Modern hospice movement: *kalothanasia* and aesthetic revivalism of good death

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Abstract

This article analyzes the concept of good death, grounding the philosophy of the modern hospice movement. From its essential features emerged a category of good death distinct from the historically known one, the euthanasia, with two essential characteristics: a peculiar arrangement to cope with illness making death meaningful and a process of dying prepared for and shared socially. That model of good death, known as *kalothanasia*, concerns a set of actions which seek to revive a smoother process of dying , taking the challenge of doing it in a medical scenario that identifies itself with the continued and persistent use of high technology.
Key words: Attitude to death. Bioethics. Palliative care. Hospice care. Terminal care. Thanatology.

Resumo

Moderno movimento *hospice*: *kalotanásia* e o revivalismo estético da boa morte

Este artigo analisa o conceito de boa morte, que fundamenta o moderno movimento *hospice*. A partir da descrição de seus elementos constitutivos, emerge uma categoria distinta da boa morte historicamente conhecida, a eutanásia, com duas características essenciais: uma peculiar disposição de enfrentamento da doença, que dá sentido à morte, e um processo de morrer ritualizado e socialmente compartilhado. Esse modelo de boa morte, conhecido como *kalotanásia*, organiza um conjunto de ações que busca reviver um processo de morrer e uma morte mais suave, tendo como desafio fazê-lo em um cenário médico identificado com o uso continuado e persistente de alta tecnologia.
Palavras-chave: Atitude frente à morte. Bioética. Cuidados paliativos. Cuidados paliativos na terminalidade da vida. Assistência terminal. Tanatologia.

Resumen

El moderno movimiento *hospice*: *kalotanasia* y el revivalismo estético del buen morir

Este artículo analiza el concepto del buen morir que fundamenta el moderno movimiento *hospice*. A partir de la descripción de sus elementos constitutivos, emerge una categoría distinta del buen morir históricamente conocida, la eutanasia, con dos características esenciales: una peculiar disposición de enfrentamiento de la enfermedad, que da sentido a la muerte, y un proceso de morir ritualizado y socialmente compartido. Tal modelo del buen morir, conocido como *kalotanasia*, organiza un conjunto de acciones que busca revivir un proceso de morir y una muerte más suave, teniendo como desafío hacerlo en un panorama médico identificado con el uso continuo y persistente de alta tecnología.
Palabras-clave: Actitud frente a la muerte. Bioética. Cuidados paliativos. Cuidados paliativos al final de la vida Cuidado terminal. Tanatologia.

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The modern *hospice movement* provides comprehensive care for terminal patients and patients with diseases at an advanced stage, housing two ways of assistance: palliative care, commonly organized in general hospitals, either in the form of a liaison consultation or within own units; and *hospice* care, offered in locations called *hospice* which are geographically distant from hospitals and arranged to accommodate dying patients, both with extension for assistance at home[1]. Person-centered, unlike the current biomedical model which focuses its interventions in the disease, this movement formally emerged during the 20th century, at the end of the 60s, with the construction of St. Christopher's Hospice in 1967, in England[1]. Since then, its inclusion in the traditional health care system has increased[2], responding to a need which is not only technical, concerning the scope of interventions in which predominates the continued and persistent use of high technology, but also moral, facing situations of abandonment of patients who require interventions compatible with the relief of unnecessary suffering at the end of life[3,4].

One of the core concepts of the modern *hospice* movement is the good death, which from a semantic point of view is configured in a set of characteristics of facing death, seeking to improve the patient's quality of life during the time they have left, through interdisciplinary activities [5]. This is a model of death whose goals are to achieve a socially shared and also smoother process of dying, creating conditions for a peculiar willingness to coping during this process, giving meaning to death[6].

The good death has been such an important and central concept for the modern *hospice* movement that, at present, palliative care and *hospice* care can be understood as synonyms for "good death", which creates an expectation about the peculiar way of how to die, when it comes to palliative care or *hospice* care. Speaking about palliative care or *hospice* care implies in the search for this ideal and represents a real *leitmotiv* for professionals involved in their daily practice: the *hospice* care, the *hospice* way of dying[7,8].

