

Bioethical considerations on models for end-of-life care

Considerações bioéticas sobre os modelos de assistência no fim da vida

Consideraciones bioéticas sobre los modelos de asistencia al fin de la vida

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Abstract

The article discusses contemporary societies' three institutionalized fields in end-of-life care and their respective models of death: euthanasia/assisted suicide; medical futility; and kalothanasia, the basis for the modern hospice movement. The article also analyzes how these models impact patients' lives and the conceptual weakness of some traditionally used banners such as that of human dignity. It also comments on orthothanasia, a widely used concept in the Brazilian bioethical literature, as well as rational suicide in the elderly. Questions are posed for the bioethical debate on the need to rethink some postulates, especially pertaining to euthanasia. Finally, the article presents and analyzes the ethical and philosophical basis for kalothanasia and its implications for the organization of good practices in end-of-life care.

Bioethics; Attitude to Death; Medical Futility; Euthanasia; Palliative Care

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Introduction

The construction and organization of models of care that include an adequate and compassionate approach to patients with advanced and terminal illnesses necessarily involve training of skilled human resources in both ethical and technical terms. They also involve raising the awareness and providing proper conditions for public and private health policymakers in this construction and organization. This entails creating an effective national policy for end-of-life care, including both the search for better quality of life and the provision of better quality of death for these patients. This calls attention to the failure to address end-of-life care in the Brazilian National Policy for the Elderly and the Statute of the Elderly, even though this age group is extensively affected by this issue. This is an ethical and public health problem that needs to be widely addressed and discussed.

Why should such effort be invested in quality of death when so much is said about quality of life? Intuitively, would they not be mutually exclusive fields? Is it not strange to speak of quality of death, precisely when enormous biotechnological and scientific strides in the last 50 years have organized a medical scenario with such promising interventions? One could draw on various moral imperatives to answer these questions. Still, the principle of human dignity, although conceptually diffuse and heterogeneous, is widely used in reflections on harmful consequences by breaking the limits of reasonability of therapeutic interventions applied to patients with advanced and terminal illnesses¹, frequently proving to be obstinate and thus more maleficent than beneficent. Such patients are in a state of vulnerability and lack of protection, suffering disproportionately, often with only a biological life (*zoê*) available to them, as opposed to a life of affective, social, and existential plenitude (*bios*), with a significant impact not only on the patients themselves but also on their families and the health system.

The concept of good death, in the context of end-of-life care, has been proposed with certain characteristics, such as: death without pain; death when the patient's wishes are respected (verbalized or recorded in an expressed request); death at home, surrounded by family and friends; absence of avoidable misfortune and suffering for the patient, family, and caregiver; death in a context where the patient's pending issues are resolved and with a good relationship between the patient and family and the healthcare professional. However, it is important to consider the conditions in which the patient faces his or her death, thereby avoiding false expectations concerning this process while not overlooking specific cultural aspects to which the patient belongs, especially in purportedly pluralist societies which have different definitions of good death².

This article discusses the three institutionalized fields of end-of-life care in contemporary societies and their respective models of death: euthanasia/assisted suicide; medical futility; and kalothanasia, the basis of the modern hospice movement. It analyzes the way these models impact patients' lives, as well as the ambiguities and the conceptual weakness of some traditionally used banners such as that of human dignity. The article also discusses orthothanasia, a widely used concept in the contemporary Brazilian bioethical literature, as well as rational suicide in the elderly. The text also poses questions for the bioethical debate on the need for rethinking some postulates, especially pertaining to euthanasia. Finally, the article presents and analyzes the ethical and philosophical foundations of kalothanasia and implications for organization of good practices in end-of-life care.

Care in death and dying

In recent decades, Western society has built a relationship of avoidance of everything that might remind us of death, especially death from natural illness, isolating it steadily from our daily experience, in a process observed most clearly since the late 19th century³. This was an abrupt transformation, which in a few decades changes a centuries-old way of society's relating to death and its rituals. In fact, "death, so present in the past, so familiar, was steadily erased and disappeared. It became shameful and the object of interdiction"⁴ (p. 84).

