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Anastasios Giasafakis, Michail Giasafakis

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SPECIAL ARTICLE

CARE AND SUPPORT OF PATIENTS WITH END-STAGE RESPIRATORY DISEASE ON HOME MECHANICAL VENTILATION – ETHICAL AND LEGAL ISSUES

Anastasios Giasafakis¹, Michail Giasafakis¹

1. Medical School, National and Kapodistrian University of Athens, Athens, Greece

Abstract

Home mechanical ventilation (HMV), either invasive or non-invasive, can play a vital role in managing respiratory insufficiency in patients with end-stage lung diseases. However, a range of ethical considerations arise, due to its impact on patients, families, physicians and healthcare systems. Key ethical concerns include obtaining informed consent, evaluating patients' decision-making capacity, addressing the potential withdrawal of ventilation, and managing the emotional and practical burden placed on family members. These issues require careful, patient-centered deliberation. At the same time, the development of a clear and comprehensive legal framework governing home health care (HHC) services remains a significant challenge. This review aims to gather and present information from the existing literature regarding the ethical and legal perspective of HMV, as well as illustrate the greek legal framework about home health care. A detailed legislation is indeed demanded in order to determine each party's role (physicians, families, patients), minimise ethical issues and render HHC an equal alternative model of patient-oriented therapy. Despite the legal framework, the implementation of Hospital-at-Home (HaH) in Greece is still in its infancy, raising ethical concerns about unequal access to palliative care, regional disparities, and the disproportionate burden placed on patients and families managing end-stage diseases at home.

Keywords: Home mechanical ventilation (HMV), end-stage, ethics, legislation, home health care (HHC), Greece.

Corresponding Author: Michail Giasafakis, 5th year undergraduate student, Medical School, N.K.U.A., Athens, Greece E-mail: mixalisgiasafakis@gmail.com

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INTRODUCTION

Home mechanical ventilation (HMV) constitutes a way of supporting or fully substituting breathing in patients with chronic respiratory failure using a mechanical ventilator at home. It can be either invasive or non-invasive, depending on whether a tracheostomy is required or it is delivered through a face mask respectively.

The main indication for HMV is chronic respiratory failure, which can be caused by COPD, neuromuscular diseases and chest wall deformities. It can also be used in patients who survived from acute respiratory failure (e.g. ARDS).¹ Inevitably, HMV is accompanied by ethical issues, especially when patients face the final stage of their disease. For instance, patients with COPD receiving non-invasive HMV may experience worsening of their symptoms leading to more frequent hospitalisations. The question that arises is whether to increase the use of non-invasive HMV, to proceed to invasive HMV (tracheostomy) or even to withhold therapy and focus on palliative care if all possible treatments are unable to offer the desirable quality of life.² Addressing such issues presents significant challenges for all parties involved in the patient's care, including the patients themselves, when they retain the capacity to make autonomous decisions. Specifically, physicians face considerable challenges in managing such cases, as they require highly effective communication with both patients and their families, as well as complex and often burdensome decision-making regarding therapeutic options—decisions that may ultimately carry life-or-death implications. As expected, the establishment of a legal framework for home health care (HHC) is a complex process, as it must account for a wide range of parameters. In Greece, the regulatory details concerning HHC were not formally clarified until 2023.⁴

Ethical considerations

The patient

When referring to patients' rights, we primarily address their entitlement to make autonomous decisions regarding their care, including the right to choose among proposed therapeutic options and to give or withhold consent for invasive procedures. This reflects the fundamental principle of patient autonomy. Through advance care planning (ACP), patients can articulate

their preferences concerning all aspects of their healthcare management ahead of time. This ensures that their wishes are known to both healthcare providers and family members, particularly in situations where they may become critically ill and unable to communicate their decisions.⁵ However, it is obvious that patients lack medical knowledge in order to judge what is best for them regarding possible future treatments. Therefore, their decisions are influenced by the way in which the different therapeutic options and their consequences are explained by the doctors.⁶ This poses an ethical burden for physicians, who must carefully evaluate the relative weight of the potential benefits, risks, and harms associated with each treatment option. However, some patients prefer to adopt a more passive role in the decision-making process, entrusting full responsibility to the physician, as this approach offers them a sense of security and comfort. This perspective should be equally respected by healthcare professionals.