In this article, the concept of good death that underlies the philosophy of the *hospice* movement will be historically and conceptually characterized. It will be possible to verify that this concept incorporates community sharing features associated with the patient's peculiar willingness to coping during his disease journey. This model of death has its origins in ancient societies, such as agricultural societies, in which social ritualization of death has been established; and also in ethical and aesthetic elements of ancient Greece, especially in Spartan society, where the willingness to coping during the journey of struggle was seen as virtuous. This dual configuration organizes a model of good death that gives meaning to the modern *hospice* movement and finds in it its full expression.

With this background it will be possible to identify the good death category that sustains the know-how of the modern *hospice* movement – the *kalothanasia* –, which is distinct from the commonly referred to and historically known as good death – the euthanasia. It is, as we shall see, a set of features that intends to revive a ritualized and socially transformative process of dying, but with the challenge of doing it in a medical scenario subjected to constant and increasing incorporation of technology, according to the current biotechnoscientific paradigm.

In our environment, the term orthotanasia (*ortho*: right, correct, fair; *thanatos*: death) has been used to characterize a type of death that is considered more natural and at the right time[9]. The characterization described in this article regarding the *hospice* movement's good death – the *kalothanasia* –, with the description of its historical and cultural elements, does not exclude and, on the contrary, can contribute to better systematize the meaning of orthotanasia. Therefore, for the purposes of what is intended here, it will be able to verify that the *kalothanasia* may provide important insights to the conceptual construction of orthotanasia.

The social ritualization of death

Despite the fact that the *hospice* movement's good death is culturally and historically circumscribed, the foundations of its categorization can be identified at different times and cultures and relate *to a dying process that allows each one to prepare for death with the cooperation of family and community*[10]. In various societies, this collective ritualization of death is a constitutive part of the social organization support and protection.

The body dissipation from the death of the individual threatens the collectivity he lives in, taking it to ritualize the loss in order to strengthen the bonds among its members. A cycle of social self-regulation from the death of their loved one is closed, it seems natural to think that *for the dead nothing* [seems] *more evident than attending the living ones* and *for the living ones* [than] *to forget* [this way] *the dead*[11]. Thus, social autopoiesis can be organized by individual death[12,13].

Kellehear[14] found the structuring elements of good death by studying the development of agricultural societies twelve thousand years ago. Those elements were crucial to the adaptation process of these societies in their historical course: active participation of those who were in process of dying, including the control over their assets distribution and the way their funeral should take place; the presence of family at the time of death and the intimate scenes of farewell; preparatory meetings with the dying ones, and, as a result, a more predictable and within certain guarantee rights death.

Thus, in a society heavily influenced by the rhythms of successive repetitions of cycles, *dying and death have become, like marriage and birth, to sow and to reap, good seasons and* [periods] *of hunger, part of the succession of predictable cycles* [15]. The process of dying and death itself became part of these rhythms and gave its members a fatalistic understanding of death. The way individuals should prepare for death would be wrought by the choices made in their lives, with rights and duties to be assumed. It can be said to this society that the journey to the other world had already initiated in this earthly life.

Still today it is possible to see the importance of the preparation ritual for death, funeral and the mourning ceremony itself in agricultural societies, especially in the first days after death until a six-week period[16]. In Tolstoy's tale, Lord and servant, we can find an example of ritual for death in these societies, within the death experience narrative by a Russian peasant to the late nineteenth century:

Nikita ended up dying at home, as he had wished, under the icons and with a lighted taper in his hands. Before he died he asked his wife's forgiveness and, in turn, forgave her for the cooper. He also took leave of his son and grandchildren, and died sincerely glad that he was relieving his son and daughter-in-law of the burden of having to feed him, and that he was now really passing from this life of which he was weary into that other life which every year and every hour grew clearer and more desirable to him[17].

In summary, the death shared in the family environment and with strong community participation are two historically important features of a good death. This model of ritualized death, so necessary to the contemporary construction of the journey of struggle and the *hospice* way of dying, also finds in ancient Greece one of the foundations to build its concept.

The journey of struggle as a criterion of happiness

The term good death has two origins. One is *eu thanatos* (*eu*: good; *thanatos*: death), from which originates the word euthanasia, meaning, in its beginnings, the gentle, painless and fast death, or dying well – currently understood as the desired death, which is temporally sustained by its requestor and based on an autonomous decision[18].