In fact, starting with World War I, there was a progressive interdiction of mourning and everything that publicly reminded people of death; however, with death still taking place at home, and with the preservation of final moments and farewell scenes, starting in 1945 – with the growing incorpora-

tion of technology in medical acts, and having “*the moral security of the hospital*”³ (p. 640) as the prime place for this intervention – the total medicalization of death was installed. Since then, the great majority of deaths occur in the hospital, far from the presence of the patient’s loved ones and close to the entire available medical apparatus. This consolidated the “*triumph of medicalization: (...) the most recent model of death is linked to the medicalization of society, that is, to one of the sectors of industrial society where the power of technology was more welcomed and is still less contested*”³ (p. 637; 647).

According to Norbert Elias⁵, another factor contributing to this isolation of patients – at least in developed industrial societies – is what he describes as a state of antipathetic and silent animus in relation to the dying and to everything that may remind us of this process of death. Elias believes that this sentiment of antipathy emerged from a certain state of inner pacification and containment and is also due to the greater difficulty these societies experience in reacting to violence.

The problem of human dignity

Beginning in the 1960s, voices cried out to denounce the discomfort with the way patients with advanced illnesses had been treated, frequently abandoned by their physicians and living out their final moments in the cold isolation of an emergency ward, a hospital room, or an intensive care unit, often surrounded by tubes and devices rather than by the patient’s loved ones. As Elias⁵ (p. 98) emphasized: “*Never before have people died so silently and hygienically as in our societies today, and never in conditions so prone to loneliness*”. Thus, the demand for a “decent death” began to emerge, especially in the Anglo-Saxon countries^{6,7}. According to Clark⁸, in Great Britain, the birthplace of the modern hospice movement, this demand emerged as another facet in the observations of patients’ abandonment by their physicians, while in the United States the frequent use of technology to perpetuate life was the principal factor. However, according to Ariès³ (p. 643-4): “*The essential issue is the dignity of death. This dignity requires, first and foremost, that death is acknowledged not only as real state, but as an essential occurrence that one is not allowed to shirk. One essential condition for this recognition is that dying persons be informed of their state (...) and are we thus on the eve of a profound change in the face of death? Is the rule of silence beginning to expire?*”.

The issue of decent death is evoked frequently in end-of-life care^{9,10}, although often without a more precise definition of its meaning. Despite this imprecision, the theme of dignity (from the Latin *dignitas*, value, merit) is evoked reasonably when the subject is the end of life, death, dying, and when speaking of good death.

For Bayertz¹¹, human dignity is backed by two sources of authority: the first pertains to its root, which is centered at least in part on the Christian idea of *imago Dei* (in God’s image) and the second to various national and international laws. The author emphasizes that the term is controversial in philosophy, where there is no clear definition of human dignity (an opinion shared by other authors¹²) and as a term with purportedly uncertain importance, characterizing an “*empty formula, to be filled with varying contents*”¹¹ (p. xv).

For Sandman¹³, dignity entails prescriptive or evaluative elements as well as descriptive traits. He distinguishes between two types of dignity, which he calls “human dignity” and “contingent dignity” and defends this distinction for a better understanding of what is meant when evoking “dignity”. “Human dignity” has characteristics that apply to all human beings indistinctly, with an extremely high value, distinguishing them from other living beings. Meanwhile, “contingent dignity”, depending on the evoked characteristics, may not necessarily be applicable to all human beings. Some ways by which “contingent dignity” becomes evident include autonomy or rationality, the potential to cause fear in others, self-respect, self-esteem, or playing a given social role. Sandman¹³ suggests that these characteristics are not always present in all human beings, and one should thus not invoke “human dignity” simply because everyone is human.

Further according to Sandman, one possible implication of palliative care only addressing dignity as an extremely high value and equal for all human beings is that no death can be good, since it would mean the loss of a high value. Consequently, it could justify efforts to prolong life and thereby postpone the loss of this high value, which would be problematic for palliative care. And he concludes, “*Ideas and discussions of human dignity do not seem to lead us any further along that road and hence would*

seem quite unhelpful for determining what it is to provide someone with good palliative (or other) care if such care should have as its goal the good of the dying person"¹³ (p. 180).

