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RESEARCH ARTICLE

PHILOSOPHICAL AND ETHICAL ISSUES OF SEDATION IN THE TERMINAL PHASE OF DISEASE: A RETURN TO EXISTENTIAL QUESTIONS

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ABSTRACT

Sedation in the terminal phase of disease or outside any progressive pathology leads us today to rethink the paradigm of life, existence and destiny. This paper addresses the philosophical issue of the "desire to live" and the "un-willingness to live". For any person – sick or not – who has no belief in "another" life, or in a superior being who is the master of their life, is it legitimate to force them to wait for their "death"? Should doctors or their relatives decide on their "life" and "death" by keeping them "alive" for the inevitable outcome? The current debate seems to make doctors and relatives of terminally ill patients feel guilty, accusing them of "deliberate-murder"; the State itself, by refusing to legalize euthanasia through sedation is accused of "moral-torture". Among practitioners, the debate is no less heated and the arguments put forward on both sides – whether for terminal sedation or for the rejection of a form of "assisted suicide" – are shaking the philosophers in their reflection more than we think. Arguments such as "accomplished life" and "life fatigue" are increasingly raised and could justify the free choice of euthanasia by elderly people, or those tired of living! The aim of this article is threefold to1. lay the foundations of the contemporary debate on the progress of medicine in the management of physical and psychological pain/suffering; 2. help relatives in their duty to assist; and finally, 3. provide practitioners with benchmarks and points of reference, respecting the Hippocratic Oath, and their duties as humanists.

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INTRODUCTION

In recent years, physicians and bioethicists have come to regard palliative sedation (PS) as "the search – by drug means – for a reduction in awareness that may even lead to unconsciousness, with the aim of reducing or eliminating the perception of a situation experienced as unbearable by the patient, whereas all available and adapted means have been proposed and implemented without allowing the patient to obtain the relief expected" (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016; Salins *et al.,* 2018). The issue at stake here is the philosophical question of the "end of life" and the "choice of the end of life", if for so many individuals "living is knowing how to die"! (See the Recommendations of the High Authority of Health 2009). For some wise people, "true philosophers learn how to die, and they are, of all men, those who are least afraid of death... Dying is not dying, my friends, it is changing. Life is a fight and my death is the victory. And this happy death, so feared by the weak is only a birth to immortality." (Plato 428 AC - 348 AC.); "Sometimes, it's the fear of death that pushes people to death" (Epicurus: 342 AC - 270 AC); "Death does not frighten me. What frightens me is the suffering of the fact that I have had it too much in my lifetime". Therefore, for many, death does not frighten them, but the fact of dying (Douglas *et al.,* 2008). It is clear that PS can be applied intermittently, transiently or continuously. The term "palliative terminal sedation" refers to sedation in the last days or weeks of life, without the intention of causing death, even if the products used may indirectly result in a faster death (but within a timeframe that cannot be accurately measured) (Douglas *et al.,* 2008). However, the current debate seems to focus only on the essential ethical issue of "dying well"; How do we rethink the issue of "dying well" as a "good ending" of one's life, based on the proposals of death clinics with evocative names: *Exit, Dignitas, Libertas (i.e. Exit, Dignity, Liberty)...*Shouldn't the current well-mastered PS techniques make it possible to rethink another end-of-life wisdom that is not considered by those who are "tired of living" as a "cowardice" or "medicalized suicide"; and by (ordering or performing PS) doctors as a "slow euthanasia?" (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016). The argument of the dual effect act is not taken into account in the case of "deep and continuous sedation" because the intention would be clearly defined. Therefore,

terminological clarifications are needed in order to better understand the respective arguments of both sides.

Conceptual Definitions

Palliative sedation (from Latin: *sedatio*): "Use of mainly medicinal means to calm the patient in order to ensure their physical and psychological comfort while facilitating care" (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016; Salins *et al.,* 2018). In other words, it is the administration of sedative substances at the minimum doses necessary to reduce intentionally the level of consciousness permanently or temporarily in a terminally ill patient (Claude Obadia, 2016). The aim is to calm the patient, and to establish a certain comfort for the patient and their environment to help them relieve their physical and psychological pain.

Deep Sedation: Drowsiness leading to a complete loss of consciousness induced by drugs. "Deep sedation" is the induction of a complete loss of consciousness through the use of chemical substances (Claude Obadia, 2016).