The other term's origin comes from *kalos, thanatos* (*kalos*: good, beautiful; *thanatos*: death), meaning beautiful, noble and exemplary death[14]. This type of coping with death, dying nobly – *kalós thanein* –, lies between the categories of the beautiful and heroic and, in fact, the beauty and heroism categories are constructions from the *aisthesis*, which indicates, at the same time, sensitivity (or feeling faculty) and sensation (or the act of feeling), which, in turn, refers to both the sensory knowledge of an object (or perception) and the sensory knowledge of one of its qualities [19]. But euthanasia's good death is also not separated from the *aisthesis*. It can be said that there is a complex relationship between euthanasia – with its spiritual dimension present in the Greek word *eu* – and *kalothanasia*, since both are products of the *aisthesis*, which refers to both a body and a symbolic phenomenon.

According to Soares, the ancient Greek Spartan has found in *kalós thanatos the culmination of a life, the dignity in death*[20]. This possibility was not restricted to the warrior, who was subjected to a code (*nomos*) of military honor, but to all members of society, since *the treatment applied, in particular, to the corpses of soldiers and, in general, to any man, was vital to the achievement of the ambitious plan of 'dying with dignity'* [21].

This way of dying was the crowning of the life course, the recognition of their *eudaimonia* (happiness)[22]. This symbolic pattern and ritual can be seen in the registry of Herodotus, in his Histories, through the response given by the Greek sage Solon when asked by the barbaric Lydian Croesus about whether he, Lydian, in view of Solon, had reached happiness: *I see that thou art wonderfully rich, and art the lord of many nations. But with respect to that whereon thou questionest me, I have no answer to give, until I hear that thou hast closed thy life happily*[23].

To the Spartan society of the time, a good death would be configured when certain elements were identified: the warrior needed to be fully aware that his journey was undertaken either by

winning or dying in battle – this assumed risk could not make him retreat, run away, kill himself or stay hostage. As these situations would be a dishonor to him and his family, with the break – *anomie* – of current *nomos*. Dying or living under such circumstances was a disgrace, the expression of suffering imposed on him and his family: the *kakos thanatos* (*kakos*: bad; *thanatos*: death). In other words, this was a death in distress, the antithesis to the desired happiness in life[24].

Despite the indisputable interface between the symbolic conception of death in the Greek context and that experienced in the *hospice* movement, the interest of this article is not to deepen this scenario, detailing the specificity of the death in combat of the Spartan wrestler. It aims to recognize which elements of *kalós thanatos* could ground the good death, that would be configured in the expression of this ideal of death for the modern *hospice* movement. An ideology inscribed not only in a specific type of death, but also in a specific process of dying, forged in a journey of struggle, a "die nobly", i.e. a profound aesthetic conception of the beautiful, the noble, that permeates this peculiar way of dealing with death, a beautiful, noble and exemplary death[14].

Thus, the *kalós thanatos* – and its adverb *kalós thanein* – gives an aesthetic and ethical sense to death, and to the process of dying senses of beauty, nobility and transcendence. Or, as summarized by Kellehear, it appears as a *set of culturally sanctioned and prescribed behavioral trends set in motion by those who are dying, and designed to make death full of meaning as much as possible*[25,26].

Nowadays, it is necessary strong internal motivation to enroll in the spirit of *kalós thanatos*, as there are those who see no meaning in death, as it cannot be realized or viewed, or represented, it could be, before anything else, an *absolute nothingness* (emphasis in original) and *an absolute nothingness does not make sense*[27]. But some may see a reductionism in this ontological nothingness, as expressed by Levinas: *But what does it open with death, nothing or unknown? Being at death's door will be reduced to the ontological dilemma "Being and Nothing"? That is the question that is posed here. Because reducing death to the dilemma being-nothing is bigotry in reverse, regardless of the feeling of an entire generation suspicious of the soul immortality positive dogmatism considered as the smoother 'opium of the people'* [28].

Kalothanasia and its meaning to the field of the end of life

Kalothanasia is a peculiar kind of fight. Not to be defeated by death, even knowing death is a certainty, the person hangs a fight in deeper bodies of his nature, giving it a motive and willingness to coping. This is a struggle not to succumb to death, a peculiar willingness to transcend it. That is, for these situations, the fight would not be *against* death, but *with* death.