Another question is whether doctors should offer all treatment choices and let the patient (or the family) decide, without intervening in the decision-making process. Indeed, according to a small scale study conducted in Australia among clinicians working with children with chronic respiratory insufficiency, the view that the final decision should be taken exclusively by the family was prevalent.⁸ However, the physician's role is not merely that of a 'medical advocate.' A balance must be struck between the traditional model, in which the physician holds primary decision-making authority, and the patient-centred approach, which places greater emphasis on patient autonomy. Achieving this balance is essential for fostering effective and collaborative therapeutic relationships (see Fig. 1). Moreover, the obligation of physicians to present all available therapeutic alternatives—even those they believe may not offer patients a dignified quality of life—remains a subject of ethical debate. For example, patients with severe respiratory failure resulting from neuromuscular diseases who receive invasive HMV may be confined to bed, with little or no ability to move independently. The medical principle of beneficence and non-maleficence (guiding professionals to act in ways that maximise benefits while minimising harm) is unable to indicate whether the patients should be offered life-sustaining therapy, because the prolongation of human life on the

one hand and the poor quality of life on the other hand, makes it difficult to judge what is the benefit of the patient³ (Fig. 2). Even if we accept that the collaboration between patients and doctors demands that all choices should be discussed, it is necessary that doctors have the ability to discourage patients (or their families) from opting for treatments that would keep them alive with little or no functionality.

Withholding treatment in end-stage patients does not imply abandonment or the absence of care; rather, it signifies a shift in focus toward comfort measures and palliative support. Palliative care will continue to be offered so as to relieve symptoms like pain and dyspnea and to reduce suffering in the terminal stage of conditions like COPD, interstitial lung diseases, cystic fibrosis and pulmonary hypertension. However, it is important to emphasize that palliative care should not be reserved solely for situations in which curative treatments are no longer viable or effective. Rather, it ought to be integrated alongside curative interventions from an early stage in the treatment process. The timely initiation of palliative care can improve quality of life and limit the negative impacts of the disease, especially if it is implemented by a multidisciplinary team of specialists.⁹

Of course, physicians are not the only individuals confronted with such ethical dilemmas. Family members are often entrusted with the responsibility of making decisions on behalf of patients who are either unable to communicate or are legally incapable of providing consent, such as in the case of minors. This tends to be an uncomfortable situation, especially when the patients' wishes have not been prediscussed. It can be easily understood that choosing to withhold or not initiate HMV in end-stage patients with the notion that lengthening their lives will only prolong their suffering is a very difficult decision from family members to make. It is doubted that deciding not to keep a person alive (when there are measures that could do so, such as HMV) is ethical. On the other hand, some family members may struggle with uncertainty about whether their desire to prolong the life of a loved one and provide continued care is ethically justifiable, particularly when it results in a poor quality of life associated with ventilator dependence.³ The ethical dilemma becomes even more complex when the patient is a child, as parental judgment may be influenced by strong emotional factors. In some

cases, parents may experience feelings of guilt or question whether their decision to prolong their child's life—despite severe physical limitations, such as in cases of spinal muscular atrophy with advanced respiratory failure—is motivated by love or by an underlying sense of selfishness.

Taking into account the patients' desires concerning future medical decisions is significant for another reason too. It gives them the opportunity to have some sort of control over their inevitable end.¹⁰ Patients have the right to indicate their wishes around this sensitive matter, such as the place they prefer to be (e.g. their home) and the degree to which they are willing to accept invasive procedures in order to prolong their life. Knowing that their decisions will be respected when the time comes can relieve patients from anxiety about the possible outcomes of their condition.⁶ The most formal way in which this can be achieved is through ACP, as mentioned above. ACP enables patients to clarify their goals about their treatment, the desirable quality of life, personal values that they want to be respected, and specific details, such as transition from non-invasive to invasive HMV or Cardiopulmonary Resuscitation (CPR) attempt. ACP should begin early in the course of the disease and continue throughout its trajectory, in order to avoid making important decisions in a situation of crisis. Of course, ACP can be reassessed and modified, especially when it is time to make changes in treatment or after an unexpected health deterioration.¹⁰ Moreover, the aim of ACP is not only to determine clearly every aspect of medical care, but to build a relationship between the patient and the doctor or relatives, in which it is understood what matters more for the patient; a good quality of life with the minimum suffering, prolongation of life even if accompanied by significant loss of functionality (palliative care will of course be provided), or something in between. This way, patients trust their caregivers more and achieve better communication with them. Although this sounds ideal, some patients tend to be more reluctant to discuss the end of life because they may feel uncomfortable or even scared about the future. Physicians have to be patient and encouraging towards these individuals, in order to help them to accept their condition and reflect on their wishes and expectations.¹⁰

