

**UPDATE**

Euthanasia from the perspective of extended bioethics and clinics

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Abstract

Euthanasia is the act of intentionally ending a life quickly and painlessly, or omitting to prevent it, to alleviate suffering when death is understood as the greater good or the lesser evil. An extended clinical approach refers to the expansion of the object of clinical interest, which is concerned not only with the disease, but also and above all with the individual. This study analyzes euthanasia from the perspective of extended bioethics. To this end, we used an excerpt from the novel *Anne Prédaille* by French writer Henri Troyat, in which the main character causes the death of her mother, who suffers from a terminal illness, by applying a high dose of morphine. The literary fragment was intended to show euthanasia as a matter of subjects with unique interrelated life stories, and not as the aseptic passage from life to death. We concluded that bioethics must consider the life history of people involved in the process of euthanasia.

Keywords: Euthanasia. Bioethics. Clinical medicine. Medicine in literature.

Resumo**Eutanásia sob a perspectiva da bioética e clínica ampliada**

“Eutanásia” significa causar óbito rápido e indolor ou não o evitar, visando aliviar o sofrimento do paciente quando a morte é entendida como melhor bem ou menor mal. “Clínica ampliada” diz respeito à expansão do objeto de interesse clínico, ocupando-se não apenas da doença, mas também e sobretudo do sujeito singular. O objetivo deste trabalho é analisar a eutanásia a partir da bioética ampliada. Para isso, utilizou-se trecho do romance *Anne Prédaille*, do escritor francês Henri Troyat, no qual a personagem principal provoca a morte da mãe aplicando dose elevada de morfina. O fragmento mostra a eutanásia como questão de sujeitos com histórias de vida singulares que se inter-relacionam, e não como a passagem asséptica da vida para a morte. Concluiu-se que a bioética deve considerar a história das pessoas envolvidas no processo da eutanásia.

Palavras-chave: Eutanásia. Bioética. Medicina clínica. Medicina na literatura.

Resumen**La eutanasia desde la perspectiva de la bioética y la clínica ampliada**

“Eutanasia” es hacer que una persona muera rápidamente y sin dolor, o no evitarlo, con el fin de aliviar el sufrimiento, cuando la muerte se entiende como el mejor bien o el menor mal. “Clínica ampliada” se refiere a la expansión del objeto de interés de la clínica, que se ocupa no solo de la enfermedad, sino también y sobre todo del individuo. El objetivo de este trabajo es analizar la eutanasia desde una bioética ampliada. Para ello, se utilizó un extracto de la novela *Anne Prédaille* del escritor francés Henri Troyat, en la que el personaje principal provoca la muerte de la madre por la aplicación de una alta dosis de morfina. El fragmento muestra la eutanasia como una cuestión de sujetos con historias de vida únicas que se interrelacionan, y no como la transición aséptica de la vida a la muerte. Se llegó a la conclusión de que la bioética debe considerar la historia de la vida de las personas que participan en el proceso de eutanasia.

Palabras clave: Eutanasia. Bioética. Medicina clínica. Medicina en la literatura.

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Bioethics is a multi and interdisciplinary field of knowledge that studies human conduct in life sciences and healthcare, in the light of moral values and principles^{1,2}. Its interests encompass a wide range of events that take place from the beginning of human existence to its end. This article focuses on the end of life, more particularly, euthanasia.

In Simon Blackburn's *Oxford Dictionary of Philosophy*, the entry "euthanasia" appears as *the action of directly causing the quick and painless death of a person, or omitting to prevent it when the intervention was within the agent's powers*³. Oliveira and Baptista, in turn, define "euthanasia" as *the death caused by compassion, without any self-interest, at the request of a patient with intense physical suffering, with end-stage disease, but capable and conscious at the time of the request*⁴.

When discussing this subject, the question of its legalization in Belgium and the Netherlands after 2002 is usually brought up. But even in these countries the discussion is far from over. For instance, some pediatricians and groups of parents claim the same right for children under 12, who are currently prevented from requesting euthanasia. Others criticize the premise that death is the only way of alleviating unbearable suffering, as there are potent sedatives capable of also achieving this goal. For them, the practice of euthanasia would hinder the development of palliative care⁵.

This study aims to discuss euthanasia from the perspective of extended bioethics, in analogy to extended clinic, considering the life history, desires, affections, knowledge, and powers of the people involved in the process. For this purpose, we start from an excerpt from the novel *Anne Prédaille*, by French writer Henri Troyat⁶, in which the daughter of a terminally ill character ends her mother's suffering by causing her death.

