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Palliative extubation: bioethical reflections on end-of-life care

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Abstract

Palliative care is part of a set of approaches aimed at improving quality of life in the face of an incurable and potentially life-threatening disease. In this context, among the therapies for critically ill patients, palliative extubation is performed when all attempts of withdrawing mechanical ventilation have failed, an alternative to avoid prolonging life at any cost. Despite the limited number of studies published on the subject, important biomedical, ethical, religious and legal discussions have emerged, bringing new reflections on the theme. In Brazil, the procedure still faces many obstacles, making it an inspiring subject for bioethical discussions.

Keywords: Palliative care. Respiration, artificial. Personal autonomy.

Resumo

Extubação paliativa: reflexões bioéticas sobre cuidados em fim de vida

Cuidados paliativos integram um conjunto de abordagens que objetivam incrementar a qualidade de vida diante de uma doença incurável e potencialmente ameaçadora para a vida. Nesse cenário, dentre as terapêuticas utilizadas no cuidado a pacientes críticos, a extubação paliativa é implementada quando as tentativas de desmame da ventilação mecânica falharam, a fim de evitar o prolongamento da vida a qualquer custo. Mesmo com o limitado número de pesquisas sobre o assunto, importantes debates têm emergido no campo biomédico, ético, religioso e legal, trazendo novas reflexões sobre o tema. No Brasil, ainda há muitos entraves para o procedimento, o que inspira o debate bioético.

Palavras-chave: Cuidados paliativos. Ventilação mecânica. Autonomia.

Resumen

Extubación paliativa: reflexiones bioéticas sobre los cuidados al final de la vida

Los cuidados paliativos integran un conjunto de enfoques dirigidos a aumentar la calidad de vida ante una enfermedad incurable y potencialmente amenazadora para la vida. En este escenario, entre las terapéuticas utilizadas en el cuidado a pacientes críticos, la extubación paliativa se implementa cuando los intentos de destete de la ventilación mecánica fallan, con el objetivo de evitar prolongar la vida a toda costa. Incluso con el limitado número de investigaciones sobre el asunto, han surgido debates importantes en los campos biomédico, ético, religioso y legal, aportando nuevas reflexiones sobre el tema. En Brasil, aún hay muchos obstáculos frente a este procedimiento, lo que inspira el debate bioético.

Palabras clave: Cuidados paliativos. Ventilación mecánica. Autonomía.

Research

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The continuing modernization of medicine has prolonged life expectancy and significantly reduced mortality [1]. Increased longevity, however, has also increased the prevalence of chronic and degenerative diseases and the demand for continuous and integrated health care. Thus, even with the various major human achievements in the fight against disease and death, living and dying with dignity generate a series of important reflections.

Currently, palliative care (PC) has motivated important discussions about the use of biomedical knowledge and technology, as life-saving technological advances can also preserve life regardless of the patient's suffering. And this occurs not just because curative therapy is not possible, but due to the investment in procedures that contribute little to improve the quality of life [2]. In this context, the single-minded pursuit of prolonging life raises challenging ethical issues – not only for medical professionals, but for the entire health team – regarding the possibilities and limits of therapeutic interventions, a debate that has gained greater visibility in the field of bioethics.

Method

This literature review study sought to discuss compassionate extubation (CE) in health care, centered on the contributions of bioethics. Carried out between October 2019 and February 2020, the literature survey searched for studies using the descriptors "palliative care," "compassionate extubation," "end of life" and "bioethics," and considered articles published in Portuguese, English and Spanish available in the SciELO, BVS, MedLine and PubMed databases. The survey selected forty articles published in journals, four guides on the topic, three resolutions of the Federal Council of Medicine (CFM), two book chapters and the current Code of Medical Ethics.

Results and discussion

The widespread adoption of PC has exerted great impact on and helping to strengthen new therapeutic approaches to the care of patients with incurable diseases. As a result, some procedures used in attempts to delay the outcome of unchangeable prognoses started to be questioned due to their consequences not only for the patient, but also for the patient's family members [3], as they are equally involved in the patient's care.

Palliative care in the current medical context

Seeking dignity in living and dying

In medical ethics, the concept of "palliative" (from the Latin *palliare*), with the meaning of provisionally alleviating, delaying or remedying [4], is related to the prudence and discernment necessary to choose among available therapies. In the latest versions of the Code of Medical Ethics [5], PC is integrated into some of the profession's deontological guidelines, demarcating the rights and duties of medical professionals in the care of patients and their families.

