



## Controlling Death. Highlights from Harvard Medical School Annual Bioethics Conference

Controlando la Muerte. Aspectos destacados de la Conferencia Anual de Bioética de la Facultad de Medicina de Harvard



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## Abstract

The 2019 Harvard Medical School Annual Bioethics Conference questioned if we're controlling death by choosing when and how we die. This integrative review compared literature findings with the discussion of the Conference. While people discuss comfort and dignity in their end-of-life, legal and ethical aspects of Palliative Care and other exit options like Palliative Sedation to Unconsciousness, Voluntarily stopping eating and drinking, Physician-assisted death and Voluntary active euthanasia must be discussed, as well as Advance Directives and palliative care team. We concluded arguing which other health conditions (psychiatric, cardiovascular or respiratory) could benefit from the exit options.



## Resumen

*En 2019, la Conferencia Anual de Bioética de la Facultad de Medicina de Harvard se cuestionó si estamos controlando la muerte eligiendo cuándo y cómo morimos. Este artículo compara las investigaciones publicadas con el tema de la conferencia. Los participantes en la conferencia discutieron sobre la comodidad y la dignidad en el final de la vida, los aspectos legales y éticos de los cuidados paliativos, pero otras opciones de salida deben ser discutidas, como los cuidados paliativos, la suspensión voluntaria de comer y beber, la muerte asistida por un médico y la eutanasia activa voluntaria, así como el documento de voluntades anticipadas o el equipo de cuidados paliativos. Concluimos discutiendo qué otras condiciones de salud (psiquiátricas, cardiovasculares o respiratorias) podrían beneficiarse de las opciones de salida.*



## Key words

Palliative care; euthanasia; right to die; advance directives.

*Cuidados paliativos; eutanasia; derecho a morir; documento de voluntades anticipadas.*



## Fechas

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## 1. Introduction

Last April, the 2019 Harvard Medical School Annual Bioethics Conference explored the policies, practices and ethics of choosing not only when, but how we die. This two-day conference discussed aspects of euthanasia and physician-assisted death from the point of view of health and legal professions. Thus, we decided to write an integrative review under this subject.

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Patients with advanced illness, sometimes, no longer stand physical and/or psychological suffering and look for comfort and dignity in their end-of-life, even asking their physicians about options to hasten death. Beyond poor quality of life, the discussion run through fear of future suffering despite unrestrained efforts to palliate. Underlying this discussion, we have the idea that those who know having options, they probably face their end-of-life with less fear.

## 2. Methods

Considering this, we performed the following search strategy at PubMed:

(((((“suicide, assisted”[MeSH Terms] OR (“suicide”[All Fields] AND “assisted”[All Fields]) OR “assisted suicide”[All Fields] OR (“assisted”[All Fields] AND “suicide”[All Fields])) OR End-of-life[All Fields]) OR (Exit[All Fields] AND option[All Fields])) OR (Medical[All Fields] AND aid[All Fields] AND dying[All Fields])) OR (Voluntarily[All Fields] AND stopping[All Fields] AND (“eating”[MeSH Terms] OR “eating”[All Fields]) AND (“drinking”[MeSH Terms] OR “drinking”[All Fields])) AND (“2018/01/01”[PDAT] : “2019/12/31”[PDAT]) AND “humans”[MeSH Terms] AND (English[lang] OR Portuguese[lang] OR Spanish[lang]))

This search returned us 1521 articles. After, we performed a selection of articles that met the discussion we attended at the 2019 Harvard Medical School Annual Bioethics Conference. We excluded all the articles that didn't mention ethical aspects of end-of-life decisions, repeated items and those which were out of the theme.

## 3. Defining Palliative Care

As a starting point for the discussion we propose here, it is important to define Palliative Care (PC). According to the World Health Organization (WHO) definition, “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002). Neither hasten nor postpone death is included in the goals of PC, but when health condition deteriorates patients may request hastening death options in order to alleviate intractable



symptoms. Considering this, we should think whether PC practitioners would evolve their role in addressing the needs of patients who ask for last resource options (Belanger, 2018).