Thus, death with dignity may be another strategic or politically adequate banner, but will it be full of meaning? After all, dying and death are neither worthy nor unworthy, but one can assign this valuation to certain end-of-life care practices. In addition, both the modern hospice movement and the movement in defense of euthanasia and assisted suicide claim decent death, and this similarity is uncomfortable, especially for the hospice movement¹⁴. Questions such as those raised by Billings¹⁵, according to whom this issue is overvalued by the hospice movement and who questions the degree to which dignity in fact concerns dying patients (he does not identify this issue as relevant for patients in his palliative care practice) do not usually resonate greatly, especially among those who feel that there is an affirmative answer to these questions.

The three major fields in end-of-life care

End-of-life care includes three major models of institutionalized care in contemporary Western societies: the movement of defenders of euthanasia and assisted suicide; the modern hospice movement, which encompasses palliative care; and biomedicine, defined here in the sense used by Foucault¹⁶, or the traditional hospital structure forged in hierarchy, observation of clinical findings, and medical power. Added to these models, especially to the hospice movement, are a set of medical rationalities called integrative or complementary practices that propose similar end-of-life interventions to palliative care and that have gained increasing visibility and legitimacy (e.g., Ayurvedic medicine, Tibetan medicine, traditional Chinese medicine, anthroposophical medicine, among others). These three models of care create a set of characteristics that emerge from the interventions performed and their consequences, which define what have been called "models of death" here, namely, euthanasia, the basis for the movement of defenders of euthanasia and assisted suicide; kalothanasia, the basis for the modern hospice movement; and dysthanasia (or therapeutic obstinance, or medical futility, the term we prefer). The former pursue the ideals of good death (*eu*, from the Greek good, and *kalós*, from the Greek good, virtuous, noble), while the latter are based on persistent and continuing interventions, shaping a death with suffering, or kacothonasia (from the Greek *kakos*, suffering).

Although the Brazilian bioethical field currently uses the term orthothanasia associated with palliative care, we do not identify it as formative for the model of death in palliative care. Although it is beyond the scope of this article to dwell in greater depth on the conceptual aspects involved in this category's construction, it is not uncommon in the various available texts on orthothanasia to find somewhat generic expressions to characterize it, for example, "natural death", "natural process of dying", "natural course", "normal death", "death as something natural", "death without interference by science", "the art of dying well", "death in its own time", among others, revealing a problematic conceptual issue, especially considering the uncertainties concerning the right time to die¹⁷ and given the obstinate biotechnological interventions, all of which makes "natural death" a rarity in our age¹⁸. Although orthothanasia uses principles of good care underlying palliative care for its conceptual justification, in our understanding the term lacks the organizational and constitutive elements for the ethos and the anthropological, historical, and philosophical foundations of the modern hospice movement, which will be presented in this article, albeit briefly. On the other hand, we understand that orthothanasia entails a set of characteristics that can be triggered by the patient or that can help healthcare professionals, especially physicians, to review their practices, especially given the obstinate and persistent conducts found in intensive care units, their prime locus. Orthothanasia would thus open the doors to other possibilities of care, including but not limited to kalothanasia and theoretically (although prohibited in Brazil) the institutionalized model of euthanasia/assisted suicide.

This field of dynamic and unstable tensions includes many of the demands from end-of-life bioethics, suggesting the following for analysis within the hegemonic principlist view: the principle of therapeutic proportionality; the double effect principle; the principle of prevention; and the principle of non-abandonment^{19,20}. These demands are likewise grounded in the principle of self-determination (principle of autonomy and respect for autonomy), quality of life, and human dignity – the latter

three as the bulwarks of the movement of defenders of euthanasia and assisted suicide and the hospice movement; while for medical futility, the ethical basis is linked intrinsically to medical vitalism and the principle of sacredness of life ²¹.

Assisted and medicalized death

Different designations have been used for “assisted and medicalized death”. For example, euthanasia in Colombia, Netherlands, Belgium, and Luxembourg; assisted suicide in Switzerland, where there has been legislation allowing suicide for altruistic reasons since 1918 ²²; physician- assisted suicide in the Netherlands, Belgium, and Luxembourg and in the past in the United States; assisted death (Australia); death with dignity (United States), medical assistance in death (MAiD – Canada). Regardless of the terms, the definition that best sustains the current debate on assisted and medicalized death in our understanding is outlined clearly in the document by the Task Force of the European Association of Palliative Care ²³ (p. 98), which addressed this issue, after three years of meetings and debates: *“Euthanasia is killing on request and is defined as a doctor intentionally killing a person by the administration of drugs, at that person’s voluntary and competent request. Physician-assisted suicide is defined as a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request”*.