The patients themselves also face ethical questions when issues

like living with HMV are discussed. The decision to do all that is possible to prolong their lives or to refuse some treatment options, thus shortening their potential time to live, is not a matter of ethics but of personal choice. However, the dependence of ventilator-assisted individuals on continuous caregiving—primarily provided by family members—poses an ethical challenge for the patients themselves. Many express a strong desire not to burden their loved ones, and this concern often influences their healthcare decisions, as they may seek to act in what they perceive to be the best interest of their family.⁶ Considering that patients are the ones that suffer the most and experience feelings of anxiety, uncertainty about the future and fear of death makes it easy to understand that tackling this challenge is difficult and uncomfortable for them.

Family & physicians

Family members are in a hard place not only if they have to make decisions on behalf of the patient, but also when they are expected to act as caregivers for their loved ones. A ventilator-dependent individual that approaches the end of life has an impact on the everyday life of caregivers, who are inexperienced in such situations and have to act with responsibility, despite their affection. Additionally, caregivers need to sacrifice part of their personal time, which becomes demanding if they are the only ones responsible for the patient, and also face considerable financial barriers, especially if they have to quit their jobs in order to dedicate themselves exclusively to the patient's care.¹¹ More than that, family members experience a profound psychological challenge due to the constant grief they have, considering the inevitable clinical deterioration of the patient and wondering if this situation benefits the patient or constitutes a pointless torture. Therefore, the principles of beneficence and non-maleficence when considering treatments like invasive HMV have to take into account both patients but also their families, due to the impact they have on every aspect of their lives.³ It would be irresponsible to support that physicians should try to improve patients' quality of life to such an extent that families' quality of life is entirely lost. Balancing patients' and families' interest can be a moral challenge for the doctor, because all these factors must be taken into consideration.

Another reason that can hinder decision-making is the fact that health care is provided in the patient's private home. The constant interaction between patients, family members and health staff in such an environment, menaces the professional autonomy of the latter and is often a source of conflicts. Specifically, families feel that their home is invaded by physicians and expect to play a significant role in decision-making, whereas doctors feel that their scientific integrity is violated when family members try to impose their opinions on medical issues. This could be solved if end-stage patients who need continuous care were moved to nursing homes (hospices), in order to receive health services in a more professional environment. However, this solution does not respect potential wishes of patients, such as their preference to live at home¹², which is a matter of quality of life and is the main advantage of HHC.³

Financial perspective

Ideally, medical practice should be guided solely by clinical and ethical considerations, without financial constraints influencing decision-making. This implies that physicians ought to have the autonomy to recommend and administer potentially beneficial treatments, regardless of their cost. Inability to do so would translate to the abolishment of the professional freedom of physicians.¹³ However, resources are limited in health care systems and excessive resources spent in one domain (such as patients with end-stage respiratory failure who need mechanical ventilation) negatively affect other groups of patients who also need treatment. Thus, the necessity of a fair distribution of health care resources is evident.³

Even if we agree that doctors have to accept financial limitations in clinical practice, it remains morally questionable whether they are the ones who must set these limits. The role of physicians is not to allocate resources but to offer the most suitable treatment to each patient, irrespective of expense. Rationing health care resources, that is controlled distribution of services and financing¹⁴, is a responsibility of politicians and technocrats. Physicians should not be compelled to make such decisions on their own because this would not comply with their primary role to treat.¹⁵ More than that, it would be more difficult for patients to trust them, if they knew that they act as financial managers

except for health care providers. As far as patients with end-stage respiratory failure are concerned, doctors should be free to suggest mechanical ventilation, if they judge that patients could benefit from such an option, although it may be expensive and may also increase health care costs indirectly by lengthening patients' life.¹⁴ Nevertheless, the ethical perspective that expensive therapies provided to a certain group of patients result in reduced resources left for other patient groups, means that doctors should not offer futile medications just because they feel uncomfortable discussing matters such as end of life. Besides, this could deprive patients of the potential to come to terms with the trajectory of their disease.¹³