As shown by professor Quill (2018), when a patient asks a doctor about the possibilities to hasten death, the clinical team should explore all the concerns of the patient and redouble palliative resources to face these concerns. But if last resource option remains an interest, all the possibilities should be discussed and presented, including its legal and ethical aspects.

#### 4. Palliative Sedation and Stopping or Not Starting Life-Sustaining Therapy

Among legal and ethically accepted options to hasten death, as seen in Quill (2018), in the United States, there are (a) palliative sedation (PS) and (b) stopping or not starting life-sustaining therapy. Discussing (a), PS is described by the intentional administration of sedatives, more often opiates, in a proportionate way, continuous or intermittent, to reduce conscious level of a dying person after standard palliative care measures. PS could gently progress toward a continuous deep sedation. Moving forward to (b), one interpretation of this exit option should be euthanasia.

#### 5. Palliative Sedation to Unconsciousness

Other last resource option is Palliative Sedation to Unconsciousness (PSU) that is legal but ethically controversial if the intention is to hasten death. When we talk about proportionate palliative sedation (PPS), the objective is to relieve suffering and medication

Continuous sedation until death at the patient's request is obviously different from palliative sedation

is used continuously in the minimum amount needed to achieve this, being progressively increased if needed. On the other hand, PSU implies an intended reduction in consciousness (Twycross, 2019) and is used when patients find symptoms intolerable or wants to be in control. Medication is installed in a dosage to achieve unresponsiveness and remains until patient's death. "Continuous sedation until death at the patient's request is obviously different from palliative sedation" (Serey, 2019). Interpreting Twycross (2019), as the patient is unconscious, he cannot

eat or drink by mouth, and this may lead to hasten death - biological life; also, PSU ends a person's ability to interact - biographical life. One may question what is the difference between PSU and euthanasia. According to Serey (2019), it is based on the sedative drug dosage and on prescriber's intentionality. It is still controversial in the literature if PSU indeed hasten death, as expressed by Serey (2019) multicentric study. Thus, PSU has several objections, since training programs for healthcare professionals, monitoring institutions, severe recommendations for choosing it, sharing responsibilities when it is time to initiate, and understanding it as normal or exceptional choice. Moreover, conscientious objection by organizations and practitioners should be considered.



## 6. Voluntarily Stopping Eating and Drinking

Voluntarily stopping eating and drinking (VSED) isn't illegal but is ethically controversial. Although controversial, VSED is a patient's choice and in the beginning of the process is under his control, so autonomy is respected. VSED usually takes one or two weeks to achieve death and involves medical and social challenges, as it unfolds. Besides disease suffering, patient also will get a plus. He'll become very thirsty and with no physician involvement, most of the times, through the dying process. When we talk about

Voluntarily stopping eating and drinking (VSED) is an option when physician-assisted death (PAD) is not morally acceptable or for patients who are not yet terminally ill

physician involvement in VSED, there are two points of view: one sustains that there aren't no ethical issues, as it understands managing VSED symptoms similar to standard palliative care when patient can decide to refuse hydration and nutrition; but the other view says "VSED is immoral because suicide is immoral" (Quill, 2018) thus assisting the act of suicide is both morally and legally wrong. One other question is: does a physician, that believes that suicide is morally wrong, have the obligation to care of patients who chose VSED? When capable patients "have a right to refuse not only medical interventions but also any bodily invasion" (Quill, 2018), including feeding and hydrating if the patient considers them harmful, this decision must be respected. Understanding VSED process, we could say that to relieve suffering, patient will undergo even more suffering in the name of legality, when physician assisted death is not an option.

On the other hand, from the beginning until death occurs, VSED permits more time to patient and family say goodbye, and this definitely helps in the grief. According to professor Quill (2018), "VSED is an option when PAD is not morally acceptable or for patients who are not yet terminally ill". Although, VSED has been neglected by the academy and got very little judicial attention.

