. O artigo defende que a adoção do conceito de libertação na reflexão bioética sobre cuidados paliativos pode contribuir ao processo de "morrer bem".

**Palavras-chave:** Cuidados paliativos. Autonomia pessoal. Respeito.

## Resumen

### Bioética, cuidados paliativos y liberación: una contribución al "buen morir"

Los avances tecnológicos en el ámbito de la salud refuerzan la importancia de la bioética en la garantía de derechos fundamentales relativos no solo a la vida, sino también a la muerte. Este artículo presenta una reflexión sobre el morir y las contribuciones de la bioética al tema, ya sea por medio de los principios tradicionales de autonomía y dignidad, ya sea por medio de la defensa de una nueva categoría: la liberación, propuesta por la bioética de intervención con base en Paulo Freire. Se trata de una investigación cualitativa, de enfoque hermenéutico, reflexivo, sociocrítico y analítico, cuyo objetivo es demostrar que la liberación puede contribuir a la formación de profesionales y pacientes más críticos, comprometidos y libres, capaces de enfrentarse a un momento de tanta vulnerabilidad como es el momento de la muerte. Este artículo defiende que la adopción del concepto de liberación en la reflexión bioética sobre los cuidados paliativos puede contribuir al proceso de "morir bien".

**Palabras clave:** Cuidados paliativos. Autonomía personal. Respeto.

The authors declare no conflict of interest.

http://dx.doi.org/10.1590/1983-80422021292464

Although death is an indisputable event, the more we advance scientifically and technologically, the more we try to placate and tame it. When corporeal life becomes absolute and sought at any cost, regardless of dignity, we move from the therapeutic field to that of idolatry, and sometimes medicine participates in this excessive struggle against death. Discussing the end of life involves issues that are beyond conflicts between professionals and patients or family members. It requires a mature reflection on physical, spiritual, social and emotional issues, to make an equitable decision on one's own body and, consequently, deal with pain and be aware of biological and technological limits.

Beliefs and concepts have been redefined and driven by enormous and rapid scientific progress that brings new technologies and generates diverse perspectives. In this context, the concepts of health and disease are also redefined from the perspective of social welfare, which sometimes is accompanied by overconsumption of products and services generated by the pharmaceutical industry and the "medical industry" of services.

The popular belief of the doctor as a "divine being", a mediator between gods and humans, was observed even before Hippocrates and was perpetrated by the conception of medicine as a priesthood [1]. This view is still the foundation of paternalistic practice today, making some individuals believe that the doctor has divine powers and can overcome death. As a result, there is a growing enthusiasm for diagnostic tests, products, medicines and unlimited interventions, which exposes a large part of society to unnecessary risks.

This article discusses the contributions of bioethics to the field of palliative care, presenting the "liberation" principle, proposed by the intervention bioethics based on Paulo Freire's ideas, as a category to be included in the discussion. Our goal is to show that liberation, combined with the philosophy of palliative care, can lead to "good death". The research, with a qualitative, hermeneutic, reflective, sociocritical and analytical approach, is divided into three moments: 1) review of secondary (documentary) sources related to the bioethical reflection on death; 2) review, also from secondary sources, of palliative care, focusing especially on its central role in the defense of a good death; and 3) analysis of the relationship between palliative care and bioethics, emphasizing the role of liberation in end-of-life palliative care.

## Death: a bioethical issue

The survival of patients with serious illnesses has been feasible as a result of technological advances. But the indiscriminate use of these advances added to the lack of communication between peers, and the subtraction of individuals' autonomy has led to the excessive postponement of death, increasing the suffering of patients and their families. Disputing this type of medicine, Ivan Illich [2] rejected the idea that health was a function, process or behavior limited to meeting general standards designed by specialists and performed as a categorical imperative. In his last decade of life, the author, claiming for himself the supreme freedom to die without a diagnosis, drew attention to the need to recover the art of suffering and dying lost by the West [2].

The same technological progress that makes life viable raises ethical questions among health professionals, and generates inequality of power and knowledge that unbalances relationships. Each era, each society deals differently with the end of life. Currently, longevity and the absence of pain and suffering are emphasized, in a perspective that avoids thinking about death, but when it does, it longs for a quick and painless process [3].

The most common is that all available resources are used for extending life – such as, for example, extracorporeal membrane oxygenation, widely used today in patients with covid-19-related acute respiratory distress syndrome, even without sufficient data to certify its need [4]. Paradoxically, in a society that strives for the absence of pain, excessive and unnecessary suffering occurs, disregarding the quality of life. Literature calls this situation "dysthanasia", which consists of therapeutic obstinacy, with the adoption of futile treatments that unnecessarily postpone death [5]. In opposition we have end-of-life palliative care, which seeks to provide comfort and relieve the patient's pain, avoiding transforming death into a long and painful process.

