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Between Euthanasia and Dysthanasia: The Ethical Issue of Sedation in the Terminal Phase of Illness

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Abstract

Background: Deep sedation, euthanasia and therapeutic relentlessness lead us today to rethink the paradigm of life and the contingency of human existence. Between therapeutic relentlessness, the unreasonable care which uses heavy therapeutic means which are often disproportionate to the expected benefit, namely keeping alive a patient whose condition is considered medically hopeless; and euthanasia which would precipitate the process of death would be sedation in the terminal phase of the illness. Should doctors and families of comatose patients decide the "life" and "death" of their patients? For anti-euthanasia associations, doctors, relatives of terminally ill patients and the State itself, if they accept the principle of euthanasia, they are "murderers", while for pro-euthanasists, the dignity of the human being would recommend that the days of patients in situations considered critical be shortened, to avoid unnecessary suffering and humiliation. **Methods:** A systematic review of the literature was carried out to identify relevant articles relating to euthanasia, dysthanasia and sedation in the terminal phase of illness. The search was conducted in French or English in three databases: PubMed, Google Scholar and Science Direct. **Objectives**: The objectives of this article are: 1) define the terminologies and concepts of palliative sedation, deep sedation, deep and continuous sedation until death, euthanasia and dysthanasia; 2) present aspects of the meaning of life and the human person in African cultures; and 3) propose an ethical reflection on the value of life. **Results:** After precisely defining the concepts of euthanasia, dysthanasia and sedation, this research presented the African anthropological and ethical approach to the mysteries of life and death. **Conclusion:** With this in mind, the golden rule of medicine always remains as such "*Primum non nocere*".

Keywords

Euthanasia, Dysthanasia, End-Of-Life Sedation, Palliative Care, African Cultures

1. Introduction

In palliative care, continuous deep sedation until death (CDSUD) is an important therapy of last resort [1] [2]. However, this practice remains clinically and ethically controversial, particularly because of its irreversibility and undeniable lack of proportionality [3]. Numerous international comparative studies show that CDSUD is influenced by the culture, mores, and anthropology of the country where it is practiced, particularly by legal and social contexts [1]. In addition, the practice of CDSUD by doctors also depends not only on their country but also on their culture, education and beliefs [4]. Today, however, assisted dying practices, which include euthanasia and physician-assisted suicide (PAS), have grown considerably worldwide over the past 20 years. Euthanasia refers to the act of intentionally ending a patient's life by a healthcare practitioner through medical means at that patient's explicit request, while PAS involves the provision or prescription of medication by a healthcare practitioner so that a patient can end his or her life [5]. Thus, as the world's population continues to age and the prevalence of chronic diseases such as cancer and cardiovascular disease, which are the main causes of death, increases, end-of-life issues will become increasingly important, leading to relevant social and legislative debates. Indeed, in developed countries, these illnesses can have a long and debilitating course, made all the more difficult by the use of medical and technological interventions that can prolong life and lead to long-term suffering [6]. The experience of pain, suffering, and associated functional and cognitive decline, as well as the associated loss of dignity and autonomy, lead some people to desire premature death [7]. In addition, growing societal debates about patient autonomy, quality of life, and what constitutes a "good death" are also influencing awareness of and support for euthanasia laws in a growing number of countries. In the West, many countries such as the Netherlands, Belgium, Luxembourg, Italy, Germany, Spain, Austria, Portugal, and France have authorized active or passive euthanasia. In the Americas and Australia, countries such as Colombia, Canada, Australia, and some US states have also adopted active or passive euthanasia. While some European countries (e.g. Bulgaria, Poland, Ireland, Romania, etc.), African and Asian states prohibit it [5]. The aim of this article was threefold: 1) to define the following terminologies and concepts: palliative sedation, deep sedation, continuous deep sedation until death, euthanasia, and dysthanasia; 2) to present aspects of the meaning of life and the human person in African cultures; and 3) to propose an ethical reflection on the value of life. Clarification of terminology is therefore needed to better understand the respective arguments of the two parties.

2. Conceptual Definitions

2.1. Palliative Sedation (From Latin: Sedatio)

"Medical means are used above all to calm the patient, to ensure his physical and mental health and, at the same time, to facilitate his care *[8]*. In other words, it involves administering the smallest amount of sedative necessary to permanently or temporarily reduce the level of consciousness of a terminally ill patient [9]. The aim of sedation is to calm the patient, and to establish a degree of comfort for the patient and his or her environment; it also helps to relieve anxiety and physical and psychological pain.

