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REVIEW ARTICLES

Journey of struggle: Kalothanasia and the hospice way of dying

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ABSTRACT

The purpose of this article is to characterize the notion of a "good death" both historically and conceptually, grounding the philosophy of the modern hospice movement. This concept encompasses elements originating in ancient societies, such as peasant societies, where death was prepared for and shared socially, with ethical and aesthetic elements originating from Ancient Greece. These Greek elements emerged from a "journey of struggle" and can be recognized in the current day as a journey to cope with illness. From this conceptualization emerged a category of "good death" (*kalothanasia*), adding to the expertise of advocates of the modern hospice movement, who seek to revive a process of dying that is socially ritualized. However, this is challenging in the setting of a medical practice that is constantly incorporating new technology, in accordance with its present bio-techno-scientific paradigm, and in a medical scenario that identifies itself with the continued and persistent use of new technologies.

KEYWORDS: Attitude to death, Bioethics, Good death, Hospice movement, Palliative care, Terminal care

INTRODUCTION

The modern hospice movement is a movement that offers an assistance program to patients with terminal diseases and their families. The movement has proposed an innovative approach to care that is centered on patients and their active participation in decision-making; this is in direct opposition to the current biomedical paradigm, which centers its actions on treating the disease (Santina & Bernstein, 2004). The foundations of the hospice movement began to achieve more defined contours at the end of the 1950s, materializing with the construction of what would be recognized as the central hub of the hospice movement: St. Christopher's Hospice in England in 1967 (Clark, 1998).

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In the four decades since that time, the insertion of expertise from the hospice movement into traditional healthcare systems appears to be irreversible (Wright et al., 2008). The movement has responded not only to the specific need for increased expertise in end-of-life care among health professionals, but also to the moral imperative produced by patient abandonment, necessitating interventions that are consistent with the search for the alleviation of avoidable suffering at the end of life (SUPPORT, 1995; Schisler, 2003).

The modern hospice movement has proposed a set of interdisciplinary actions aimed at offering a "good death" and increasing the quality of life of patients at the end of life. The model of a "good death" encompasses several characteristics: a death without pain; a death occurring with the patient's desires being respected (verbalized or recorded in an advanced directive, a document left by the patient stating how he or she would like to die); death at home and surrounded by family and friends; absence of pain and suffering

for patients, their families, and their caregivers; the adequate management of the most stressful symptoms; death in a context where the patient's "affairs" are resolved; and death occurring with a good relationship between the patients, their families, and healthcare professionals (Emanuel & Emanuel,1998; Car, 2003; Saunders et al., 2003).

The importance of a "good death" in the hospice movement is such that the two care modalities, palliative care and hospice care, are often seen as being synonymous with a "good death." There is, in fact, an expectation of a characteristic way of dying when discussing palliative care or hospice care, i.e., the hospice way of care and the hospice way of dying (Clark & Seymour, 2002).

In this article, we will historically and conceptually characterize the notion of a "good death," which grounds the philosophy of the modern hospice movement. It will be possible to verify that such a concept presently encompasses elements originating in ancient societies, such as peasant societies, where death was socially planned and shared, with ethical and aesthetic elements originating in Ancient Greece. These Greek elements emerged from a "journey of struggle" which at the present time, can be recognized as occurring as a part of a journey to cope with illness. From this conceptualization has emerged a category of "good death" (*kalothanasia*), which is distinct from the historically known category of euthanasia, adding to the expertise of advocates of the modern hospice movement, who seek to revive a process of dying that is socially ritualized. However, this is challenging in the setting of a medical practice that is constantly incorporating new technology, in accordance with its present bio-techno-scientific paradigm, and in a medical scenario that identifies itself with the continued and persistent use of new technologies.