One of Illich[2] criticisms of modern medicine referred to the intervening character of the medical act in decisions that would be up to the individual. These interventions affect from pregnancy care, when the doctor decides who is born and how, to the end of life, when the doctor decides the type of death and the levels of pain to which the patients will be submitted, depending on their state of physical weakness. Such interference suppresses the patients' autonomy and their right to make decisions related to their own body, disregarding discussions about pain and finitude and placing the individuals in an environment that is sometimes antagonistic to their way of life[2].

Georges Canguilhem[6], in his work *The normal and the pathological*, argues similarly when he strongly defends that each one must define for oneself what is normal, bearing in mind the uniqueness of one's condition. In this way, the medicalization of life, by proposing a universal standardization, prevents the individual from defining what is normal in their particular situation.

Another point raised by Illich[2] is that the more informed the individual, the more coherent the decision making – understood as an exercise of power over one's own body – will be, preventing life from being at the mercy of the dominant social, political and economic system. Thus, promoting self-determination and autonomy will only be viable through education, transcending individuality and moving towards the collective[2].

Biotechnological and bio-scientific evolution has given rise to many conflicts of interest and concepts: while for some it is enough to prolong life or postpone death, for others to live with dignity is also to die with dignity, without giving up autonomy to decide which treatments to undergo or not and how and where to die. It is common to question the patient's ability to self-determine validly; but when a sick person with no possibility of cure is prevented from making their choices, the principle of human dignity is broken, since to impose on the patient the will of a third party is to deny that every individual is a subject of rights. Thus, scientific-technological evolution requires critical reflection that involves bioethics principles. In each specific case, limits should be established based on respect for the patient's autonomy and self-determination.

Bioethics seeks to establish a communication link between science and technology, individual and society, seeking to build a responsible and solidary ethics. Scientific and technological advances in health, which involve life and biology, bring to contemporary society unprecedent situations, that generate the need to debate limits on the management of life, formulate legal instruments compatible with the current situation, and reflect on the responsibility of health professionals.

Against a reductionist view that directs the individual based on prohibitions and static normative rules that disregard social customs and contemporary moral pluralism, bioethics thinks of the human being in a multi-, inter- and transdisciplinary manner. For this field of knowledge, individuals must have their decisions respected, as long as these do not interfere with other individuals' freedom of choice[7].

Latin American bioethics in particular, such as intervention bioethics, has incorporated several categories in addition to the principlists[7], highlighting, for example, the importance of dignity and creating innovative concepts such as liberation. The latter, proposed by the intervention bioethics based on Paulo Freire, defends the perception of the "I" and the "other" in relation to the environment they live in[8]. In this sense, vulnerable people, such as those who are at the end of their lives, must consciously fight against the injustices created by the borders established by the excluding reality, pursuing autonomy and the best results in assistance.

At the same time that it improves the inputs and allows for faster and more assertive diagnoses, in some cases, when it disregards the individual's will in a specific case, scientific-technological progress can threaten the dignity of the human person. Although it is up to the medical professional to propose the appropriate treatment and technology for each case, the most interested party, that is, the patient, cannot be left out of the decision-making process. Influenced by the culture of healing, the physician often fails to observe whether the therapeutic proposal adopted will be really beneficial. Respecting the patients autonomy means giving them visibility as citizens with their place of speech, endowed with convictions, cultural values and the ability to make decisions related to their own bodies. Autonomy, therefore, implies the social validation of the individual's choices[9].

Mill, Dworkin and Rawls converge with this perspective by arguing that, to arrive at a fair process, we must recognize the individual's ability to act in a free, genuine, rational, egalitarian and individual manner. Excepting specific cases, such as children, respecting autonomy is to practice non-interference [10]. Thus, currently, the doctor-patient relationship should no longer be associated with paternalism, but with an autonomous relationship, in which the patient decides, within legal and ethical limits, on therapeutic proposals. Life is an unavailable legal asset; but life must be seen in its entirety, and dying with dignity is related to the concept of the dignity of the human person.

But how can we guarantee respect for the patient who has no prognosis of cure or is affected by a serious illness that changes the natural course of their life? How to preserve their autonomy and dignity? This question finds an answer in the proposal of Cicely Saunders: *When looking after you at the end of life, I want you to feel that I care. You matter because you are you and you matter to the end of your life. We will do all we can, not only to help you die peacefully, but also to live until you die* [11].

## End-of-life palliative care

The contemporary concept of palliative care, updated in 2002 by the World Health Organization (WHO), defines this type of assistance as an approach that promotes the quality of life of patients (and family members) *facing life-threatening diseases*, *through prevention and relief from suffering*, *early identification*, *correct assessment and treatment of pain and other physical*, *psychosocial and spiritual problems* [12].