Deep and continuous sedation until death: The Leonetti law in force in France allows doctors, after informing the patient or relatives, to stop all treatment of the patient and to use sedation techniques – "palliative care" – until the patient's death. In other words, the law shall specify that doctors have the right to really put the patient in a coma and stop their treatments until their death. This measure addresses problems such as the lack of palliative care in some hospitals, or the persistence of pain in some cases despite mild sedation. Deep and continuous sedation until death is associated with analgesia. The objective is to relieve a sick person who presents a situation of suffering considered as unbearable when death is imminent and inevitable (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016).

Dysthanasia: This refers to someone who "dies a slow death" (from the Greek *dus-thanatos*). A "slow and painful death marked by long agony", says (Med. Biol. t. 1 1970). Based on the analysis of medical practices, bioethicists in a more recent context have coined the term "futile medical care" to refer to the aggressive use of heavy means, disproportionate to the expected benefits; and technical means or products tiring the patient more and unnecessarily prolonging their agony, while the outcome of their illness is unavoidable. The actual issue at stake is raised here: these are no longer terminally ill people, but people who believe that since the end of life is "death" it might be anticipated if one no longer expects anything from life in this world. For them, continuing to live and increasing pollution by carbon emissions is equivalent to dysthanasia (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016)!

Euthanasia: "An act of a doctor causing the death of an incurable patient to shorten their suffering or agony, which is illegal in most countries"; it's the "use of procedures that make it possible to hasten or cause the death of incurable patients who suffer and wish to die". Euthanasia, from the ancient Greek "eu" (good) and "thanatos" (death), refers to the medical act of intentionally causing the death of a patient in order to relieve their physical or moral suffering considered unbearable, either by acting for this purpose or by abstaining from acting. Euthanasia must finally be distinguished from "physician-assisted suicide" which consists for the medical professionals to give the patient the means to put an end to his or her own life (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016; Salins *et al.,* 2018; Claude Obadia, 2016).

Life fatigue and the right not to live

Living requires energy from the one who wants to live. This is much more psychological energy (the mind) than physical energy. When one declares a "life fatigue", is it a symptom of a depression or a philosophical choice not to give oneself any more energy, and not to give oneself a reason to live? Do we have the right to choose not to live anymore? (See the Recommendations of the High Authority of Health 2009; Haute Autorité de santé (HAS) Décembre 2016; Salins *et al.,* 2018; Claude Obadia, 2016).

Philosophical aspect of the joy and the desire to live

When you are young and the future seems promising and you develop projects, there is joy in living; happiness is visible through the enthusiasm with which you do everything; appreciating life as you live it (with its ups and downs) allows you to be optimistic at all times. In philosophy, it is said that the joy of living is a way of embracing life with confidence, a feeling close to bliss as professed by the Greek philosopher Epicurus, who taught the art of caring for what creates happiness (See the Recommendations of the High Authority of Health 2009). Epicurus declares in the first lines of the Letter to Menoeceus that philosophy brings health to the soul, and that we must therefore philosophize, whether we are young or old, and always have a concern for what produces happiness. Philosophy is a therapy of the soul, and therefore a practice, a continuous exercise for happiness, the supreme end of philosophical activity" (See the Recommendations of the High Authority of Health 2009). However, the joy of living is more humble, more accessible, more compatible with the inevitable hazards of life, than happiness, and more lasting than the possession of well-being, because it can be tasted at the very heart of suffering. What can thwart the joy of living are not the trials, but only the despair inherent in being, the sorrows, worry, jealousy, hatred and anger (See the Recommendations of the High Authority of Health 2009). When old age and disappointments come, when life seems to have been a constant failure, when there are no more projects to build, the perspective may change, and bitterness therefore replaces the joy of living. The desire to marvel at the little things in life may fade. We live in modern societies that are increasingly depressed, due to lifestyles, stress patterns of all kinds; the ambient individualism and materialism make us lose both the sense of the person and the meaning of life in society. Basically, the joy of living results first of all from an acquiescence to existence and to reality as it is. It implies the acceptance of the world and oneself as they present themselves, without refusal, without revolt and without bitterness. It is an intimate feeling, an inner openness, a conviction that life can win on any occasion, and it is accompanied by trust, detachment and even lightness.