2.2. Deep Sedation

Deep sedation is defined as a depressed state of consciousness in which patients are not easily aroused but will respond deliberately to verbal or painful stimulation [10]. In this light, deep sedation would be drowsiness leading to drug-induced total loss of consciousness. Deep sedation is the induction of total loss of consciousness through the use of chemical substances [8].

2.3. Deep and Continuous Sedation until Death

Sedation in the terminal stages of life is the use of sedative drugs to reduce the patient's level of consciousness and provide comfort until death. In terminal sedation, the intention is to alleviate intolerable suffering by using sedative drugs to control symptoms and relieve suffering. France's current Leonetti law allows doctors, after informing the patient or his or her next of kin, to stop all treatment of the patient and use sedation techniques—"Palliative care", until the patient's death. In other words, the law will specify that doctors have the right to put the patient into a coma and stop treatment until death. This measure responds to problems such as the lack of palliative care in some hospitals, or the persistence of pain in some cases despite light sedation. Deep and continuous sedation until death is combined with analgesia. The aim is to relieve a patient who presents a situation of suffering considered unbearable, even though death is imminent and inevitable [8] [11] [12].

2.4. Dysthanasia

The rapid development of modern technology in all scientific fields, including clinical medicine, has intensified efforts to prolong the life of healthy people, as well as those suffering from serious or terminal illness [13]. Dysthanasia (from Greek: dys, difficult; and thanatos—death; meaning "to die with difficulty") is a relatively new concept developed within bioethics, and refers to the application of medical procedures designed to maintain life at all costs, even when the disease is not curable, and the medical procedures often prolong the patient's pain and suffering. Dysthanasia is associated with futile treatment and persistence through treatment, which does not benefit a patient but prolongs the dying process and not the patient's life [14]. Consequently, dysthanasia is more fre-

quently studied and discussed in scientific and professional literature. In high-tech hospitals around the world, dysthanasia procedures are becoming commonplace and are practiced when doctors, nurses, and other healthcare providers are pressured by patients' families to do everything in their power to keep patients alive [13].

2.5. Euthanasia

The intention in the practice of euthanasia is to kill the patient by administering a lethal drug, and the positive result is immediate death [11]. Thus, euthanasia would be a medical act that causes the death of an incurable patient to shorten his suffering or agony, which is illegal in most countries [11] [15] [16]. It is "the use of procedures to hasten or bring about the death of incurable patients who are suffering and wish to die". Euthanasia, from the ancient Greek "eu" (good) and "thanatos" (death), refers to the medical act of intentionally provoking a patient's death to relieve physical or moral suffering deemed unbearable, either by acting for that intention or by refraining from acting. Lastly, euthanasia must be distinguished from "assisted suicide", which consists of healthcare professionals providing patients with the means to end their own lives [14].

3. Aspects 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 his or her life testify to the great respect Africans have for the mystery of the human person, his or her destiny and fate.

3.1. Respect for Life and Life Preservation Requirements

Africans love life and love to celebrate life; even funerals in African traditions celebrate life. This is why anything that contradicts this life and joy of living is the consequence of disharmony with nature or with the worship of ancestors. Among the Original Burkina Faso people, illness and death never occur in a population or an individual by chance. For them, there are always implicit, intangible (supernatural) or explicit, tangible (natural) causes [17]. Sickness and subsequent death can be the consequence of offenses against the Supreme Being, the One and Only Almighty God, called "*Wende or Wennaam*", *due to* irresponsible and inappropriate behavior; offenses committed against the protective spirits, the "*Kinkirsi*" living in the mountains, rivers, trees, earth, and fetishes; non-respect of customs or "*Kùdemdé*" instituted over time by the ancestors to regulate the social life of the lineage; moreover, according to the norms bequeathed by the ancestors, people publicly recognized as witches, and therefore vitiated, were eliminated, excluded or banished forever from the extended family [17] [18]. Certainly, the ancestors used to kill severely malformed babies and twins because they believed that these individuals were not human beings but evil spirits likely to bring disease, misfortune, or other damage to the social fa-

bric. 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" respects and supports children, the elderly, and the sick [19].