Besides updating the concept, WHO instituted the principles for the performance of the multiprofessional palliative care team: relieving pain and other uncomfortable symptoms; affirming life and facing death as a normal process; not anticipating or postponing death; promote holistic care; provide a support system that instigates the patient to have the most active life possible, until the moment of their death; assist family members during the patient's illness and in the period of mourning; dealing with the needs of the patient and their family through a multiprofessional approach; improve the quality of life and positively influence the course of the disease; start palliative care early, along with life-prolonging therapies; and make efforts to reduce stressful clinical situations [5,13]. WHO also recommended that the effective control of pain and symptoms of patients in palliative care should be part of public health policies – a measure that, in Brazil, was included in the National Policy for the Humanization of Health [13,14].

As for the origin of the term, the word "palliative" derived from the noun *pallium*, which means "mantle" or "blanket" (metaphorically, covering, blocking, protecting what cannot be cured) [5], and the verb *palliare* (to protect), which refer to an expanded interpretation of care, not restricted to physical healing, but capable of encompassing other spiritual, social and psychological aspects of the human essence [15]. Officially, palliative care appeared in the 1960s, in the United Kingdom, with the initial goal of providing a safe and comfortable environment for the person who is diagnosed with a serious illness, without therapeutic possibilities of cure.

The forerunner of palliative care was Cicely Saunders, a physician, social worker and nurse who disseminated a new philosophy of care worldwide. This philosophy was based on two pillars: efficiency in the control of pain and other symptoms that appear in the final stage of a disease, and extension of care to psychological, social and spiritual aspects of the patients and their families. Thus, palliative care seeks to preserve patients' dignity and provide support so that they and their families can face the challenges of a new stage of life [16].

In short, palliative care aims to: provide comprehensive assistance to the patient outside the proposed therapeutic cure; effectively control pain; provide physical, emotional, psychological and family quality of life; and respect autonomy and self-determination [17]. The practice, therefore, is based on three pillars: the right to autonomy, the preservation of social identity, and the dignity of life and death [18].

Palliative care is not exclusively related to the end of life and medical acts, since its objectives go beyond the defense of a good death, requiring the performance of a multiprofessional team. However, the next few paragraphs will focus on palliative care specifically in the end of life.

It is necessary to understand that the concepts of *vulnerability and protection* are intrinsic to the itinerary of life and death. Such an itinerary is permeated by situations of vulnerability inherent to the end of life, and it is up to the professional to provide the patient with the necessary protection and promote the acceptance of human finitude, reconciling the patient with the natural unfolding of the disease until death. For this, the professional who provides palliative care must establish a relationship based on listening, knowledge, respect and appreciation of the other in all its complexity, understanding that the assisted patient is a human being imbued with a biography and personal beliefs.

The vulnerability of the terminal patient leads us to propose that protection should be the first of the moral principles to direct choices in palliative care. Initially, the meaning given to the Greek word *ethos*, origin of ethics, was that of "protection", which in Homeric times (around 8th century BC) indicated shelter against external dangers. Later, around 5th century BC, without completely losing its initial meaning, the word expanded its meaning and started to designate customs and habits needed for harmonious coexistence among citizens. *Ethos* then went on to refer to a way to guarantee good customs, avoiding social anarchy. In the 4th century, the word already indicated a personality characteristic, a sense that, much later, in the 18th century, Immanuel Kant resignified, giving it the status of a quality inherent to the moral agent and initiating the theory of the exercise of personal autonomy[19].

Returning to the conception of death, it is worth remembering some authors who reflected on it. For one of the most powerful men in Rome, the stoic Seneca, to live was to learn to die. For the French skeptical philosopher Michel de Montaigne, philosophizing was learning to know the approach of death. And for the German existentialist philosopher Martin Heidegger, living and dying, in the condition of vulnerability, are part of the human experience as being-there (*Dasein*)[20].

Following this line, in Norbert Elias' terms, the contemporary attitude towards death is a consequence of the civilizing process: *Like other animal aspects, death, both as a process and as a mnemonic image, is pushed more and more behind the scenes of social life during the civilizing impulse. For the dying themselves, this means that they are also pushed backstage, are isolated*[21]. Thus, in addition to an inexorable process, death is also a social construction. It can wear various clothes, depending on the culture and the meanings assigned to it[22]. As Ariès notes:

> *Life in medieval society was shorter; the dangers, less controllable; death, often more painful; the sense of guilt and the fear of punishment after death, the official doctrine. However, in all cases, the participation of others in the death of an individual was much more common. Today we know how to relieve the pain of death in some cases; guilt anxieties are more fully repressed and perhaps mastered*[23].

Having reflected on death, it is convenient to reflect on the "good death", a central category in this work, directly related to dignified death, a fundamental right of the human person, since it refers to respect for the individual's choice of how to die, especially in contexts where their independence and functional capacity are compromised[24]. Dignity is one of the foundations of the democratic rule of law; however, to make it effective at all stages of life, it is necessary to reflect on the meaning of death, suffering, and protection in this final moment[25].