This is one of *kalothanasia*'s meanings, a possible willingness that is observed in certain patients who escape from that dichotomy in which they are often seen at the threshold of death[29]. This dichotomy that exists, on one hand, due to the obstinate use of interventions, extending the process of dying without improving the quality of death – death as an enemy of life, constantly being fought – and that must be understood as an obstinate *journey of struggle* and therefore different from *kalothanasia*: it is, here, a fight to the end not to die.

On the other hand, there is a voluntary and autonomous refusal to continue living, wanting to meet death – death as a desire, in an untenable life –, the foundation of euthanasia/assisted suicide: to end the struggle.

The *kalós thanaein*, however, this virtuous way of coping that can be found in the patient who is facing death, would take from him all the misleading and apparent external resignation and clothe him with an internal willingness of extreme courage, in a scenario of struggle beyond death, not wishing an instant death, as he does not tolerate the way of life imposed by his condition, not wishing life at any cost, as he does not tolerate death as a reality. *Kalothanasia* is the synthesis of a third way of possibilities being offered at the end of life care. And this approach is the expression of the modern *hospice* movement philosophy.

Accordingly, *kalothanasia* can be viewed as an important set of behaviors and trends underlying the modern *hospice* movement. It was constituted in substrate that organizes and disseminates a set of loving and transformative care actions for the dying person, in a scenario that does not depend on the way each one faces his death and dying. It is possible to verify this typical *kalothanasia* willingness in the *hospice* movement, for example, in Twycross words: *a terminal illness should not be seen as an intrusion in our lives; it is part of life and can be a time of growing maturity and spiritual experience*

deepening for all involved. It is our job as doctors to help being so[30].

This can also be seen it in the words of the *hospice* movement's founder, Cicely Saunders, when she addressed an audience of doctors at the British Medical Association: *Talking about accepting death when its approach becomes inevitable is not mere resignation or weakness of the patient, nor is defeat or negligence by the doctor. For both, it is* [rightly] *the opposite of doing nothing. Our job then is to change the attributes of this inevitable process, so it is not seen as a loss of life, but as a positive achievement in* [the process of] *dying; an intensely individual heroic act for the patient*[31].

We may also find in the literature reports of this peculiar willingness to death facing at the end of life. Tolstoy[32], in the novel The Death of Ivan Ilyich, written in 1886, gives us a detailed description of how a transformative process can be possible, even in the last moments. Ivan, the tale's central character, is affected by cancer, and passed through an extremely difficult dying process, with great physical and psychological suffering, as he was also isolated from his family and his distant doctor. The exception was his butler Gerasim, a muzhik who welcomes and takes care of him in a loving and efficiently way – currently known as caregiver – within the ancient peasant tradition of taking care at the end of life, already described in this paper. In this scenario, it can be concluded that there is something extremely current in this late nineteenth century tale.

For the purpose of this article, we are interested in Tolstoy's narrative at the final moments of Ivan's life: *He sought his former accustomed fear of death and did not find it. Where is it? What death? There was no fear because there was no death. Instead of death there was light. So, that's what it is! – he suddenly exclaimed aloud. – What joy! For him, the entire experience was a single changeless instant. For those present, however, his agony lasted two hours. Death throes escaped from his chest, his emaciated body twitched. Then, they became increasingly sparse the death throes and gasps. It's all over! – someone said leaning over him. Ivan Ilyich heard these words and repeated them within his soul. 'Death is finished', he said to himself. 'It is no more.' He inspired some air, stopped in the middle of a sigh, stretched out and died*[33].

Ivan Ilyich finds his time to die alone and with control over his body, he knows his time has come. Struggling against everything and everyone around him, and in spite of a shameful and lonely journey, within the time possible, he seems to realize the full meaning of *kalós thanatos*.