3.2. Respect for Life in Mali's Mandingo Empire

In the aftermath of the historic battle of Kirina in 1235, which ended with Soundiata Keïta's victory over King Soumaouro Kanté, he was summoned in 1236 [20] to a major meeting of the twenty ethnic groups that had taken part in the battle. The aim was to lay the foundations for a new political, social, cultural, and economic order, to preserve and defend the individual and collective life that the war had damaged. Article 5 of the Charter states: "*Everyone has the right to life and to the preservation of his physical integrity. Consequently, any act which attempts to take the life of another shall be punishable by death*". In Articles 40 and 41, the Charter also speaks of the preservation of nature: "*The bush is our most precious asset, and everyone has a duty to protect and preserve it for the happiness of all*" (*Article* 40). *Before setting fire to the bush, do not look at the ground, raise your head in the direction of the tops of the trees that bear flowers and fruit*" (*Article* 41) [21] [22].

3.3. The African Paradigm of the Meaning of Life

In Africa, the practice of euthanasia is inspired by the extraordinary cultural diversity that suggests an almost absolute cultural relativity [23]. However, a rigorous ontogenetic approach to African cultures enables 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 different cultural communities. Thus, Africa also has its paradigm of the meaning and value of life, and hence its paradigm of the end of life, whether accompanied or provoked. The specificity of euthanasia in Africa lies fundamentally in its cultural, religious, and traditional dimensions, which, according to custom, justifies, where appropriate, the sacrifice of the individual for the survival of the group and the continuity of 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 the original euthanasia is attributable to the cultural meta-standard, which idealizes the group, the community, to the detriment of the individual, the singular. According to the meta-standard, freedom, and happiness are first and foremost collective before the individual. In the process of developing well-being or protecting life, Africans have first and foremost given primacy to the social fabric, to the community, and not to the individual. This is why, on a sociological level, 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 individuals can only really live if they fit into the social mold. It's as if society could survive the loss of its members. In this

implicit dialectic of whole and part, the latter is subordinate to the former. The part always remains a negligible quantity, actually or actively neglected. "A legend has it that Queen Abla Pokou, Queen of the Baoulé tribe (an ethnic group in Côte d'Ivoire), sacrificed the part (her son) for the survival of her people, the "*Ba-ou-lé*" (the child died) [24].

In Africa, happy living conditions in the community are a kind of normalization and reinforcement of the social fabric. From this perspective, the individual comes in second place, far behind the overwhelming and omnipresent presence of the community, which must be supportive. Therefore, the individual's life has no meaning unless it is subordinated to the group's demands, or even the whims. In the African cultural context, there is a latent illusion that preserving social equilibrium inevitably saves individual lives, thereby contributing to their well-being. It should be noted, however, that this primitive assumption, which denies the individual, is unaware of the fact that he 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 higher interest of the group. It is this denial of the individual that becomes a reflex in the form of passive, involuntary euthanasia. Sometimes, in serious situations, we may choose *"death rather than dishonor"*! A saying in the ancestral culture of the Mosse postulates, "*Kûum saon Yandé*" [25]. This simply means that, for the honor of the family, the clan, the tribe or what the person himself represents, deciding to die is imperative in certain situations! If the person concerned does not decide in a fit of dignity to do so, the social group will protect itself from stigmatization by eliminating him or her with poison. This helps us to understand what happens in African religions in terms of the desire to die rather than be dishonored. In this same spirit, the "Sankarist" revolution of 1983 had as its slogan: "Fatherland or death, we shall overcome". This gives us an insight into what is experienced in African religions in terms of the desire to die or the refusal to live in this world. According to them, those who leave this life to avoid shame paradoxically retain their dignity. They say of him: "He is a man of his word, a worthy son of his father". "He has washed away the shame" that weighed on his family! On the other hand, anyone who persists in surviving opprobrium is considered a "living dead": physically alive, but dead to the clan.

4. Ethical Reflection on the Value of Life

4.1. The Concept of the Personal Value of Life

The value of each person's life is what the person has set as his or her life ideal. 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, brotherhood, affection and love towards other human beings. Virtue ethics and the morality of particular beliefs help to safeguard these values and give meaning and purpose to individual and social life.

4.2. The Concept of the Social Value of Life

If we adhere to Immanuel Kant's categorical imperative, the value of a life cannot be measured by what a person achieves or has achieved in his life. "But a person is not a thing; he is therefore not an object that can be treated merely as a means; but he must always and in all his actions be regarded as an end in himself" [26]. The person, therefore, has his end in himself; he cannot be used as a means or an object. And his dignity must not be evaluated according to his degree of usefulness.