## 7. Physician-Assisted Death (aka Medical Aid in Dying)

Physician-assisted death (PAD) or Medical aid in dying (MAID) is ethically controversial and legal only in a few US States. In the case of choosing PAD/MAID, patients obtain medication that is prescribed by their physicians for medical aid in dying. When we talk about PAD/MAID, we're being much more concerned with self-preservation than self-destruction. It is both physically and psychologically suffer that motivates patients to ask for PAD/MAID. When requesting life-ending medication, patient decision-making capacity and the ability to self-administer the medication is on the table. Recently, as written by Campbell (2018), an amendment to the Oregon Death with Dignity Act, authorized the patient to express his will on an advance directive and address a person, not necessarily a physician, to collect and administer the medication, in case he is no longer able to do so. Compared to VSED, PAD/MAID has an important role in academic discussion and legislative activity (Pope, 2017). Campbell (2018) questions if this "patient empowerment" would not transform the physician-patient relationship into a "retail" relationship. Instead of flexibilizing law, why don't we stimulate society to seek for a better



health-care, with less inequities, adequate and sufficient palliative care? One more time, conscientious objection makes presence in the discussion, even if claiming the moral conscience of healing professions.

## 8. Voluntary Active Euthanasia

We should discuss whether a person in opting to end his life is exercising rational agency or is blurred by suffering

Voluntary active euthanasia (VAE) is illegal in the US and also ethically controversial. The definition of VAE comprises the act of a physician (or third person) who intentionally ends a person's life through administering drugs, at that person's voluntary and competent request (Fontalis, 2018). Bioethicists claim that autonomy justifies a doctor giving a lethal injection to an informed and competent person who chooses to end his life due to an unbearable suffering. Therefore, we can discuss here the worth of a person and her life. As written by Kerstein (2019), "to say that the worth of a person is unconditional is to imply that she would have positive worth in every context in which she existed". And this worth doesn't diminish as this person loses her desire for life, as long as her personhood is maintained. Otherwise, this end-of-life intervention "contradicts the ethos of palliative care philosophy, at least insofar as palliative care neither hastens death or prolongs life" (Belanger, 2018). Also, we should discuss whether a person in opting to end his life is exercising rational agency or is blurred by suffering. The implications of hastening death should lead to question if it would be morally acceptable. Once more, literature says that palliative care providers struggle to conciliate the principles of palliative care with the exercise of patients' autonomy.

## 9. Issues of Concern

Each day, the use of advance directives (ADs) is increasing in the field of medicine. But there is a question related to the stability of the statements on the directives after persons who own it experience a life-event. A six-year cohort study questions not only if what is stated is stable but also if it is discussed and with whom. They found out that after a change in health status or experiencing a life-event, persons who own ADs did not change it or even became stronger in their beliefs (Wijmen, 2018). The same study reveals that regarding communication about ADs, most often they are discussed with their partners, children and last with their physician. Thus, it is an issue of concern.

Considering palliative care team, a frequent concern is whether they're acting rightly in helping ending a patient's life. If we think in a cartesian way, one could say that you just have to act according to the law to be understood as acting right. However, "uncritical use of guidelines can result in a 'onesize-fits-all' mentality" as wrote Twycross (2019). Another issue of concern is the training of the team that should involve not only technical aspects of the last resources options, but also consider legal, emotional and interdisciplinary support to those practitioners.



## 10. Conclusion

All the end-of-life options consider individuals at age 18 or more, autonomous, capable of deciding about their lives and terminally ill. Although we must bring to this discussion, that receiving some diagnosis, not only cancer, but other conditions, such as chronic kidney disease, chronic obstructive pulmonary disease, dementia, psychiatric diseases, heart failure and more, all this should sound like a death sentence to those patients. Should they have the right to be included in the criteria of eligibility to the last resources we discussed so far? Open and honest discussion about end-of-life exit options is highly recommended not only in the academic field, but also in the patient-physician relationship and among the patient loved ones.

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