Aspect of the meaning of life and the human person in African cultures

In African cultures, the anthropological and metaphysical terms used to designate the human person and their life show

the great respect Africans have for the mystery of the human person, their destiny and fate.

Respect for life and the requirements to preserve life

Africans love life and love to celebrate life; even funerals in African traditions are a celebration of life. That is why everything contradicting this life and this joy of living is the consequence of a disharmony with nature, or with the worship due to ancestors. Among the Moose of Burkina Faso, a disease and death never occurs in a population or in an individual by chance. For them, there are always implicit, intangible (supernatural) or explicit, tangible (natural) causes. The illness and death that follows may be the consequence of: an offence against the Supreme Being, the one and Almighty God, named *"Wende"* due to irresponsible and inadequate behaviour; offences committed against the protective spirits, *"Kinkirsi"* living in the mountains, rivers, trees, soil, and fetishes; non-compliance with the customs or *"Kùdemde"* instituted in the course of time by the ancestors to regulate the social life of the lineage; in addition, according to the norms bequeathed by the ancestors, persons publicly recognized as witches, and therefore vitiated were eliminated, excluded or banished forever from the great family. Certainly, the Moose used to kill babies with serious malformations and twins because they believed these individuals were not human beings but evil spirits who could bring disease, misfortune or any other harm to the social fabric. Any king who seriously violated the inalienable norms of society was forced to commit suicide for the same reason. Apart from these pathetic cases, the Moose respect and support children, the elderly and the sick (See the Recommendations of the High Authority of Health 2009). The same is true in other African cultures.

The African paradigm of the meaning of life: In Africa, the practice of these forms of euthanasia is inspired by the extraordinary cultural diversity that suggests an almost absolute cultural relativity (See the Recommendations of the High Authority of Health 2009). However, a rigorous ontogenetic approach to African cultures helps us to identify a set of meta-forms (the form of various forms) and meta-standards (the standard of standards) that structure and guide the actions of the different cultural communities. Thus, Africa also has its paradigm of the meaning and value of life, and from there, its paradigm of the end of life, accompanied or caused. The specificity of the forms of euthanasia in Africa lies fundamentally in its cultural, religious and traditional dimension; which, according to customs, justifies, if necessary, the sacrifice of the individual for the survival of the group and the sustainability of the institutions. The advent of euthanasia at the heart of traditional African cultures – according to Marcel KOUASSI – is not the corollary of a structural or formal failure. Orality does not generate euthanasia any more than any other cultural form. The appearance of original euthanasia is attributable to the cultural meta-standard that idealizes the group, the community, to the detriment of the individual, the singular. Based on the meta-standard, freedom and happiness are first collective before they are individual. In the process of developing the well-being or the protection of life, Africans first gave primacy to the social fabric, to the community and not to the individual. That is why, sociologically, there is an omnipresence of African solidarity and, ideologically, an almost natural inclination towards "socialism". The cohesion of the social fabric is so strong that the individual can only really live if he or she is part of the social mould. It is as if society can survive the loss of its members. In this implicit dialectic of the whole and the part, the latter is subordinate to the former. The part is always a negligible quantity and can be actively neglected or sacrificed. "A Legend has it that Queen Abla Pokou, Queen of the Baoulé tribe (ethnic group in Côte d'Ivoire), sacrificed the part (her son) for the survival of her people, *Ba-ou-lé* (the child died) (See the Recommendations of the High Authority of Health 2009). In Africa, therefore, the community's happy living conditions are actually a kind of normalization and strengthening of the social fabric. In this perspective, the individual comes in second position, far behind the overwhelming and pervasive omnipresence of the community, which must be in solidarity. Therefore, the subject's life only makes sense if it is subordinated to the demands or even the whims of the group. In the African cultural context, there is a latent illusion: whoever preserves the social balance inevitably saves individual lives, thus contributing to their well-being. It should be noted, however, that this primitive assumption, which denies the individual, is not conscious of the fact that the one who saves an (individual) life saves humanity in its most essential sense. In the African meta-standard lies the possibility of denying the individual in the name of the so-called highest interest of the group. It is this negationist attitude of the individual that is transformed into a reflex in the form of passive and involuntary euthanasia. Sometimes in serious situations, one may choose *"death rather than dishonor"!* A saying in the culture of the Moose goes as follows: "*Kûum saon yande!"* It simply means that for the honor of the family, the clan, the tribe or what the person himself represents, deciding to die is essential in some situations! If the person concerned does not decide in a burst of dignity to do so, the social group will protect itself from stigma by eliminating that person using poison (See the Recommendations of the High Authority of Health 2009). This helps us know what is experienced in African religions in terms of the desire to die or unwillingness to live in this world. For he who leaves this life to avoid shame paradoxically preserves his dignity; it will be said of him: "He is a man of his word, he is a worthy son of his father; he has "washed" the shame that was weighing on his family! "He who, on the contrary, persists in surviving the opprobrium, is considered as an "undead"; he is not spoken to and cannot frequent public places!