4.3. The Concept of End-of-Life Management in African Cultures

Africans' concern for their sick loved ones reflects the meaning they give to life, which they see as something "entrusted" or "loaned" by a Higher Being; life does not belong to human beings, for they are only stewards of life. Life is God's property and is in the care of the ancestors. When the time comes to return what has been lent, all humans have to do is submit! Even when a patient is terminally ill, family and friends can sometimes have long, face-to-face conversations with them, breath for breath, providing intimate care with their bare hands! The repellent aspect of certain ailments, the pestilential odors, cannot hinder their sense of solidarity and devotion! As the saying goes, "*Wênd pa ku*, *Naab pa kùud ye* [18]! In other words, if God doesn't kill the sick, neither the king nor the doctor can. 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 any means, in the form of plants, talismans or "*grigris*", or in the form of exorcism of all kinds! Relatives do not hesitate to travel long distances, or to spend large sums of money on someone who is already clinically incurable and doomed! In patients' rooms, it is common to see men or women sitting behind the patient, wedging him between their legs and pressing him against their chest to relieve him, to better feed or water him; just as they would do for childbirth, for the rite of circumcision, or other initiation rites [19]. In the typical case of a dying old man of the "*Nyo-noaga*" caste, a seated old 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 not afraid of fire or water. Ancestor Nanema, the father of your fathers, was a hero. As he was a storm and a 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. So fight the battle of life. For you, going to your ancestors is not dying, it's a way of living an even more intense life. Go go go go...*" *[18]*. When the patient dies, this woman will lower her voice. And in the end, she will close her eyes. The old man is not afraid of death; he faces it in agony (in combat) and lives his death as a passage, a departure, a journey to rejoin the ancestors.

This African approach to end-of-life care, so rich for science in its psychosomatic dimension, and for humanism in its almost naive generosity in caring for

the terminally ill—coupled with modern medical advances in pain management and psychological support, would open new perspectives in palliative care for patients at the end of life. 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 will to live. However, as in the case of Ebola infections, some of these unhygienic solidarity practices that threaten the survival of all populations will be banned. The excessive costs of medical examinations, tests and prescriptions in most African countries without basic medical insurance must also be considered, to avoid falling into an aggressive form of therapy. This implies the use of costly resources disproportionate to the financial precariousness of families or the sanitary conditions of countries. Doctors should take these aspects into account to avoid prolonging the agony of terminally ill patients unnecessarily, and to avoid overburdening families with inappropriate expenses.

This study does not address the question of euthanasia in the face of the right to die, which is increasingly being asserted in an international context. What is needed is a more in-depth discussion of the anthropological, sociological, ethical and legal aspects of a contemporary approach to death. This is a limitation of this research, which nevertheless opens the way for further investigation.

5. Conclusions

The psychosomatic dimension of the African approach to end-of-life management, combined with current medical advances, certainly opens new types of palliative care approaches for terminally ill patients suffering from disgust with life syndrome. Indeed, medical, and pharmaceutical research is now making it possible to control even the most excruciating and recurrent pain. In view of the advances 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 "dignity to be pre-served" argument is also no longer relevant since people with no physical pathology wish to "die"; they are aware of what they are asking for; it is even a condition for obtaining their right to die in some countries, from hunger and dehydration! The final argument of "death as a right" now seems to be gaining philosophical and ethical weight: what is the meaning and purpose of my life? If I feel that I have achieved my life's purpose, and if my life belongs to me, then I am responsible for its end and the quality of its end too. The current study is not concerned with these aspects, which can be highly subjective and debatable; it only considers the question of sedation, which falls between euthanasia (intentionally induced death) and dysthanasia (therapeutic relentlessness).

Wisdom might concede this, provided the courage is to face up to inescapable death and show that it doesn't have the last word! In 2019, the international press focused on the tragic death of Frenchman Vincent Lambert, who was a quadriplegic patient who had lived in a vegetative state for more than ten years and finally died on 11 July 2019, following the withdrawal of his treatment. Vin-

cent Lambert was unable to express his wish to live or die, but they decided for him to stop his feeding and hydration. When we review the national and international legal drama surrounding Vincent Lambert's end of life, and the heartbreak in his own family, we have every right to ask ourselves many questions about the real conditions of support for patients at the end of life. What ethics of life can be opposed to this "right not to live"? If life is beautiful, it must be beautiful right to the end, and open the door to another life to which we aspire with all our might! Death is not a dead end for mankind! With this in mind, the golden rule of medicine always remains as such: "*Primum non nocere*".

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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