This article will not go into the different forms of euthanasia, nor the double effect principle, also called double effect euthanasia and often used as the basis for the attempt to criminalize palliative care ²⁴, which we see as combining various types of situations and procedures in the same category, confusing and leading to erroneous interpretations. With the principle of self-determination (principle of respect for autonomy) as the defining and determinant element in societies where these practices are socially approved and legally conceivable, euthanasia is defined according to a voluntary request sustained over time by the subject who will be killed or kill himself or herself, and not according to the agent that performs the act. In other words, the request is a necessary and sufficient condition for defining euthanasia in the contemporary debate, at least in these societies, while the medical act is only a necessary (but not sufficient) condition, since the act without consent is the crime of homicide, punishable by law.

We also contend that the distinction between the active and passive form of euthanasia is artificial and confusing, because if the physician’s intention is to kill the patient (and this is a necessary condition to define active or passive euthanasia), it makes no difference from the moral point of view whether he performs an act or not, since both forms lead to his objective, which is to kill, where non-action is a form of action. And since legalized euthanasia is characteristically quick, smooth, and painless, the passive form would be counterintuitive, because it would violate these characteristics. Besides, to feel more or less guilty because of the action or omission when the intent is to kill does not make someone more or less responsible: *“So we learn to think of killing in a much worse light than letting die; and we conclude, invalidly, that there must be something about killing which makes it itself worse than letting die”* ²⁵ (p. 114, emphasis in the original).

Meanwhile, the medical decision reached jointly with the patient or with his or her family or legal proxy to suspend certain procedures or treatments in a patient with advanced and incurable illness, understanding that such procedures would increase the patient’s suffering or worsen their quality of life, deciding not to postpone the evolution that will occur, or to not submit the patient to an intervention that may lead to death, cannot be categorized as a form of euthanasia, since there is no intent by the physician to kill the patient by proceeding in this manner. Without the intent to kill in the act, how can one morally impute the act of killing to the physician? Here, we would have to admit that physicians intend to kill patients by proceeding this way. Such situations, which are usual in routine medical work, are often interpreted erroneously as a type of euthanasia. They lack the characteristics of an act motivated by the physician’s wish for the patient to die, besides failing to link the act’s intentionality (and overlooking this fundamental point), that is, of wanting to kill another person. The issue is much more the adequacy of means that lead to an end without additional suffering, without actions that do not reach the objectives, and we see this adequacy as well demarcated in the construction of the concept of orthothanasia. Otherwise, we will necessarily have to admit that palliative care is based

on passive euthanasia, which would mean legitimizing this modality of euthanasia in the dozens of countries in which such care is established, which does not make sense. We contend that many issues that could be defined as the practice of passive euthanasia in fact are part of the field of medical futility, amenable to review and joint decisions, without imputation, at least in the moral sense, of harm to the patient. In various contexts of advanced and terminal illnesses, the cause of death is not the change in procedures, which aims to add quality of death and is part of a plan for care developed with the patient and family, but the inexorable evolution of the underlying disease. As stated by Callahan ²⁶, causality and culpability are confused here.

Constrained by a legal framework that criminalizes the practice of euthanasia in Brazil, we have difficulty in proceeding with the discussion on this complex medical practice and are left with the discussion of the confounding established classifications. On this point, a substantial part of the Brazilian bioethical literature relates to the prevailing legal order, which should be one of the last recourses in the legislative organization, a consequence of wide and deep discussion in society on this specific model of medical intervention. We do not mean to say with this that we favor or oppose euthanasia/assisted suicide in principle, but we do hold that society should discuss this model of care openly (i.e., to kill or let die at the sustained request of the individual that will receive the act) by bringing to the debate the various classificatory types of euthanasia and the legal provisions that formed the basis for consolidating the issue's normative understanding in Brazil. We are thus at least 30 years behind in the contemporary debate on euthanasia/assisted suicide, given that this intense debate has taken place in Europe and the United States since the 1990s. We can infer the discussion's evolution in these countries when we read a manifesto by an important German Catholic theologian openly defending the right to euthanasia for an elderly individual that has lost his or her autonomy, having manifested this wish ²⁷.