## Bioethics and palliative care: autonomy and dignity

The contributions of bioethics to palliative care have historically been guided by the principles of dignity and autonomy. In this sense, it is important to clarify the meaning of these principles and their applicability in palliative care.

The concern with the dignity of the human person goes back to the Declaration of the Rights of Man and the Citizen, promulgated in France in 1793. Since then, this value has been the subject of international conventions and pacts. A landmark for these conventions and pacts is the post-World War II period, when the world dealt with serious violations perpetrated against human beings: torture, inhuman treatment, the search for a pure race, the extermination of those who did not fit the ideal of perfection. After these violations, the international community sought ways to rescue the right to life and a dignified life, ratifying documents that guaranteed the rights of the human person[26]. Countries that signed these treaties would no longer have the power to suppress rights by alleging a hierarchy between different rules.

In 1948, the United Nations (UN), through the Universal Declaration of Human Rights, established that no person could be subjected to torture or cruel, inhuman or degrading punishment. The declaration also guaranteed the right to life, freedom and personal security [26,27]. In 1984, the UN General Assembly adopted the United Nations Convention Against Torture, Cruel Punishment and Other Inhuman or Degrading Treatment, which came into force in 1987, being ratified by Brazil on September 28, 1989 [27].

With the Federal Constitution of 1988, health became a citizen's right and a duty of the Brazilian State. Along with the right to health, the Constitution affirmed the right to life, which in turn encompasses dignity [26,27]. Thus, it can be said that the principle of human dignity is one of the pillars of contemporary Brazilian society.

Human dignity is also advocated by the international instruments that guide bioethical discussions, such as the Universal Declaration on the Human Genome and Human Rights, the International Declaration on Genetic Data and the Universal Declaration on Bioethics and Human Rights, adopted by the Organization of United Nations for Education, Science and Culture (Unesco), and the Oviedo Convention, agreed within the framework of the Council of Europe [24]. However, as Albuquerque points out, although "human dignity" is present in all these documents, there is no consensus on its definition [28].

In this text, it is assumed that dignity is an intrinsic value to human beings, from which three principles arise: respect for the person, non-instrumentalization, and the prohibition of humiliating, inhuman or degrading treatment [29]. Therefore, human dignity cannot be dissociated from the right to life. Both values point to the maxim of the democratic rule of law: the effectiveness of fundamental rights.

The principle of autonomy, in turn, arises from the need to restructure cultural, philosophical, political and economic relations. If we think, for example, about medieval society, we will see a relationship of complete subordination to the divine, to the power of the king and the Church, both in relations between masters and vassals as well as in family relations. At the time, the term "autonomy" was not yet used with its modern connotation. The idea of free will prevailed as a choice between good and evil, since all relationships were directly linked to the divine.

Thus, Saint Augustine, in his work *De libero arbitrio*, not only defined what would be "free will" (the human power to choose between beneficial or evil conduct), but also "freedom" (the proper practice of free will) [30]. Centuries later, Martin Luther proposed that if there is predestination, then there is no need to talk about "free will", and human freedom would be a fallacy. In fact, it can be said that the Protestant Reformation, started by Luther and continued by Calvin, is a watershed for autonomy, for even if at the time the motives of the movement were different, the right of theological freedom implies autonomous decisions [30].

From Descartes onwards, the vision of the divine is no longer central, and man is granted independence from experiments based on the free will of a subject endowed with reason and conscience. Subsequently, Kant strengthens this respect for autonomy by emphasizing the individual's power of choice and recognition, establishing an important milestone for Western philosophy. For Kant, autonomy is a form of respect for human dignity [31].

In bioethics, the concept of autonomy is defined from different perspectives. The most traditional one, which refers to the principle of Beauchamp and Childress [9], affirms the individual's ability to make personal choices regarding their life and body. However, for intervention bioethics, as proposed by Bottle [32], it is not enough to relate autonomy to the individual sphere, since the social context must be observed in decision making, as situations of vulnerability to which individuals may be subjected directly affect their autonomy [32].

The dominant and individualistic understanding of autonomy, which appears in clinical practice and research, rests on the thought that people ideally make independent and rational decisions, which maximize the gain. In the last decades, however, this view has been challenged by several theoretical perspectives (among them that of intervention bioethics) that defend a relational concept of autonomy. These perspectives argue that people's identities, needs, interests and their own autonomy are always shaped by their relationships with others [33].

In addition, relational autonomy has the premise of decentralizing decisions through a support network for the individual/patient. This model of autonomy can be found, for example, in some French authors who view autonomy with caution, beyond the individual, as a medical practice centered on the individual would be antagonistic to collective interests[34]. In the conflict between autonomy and solidarity, autonomy is mainly characterized by a state of empowerment, while solidarity is more focused on individuals in a state of vulnerability[35].