Another question is whether HMV is cost-effective for families and health care systems, in comparison to mechanical ventilation exercised in hospitals. While HHC in general has proved to reduce health care costs¹⁶ and to result in better clinical outcomes in some cases¹⁷, HMV is a distinct treatment option. Evidence is scattered in the existing literature, however there are some parameters that deserve to be mentioned. For example, hospitalisations are accompanied by a set of costs such as the cost of hospital equipment, functional expenses, medical staff's salary and possible hospitalisation's charge, depending on each country's health care system. Even though HMV may be a more cost-effective solution because part of this cost is avoided, families and health care systems will still need to cover some costs. The costs associated with HMV include expenses related to technical support, nursing care, and additional items such as consumables required for the maintenance and operation of the equipment. Despite the fact that some of these expenses are covered by medical insurance, families often have to take time off work or hire professional caregivers in order to fulfil the patient's care needs.¹⁸ However, several studies suggest that HMV remains cost-effective both for health care systems and for families.¹⁶ Especially for palliative care, a randomised controlled clinical trial conducted in the USA in 2007 showed increased satisfaction of end-stage patients who received palliative care in comparison to those who received hospital treatment, as well as lower costs of care for the first ones, due to less frequent need for hospitalisation.¹⁹ (Fig. 3)

Legal framework

As it has already been explained above, HHC is a complex procedure that demands the collaboration of many individuals (e.g. doctors, nurses, physical therapists, administrative staff, patients and their families). A legal framework that determines the responsibilities of all the parties involved and ensures HHC team coordination is therefore required, aiming to the maximum benefit of the patients.

As already mentioned, the details about HHC were legally clarified in Greece in 2023. Hospital at Home (HaH) is the term used to describe HHC in Greek legislation. However, HHC had already been legally institutionalised in the national health system since 1992²⁰ and in 2014 it was expanded to include private health providers (hospitals, individuals). Nonetheless, legislation was not applied to a satisfying extent and HHC was provided in an unorganised manner.

In particular, the law about HaH published in the official gazette of Greece on May 19th, 2023 determines the terms in which HHC is provided. First of all, it is legally ensured that patients receiving HHC will always have rapid access to the hospitals in which they had been previously hospitalised, in case of deterioration of their health. Hospitals are obliged to maintain two beds available for this reason. In order to provide health care in the most efficient way, each clinic that is responsible for patients who receive HHC (defined as HaH reference centre) must have already determined a physician and a team of nurses that have attended an educational programme for at least three months. These individuals cooperate with doctors of different specialties as well as physical therapists, psychologists and social workers in order to supervise patients' health and support the caregivers. Moreover, the law demands the existence of a specific treatment area within the hospital for the needs of HHC patients.

The basic criteria for inclusion in a HaH programme are mainly based on the complexity and the chronicity of the disease, as well as the need of technical support and not necessarily on the specific diagnosis of the disease. Patients who need invasive or non-invasive mechanical ventilation are eligible for such a treatment. Patient's health progress, compliance and response to treatment define the intensity and the duration of care according to estimates of the HaH team. Other categories of patients

that could be included in HaH, according to the 2023 law, are patients with; persistent respiratory distress after leaving ICU, tracheostomy, breathing-related sleep disorders demanding respiratory support along with comorbidities (e.g. obesity-hypoventilation syndrome), long-term oxygen therapy, eating disorders, need of respiratory or kinetic physical therapy, neurological diseases and oncologic patients who can receive treatment at home.