Ethical reflection on the value of life

The concept of the personal value of life

The value of each person's life is what the person has set itself to achieve as an ideal of life. This ideal is based on the values of social life that the person has acquired through education and socialization; he or she then assumes these human values, which can be listed as follows: respect, acceptance, consideration, appreciation, fraternity, affection and love towards other human beings. The ethics of virtues and the morals of this or that belief help to safeguard these values, and give meaning and purpose to individual and social life. The African who enters the adult world through the rites of initiation, becomes aware of the value of his personal life as a collective good; the trials of the rites of initiation test his ability to face all life situations; and as in the Charter of the Mandé, he learns that life is sacred: "Everyone has the right to life and to the preservation of his physical integrity. Consequently, any attempt to take the life of one's neighbor is

punishable by the death penalty. "The African learns, as an adult, that he can or must "sacrifice" his life for noble causes, such as the defense of his family or his country! His life "belongs" in a way to his own, to his community of life! The clan and the tribe also guarantee him the right to life and the freedom to carry out his activities, while preserving his dignity from any offence. If someone from outside disrespects a member of the community, the whole community carries the offence, and this can even lead to tribal wars.

The concept of the social value of life

If we stick to Emmanuel Kant's categorical imperative, the value of a life cannot be measured based on what a person achieves or has achieved in his or her life. "But a person is not a thing; therefore, he or she is not an object that can be treated simply as a means; but he or she must always and in all his or her actions be considered as an end in itself" (See the Recommendations of the High Authority of Health 2009). The person therefore has his or her end in himself or herself; he or she cannot be used as a means, or as an object. And one should not assess one's dignity according to one's degree of usefulness. But when the person himself or herself decides that he or she has contributed enough to the advancement of science, culture and the development of the world and considers that he or she has "accomplished his/her life" (See the Recommendations of the High Authority of Health 2009)., what can other citizens say, without giving the impression that he or she is still "useful" as a "means" from which one could still "benefit"?

The concept of the end-of-life management in African cultures

The concerns of Africans for their sick relatives reflects the meaning they give to life they consider as something "entrusted" or "lent" by a Superior Being; Life does not belong to human beings; it is the property of God and is under the care of ancestors. When the time of giving back what was lent arrives, humans only have to submit!

Even when a patient is terminally ill, relatives and friends can sometimes hold long conversations with him or her, face to face, breath for breath, providing intimate care with their bare hands! The repulsive aspect of certain affections, the pestilential smells cannot hinder their sense of solidarity and devotion! For them, it is always necessary to watch over and treat the sick because, as the saying goes: *"Wênd pa ku, Naab pa kùud ye!"* i.e., if God does not kill the sick, the king or doctor cannot kill him. This justifies the endless visits to relatives who often suffer from the most serious infectious diseases. Solidarity is expressed by the commitment to seek remedies everywhere and by all means, in the form of plants, talismans or *gris-gris*, or in the form of exorcism of any kind! Relatives do not hesitate to travel long distances, or to spend large sums of money for someone who is already clinically incurable and condemned! In the patients' rooms it is common to see men or women who sit behind the patient, wedging him/her between their legs and pressing him/her against their chest to relieve him/her, to better feed or water him/her; just as they would do for a childbirth, for the rite of circumcision, or other rites of initiation (See the Recommendations of the High Authority of Health 2009). In the typical case of an old man from the *"Nyo-noaga"* caste who is dying, an old seated woman will hold him down and sing the glory of his ancestors as follows:

"Do not be afraid; enter into the glory of your ancestors. They were neither afraid of fire nor water. Ancestor Nanema, your fathers' father was a hero. As he was a storm anda hurricane, he could appear and disappear before his enemies and defeat them. He never accepted shame. His motto was "death rather than dishonor". Worthy son of Nanema, you are an authentic nyoa-nyoaga. Then fight the fight of life. For you, going to your ancestors is not dying; it is a way to experience an even more intense life. Go, go, go, go... »[11,]. As the patient dies, this woman will lower her voice. And at the end, she will close his eyes. The old man is not afraid of death; he faces it in agony (in a fight) and experiences his death as a passage, a departure, a journey to join the ancestors.

This African approach to end-of-life management – which is so rich for science in its psychosomatic dimension, and for humanism in its almost naive generosity in caring for terminally ill patients – coupled with the progress of modern medicine in pain management and psychological support, would open up new avenues for palliative care for patients at the end of their lives. The risks taken in caring for contagious patients until their death reflect the desire to show them their intrinsic dignity, their belonging to the group, despite their total dependence, and to preserve in them the desire to live. However, as in the case of Ebola infections, some of these non-hygienic solidarity practices that threaten the survival of all the populations shall be banned. Consideration should also be given to the excessive costs of medical examinations, tests and prescriptions in most African countries, without basic medical insurance, in order to avoid falling into a form of aggressive therapy. This involves the use of expensive and disproportionate resources in relation to the financial precariousness of families or the health conditions of the countries. Medical practitioners should take these aspects into account to avoid prolonging the agony of terminally ill patients unnecessarily, and avoid overburdening families with inappropriate expenses.

Conclusion

The psychosomatic dimension of the African approach to end-of-life management, combined with advances in current medicine, certainly opens up new types of palliative care approaches for patients with life disgust syndrome. Indeed, we can see that medical and pharmaceutical research nowadays makes it possible to control even the most atrocious and recurrent pains; Based on the progress in this field, the first argument built around "compassion and pity" and used in the past to call for the legalization of euthanasia is no longer relevant. The argument of "dignity to be preserved" is also no longer relevant, since people without any physical pathology desire to "die"; they are aware of what they are asking for; it is even a condition for obtaining their right to die in certain countries, by starvation and dehydration! [39]. The last argument of "death as a right" seems to be gaining philosophical and ethical weight today: what is the meaning and purpose of my life? If I feel that I have achieved the purpose of my life and if my life belongs to me, then I am responsible for its end and the quality of its end as well. Wisdom could concede it provided courage is to face unavoidable death, and show it does not have the last word!

Recent news focused on two emblematic cases: the "suicide" of a 17-year-old Dutch girl named Noa Pothoven [39], and the tragic death of Vincent Lambert, a French citizen. The pathetic case of the girl is totally different from the politicized, mediated and judicialized living conditions of Vincent Lambert, a quadriplegic patient who lived in a vegetative state for more than ten years and who, at the end, died on 11 July 2019, following the cessation of his treatments. Vincent Lambert was not able to express his desire to live or die, but people decided in his place by interrupting his diet and hydration (See the Recommendations of the High Authority of Health 2009). When we review the national and international judicial soap opera around Vincent Lambert's end of life and the tearing in his own family, we are entitled to ask ourselves many questions about the real conditions for accompanying patients at the end of life. As for the Dutch teenager, she deliberately let herself die of hunger and thirst because she no longer wanted to live. She was refused assisted suicide in specialized clinics because she was still a minor. Her death "was associated with severe psychological suffering following sexual abuse at 11 and 12 years of age and double rape at 14 years of age". She was not a terminally ill cancer patient who could no longer tolerate physical pain, but a dynamic teenager who had suffered "a fate worse than death", traumas when she was just a child, and whose depression had finally led her to refuse life itself. By also considering the suffering of the relatives of the adolescent who refused to "live" or "survive", one wonders about the limits of our duty of humanity towards those who no longer have a "taste for life". What ethics of life should be used to oppose this "right to no longer live? (See the Recommendations of the High Authority of Health 2009)"

What ethic of freedom should we oppose this "disgust of life" because of what it causes?

If life is beautiful, it must be beautiful to the end, and open us to another life to which we aspire with all our strength! Death is not a dead end for mankind!

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