Precisely, one of the central concepts (that of *habitus*) by French thinker Pierre Bourdieu is based on a relational conception of autonomy. The author argues that the individual is only autonomous based on their social and individual constructions, and this is clear in the definition of *habitus* itself: *a system of durable and transposable dispositions that, integrating all past experiences, works every moment as a matrix of perceptions, appraisals and actions – and makes it possible to carry out infinitely different tasks, thanks to the analogic transfers of schemes*[36].

The concept of *habitus* can thus be understood as a relational bridge between external social constructions and individual experiments. The coexistence of different instances of socialization, with multiple projects and a greater circularity of value and identity references, constitutes a diversified field of socialization[37].

But it is not only in France that the concept of relational autonomy has been discussed. In other countries in the West, too, the principle of solidarity has anchored autonomous practice. This coexistence between autonomy and solidarity is more effective in protecting the individual, and there is no opposition between the two principles, but a complementarity that promotes a sense of responsibility towards the vulnerable person. In this way, bioethics has shown that autonomy is a capacity of the human person to deliberate based on their designs and the appropriate means to achieve success, having as a guiding thread their beliefs, convictions and moral or normative values.

Important philosophers for bioethics, such as Immanuel Kant[19], reinforce that the freedom of individuals can coexist in harmony, as long as there is respect for each individual's peculiar way of acting, without imposing personal choices on the other. John Stuart Mill, in his work *On liberty*, admits as limiting of individual freedom the damage – physical or spiritual – that can affect the collective[38].

Bioethics also contributes to this debate by stating that autonomy is linked to moral pluralism, so that individuals' autonomous choices are always related to the contexts in which they live and interact. Another contribution is the definition that respecting autonomous decisions is a premise to ensure the dignity of the human person, and that guaranteeing respect for moral pluralism and preserving the right to self-determination of individuals who have their capacity mitigated, cultural, social, economic and legal issues must be considered.

These contributions are essential not only for discussions regarding autonomy and dignity, but especially for the debate on palliative care. This is because palliative medicine is practiced mainly in situations related to death, suffering, pain and multidimensional disability[39]. In all these circumstances, dignity and autonomy are strongly compromised, and important social, cultural, economic and legal determinants are present. Hence the importance of defending relational autonomy closely linked to dignity.

Bioethics contributions regarding autonomy and dignity are also important because they recognize that, to make decisions, the patient in palliative care needs to clearly reflect on life goals, family interests, meaning system, their inner self and trajectory. And pain, fear of the unknown and suffering can compromise intellectual capacity in this decision-making process. In this context, bioethics, especially through the principles discussed, can contribute to restoring this competence, helping patients, or their legal representatives, to make choices that preserve autonomy and dignity[40].

Finally, it should be noted that being autonomous does not necessarily mean being recognized as an autonomous agent, as such recognition depends on effective respect for the individual's choices, even if based on particular beliefs and values. According to bioethics, the autonomous individual must have a reflective capacity to decide on their purposes, be consistent in their choices and not succumb to external coercions[9].

## End-of-life palliative care and liberation

Bioethics, which emerged in the 1970s as an instrument of reflection on moral and practical issues that lacked an interdisciplinary approach, saw great development in the last twenty years. At first, this field of study was concerned exclusively with biomedical and biotechnological issues, traditionally associated with research with human beings in developed countries, such as the United States. In the period, the most important expression of bioethics was in 1979, with the Belmont Report, which instituted three principles: autonomy, beneficence and justice, giving a new perspective to the ethical analysis of research involving human beings[41-42].

In the *Encyclopedia of bioethics*, work published in the United States in three different editions (1978, 1995 and 2004), bioethics was defined as *the systematic study of the moral dimensions – including vision, decision, conduct and moral norms – of life sciences and health, using a variety of ethical methodologies in an interdisciplinary context*[43]. However, afterwards, the field was expanded, which is evident, for example, in the assumptions of the previously mentioned intervention bioethics[32]. This expansion included social, economic, political and cultural determinants of moral reflection, as well as the analysis of situations not previously addressed, such as poverty, exclusion and vulnerability – and not only from a biological standpoint.

Based on vulnerability, the most recent forms of bioethics, which are disruptive, highly politicized and human rights defenders – and among them, as a more consolidated example, intervention bioethics –, proposed the inclusion of the Freirian concept[44] of liberation in this field of knowledge. The aim is to defend a concrete, critical and committed reflection that leads to social transformation.

Liberation, as defined by Freire, contributes to forming individuals who, in addition to reflecting, act, and even in the midst of their vulnerability, understand that they are the protagonists of their lives and the struggle to defend their interests[45]. In other words, liberation defends the existence of an individual whose freedom (in relation to misery, but also in relation to suffering and pain) will only be achieved through critical reflection, whereby the dominated are no longer oppressed by the dominator, for they are no longer afraid to be free. In the health field, this means breaking the principlist hegemony and escape from biological and cultural determinism[46].