In this sense, the provision for explicit requests is a recent stride in Brazil ²⁸, although it does not cover a request for euthanasia, making it limited in terms of the principle of respect for autonomy, since this principle is constrained in the broader sense, that is, that the patient should be the subject of his or her life and death, an essential aspect of their existence.

Initially determined only for patients with advanced, terminal, progressive, and active illnesses, euthanasia/physician-assisted suicide is already contemplated for patients in whom the illness is not the inclusion criterion, but in whom psychological or existential suffering is also a criterion, which opens the doors for important and complex flexibilization, for example, treatment-resistant depression resulting from intense suffering. Or for what has been called "rational suicide in the elderly", the most recently publicized case in the media was that of British scientist David Goodal, 104 years of age, who traveled from Australia to Switzerland to be killed, since his life no longer made sense to him. In rational suicide, the oldest elderly individuals conclude that they have lived their lives, achieved what they had to achieve, conquered and lost what they had to conquer or lose, that there is nothing more to be done in the present or future, and that they have lost their relational references. "*I had passed my expiration date*", to quote a centenarian patient. In this type of request, there is no illness that will lead to death, but the observation and wish to put an end to life, and the understanding that the individual has the right to be assisted in this wish. The life of a centenarian in these circumstances has lost its meaning, their reason for being, as Goodal says: "*They realise how unsatisfactory my life here is, unsatisfactory in almost every respect. The sooner it comes to an end the better. (...) I'm saying farewell all the time (...) One should be free to use the rest of his life as one chooses (...) If one chooses to kill oneself then that's fair enough. I don't think anyone else should interfere*" ²⁹.

It may be legitimate for very old persons living in these existential circumstances to want to kill themselves, no matter how tragic, good, or bad the act may be; after all, people kill themselves. Depending on where we seek strength and confidence to exist, we will respond in different ways, and one of these ways may be suicide. It was Camus who observed, reflecting on the feeling of absurdity in the existential relationship of transcendence in a human being divorced from their setting: "*There is only one truly serious philosophical problem: it is suicide*" ³⁰ (p. 13).

The question posed here in the debate on euthanasia is: why do we need another person to do it? And if we do need someone else, who will do it? The physician? In assisted suicide, the physician's interference is more distant, even though he participates in the act and is linked to the event, since he knows what he is doing by prescribing drugs and providing support and orientation, offering the

means for the person to kill himself. In the case of euthanasia, a question we consider relevant is not whether the principle of self-determination should be respected and taken to the ultimate consequences, but what will happen when a society, to accept the patient's legally established right (namely to be killed), to accept this determination of the patient's will, establishes a right for the physician, the right to kill. By proceeding in this manner, society legitimizes physicians' ability to kill within their daily routine of care. The physician's duty to kill is overriding, since he is the one who can kill (although it is often the nurse that performs the act itself, which can be refused by both based on the conscientious objection clause), and this duty emerged from a patient's right, legally acknowledged and authorized. The medical duty to kill will legitimize a medical right to kill. We should thus acknowledge that medical work has long been associated with practices in which physicians act to save lives, to cure illness, to mitigate suffering in favor of life. With the decriminalization of euthanasia, the doors are open to legitimize physicians being able to kill. How do we socially maintain the physician-patient relationship sustained by the belief and trust that the physician will act in the patient's best interests, since these best interests are understood in favor of the preservation of life? How will we avoid a slippery slope (regardless of the fact that the slope can always be invoked, a scenario of catastrophic future) in which physicians can decide to kill, opening possibilities for other forms of interests to interfere in the medical act, long associated with a curative and non-maleficent practice (*primum non nocere*)? By killing an innocent person, understood as someone whose acts do not violate another's physical integrity, will the medical act itself will be morally less relevant because it is backed by the law? These and other questions have been identified in countries where this practice is decriminalized, and we should be open to discussing them ^{31,32}.

Medical futility and the tub of the Danaids

In relation to medical futility (from the Latin *futilis*, letting escape what it contains), contemporary medicine has achieved such impressive technical development that physicians tend to consider its incorporation as an imperative – and thus also its use in daily practice – constantly running the risk of demanding it also as an ethical requirement. That is, technological development at the service of medicine has imposed itself with such force due to the stupendous development in this field, and perhaps irreversibly, making the physician somewhat uncomfortable when not using this technology, leading to a sort of technological imperative in medical practice. With this, what may have occurred is an inversion in the relationship between medicine and technology: the latter no longer at the former's service, but on the contrary, medicine at the service of technology, and thus when physicians feel compelled to use an available technology, they would in fact be confusing a possibility to act, provided by the technique, with a duty to act, which can only derive its justification within a value system, and not from a mere pragmatic relationship of optimization of means and ends.