The expanded clinic

The adjective appended to the word "clinic" refers to the extent of its object, means, and objectives. While traditional care focuses on the disease, the expanded clinic emphasizes the subject and context, without neglecting the disease. The expression was coined by Campos⁷, influenced by Basaglia, Sartre, and Gramsci, and concerns the subject's clinic.

From Basaglia, Campos⁷ assimilated the appreciation of the opinion of the sick person or at risk of becoming ill, his inclusion in the elaboration of

his therapeutic project, and the refusal to objectify and reduce the ill to a pathological case. From Sartre, he borrowed the concept of a person's responsibility for its decisions in life, being averse to the passive stance according to which someone else (the health professional) is the one who decides, alone, the future trajectory of the sick person. As such, the expanded clinic distances itself from the traditional clinic because it disallows the consented domination (Gramsci's concept), that is, the patient's passive agreement with the health professional, holder of knowledge and power. Thus, the consultation becomes a space for medical practice in the strict sense, as well as for agreement and negotiation.

The expanded clinics offers more room for the unpredictable and for singular demands that cannot simply be labeled into diseases. This requires tools that go beyond traditional anamnesis, physical examination, and pathophysiological reasoning. It is necessary to explore the subjects' life history, with a listening that is less selective and less directed while being more open and tolerant of the unexpected.

It is also necessary that professionals other than the physician and other theories besides biomedicine contribute to this idea, as well as team meetings, matrix support, and construction of unique therapeutic projects. The expanded clinic aims not only to prevent, treat and cure diseases, it intends not only to rehabilitate and promote the patient's health, but to allow people to choose and not be reduced to the disease that may accompany them. This proposal to reformulate and expand the clinic is part of a broader project called "the wheel method" or "paideia methodology," which focuses on co-management to understand and interfere with affections, knowledge, and power relations⁸.

Euthanasia in the novel *Anne Prédaille*

French writer Henri Troyat⁶ published *Anne Prédaille* in 1973, the same year that the Leeuwarden Court, in the Netherlands, found physician Truus Postma guilty, as she shortened her mother's life, with the help of her general practitioner husband, Andries Postma. A victim of a severe cerebral hemorrhage, with hearing loss, speech difficulties, and needing to be tied to a chair to keep from falling, she repeatedly pleaded with her daughter to stop living, finally being injected with 200 mg of morphine. At that time, euthanasia was prohibited in Holland, and theoretically, the physician would be sentenced to 12 years in prison. However, the

penalty was only symbolic⁹. The Postma's case had great repercussions in the press, and most likely induced Troyat to write the work that served as the basis for this discussion.

Henri Troyat is a pseudonym of Lev Aslanovitch Tarrasoff, who was born in Moscow in 1911 and emigrated to France due to the Bolshevik Revolution. He was a member of the French Academy of Letters and wrote more than 100 works. He died in 2007, at the age of 95. It is possible that living with his mother-in-law in a terminal phase also influenced him in the writing of *Anne Prédaille*^{6,10}.

The protagonist of the novel is a divorced woman who lives in the apartment of her parents, Pierre and Emilienne (Mily). It is up to her to take care of her mother, who has terminal cancer. Suffering is fought daily with doses of morphine:

Tears streamed from her wrinkled eyelids:

– *I'm in pain, Anne... I can't take it any longer...*

This miserable complaint hit Anne in the flesh. She didn't want to hear that anymore. Never!

– *Where are you in pain, mom?*

Emilienne did not answer and turned her head on the pillow, whining. A monster devoured her interior. Enough! Enough!... Determined, Anne approached the table where the medications were. Her hands were shaking. "It is now that I must act. If I take any longer, I won't be able to. She is suffering a lot. But what will I give her in return for this suffering? What do I know about the night I'm sending her to? My God, help me!... No, not God!... I just... Quick!" She took a morphine ampoule and sawed its end. Her fingers no longer had strength. The vial escaped her. Some of its contents spread out on the floor. She aspirated what was left. The liquid rose in the syringe. The water of death, clear, transparent. Another ampoule. The certain shattering. The needle was pumping the poison. The plunger forced into the tube. Anne's hand twitched. She was going to give up. Another ampoule. And another... Dr. Maurin said not to exceed the dose. This time the syringe was full. The plunger almost entirely out. No air bubbles. Everything was ready. Neither cotton nor alcohol. "Sorry, Mom!" This silent exclamation exploded in Anne's head and she found herself about to pass out, to empty the syringe into the sink, and forget everything. No. In a willing effort, she leaned over the bed. "Let's go! Now... now..." She murmured. She took Emilienne's arm and lifted it carefully. She was manipulating a skeleton. So dry, so light. Under her eyes, that ivory skin, withered and sweet, of which every inch was

more dear to her than her own skin. She planted the needle. The patient did not shiver. It was Anne who felt the sting. Deep in her heart. She bit her lip to keep from screaming. The syringe plunger expelled the liquid. But so slowly! The level did not finish dropping. She was going to go crazy. There were still a few drops left. Anne withdrew the needle with a dry gesture. Her legs were bending. She arranged Mily's head on the pillow, right in the center.