That is why we defend that liberation can be a new contribution of bioethics to palliative care. We believe that – as proposed by Elisabeth Kübler-Ross[47], perhaps the greatest palliativist of all time – patients must be empowered without leaving aside their human existence. It is necessary to start with respect for individuality and the patient's trajectory to promote an institutional restructuring that meets the subject's best interest.

Liberation also reveals the need to defend a professional training that frees health field students, so they understand that their task is both to educate and to learn from the patient, in a relationship of freedom in the construction of knowledge. Constructing critical thinking, through a liberating practice, involves identifying one's own limitations and facing fears, so that what is unknown is not seen as an adversary. And here we talk about reconciling life and death, considering, as Moller[48] points out, that humans find it hard to accept finitude, especially in societies where life-prolonging technologies have generated an increasing obstinacy in postponing death.

To discuss death from a bioethical perspective based on liberation, all the elements that involve the end of life must be considered. It is necessary, for example, to try and answer the question made by Kovács[49]: is a good death possible? Therefore, we must take as a premise that a dignified, humanized death cannot be extended or shortened, and suffering should be avoided. It is also worth reflecting on specific cases, for example, on how patients affected by degenerative diseases such as dementia fit the pattern proposed here[49].

The discussion is still far from complete. As Logue[50] shows, there is still a split within the theory of palliative care: although such care promotes quality of life, sometimes the discussion skips the right to die, since palliative care is not always accessible or made available to all patients[50]. And here is one more point to whose solution liberation-based bioethics can contribute too.

Hopefully it has become clear, with the arguments in this section, that liberation-based bioethics may respond to pressing practical dilemmas posed by palliative care. Due to its solid theoretical and interdisciplinary framework, such an approach promotes interaction between health professionals and sustains actions in a critical reflection, which considers the various determinants of a given situation[51].

## Final considerations

"Good death" is anchored in the quality of life promoted by palliative care. But to achieve it patients must be aware of their terminal condition, accept it, and be able to make autonomous decisions. They must abandon the idea that dying is a process that must be concealed and stop mascarading death with euphemisms, because liberation cannot coexist with fear.

Resolving conflicts, resolving pending issues, feeling comfortable, participating in therapeutic decisions and sharing with the team when and how you want the final moment to occur are acts that inform "dying well". However, for this to be feasible, it is not enough to know the diagnosis, it is also necessary to know the patient's prognosis. Hence the importance that bioethics, in addition to the traditional principles of dignity and autonomy, take up the idea of liberation in palliative care.

Unfortunately, not all patients are sufficiently prepared to understand the extent of their disease – and here we come up against moral and ethical issues that have been the subject of research and debate. There are no universal standards and principles, for the simple fact that the individual is not a metric with immutable proportions. And considering this complexity is another of the essential contributions of the concept of liberation, in its critical and committed character.

As this text has shown, our society has sought to institutionalize life and death, undertaking a search for longevity that almost denies the human condition. On the other hand, there are efforts to rescue the "good death" by respecting the patient's autonomy and care practices that preserve the individual's dignity and freedom. Reconciliation between these opposing poles will only be achieved through the education and critical reflection proposed by liberation.

Thus, it is worth reflecting on the role of health education, since the achievement of liberation in current care and training practices depends on it. In this sense, patient-focused education is not only desirable, but also mandatory, to ensure that palliative care, especially at the end of life, contributes to a good death, with autonomy and dignity. For this, public policies and intersectoral actions that involve several professionals (not only in the health area) are needed. In this respect, intervention bioethics is also very useful, in view of its unrestricted defense of the role of the State in guaranteeing citizens' rights[45].

Finally, it was not the intention of this work to exhaust the topic addressed, but only to show that the concept of liberation, in palliative care, within the perspective of intervention bioethics, can contribute to the construction of "good death".

## References

1. Beier M, Iannotti GC. O paternalismo e o juramento hipocrático. Rev Bras Saude Mater Infant [Internet]. 2010 [acesso 28 abr 2021];10(2 Supl):383-9. DOI: 10.1590/S1519-38292010000600017
2. Illich I. A expropriação da saúde: nêmesis da medicina. 3ª ed. Rio de Janeiro: Nova Fronteira; 1975.
3. Mendes JA, Lustosa MA, Andrade MCM. Paciente terminal, família e equipe de saúde. Rev SBPH [Internet]. 2009 [acesso 28 abr 2021];12(1):151-73. Disponível: https://bit.ly/3vJ9Bi3
4. Ramanathan K, Antognini D, Combes A, Paden M, Zakhary B, Ogino M, *et al*. Planning and provision of ECMO services for severe ARDS during the COVID-19 pandemic and other outbreaks of emerging infectious diseases. Lancet Respir Med [Internet]. 2020 [acesso 28 abr 2021];8(5):518-26. DOI: 10.1016/S2213-2600(20)30121-1
5. Pessini L, Bertachini L, editores. Humanização e cuidados paliativos. São Paulo: Loyola; 2004.
6. Canguilhem G. O normal e o patológico. Rio de Janeiro: Forense Universitária; 2000.