HISTORICAL ROOTS OF "GOOD DEATH"

A "good death," the concept that unifies the hospice movement, is situated in both a cultural and historical context. However, elements common to distinct periods and cultures can be identified. For example, the social reference that emerges and sustains the idea of "good death" in the course of historical development, concerns "the dying that permits one to prepare for death with the cooperation of family and community" (Kellehear, 2007, p. 86). In fact, in both primitive and Western societies, collectively ritualized death is a necessary part of a scenario of sustainment and social protection (Rodrigues, 1983; Bourgeois & Johnson, 2004). In dying, the individual subject physically disappears and threatens the collective in which he or she lives; therefore, in ritualizing this loss, the society is able to maintain life and strength, because it appears natural to think that "for the dead, [there is] nothing more obvious than visiting the living" and that "for the living, [the most natural thing] is forgetting [in this manner] the dead" (Sloterdijk, 2009, p. 9).The death of a member in a society that ritualizes this loss offers power to the members that remain, remodeling the social texture. In other words, social autopoiesis depends on individual death (Morin, 1970).

According to Kellehear (2007), the configuration and incorporation of the constitutive elements of a "good death" were established with the development of the peasant society 12,000 years ago. In distinct periods, these elements had a crucial role in the adaptive process of that society. They included the progressive development of a socially shared death in the arms of another; and the active participation of those dying in the planning of their funeral, burial, and intimate scenes of farewell as well as in the control of the distribution of their goods and properties.

It is in this peasant society that, for the first time, the occurrence of preparatory meetings with those who were dying has been verified, making dying and death more predictable. The process was ritualized in accordance with the determined rights and duties of all those involved. With this, "dying and death become like marriage and births, like sowing and harvesting, like good seasons and famines, part of the round of predictable cycles" (Kellehear, 2007, p. 85). Therefore, in a society that lives in this rhythm of successive repetitious cycles, dying and death came to be a part of these cycles, constituting a fatalistic approach for all of its members. It was thought that the preparation for this important event should be created during the person's existence, with the type of life already chosen and with the types of duties already assumed during the course of one's life. Therefore, the otherworld journey had already begun during one's earthly life (Kellehear, 2007).

In current peasant societies, we still find a strong valorization of the preparation process for death, the funeral ceremony, and the mourning phase, especially in the first three days after death, which can extend until the end of the sixth week. In studying Hungarian and Romanian peasant societies, Berta (2001) demonstrates that the individual that breaks with this ritual suffers harsh sanctions. For example, the author describes what occurs within this community when a person commits suicide. There are many important constraints in this setting, such as, for example, the loss of the right to purification rituals and the segregation of the person's soul in the afterworld, resulting in a "frightening otherworldly perspective of the future" (Berta, 2001, p. 108). In addition, their families come to suffer constriction and restrictions, as well as an intense

feeling of shame, which only increases their pain and feelings of loss.

Another example of the ritual of death among peasants appears in the story "Master and Man" by the Russian writer Tolstoy, narrating how a Russian peasant at the end of the nineteenth century experienced the death process: "Nikita died at home as he had wished, only this year, under the icons with a lighted taper in his hands. Before he died he asked his wife's forgiveness and 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." (Tolstóy, 1991, p. 66)

In short, death in a family setting and with strong community participation are two historically important characteristics of a "good death." This ritualized model of death, so necessary for the contemporary construction of the "journey of struggle" of the hospice way of dying, also finds its foundation in Ancient Greek customs.

KALÓS THÁNATOS AND THE CONSCIOUS JOURNEY TO DEATH

There are two origins of the expression of a "good death," both of which are Greek in origin. One derives from *eu, thánatos* (*eu:* good; *thánatos*: death), from which the word euthanasia originates. It has signified, since its inception, a gentle, painless, rapid death, a "dying well." At present, it is understood as a death temporarily desired, sustained by its solicitor, and grounded in an autonomous decision (European Association of Palliative Care Task Force, 2003).

Another origin of the term derives from *kalós, thánatos* (*kalós*: good, beautiful; *thánatos*: death). The term refers to an event considered as exemplary, beautiful, and noble (Kellehear, 2007). This type of confrontation with death, i.e., *kalós thanein*, is situated between the categories of "beautiful" and "heroic," and, in fact, the categories of *beauty* and *heroism* are constructions of the term *aisthesis.* At the same time, *aisthesis* indicates *sensibility* (or capacity of feeling) and *sensation* (or act of feeling), which, in turn, refers both to the sensory knowledge of an object (or *perception*) and to the sensory knowledge of its qualities (Gobry, 2007).