Regarding therapeutic investments, recent versions of the Code of Medical Ethics protect the physician's right to limit or suspend life-prolonging procedures if this is the wish of the patient or their legal representative, while fully providing palliative care. The ethical guidelines of the medical profession agree that PC should be offered as a model of transdisciplinary intervention involving various medical specialties, entailing, above all, the recognition of the limits of interventions [5].

PC is defined by the World Health Organization (WHO) as the active and comprehensive care provided to patients who no longer respond to curative therapy. Managing pain and symptoms in such a situation is a priority, as well as addressing psychological, social and spiritual issues, with the aim of improving quality of life. From this perspective, therapeutic measures are the result of teamwork and should focus especially on symptom control and ensuring the patient's comfort, which implies neither hastening nor prolonging death [6].

It is worth mentioning that, although PC initially focused on cancer patients, it is currently applied to many situations resulting from epidemiological and demographic changes, which presupposes its early application in the care of illness. However, several studies point out gaps in the training of health professionals in view of the technical and personal challenges brought by this new approach to end-of-life care [7-9].

Ventilatory support in end-of-life care

Delicate balance between beneficence and non-maleficence

End-of-life care includes different therapeutic approaches, hence the importance of teamwork in comprehensive patient care. Depending on the specifics of each case, interventions aim to minimize symptoms such as pain, nausea and vomiting, constipation, intestinal obstruction, cachexia, depression, anxiety, delirium, terminal agitation, dyspnea and respiratory hypersecretion. In general, while some actions are recommended, others are avoided, striking a delicate balance between beneficence and non-maleficence, seeking to improve patients' quality of life and survival [10,11].

When all weaning attempts fail, especially in cases where the clinical condition is irreversible, the maintenance of invasive mechanical ventilation only delays an inevitable outcome. More recently, this led to the removal of mechanical ventilation to be considered a therapeutic measure whose objective is to prevent the patient's suffering, mainly due to the pain and discomfort associated with the procedure. Nevertheless, ventilator withdrawal still faces strong resistance in Brazil, possibly due to its double effect [12,13].

CE, also called palliative extubation (PE) [14,15], applies to cases in which it is necessary to limit therapeutic investment, particularly when all possibilities of ventilatory withdrawal have failed or the patient has an unfavorable, severe and irreversible prognosis, due to unresponsiveness to treatment [16]. In such situations, prolonging life at any cost would be unjustified and, to a large extent, a result of the therapeutic obstinacy of professionals [17]. But despite the benefits involved, evidence from the literature indicates that CE is still seldom performed in Brazil [13].

In adult intensive care units (ICU), some criteria are considered when limiting advanced life support, including older age, greater possibility of compromising quality of life after the procedure and the score obtained on widely used and scientifically recommended scales – such as low scores in the Karnofsky Performance Status scale and high scores in the Simplified Acute Physiology State 3 scale [18]. In these cases, starting or terminating mechanical ventilation is not recommended, as the purpose of this procedure is to prolong life [19], a goal that is not always ethically acceptable, considering the effects on the patient's quality of life [20].

Coradazzi and collaborators [3] emphasize the importance of preparation before the procedure, which must include three stages. The first consists of a multidisciplinary team meeting to investigate whether there is a consensus on the need for CE. In this case, the indication should be based on the ventilatory parameters used and on the impossibility of maintaining life after extubation, even considering that death will probably not be immediate.

In the second stage, the multidisciplinary team and the patient and/or their family should opine on the proposed interventions. At this stage, which may require more than one meeting, the available options will be clarified, including when and how CE will be performed, and, due to the intense emotional involvement, all information should be given to the family in an understandable way, so as to clarify any doubts, with a view to making a joint decision. As this is an intervention with clinical consequences, family members must be included in the decision-making process, particularly if the patient's participation in this process is impossible [21].

In the third stage, which comprises the preparatory procedures, the entire team must be prepared for the CE, as it will be necessary to assess the patient's consciousness level during the postextubation period, which can be conscious and calm, asleep or profoundly sedated. The discussion of cases by the multidisciplinary team allows joint planning of actions, including meetings with the family, to review the diagnosis and prognosis and clarify possible care options, informing the difference between CE and euthanasia [22,23]. A clear and harmonious communication increases the proximity with the family and the success rate by up to 96%, since an effective communication ensures that all team members have certainty as to the strategy adopted [3].