– *You gave me my injection, whispered Emilienne without opening her eyes again. Thank you, my dear...*

Anne came round herself and said in a weak voice:

– *Now, Mily, everything will be fine. You need to sleep.*

– *Well... So, that's it... You want me to sleep... But give me your hand... Hold on tight.*

Anne settled down, devastated, in the armchair, at the head of the bed, and took her mother's surrendering hand in her hands. At this point, it seemed that Mily smiled, with malice. As if she understood everything, as if she approved everything.

(...)

Suddenly awake, Anne lifted herself partially on the pillows. For two weeks she had been taken out of her sleep, every night, at the same time, by the same obsessive thought. For the hundredth time, she pierced Mily's arm. The needle in the skin. The endless drop of liquid in the syringe. To love a being is to try the impossible to avoid its pain. She was left to take on an atrocious responsibility herself. Now Mily's suffering was over, and hers was beginning. Not physical, but moral. And there was no drug to cure her. If she had had religious convictions, perhaps she would have quit. It is sweet the cowardice of believers who, at any time, resort to a rule to spare themselves the effort of decision and the torture of remorse¹¹.

Euthanasia from a traditional bioethics perspective

Mily's death, next to her daughter, at home and not in the hospital, corresponds to what Berlinguer¹² considered "dying well". From the etymological point of view, euthanasia corresponds to a good death: "eu," from the Greek, is equivalent to "good," "true," while "thanatos" means "death".

Anne suffers because she disobeyed one of the basic moral norms: “do not kill”¹³. She practiced what is known as “active euthanasia” – she deliberately acted to cause death with the intention of relieving suffering, as she thought death was the greater good, or the lesser evil, for her mother¹⁴. Her torment is undoubtedly moralistic since under this perspective she could not shorten Mily’s life and place her individual choices above a greater and general good, not subject to questioning^{13,15}.

Notions such as duty, obligation, and principles of conduct, present in Kantian morality, have produced, at least in part, feelings of uncertainty and remorse in Anne. The moral rule she disrespected by causing her mother’s death is part of a system of values considered correct by the society to which she belongs. According to Segre¹⁶, the preceding generations transfer to the current one a moral with obligations.

Anne Prédaille’s act can be analyzed under the principles of bioethics, present in the *Belmont Report*¹⁷ and in the book *Principles of biomedical ethics*, by Beauchamp and Childress¹⁸. Her attitude is considered ethically correct, given that she was consistent with her internal conflict, actively and autonomously deciding on the death of her mother¹⁴. According to Segre¹⁶, the ethics in Anne’s action is not in her obedience to rules, codes or principles, but in her ability to recognize the dilemma between the moral norm and the benefit of ending the suffering of the mother, to whom she had dedicated herself during the evolution of the incurable disease.

According to Emanuel¹⁹, both autonomy and beneficence are arguments in favor of euthanasia. The principle of beneficence precedes that of autonomy and was already present in the professional vow of physicians – also known as the Hippocratic oath, although it was not written by him, nor was it even part of the teachings of the schools in Kos or Cnidus; it probably predates Hippocrates, of Pythagorean origin^{20,21}. Through this vow, physicians swear to apply their knowledge for the sake of the patient according to their power and understanding, never to cause harm or hurt someone. In every home one will enter for the good of the sick, keeping itself away from any voluntary damage.

The Brazilian Code of Medical Ethics²² includes in its fundamental principles beneficence, non-maleficence, and autonomy. Regarding beneficence, it shows that the target of medical attention is the health of the human being, in

benefit of which the professional must act and use the best of scientific knowledge. Non-maleficence prevents the physician from using his knowledge to cause physical or moral suffering. Autonomy, on the other hand, is guaranteed both for the physician, who is released from exercising the profession if it contradicts the dictates of his conscience, and for the patient, who will make therapeutic choices as long as they are appropriate to the case and scientifically recognized.

If, on the one hand, Anne relied on her individual reflective decision-making ability, on the possibility of choosing to exercise her autonomy as a caregiver, on the other, she acted in a paternalistic manner, based essentially on beneficence, regardless of the mother’s explicit consent and the violation of a moral rule shared by both²³. Despite these paternalistic traits, the transcribed excerpt from Troyat’s⁶ novel also leaves the impression that the complicity that united the characters during the months of illness meant that the decision was not just the daughter’s. When Mily smiles after receiving the morphine, Anne realizes that her mother has approved of her attitude.