However, the "good death" of euthanasia is not separate from the concept of *aisthesis.* There is, it can be said, a complex relationship between euthanasia, with its spiritual dimension present in the Greek word *eu*, and *kalotanásia*, as both are the product of *aisthesis*, which refers both bodily and symbolic phenomena. For Plato, for example, this appears clear in the Banquet (206e, 210a-212c) (Platão, 2006); he affirms that we are taken to the Idea of Beauty through *éros* or Love, which is the force that takes the spirit toward an object. This is as much in the sense of irrational passion as in that of "divine attraction for beauty" (Groby, 2007, p. 58).

Herodotus in his *Histories* tells us how an ancient Spartan would perceive *kalós thánatos* as being "the corollary of a life, the dignity in death (. . .)" (Soares, 2003, p. 103). Although the constitutive elements of "good death" were collected from the stories of the Spartan combatants and were born from a code (*nomos*) of military honor, "good death" was not limited to warriors. In principle, it included much more, because, for the Spartan, "the treatment reserved, in particular, to soldiers' cadavers and, generally, to any man, is fundamental for achieving the ambitious plan of 'dying with dignity'" (Soares, 2003, p. 103).

It is necessary to remember that happiness (*eudaimonia)*, to which the ancient Greek man would aspire to, was only, possibly, attained and recognized with death (Soares, 2002). Depending on how a man died, he would reach it or not, as Herodotus recounts well in *Histories* in the response of the Greek philosopher Solon to King Croesus of Lydia: "To my eyes you give displays of possessing a colossal fortune and of being master of a multitude of men. However, to the question that you asked me, I respond to you without before taking into account that which terminates well the course of your life" (Soares, 2003, p. 62).

Thus, the constitutive elements of *kalós thánatos* that configure "good death" are as follows: death in combat, with the total awareness of the possibility of its occurrence; the impossibility of the warrior killing himself or fleeing; a death outside of prison without being held hostage by another; a death during a difficult journey; and the reception of the death and burial by his family (Soares, 2003).

It should be stressed that a death with these attributes would occur within a code (*nomos)* of moral force; suicide and escaping were situations that were considered dishonorable due to the breaking of this moral code (*anomia*) in the community. Therefore, this dishonor would result in a death of suffering, *kakós thánatos* (*kakós*: bad; *thánatos*: death); this occurred regardless of how long after the death the act that had caused the dishonor had transpired, unless the act had been repaired (Soares, 2003).

Therefore, *kalós thánatos* is expressed as a true "death journey," which makes the act heroic and exemplary. There is, in this conception of death, a deep aesthetic sense, a beautiful feeling, which gives this kind of death a noble connotation, a beautiful death, an ideal or exemplary death. This is not only

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considering one type of death, but principally, a process (*kalós thanein*) of "dying nobly" (Kellehear, 2007).This type of death occurs during confrontation with an enemy and during a journey of fight that is consciously travelled with courage, and as such, is morally legitimate.

An ideal of virtue permeates all of the drama of *kalós thánatos* and its honors, interweaving an aesthetic sense of beauty with an ethical desire for good in consonance with a code of moral force (*nomos*), therefore constructing a feeling for the beyond, a heroic inscription for those that stayed, performed by those who died. In other terms, *kalós thánatos* and its adverbial form *kalós thanein* — dying nobly — are describer as "a set of culturally sanctioned and prescribed behaviours set in motion by the dying and designed to make death meaningful for as many concerned as possible" (Kellehear, 1990, p. 29).

Kalós thánatos incorporates an achievement with strong internally and morally sanctioned motivation; it is a type of journey toward beyond death in a social inscription that glorifies it, and all the mishaps on the path must be confronted with virtuosity and meaning. Presently, this grounded interior position is necessary to ascribe to the spirit of *kalós thánatos*. Even because there are those who do not perceive meaning in death, which cannot be perceived, nor visualized or represented, it would be, before anything else, an "absolute *nothing*" (italic by author), and because "an absolute nothing has no meaning" (Bauman, 1992, p. 2).