Before the CE procedure, it is also important to monitor the consciousness level, discontinue curative medications and maintain only those necessary to relieve pain or dyspnea, in addition to discontinuing procedures that will not change the prognosis, such as dialysis [22]. It is important to emphasize that the withdrawal of mechanical ventilation is not intended to accelerate the patient's death, which is why it should not be

confused with euthanasia. On the contrary, it is about support in the face of an irreversible clinical condition, prioritizing the necessary care so that the patient does not suffer unnecessarily during their death, without performing actions whose harmful effects outweighs the benefits to be achieved [24,25].

In the hospital environment, CE has shown positive impacts on patients, families and teams, as long as it follows current recommendations, given the procedure's complexity [3], reason why it should be performed by an intensivist medical professional [12]. When incorrectly performed, CE can lead to pain and dyspnea, reactions that should be avoided when the procedure is performed.

Different withdrawal methods are found in the literature since various measures for performing CE exist. In the first case, immediate withdrawal is recommended, however the literature indicates this method shows a greater association with complications such as pain and stress, which are completely opposed to the primary objective of CE. Another possibility is terminal extubation, performed to progressively decrease ventilatory parameters until complete extubation, always with the concern of preventing any sign of discomfort pre or post extubation, which can be achieved with the use of opioids and/or benzodiazepines and oxygen therapy, maintaining adequate sedation [3,26,27].

In the field of bioethics, concerns about avoiding dysthanasia have had an impact on therapeutic decisions on the limits of interventions, including CE, so as to safeguard the patients' well-being. The finiteness of life and concerns about death and dying have gained greater visibility, no longer as facts of biological life, but as psychological, social and spiritual experiences that need to be integrated as a goal of health care. But even with the increasing adoption of CE in recent decades, until recently Brazil still occupied a modest 42nd place in the quality of death index [28].

Compassionate extubation and decision-making process

A shared decison?

Regarding therapeutic relationship, especially in developed countries, CE entailed new forms of it, with the inclusion of patients and family members in the decision-making process that previously were solely medical. This was one of the decisive changes for improving the quality of service provided in CE [29], on which, considering the importance of preserving autonomy as an ethical principle, CFM issued Resolution No. 1,995/2012, which addresses advance directives of will (ADW). These are intended to previously define the patient's wishes, who now has the right to refuse therapies they deem aggressive, even when unable to freely and autonomously express their will.

Thus, even in situations where the patient is unable to communicate, their expressed desires must be declared by their legal representative for consideration by the health team [30]. This shows how the increasing value given to autonomy has had a significant impact on clinical decisions and on the relationship of the care team with patients and family members, who began to be increasingly included in the decision-making process [31]. In this regard, the investment in improving communication is not only a humanization strategy, but also a reflection of professional commitment and ethics in the relationship with patients and their families [31,32].

In general, CE should also be discussed by the care team, with the participation of the patient and family members. But to put this ideal into practice, the patient's desires should be previously addressed, which is not common yet, especially in Brazil [33]. Moral and legal limitations, in addition to the predominance of a paternalistic relationship model, still lead to major obstacles to shared decision making. Decisions should thus be made together by the team and the family, based on their beliefs, expectations and values, which directly interfere with the choice of performing or not the procedure [19,20].

It is important to emphasize that Brazil still does not have specific legislation on orthothanasia, or on Advance Directives of Will. Although the CFM has issued Resolution No. 1,995/2012 [30], which addresses the matter, there are still no national legislation on it as in other countries, including in Latin America. This is why, in case CE is indicated, both the ICU physician and an independent physician need to carefully evaluate the patient, a recommended procedure for confirming the prognosis [3,12].

Besides clinical evaluation, the multidisciplinary team is responsible for providing information

about CE to the patient's companions and family members, including the method to be used and its risks and benefits. Lack of clarification can lead to a reluctance to accept the procedure, causing anxiety and depression, as well as other grief-related complications [21,34]. Moreover, poor communication with the team can make family members and other close ones feel guilty for the death of a loved one, which justifies the importance of a clear and supportive communication with the team [35,36].

As survival time varies, the presence and support of the family become essential and the team must allow social and farewell rituals to be conducted, as well as the fulfillment of end-of-life wishes [37]. At this point, it is necessary to respect the privacy of the family and stable patients can be transferred to beds outside the ICU [16,38]. Contact between the health team and family after the patient's death is highly recommended to improve the quality of the hospital program [3] and fulfill one of the structuring principles of PC, which provides for follow up during the grieving process [10,11].

The psychological follow-up of the team can also be of great value, considering that the professionals have values and expectations that can influence their psychological health during the procedure, due to reactions related to countertransference and to ethical and religious issues that can also interfere with the team members' judgment [39].