We are referring specifically to a model of interventions characterized by *“the absence of a useful purpose or useful result in a diagnostic procedure or therapeutic intervention. The situation of a patient whose condition will not be improved by treatment or instances in which treatment preserves permanent unconsciousness or cannot end dependence on intensive medical care”* ³³.

Moller ³⁴ searches current medical training for possible explanations for physicians' distancing from the patient with advanced illness; for the author, this is due much more to the way this training occurs than to a personal issue on the physician's part. Moller states that both physicians and medical students are overloaded with demands of technical knowledge, continuously taught as determinants for their training, which would lead them to dedicate more time to their studies in this domain, to the detriment of other forms of knowledge, with little time for familiarity with patients and their life stories. Physicians need and must know illnesses and are trained for a context of heroic technological interventions, leading to significant difficulty in accepting non-intervention or the interruption of a treatment. The consequence is successive interventions, with prolongation of treatment and the patient dying surrounded by machines and tubes. Added to this is the physician's inability to listen to and respond to the patient's demands and surroundings; inadequate communication, especially for communicating bad news; and the unsatisfactory approach to the patient's pain and suffering, shaping a difficult environment for interrelations between the physician, patient, and family.

In addition, many medical students and physicians believe that in the face of an advanced or terminal illness, “there is very little to be done”, or worse yet, “there is nothing to be done”; therefore, they are unable to take interest in the patient, since they have lost interest in the illness, in the treatment response. This disinterest may be due partly to the fact that medicine as we conceive it today was built on a rationality that occupied itself and took intense interest in the illness and the clinical observations of a growing set of interventions. Regardless of the causes, the emerging scenario is one of expropriation and major medicalization of the process of dying, and of the patient’s isolation, from a death with disproportional suffering. The term is “disproportional”, since suffering is inevitable in the human condition, and within this inevitability, there is a limit to this suffering, which is independent of the presence or absence of pain.

This is the prevailing scenario in traditional hospitals, a scenario of practices which progress, given the inexorability of the illness, and that lead the patient to death, failing to achieve the ultimate objective, which would be to recover health and offer quality of life. In fact, they constitute a scenario of futile practices that improve the parts without benefiting the whole, in a ceaseless and persistent conduct, purportedly beneficent – and herein lies the confusion and difficulty in stopping or changing the procedures –; but maleficent practices in essence, since they do not add benefits to the recovery of a full life, so that these practices should not be confused with impossible interventions (e.g., cardiac massage in a patient in hypovolemic shock without reversal of hypovolemia) or in theoretically possible but extremely complicated acts (e.g., ex utero pregnancy)³⁵.

As in the Greek myth of the Danaids, the physician is condemned to repeating the procedures endlessly, the results of which vanish, as happened with the intense work of the Danaids, condemned for their sins and only able to escape their condition if they can fill the tub with their jugs full of holes, which is a futile activity. Hence the expression “*the tub of the Danaids*” metaphorically meaning a permanent effort, since it never ends, repeated without ever reaching its objectives. Paradoxically, the hospital, socially identified with the ideology of rescue, is still the final path for referring patients with advanced illnesses, that is, considered the appropriate place of receiving severely infirm patients, many in the terminal phase. It thus also becomes the space for organizing palliative care, although the latter did not emerge in the hospital setting, increasingly engaging within a scenario of on-going and persistent interventions.

On the dimension of care and its relationship with the development of virtues

This reality is perhaps about the physician being able to understand the importance of “care”, of understanding and responding adequately to the vulnerability of a person living with an illness, that is, becoming sensitive and succeeding empathetically in perceiving the weakness in the moment lived by the patient, imposed by their illness and the successive attempts at curative treatment, often with inexorable and overwhelming evolution. As summarized quite well by Callahan³⁶ (p. 144): “*Caring should always take priority over curing for the most obvious of reasons: There is never any certainty that our illnesses can be cured, or our death averted. Eventually they will and must triumph. Our victories over sickness and death are always temporary, but our need for support, for caring, in the face of them is always permanent*”.