A PORTRAYAL OF CONTEMPORARY DEATH: THE DEATH OF IVAN ILYCH

One of the most important descriptions of the modern human process of dying is found in Tolstoy's novel, *The Death of Ivan Ilych*, which was written in 1886 and is about the dying process of one Russian middle-class man during that period (Tolstóy, 1991). In a striking manner, due to the realism and the drama experienced by his characters, Tolstoy anticipates us in his way of dealing with death that is still, to this day, sufficiently familiar and common in many cultures. In an environment constructed on top of lies, family and doctors decide for the ill person the uncertain direction of his or her life, thus excluding the person from any participation in decision-making. This is done by hiding the disease, in this case cancer, from the one who has it. The patient then suffers both a devouring disease and the psychic torments of internal uncertainties and negotiations in an agonizing crescendo of loneliness, denial, anger, and bargaining.

The servant of his house, Gerasim, who protects and cares for him, comes from a more simple class; he is muzhik, a Russian peasant. The relationship between this simple man and the care that he has for his seriously ill master returns, as we see, to the ancient tradition of the "good death," borne between peasants, and still present in the Russian peasantry in the nineteenth century.

Tolstoy anticipates, with this novel, the discussion about the lie surrounding illness and the importance of caring for the dying. He brilliantly describes the internal clashes, negations, anger, and all sorts of emotional fluxes that one has while dying (Young-Mason, 1988; Brungardt, 2009). Many years later, Kübler-Ross would systematize this as the phases in the dying process (Kübler-Ross, 1969).

However, in the end, Tolstoy makes it clear that even with the silence of all, the isolation, the loneliness, and the abandonment that his suffering character was submitted, it could be possible to find comfort and redemption, a distancing from any feeling or suffering:

> He sought his old and usual fear of death, but he could not find it. Where is it? What death? There was no fear, because there was no death. Instead of death there is light. So it is this! — he said suddenly, in a loud voice. — What happiness! For him, all this passed in an instant, and the meaning of this instance had not further changed. For those present, however, his agony still lasted for two hours. From his chest escaped death throes; his emaciated body shivered. Then increasingly more throes and panting escaped. It's over! — said someone leaning over him. Ivan Ilitch heard these words and repeated them to his soul. 'Death is over,' he said to himself. 'It does not exist anymore.' He breathed the air, stopped mid-gasp, stiffened up and died (Tolstóy, 1991, p. 181).

One can inquire if today the dying and death of Ivan Ilych would not be in opposition to the defended precepts of the modern hospice movement. It would not be difficult to respond affirmatively, because Ivan endured every type of hardship possible, from uncontrollable pain, which left him sleepy when controlled, to his lack of proximity to his family and close friends. In addition, he had a barely interested doctor with him (or the doctor did not know what to do). The exception was his faithful servant, who nowadays would be called a caregiver, who was always present and helpful. Therefore, we can only conclude that there is something extremely modern about this story written at the end of the nineteenth century.

However, delving deeper into this question, the manner in which Ivan Ilych lived his last moments provides for a most important discussion point: the process that he lived through was absolutely

individualistic, because one who is at the threshold of death does not necessarily have a relationship with the care that can be received. Here, we can only speculate that in the face of a dying process as anguished and miserable as Ivan's, it can be risky to valorize death as good or bad, because, as described in this novel and also in others (Hennezel, 2001), transformative transcendental experiences can occur even in the last moments of life. The care provided does not guarantee that the dying person will have a "good death," and the unsuccessful experience of this care, or that which is understood to be so, should not be a discouragement for one who seeks to care for those at the threshold of death (McNamara et al., 1995; Menezes, 2004). There is no guarantee that one who dies in supposed suffering, to the outside observer, is really suffering. The ordinary human senses, in this case, of the caregiver to the dying, normally preclude capturing such profoundly layered experiences as those that can occur in one who is dying. As such, it is important that this outside observer evaluate if there is suffering and who is suffering: whether it is the one suffering or the one observing such suffering. As such, returning to Tolstoy's novel, without being able to depend upon the help of the professionals for the dying process and death itself, Ivan encounters his time of dying with control of his body, knowing that the hour has arrived. Fighting against everything and everyone around him, and despite an inglorious and solitary journey, Ivan appears to achieve the full meaning of *kálos thánatos*.