Compassionate extubation in the context of bioethical reflections on the finiteness of life

A significant part of bioethical reflections on human finitude include questions about the limits of performing medical interventions to prolong life [40]. Such reflections have intensified with current discussions about certain health concepts, such as active euthanasia, passive euthanasia, dysthanasia, orthothanasia and assisted suicide and their relationship with CE, especially because they are closely related to the finiteness of life [41].

The expression "euthanasia" comes from the Greek language and is historically associated with the idea of a good death; it is defined as a process by which life is shortened to avoid physical or psychological suffering. Countries such as the Netherlands, Switzerland and Belgium have already legalized euthanasia, which made it possible to fulfill a person's wish to die, albeit under a series of conditions [40]. Orthothanasia, in turn, is the interruption of procedures aimed at artificially prolonging life but which can cause unnecessary suffering to the patient [41].

Importantly, many measures aimed at prolonging life can also be considered palliative, as they are introduced to provide greater comfort and dignity to the patient. This means that even considering the natural course of a disease, certain therapies are offered as a measure to control pain and various symptoms, whether physical or psychological [42]. On the other hand, dysthanasia, also called "difficult death" in opposition to orthothanasia [43], refers to the prolongation of life by artificial means with the purpose of delaying the natural process of death, causing more suffering to the patient.

It is also important to emphasize that in orthothanasia it is the disease that causes death, unlike passive euthanasia, in which the disease is not fatal or does not represent an imminent threat to the patient's life. Therefore, while passive euthanasia shortens life, dysthanasia prolongs it, even when the patient no longer has a chance of cure, as a result of therapeutic obstinacy, which is known to lead to agony and suffering [17,43]. Considering the three concepts, CE is aligned with the goals of orthothanasia, as it does not aim to artificially prolong life while also causing suffering, nor to change the natural process of death, given that the therapies provided will no longer interfere with the natural course of the disease.

Supplemental therapies can also be provided in association with CE, such as palliative sedation (PS), which can help reduce respiratory symptoms [44,45] when other forms of care do not provide relief, as suffering is often caused by resistance to death [42]. Another aspect to be considered is the patient's desire to live or die, which may influence their decisions since they may choose to maintain the life prolonging procedures, even if no relief is provided [1,42]. However, in a context of shortage of human and material resources to meet the demand for PC,

one must consider that this option is not always viable, which raises other relevant ethical issues.

It is worth mentioning that clinical decisions for orthothanasia are primarily aimed at maintaining the patient's comfort and dignity, as well as the well-being of the family, preventing uncomfortable and painful situations, and that discontinuing dysthanasia therapies does not mean interrupting the provision of care [1]. This point also entails legal issues since the Brazilian Penal Code characterizes euthanasia as a crime [46]. The difficulty in implementing CE in PC also stems from the lack of qualified teams and gaps in PC training [7-9].

Another factor to be considered is the possible influence of religious beliefs on clinical decisions made by the team and the family [47]. Since different religions approach end of life differently, based on different perspectives and value judgments, the procedure can be hindered by religious beliefs and precepts, which can affect the decisions of family members, as much as the country's legislation [48]. Moreover, performing CE raises bioethical issues, since although the Brazilian Code of Medical Ethics establishes that the physician has the duty to respect the patient's autonomy, in some situations the final decision is still up to the medical professional, which may lead to many contradictions.

CFM has recently issued Resolution No. 2.232/2019 [49], which is controversial for many scholars who consider it a setback in the field of PC, since, in urgent and emergency situations, the doctor is authorized to adopt measures to preserve the patient's life, regardless of therapeutic refusal.

Overall, CE requires further discussions, so ethical parameters for its use can be established. Besides technical-scientific knowledge on the matter, humanization, respect and understanding of the impacts of therapeutic actions must prevail, in order to preserve human dignity in end-of-life care. The training of teams in PC, a greater investment in and awareness of the importance of the informed consent process, and the creation of clinical bioethics committees emerge as important strategies towards this goal.

Final considerations

Although CE is well consolidated in developed countries, Brazil has little research on the topic. Moreover, there is an opposition to carrying out an ethical debate about CE due to taboos and religious conceptions, which are hindering its application [46,47]. Part of the problem possibly originates in technical issues, but also due to the links between this issue and the moral and religious values involved in end-of-life as a theme, despite the advances achieved with the consolidation of PC. Our aim is that the issues raised in this discussion may facilitate facing the challenges that permeate PC, giving an important contribution to the clinical decisions within the scope of end-of-life care.

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