Here, one should ponder on the dichotomy between cure and care, which appears to justify, even among defenders of palliative care, a “doing-everything”, when the search is for cure, as if this “doing-everything” justifies “not caring”, or (and this is worse) as if it implies “not caring”. In this type of proposition there lies an important segmentation of artificially distinct actions with harmful consequences, especially for the patient. At the same time, this segmentation justifies conducts of cure without care, which only goes to reinforce the fragmentation implied by this dichotomy, which is consistent with the social desire that pressures the physician: “cure” at any cost. Thus, the illusion is sold that illnesses have a cure, when most illnesses are chronic, which defines the nonexistence of cure. This fragmentation also leads to the harmful social consequence of often exempting the physician, especially the specialist, of any responsibility for the consequences from successive attempts at curative treatment, and consistent with this, without the need to act through care, since he does not provide care; he purportedly cures, considering that his actions are technically correct and well indicated and thus free of any potential legal sanctions. It is thus socially legitimized that the specialist

is exempt from following up the care in the final phase of illness, when the problem is no longer his, since he supposedly cures, not cares. As the daughter of a patient dying from cancer once said, “*She has an oncologist, but now she says it’s no longer him, so we brought her here, he has nothing more to treat*”. It is no longer the specialist’s problem. So, whose is it?

The priority of care over cure should be understood within a medical model in which cure is exercised with care, understood as support, welcoming, and protection. This discussion’s complexity lies in the fact that any physician attending a sick person is obviously caring, but this action is subsumed by the pursuit of cure. Separated, cure and care illustrate the magnitude of the problems that exempt the curative medical act from caring.

The solution presented to complement the physician’s “cure without care” with “care without cure” can be contemplated with the creation of a new medical specialty, palliative medicine, which trains physicians who in principle care for the dying and are not at the service of cure. When it is no longer possible to cure an illness, all hopes are placed in the “specialists of comfort”. How is this integrated into daily medical activity? How will this transition occur within a prevailing model of that values specialists, and at what cost to the patient?

This is the role of the third major field of end-of-life care, namely, palliative care, which intends (through the search to transcend the patient’s journey of struggle, of the illness as meaning, of the unconditional reception of this stranger that arrives, the patient with advanced illness, and of non-abandonment) to build a “hospice way of caring”, a “hospice way of dying”, unconditionally encompassing this unique moment of life, on death’s doorway, a process of transformations and learning: “*Terminal illness should not be regarded as an intrusion into life; it is part of life and can be a time of increasing maturity and deepening spiritual experience for all concerned. It is our job as doctors to help it be so*”³⁷ (p. 21).

Palliative care’s proposal is the dimension of care extended to its maximum, in acceptance of the other, and in unconditional welcoming. The good death of palliative care emerged with the ethical basis for the development of certain virtues based on its on-going improvement, materialized through the other, the stranger that arrives, in passing, the patient in the face of death. As the founder of the modern hospice movement, Cicely Saunders³⁸ (p. 165), teaches us, “*The place to find meaning is so often in the ordinary, in the endlessly repetitive and insignificant. A true meeting between two people is a gift coming unbidden into the midst of such action*”.

We consider this ethos more adequate than a set of internalized duties, a code of moral rules that echo within a moral agent, but external to this agent: perception of the other, compassion, consideration for the other, cooperation, courage, benevolence (internal disposition to do good, unlike a duty to do good, that is, beneficence), patience, prudence, respect, tolerance, among other virtuous attributes, are indispensable in our view for unconditionally welcoming the other. Acts motivated by genuine compassion form the ground for welcoming patients, helping them in their individual journal of struggle on death’s doorway.