7. Garrafa V. Genoma, pesquisa com seres humanos e biotecnologia: proteção pelo direito. In: Costa AB, Sousa JG Jr, Delduque MC, Oliveira MSC, Dallari SG, editores. Introdução crítica ao direito à saúde [Internet]. Brasília: Cead/UNB; 2008 [acesso 28 abr 2021]. p. 423-34. (O Direito Achado na Rua; 4). Disponível: https://bit.ly/3h6ilKS
8. Freire P. Pedagogia da indignação: cartas pedagógicas e outros escritos. São Paulo: Editora Unesp; 2000.
9. Beauchamp TL, Childress JF. Princípios de ética biomédica. 3ª ed. São Paulo: Loyola; 2002.
10. Herring J. Relational autonomy and family law. Cham: Springer; 2014.
11. Saunders C. Velai comigo: inspiração para uma vida em cuidados paliativos. Rio de Janeiro: FSS; 2018. p. 94.
12. World Health Organization. National cancer control programmes: policies and managerial guidelines [Internet]. Geneva: WHO; 2002 [acesso 28 abr 2021]. p. xv-xvi. Disponível: https://bit.ly/33pwXx3
13. World Health Organization. Op. cit.
14. Brasil. Ministério da Saúde. HumanizaSUS: documento base para gestores e trabalhadores do SUS [Internet]. Brasília: Editora do Ministério da Saúde; 2010 [acesso 28 abr 2021]. Disponível: https://bit.ly/3errZpC
15. Melo AGC, Caponero R. Cuidados paliativos: abordagem contínua e integral. In: Santos FS, organizadores. Cuidados paliativos: discutindo a vida, a morte e o morrer. São Paulo: Atheneu; 2009. p. 257-67.
16. Cervelin AF, Kruse MHL. Espiritualidade e religiosidade nos cuidados paliativos: conhecer para governar. Esc. Anna Nery [Internet]. 2014 [acesso 28 abr 2021];18(1):136-42. DOI: 10.5935/1414-8145.20140020
17. Drane J, Pessini L. Bioética, medicina e tecnologia: desafios éticos na fronteira do conhecimento humano. São Paulo: Loyola; 2005. p. 53-64.
18. Menezes RA, Barbosa PA. A construção da "boa morte" em diferentes etapas da vida: reflexões em torno do ideário paliativista para adultos e crianças. Ciênc Saúde Coletiva [Internet]. 2013 [acesso 28 abr 2021];9(18):2653-62. DOI: 10.1590/S1413-81232013000900020
19. Kant I. Fundamentação da metafísica dos costumes. São Paulo: Companhia Editorial Nacional; 1964.
20. Heidegger M. Ser e tempo. Petrópolis: Vozes; 1989.
21. Elias N. A solidão dos moribundos. Rio de Janeiro: Jorge Zahar; 2001. p. 19.
22. Rodrigues IG. Os significados do trabalho em equipes de cuidados paliativos oncológico domiciliar: um estudo etnográfico [tese] [Internet]. Ribeirão Preto: Universidade de São Paulo; 2009 [acesso 28 abr 2021]. DOI: 10.11606/T.22.2009.tde-08012010-130039
23. Ariès P. O homem diante da morte. Rio de Janeiro: Francisco Alves; 1982.
24. Dadalto L. Morte digna para quem? O direito fundamental de escolha do próprio fim. Pensar [Internet]. 2019 [acesso 28 abr 2021];24(3):1-11. DOI: 10.5020/2317-2150.2018.9555
25. Martini SR, Sturza JM. A dignidade humana enquanto princípio de proteção e garantia dos direitos fundamentais sociais: o direito à saúde. Cad Ibero-Amer Dir Sanit [Internet]. 2017 [acesso 28 abr 2021];6(2):25-41. DOI: 10.17566/ciads.v6i2.367
26. Hunt L. A invenção dos direitos humanos: uma história. São Paulo: Companhia das Letras; 2007.
27. Brasil. Senado Federal. Direitos Humanos: atos internacionais e normas correlatas [Internet]. 4ª ed. Brasília: Senado Federal; 2013 [acesso 28 abr 2021]. Disponível: https://bit.ly/3xNzBL7
28. Albuquerque A. Dignidade humana: proposta e uma abordagem bioética baseada em princípios. Rev Direitos Garantias Fundamentais [Internet]. 2017 [acesso 28 abr 2021];18(3):111-38. DOI: 10.18759/rdgf.v18i3.1140
29. Albuquerque A. Direitos humanos dos pacientes. Curitiba: Juruá; 2016.
30. Selleti JC, Garrafa V. As raízes cristãs da autonomia. Petrópolis: Vozes; 2005.
31. Tonetto MC. Sobre a caracterização do conceito de dignidade em Kant. Princípios [Internet]. 2013 [acesso 28 abr 2021];20(33):181-94. Disponível: https://bit.ly/33iTJ9Q
32. Garrafa V. De uma "bioética de princípios" a uma "bioética interventiva": crítica e socialmente comprometida [Internet]. Brasília: Agência Nacional de Vigilância Sanitária; 2003 [acesso 28 abr 2021]. Disponível: https://bit.ly/3epNrLI