Good death in contemporary society and the way *hospice* of dying

In 1997, the Institute of Medicine has defined "good death" as: *a good death or an appropriate* [death] *is one that is free from avoidable burden and suffering for patients, families, and caregivers*; [occurring] *generally in accordance with the wishes of patients and families, and reasonably consistent with clinical, cultural and ethical norms*[34]. A British study group on aging, in turn, identified twelve principles of a good death:

1. *To know when death is coming, and to understand what can be expected;*
2. *To be able to retain control of what happens;*
3. *To be afforded dignity and privacy;*
4. *To have control over pain relief and other symptom control;*
5. *To have choice and control over where death occurs (at home or elsewhere);*
6. *To have access to information and expertise of whatever kind is necessary;*
7. *To have access to any spiritual or emotional support required;*
8. *To have access to hospice care in any location, not only in hospital;*
9. *To have control over who is present and who shares the end;*
10. *To be able to issue advance directives which ensure wishes are respected;*
11. *To have time to say goodbye, and control over other aspects of timing;*
12. *To be able to leave when it is time to go, and not to have life prolonged pointlessly*[35].

All these principles can be found in many narratives about what it would be a good death. Among them it is possible to see, besides other aspects: 1) strict control of treatable symptoms**,** e.g., pain; 2) awareness of death by the patient; 3) respect patients' wishes, reflecting the respect for their autonomy at the end of life; 4) share the last moments with loved ones; 5) reduce the internal conflict with death and personal preparation for the dying process; 6) social settings, with redemptions and possible adjustments; 7) farewell moments; 8) several levels of support, both for patients and the close ones (caregiver, family and close friends), including the grieving stage; and 9) an ideology that permeates many professionals engaged in pursuing this way of dying, idealized expectations of a good death occurring in such a serene and peaceful way[6,7,36-43].

We have also found in the literature other meanings for the good death concept under the *hospice* movement which summarize – despite often being evaluative and without conceptual precision expressions – this particular way of coping, always bringing in their descriptions the ritualization and the seeking for the resolution of major conflicts in the patient's journey of struggle against a disease threatening his life. In other words, in these expressions we find the components of a trajectory of struggle against the disease; trajectory identified in the social characteristics of acceptance and welcome which give meaning to those who participate in it: dignified death; smooth death; death in peace; happy death; healthy death; dying well; certain death (often described in our midst, as orthotanasia; natural death; heroic death)[9,44-49].

What is behind those components is a set of characteristics that coalesce expectations of softer medical conduct to suffering relief, unconditional acceptance, respect for the decisions of the dying person and a process of dying that can be faced by the patient and socially ritualized in a medical scenario identified with the continued and persistent use of high technology. These are metamorphoses of dying processes which are historically identified in family and community death in agricultural societies and also in the ethics and aesthetics journey of the Greek *kalós thanatos*, that reframe to organize the *hospice* way of taking care and dying.

Good death is therefore the expression of the trend observed in the *hospice* movement today: the movement's *leitmotiv* would not be the compassion for the dying person – a fundamental aspect of its origins – but what would appear to be more important and which merges itself with the *hospice* movement nowadays, would be the way you die, that is, the process of dying itself, the *kalothanasia*[50].

Final Considerations

The *kalothanasia* configures itself in a set of prerogatives which guide the modern *hospice* movement's knowhow. It is the central axis for this movement, building its *ethos* around the ritualization of death, trying to give meaning and transcendence to its concept, being an important motivator for its practices.

The modern *hospice* movement pleads to achieve, with the construction of its model of "good death", the delicate position of offering a right way to die, a model of death which is considered noble and beautiful, full of meaning, in a medical scenario identified with the continued use of high technology. Behind the various constituent characteristics of a good death espoused by this movement, it can be found an aesthetically and ethically perceived and desirable death: the *kalothanasia*.

The growing institutionalization of the modern *hospice* movement's good death is a reality in the traditional health care system in many countries, to a greater or lesser extent, including Brazil. It is this theoretical framework that mobilizes significant portion of the professionals involved with the *hospice* movement and which gave important insights into the construction of its philosophical building in its beginnings. Indeed, it can be identified in the modern *hospice* movement a model of care that, in its activism, if fully followed, is supposed to be the best suited model to those who are on the threshold of death, leading to a smoother death. The modern *hospice* movement intends, therefore, to be an important route of achievements and care within a health system in which the medical practice at the end of life is quite often characterized by excessive interventions or abandonment, or by both situations at the same time.

However, the robustness or fragility of the *hospice* movement's good death in its growing interface with biomedicine will depend, to a significant extent, on how people who are on the threshold of death will be heard on their needs and respected in their decisions; that is, it will depend on the means adopted so that the dying person can take ownership of his own process of dying, becoming the subject of his life and death, essential aspects of his existence.

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