The constitutive characteristics of this specific model of end-of-life care relive old processes of ritualization of dying, what Walter³⁹ called thanatological revivalism, incorporating the Latin word hospice, derived from the Latin *hospes*, “*one who receives another*”, which has the same semantic origin as hospitality, understood here as unconditional reception of the Other, in Lévinas’ sense of this stranger⁴⁰, this stranger that comes asking for shelter on death’s threshold; and likewise having the same semantic origin as the Latin word *hospitium*, that is, a warm feeling of belonging that develops between the host, the one who shelters, and the guest, the one who arrives⁴¹. These constitutive elements of the philosophical and ethical edifice of the modern hospice movement can be found in the emblem of Saint Christopher’s Hospice (London, England), the center from which the movement branched out worldwide: the Christian *ethos*, identified in the name Christopher, “*bearer of Christ*”, and in the staff that takes root and bears fruit; the journey of struggle, the crossing between two solid banks, the earthly and the beyond-death as the other side of the crossing, in a period of significant turbulence in troubled waters; the need for succor, protection, the stranger who comes and is borne carefully in this trajectory; the Other, the curer of the caregiver’s wound, the one who gives meaning to care; and the potential process of spiritual growth for all involved.

Based on the ritualization of farewell scenes, the search for a transformative meaning of the illness, and within this Christian *ethos*, kalothanasia, the good death of the modern hospice movement, and its dynamic process are triggered by the dying one and put into practice, if possible, as the basis

for a model of death that aims to shelter, support, protect, and give meaning to the patient's process of dying at the twilight of their existence, on the threshold of death. It is thus presented as counterpoint know-how to the model of rapid, seamless, and painless death represented by the good death of the movement of defenders of euthanasia and assisted suicide. It is thus intended to be an important path for fulfillment and care in a health system centered on the ideology of rescue, present in general hospitals, in which quite frequently there is a medical end-of-life practice characterized either by excessive interventions or abandonment, or by both situations at the same time.

Final remarks

Adequate models for end-of-life care have proven to be imperative, with an impact on patients, their surroundings, and the organization and allocation of human, technological, and economic resources in the health system. Patients with advanced, progressive, and terminal illnesses are frequently admitted to hospitals, structured with an ideology of rescue, which has proven inadequate, disproportional, and maleficent, despite single benefits. A concrete stride in the organization of these models of death in Brazil should include a conceptual revision and deepening debate on the current understanding of euthanasia and assisted suicide, as well as their implications. Likewise, an effective national policy is needed to back the practice of palliative care, to be established in diverse scenarios such as the case of Brazil, based on a model of good death that proposes to unconditionally welcome patients and their surroundings in a scenario of potential transformations in all those involved.

Additional information

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Resumo

Este artigo discute os três campos assistenciais institucionalizados nas sociedades contemporâneas para cuidados no fim da vida e seus respectivos modelos de morte: a eutanásia/suicídio assistido; a futilidade médica; e a kalotanásia, fundamento do moderno movimento hospice. Analisa, também, de que modo estes modelos impactam a vida dos pacientes, bem como a fragilidade conceitual de algumas das bandeiras tradicionalmente utilizadas, como a da dignidade humana. São feitas, também, considerações à ortotanásia, conceito muito utilizado na literatura bioética nacional, bem como ao suicídio racional nos idosos. Além disso, propõem-se questões para o debate bioético acerca da necessidade de serem repensados, em nosso meio, alguns postulados, especialmente aqueles referentes à eutanásia. Por último, apresenta e analisa a fundamentação ética e filosófica da kalotanásia e suas implicações para a organização de boas práticas de cuidados no fim da vida.

Bioética; Atitude Frente a Morte; Futilidade Médica; Eutanásia; Cuidados Paliativos

Resumen

Este artículo discute los tres campos asistenciales institucionalizados en sociedades contemporâneas para los cuidados al fin de la vida, y sus respectivos modelos de muerte: eutanasia/suicidio asistido; futilidad médica; y kalotanasia, fundamentada en el moderno movimiento hospice. Analiza, también, de qué modo estos modelos impactan en la vida de los pacientes, así como la fragilidad conceptual de algunas de las banderas tradicionalmente utilizadas, como la de la dignidad humana. Se realizan, también, consideraciones sobre la ortotanasia, concepto muy utilizado en la literatura bioética nacional, así como respecto al suicidio racional en ancianos. Además, en nuestro medio, se proponen cuestiones para el debate bioético acerca de la necesidad de que sean repensados algunos postulados, especialmente, aquellos que se refieren a la eutanasia. Por último, presenta y analiza la base ética y filosófica de la kalotanasia, y sus implicaciones para la organización de buenas prácticas de cuidados durante el fin de la vida.

Bioética; Actitud Frente a la Muerte; Inutilidad Médica; Eutanasia; Cuidados Paliativos

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