According to Segre¹⁶, the human being is culturally paternalistic, and beneficence precedes autonomy. This means that the desire to end the mother’s suffering precedes the ethical principle that justifies Anne’s act. For this author, purely academic differences, dependent on interpretations, separate doing no harm from doing good. For this reason, Segre¹⁶ disagrees with the criminalization of active euthanasia, while passive euthanasia (at the express request of the terminally ill patient) is considered non-maleficent.

Principlist bioethics, however, proves to be insufficient to understand the euthanasia practiced by the character Anne Prédaille as a matter of subjects with unique interrelated histories, and not only as an aseptic passage from life to death. This observation is added to several criticisms that principlism has been receiving, especially concerning the limits of its applicability, not constituting a theory of universal character compatible with the *moral diversity of contemporary societies*²⁴.

Euthanasia from the perspective of expanded bioethics

Expanding the bioethics as proposed by Campos⁷ to the clinical practice corresponds to consider euthanasia not as a conceptually separate

entity from the subjects involved in the process, but as a singular event, determined by the history and resources of each individual, family or social group. Besides the intentional end of biological life, even if ethical, euthanasia consists of a complex event that involves power relations, knowledge, feelings, affections, religious beliefs, and cultural values, both individual and of the society in which the subjects participate.

Therefore, expanded bioethics is not limited to recognizing two types of euthanasia, passive and active, but also interested in other topics, inviting patients and other subjects to participate in decisions about care and the death process, without avoiding the emotional, social, cultural, and economic challenges involved in this dynamic.

When approaching euthanasia from the perspective of expanded bioethics, what is often undervalued by the social environment, especially in the scientific world, is welcomed and valued: people's opinion. The subject's autonomy and ability to manage his own life and death are essential to this process. Space for negotiation is opened, removing sick and relatives from the condition of being dominated by consent. Therefore, this perspective comes close to Sartre's thought by preventing the patient from being just a spectator, offering him the possibility of thinking and deciding, of making joint choices, even if that brings him some anguish, especially if he violates moral rules.

In Anne Prédaille's case, expanding bioethics would mean listening to her story, particularly alongside her mother, valuing her unique look at suffering and death, making room for her moral fears and dilemmas, without being restricted to the biological challenges of the end of life nor avoid the complexity of the process of becoming ill and dying. For Anne, to end Mily's life was to end an intimate relationship between mother and daughter, narrowed with the arrival of the malignant and incurable disease, responsible for atrocious physical and emotional suffering, which implied the need to build a future without the mother.

In conversations between health professionals, the ill, or family members, relevant issues could emerge from attentive listening to the free narrative. Their stories break the centrality of the biomedical model in the discourse of the disease and allow the subjects to give meaning to life and suffering, thus reducing their dependence on biomedicine and increasing their role and autonomy²⁵. It is under this perspective, expanded

by the previous knowledge of elements of Anne's story, that her attitude can be understood and analyzed from an ethical point of view.

The expanded clinic and bioethics advance beyond what reason and conscience allow us to see, including in their practice concepts of psychoanalytic theory²⁶. In other words, they consider the personal conflicts present in each individual's unconscious as the determinants of their actions.

Troyat's text reveals elements of Anne's unconscious that can be considered when approaching her, both from a clinical and ethical point of view: *This miserable complaint hit Anne in the flesh (...) It was Anne who felt the sting (...) she had been taken out of her sleep, every night, at the same time, by the same obsessive thought*¹¹. Such passages express the great suffering of the character, as well as the persistence of a thought strong enough to wake her up every night, and these are the subliminal elements that the expanded approach avoids neglecting.

People's relationship to death has changed throughout history. Until the end of the Modern Age, life and death coexisted in the domestic and family environment, but from the 19th century onwards, deaths began to happen in hospitals, handed to the cold rationality of health professionals²⁷. Expanded bioethics, which values the narrative of patients, proves to be powerful in dealing with current issues related to the end of life, such as euthanasia, palliative care, and advance directives.

Final considerations

The analysis of euthanasia from the fragment of Troyat's⁶ novel reveals that this procedure is complex and singular, involving not only the person who dies, but also family members, friends, and caregivers. Furthermore, it is not limited to the moment of death itself, as it encompasses different aspects of individuals, before and after the fatal event. In the same way that expanded clinic uses the subjects' history to develop unique therapeutic projects that allow them to continue making choices and managing their own lives, even if they are affected by illness, expanded bioethics considers the narrative of the people involved in the euthanasia process and is more consistent with the complexity of human existence.


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