33. Dove ES, Kelly SE, Lucivero F, Machirori M, Dheensa S, Prainsack B. Beyond individualism: is there a place for relational autonomy in clinical practice and research? Clin Ethics [Internet]. 2017 [acesso 28 abr 2021];12(3):150-65. DOI: 10.1177/1477750917704156
34. Le Coadic R. L'autonomie, illusion ou projet de société?. Cahiers internationaux de sociologie [Internet]. 2006 [acesso 17 maio 2021]; 2(2):317-40. Disponível: https://www.cairn.info/revue-cahiers-internationaux-de-sociologie-2006-2-page-317.htm
35. Fainzang S. From solidarity to autonomy: towards a redefinition of the parameters of the notion of autonomy. Theor Med Bioeth [Internet]. 2016 [acesso 28 abr 2021];37(6):463-72. DOI: 10.1007/s11017-016-9385-5
36. Bourdieu P. Sociologia. São Paulo: Ática; 1983. p. 65.
37. Montagner MA. Trajetórias e biografias: notas para uma análise bourdieusiana. Sociologias [Internet]. 2007 [acesso 28 abr 2021];9(17):240-64. Disponível: https://bit.ly/3enYsNG
38. Prudente MG. Bioética: conceitos fundamentais. Porto Alegre: Edição do Autor; 2000.
39. Guevara-López U, Altamirano-Bustamante M, Viesca-Treviño C. New frontiers in the future of palliative care: real-world bioethical dilemmas and axiology of clinical practice. BMC Medical Ethics [Internet]. 2015 [acesso 28 abr 2021];16. DOI: 10.1186/s12910-015-0003-2
40. Drane J, Pessini L. Bioética, medicina e tecnologia: desafios éticos na fronteira do conhecimento humano. São Paulo: Centro Universitário São Camilo; 2005. p. 127-40.
41. Beauchamp T, Childress J. Principles of biomedical ethics. Nova York: Oxford University Press; 1979.
42. Rodrigues Filho ER, Prado MM, Prudente COM. O princípio da autonomia como fundamento do consentimento livre e esclarecido. Estudos Vida e Saúde [Internet]. 2015 [acesso 28 abr 2021];42(4):613-25. DOI: 10.18224/est.v42i4.4380
43. Reich WT. Encyclopedia of Bioethics. 2ª ed. New York; MacMillan, 1995.p. XXI.
44. Freire P. Pedagogia do oprimido. Rio de Janeiro: Paz e Terra; 2005.
45. Manchola-Castillo C, Garrafa V. Enfoques participativos latinoamericanos para la educación en bioética. In: Unesco, editor. Manual de Educación en Bioética la agenda curricular en bioética: abriendo horizontes, volumen 1. México: Unesco; 2021. p. 3-11.
46. Laraio RB. Cultura: um conceito antropológico. 26ª ed. Rio de Janeiro: Zahar; 1986.
47. Kübler-Ross E. Sobre a morte e o morrer: os que os doentes terminais têm para ensinar a médicos, enfermeiras, religiosos e a seus próprios parentes. 9ª ed. São Paulo: Editora WMF Martins Fontes; 2008.
48. Moller LL. Direito à morte com dignidade e autonomia. 22ª ed. Curitiba: Juruá; 2007.
49. Kovács MJ. Bioethics oncerning life and death. Psicol USP [Internet]. 2003 [acesso 28 abr 2021];14(2):115-67. DOI: 10.1590/S0103-65642003000200008
50. Logue BJ. When hospice fails: the limits of palliative care. Omega [Internet]. 1994 [acesso 28 abr 2021];29(4):291-301. DOI: 10.2190/EG0J-T0G5-1LJ4-KTPW
51. Manchola-Castillo CC, Garrafa V. Interfaz entre bioética y relaciones internacionales. Salud Pública Méx [Internet]. 2016 [acesso 28 abr 2021];58(4)476-82. DOI: 10.21149/spm.v58i4.8031

**Meiriany Arruda Lima** – Master – pbslima@hotmail.com
0000-0003-3046-7165

**Camilo Hernan Manchola Castillo** – PhD – camilomanchola@gmail.com
0000-0003-4084-610X

**Correspondence**

Meiriany Lima – QNL 3, conjunto I casa 17, Taguatinga Norte
CEP 72150-309. Brasília/DF, Brazil.

**Participation of the authors**

All authors participated equally in the writing of this article.

**Received:** 8.3.2020
**Revised:** 2.2.2021
**Approved:** 4.29.2021