Of course, the law suggests that the decision that a patient will receive HHC is made after the multidisciplinary medical team has confirmed the ability of caregivers to fulfil the needs of the patient and after the social worker has assessed the home environment. It is also mentioned that HaH doctors and nurses have to accompany the patients to their home when they leave hospital with an ambulance and make daily visits for the first week of the programme, so as to ascertain patients' adjustment to the new environment of care. After the first week, the frequency of visits is determined depending on the needs, but the HaH team continues to supervise patients' health progress by communicating with patients or their caregivers and by using telemedicine technologies. Patients (and caregivers) have to follow medical instructions and inform physicians about any change of their health status. If patients need to take medication such as IV or IM treatment and narcotic drugs, the HaH supervisor and a HaH nurse are the ones who must transfer and administer this medication at the patients' home using a special HaH vehicle, ensuring that each patient is offered the correct treatment. All expenses associated with HaH services are covered by the budget of the hospital designated as the reference centre for each patient, in accordance with the applicable legal provisions.⁴

Despite the existing legislation, everyone involved in HaH practice deals with matters of potential legal consequences. In Greece, all doctors must apply with the Code of Medical Ethics (CME), a set of moral norms that define honourable behaviour for a physician. CME inevitably deals with the matter of end of life. Its 29th article dictates that "the doctors, in case of an incurable disease that is in its final stage, even if all medical treatment options are exhausted, must take care of alleviating the patients' psychosomatic pain. They offer palliative treatment and work with relatives in this direction. In any case, they sympathise with

the patient until the end of their life and make sure that they maintain their dignity. Physicians are obligated to take into account patients' previously expressed wishes, even in cases where patients are no longer able to reaffirm them. However, it is essential for physicians to recognise that a patient's desire to die does not constitute legal grounds for performing actions intended to intentionally hasten death". These principles are implemented by exercising palliative care, as mentioned above, and by formally writing down patients' wishes using ACP. ACP involves legal documents like Advance Directives, which cover extensive medical wishes and decisions, Living Wills, which details the types of medical treatment the patient would want to receive or not during the final stage of the disease (end of life), and Durables Powers of Attorney, which give legal authority to another person to make decision on behalf of the patient in case of incapability.²¹ However, it remains a matter of ethical and legal controversy whether it can be presumed that patients continue to have the same desires about potential medical treatments when they are no longer able to communicate, if these decisions were made under completely different circumstances and before entering the terminal stage.²² However, ACP cannot completely relieve doctors from their legal and moral responsibilities. In any case, the 15th article of CME declares that "doctors facing conflict of duties, must deal with this conflict based on their scientific knowledge, the comparison of the legal goods at stake, the absolute respect for human life and dignity and their moral conscience with respect to basic principles of medical ethics".

In addition, there are practical issues that have yet to be legally addressed. Matters of liability arise because physicians are responsible for patients outside the traditional environment of the hospital and therefore they are unable to monitor their health systematically. The extent to which a doctor is answerable for potential harm in patients' health that happens in the home environment is ambiguous. For example, in emergency situations, the ability of the HaH team to respond promptly may be influenced by uncontrollable external factors, such as weather conditions, traffic congestion, or significant geographical distance between the hospital and the patient's residence. It remains unclear whether the team's effectiveness should be assessed solely

on the basis of prompt departure from the hospital, or whether the actual time of arrival at the patient's location should also be subject to evaluation. In the latter case, delays in response time could potentially be interpreted as negligence, thereby giving rise to legal implications. To mitigate such liability, it would be necessary to demonstrate the presence of force majeure circumstances. Moreover, the inclusion of a patient in a HaH programme should only be determined following a thorough assessment of the home environment to ensure the absence of potential hazards—such as unsafe individuals (e.g., caregivers or visitors) or environmental risks (e.g., exposed wiring, structural instability). Failure to verify the safety of the home setting may expose physicians to liability should any of these factors result in harm to the patient. For this reason, disclusion from HaH might be a sensible idea, though morally questionable, in order for doctors to avoid legal consequences, if the home environment is evaluated as inappropriate and this cannot be fixed.

Except for physicians, caregivers could also face liability issues in case they provide insufficient care or if they fail to act upon an emergency situation. The fact that caregivers could be relatives or unpaid volunteers, or even employees of the family does not mean that they do not have legal responsibility for the adequacy of their care.

Potential liability may also arise for medical device manufacturers in cases where defective equipment is used in the context of HaH monitoring. Hospitals may likewise bear responsibility if they fail to identify and address device malfunctions in a timely manner, particularly when such failures result in harm or pose a significant risk to patient health.²³ The fact that everyone involved in HaH daily practice is susceptible to liability concerns dictates that legislation should become even more specific and practice guidelines should be implemented in order to avoid such risks and reduce legal controversy. In this way, health providers would be legally protected and consider HHC as a more appealing choice of treatment.

The present situation in Greece - Implementation and ethical aspects

Despite the existing legal framework, the implementation of HaH in Greece remains at a very early stage. Except for some

oncology centres like “Agios Savvas”, “Metaxa” and “Theage-neio” that already provide HHC services for their patients, such as chemotherapies at home, other general hospitals are still making efforts in order to become ready to offer HHC services to patients with chronic or end-stage diseases. According to the announcements of ODIPY, the Agency for Quality Assurance in Health, which is a governmental agency under the Ministry of Health, the hospitals that will soon be included in the HaH programme for adult patients are “G. Papanikolaou General Hospital of Thessaloniki”, “University General Hospital of Alexandroupolis” and “PAGNI University General Hospital of Heraklion”. “Ippokrateion General Hospital of Thessaloniki” already offers HHC to pediatric patients and “Attikon General University Hospital” as well as “Children’s Hospital Agia Sofia” are currently organising their inclusion in the HaH programme. However, the extent to which the existing legislation will be implemented remains unclear at this early stage.

The procrastination of the application of HaH is itself a source of ethical considerations as it renders the care of end-stage patients a matter of individual responsibility that burdens the patient and the family. This raises questions about fairness in access to palliative care. If an organised HaH programme is not offered by all general hospitals, discriminations will continue to reign over the quality of medical care these patients will receive, concerning not only the financial state of families but also the location of their residence in relation to the existence or not of a HaH centre around.

CONCLUSION

As medical knowledge increases, fatal diseases of the past that led to death shortly after the diagnosis, are now characterised as chronic diseases, because the available medical treatment and technology enables patients to lengthen their lifespan and at the same time control their symptoms. This means that HHC practice may eventually become the standard of care for such patients. Especially for end-stage patients, HHC refers to both palliative care and treatment options, such as mechanical ventilation. As extensively explained above, this practice is accompanied by a range of ethical and legal parameters that make it challenging for everyone involved. Although ethical dilemmas

cannot have a permanent answer and depend on personal values, legal challenges can be tackled by a more precise and pioneering legislation. The recent legislation in Greece concerning HHC is a significant progress, but a lot more has to be done in order for this practice to be established in health care system. The determination of each one's responsibilities and of the details of HHC would potentially make physicians more willing to suggest HHC and render this option more appealing to patients and their families.

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ANNEX

FIGURE 1. Decision making in home health care.



FIGURE 2. Quality of life vs Prolongation of life

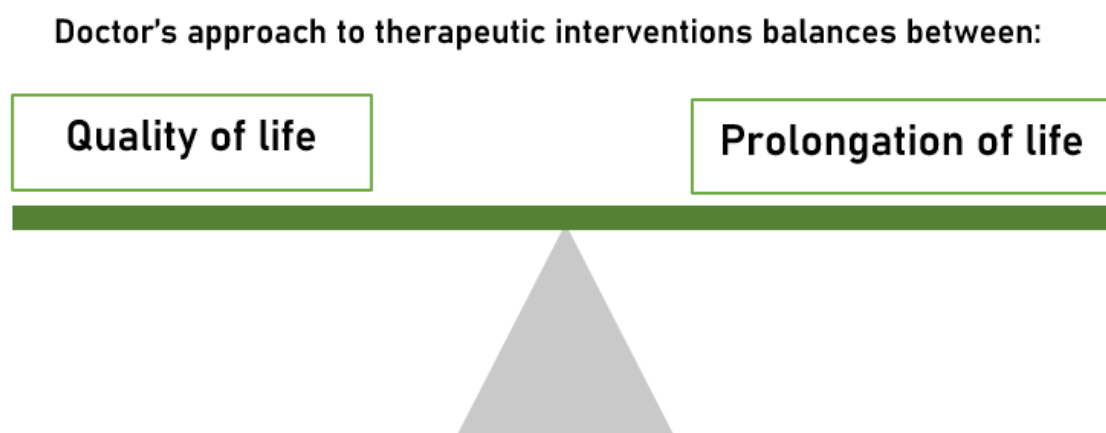


FIGURE 3. Ethical parameters of home mechanical ventilation