The death of Ivan, even in the setting of a death that is uncomfortable to be seen, is perceived and determined by one who is dying in his or her last moments. From this perspective, we can understand Levinas' words when the philosopher denounced the implicit reductionism in the "ontological dilemma of being nothingness" as "reverse" dogmatism:

> But is that which opens with death nothingness, or the unknown? Can being at the point of death be reduced to the ontological dilemma of being or nothingness? – That is the question that is posed here. For the reduction of death to this dilemma of being or nothingness is a reverse dogmatism, whatever the feelings of an entire generation suspicious of the positive dogmatism about of the immortality of the soul, considered as the sweetest 'opium of the people' (Levinas, 2000, p. 8).

It was by assuming a critical position with respect to the process of dying, as brilliantly described by Tolstoy, that the hospice movement constructed the foundations of a "good death." In the portrayal of the constitutive characteristics of the hospice movement's "good death," we can extract the formative elements of the perceptions of death in peasant societies, and from the Greek *kalós thánatos*; we will analyze this in the following paragraphs.

"GOOD DEATH" IN THE CONTEMPORARY WORLD: THE HOSPICE WAY OF CARE

Weisman and Hackett (1961) in their hypothetical model of "good death" or "appropriate death" describe it as the inevitability of personal death being recognized as an achievement or a realization of life. For both, "appropriate death" would depend upon meeting four conditions that were addressed with the patient: need to reduce the internal conflict with death; finding compatibility with the ego ideal; repair or preservation of important relationships; and consummation of a wish is brought about.

Kellehear (1990), already studying the behavior of 100 patients with cancer in the last year of their lives, found five repetitive, sequential, and interdependent stages: the first stage would be an awareness of dying; the second stage would be the social adjustment and personal preparation phase; the third stage would be divulging to the community, the public preparation phase; the fourth stage would be that in which the patient surrenders his or her responsibilities and commitments; and lastly, the fifth stage would be the moment of farewell.

In 1997, the Institute of Medicine defined "good death" as "one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1977).

In Webber's study we find various narratives about death and some characteristics of a "good death," which include: a death without treatments that persist beyond what the patient wants; with the absence of treatable symptoms, for example, pain; where the patient has decision-making power; with the appropriate psychological approach; and where the patient, family, and friends can count on help on various levels (Webber, 1999).

Other authors identify a "good death" as a death without pain, that is comfortable, and where the patient is surrounded by those that he or she loves and is being cared for with love, dedication, and competence. In a "good death," psychological symptoms are addressed within a healthcare system that is orderly and functions to care for those at the end of life. In addition, a "good death" may be one that occurs at home, without conflict with heathcare professionals, and where the one who is dying has control in that moment (Pierce, 1999; Singer & MacDonald, 1999; Bowling, 2000; Grogono, 2000;

Steinhauser et al., 2000; Thomas & Day, 2000; Ganstal, 2003; Prigerson & Bradley, 2003; Breitbart, 2006).

A group from a British study concerning aging identified twelve characteristics of a "good death" (Smith, 2000):

1 To know when death is coming, and to understand what can be expected.
2 To be able of retain control of what occurs.
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 with who shares the end.
10 To be able to issue advanced 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.

Seale (1995) discusses attempts to share positively in the relationships between those who are dying and their companions; a search for social connection with others and self-esteem affirmation were noted in the stories provided by the companions; it is these deaths that the author called "heroic deaths."

We find other names for "good death," which are defended by the hospice movement. They, in essence, refer to ritualism in the journey to death and include the following terms: "dignified death," "serene death," "in peace," "happy death," which encompass a model of acceptability and a lack of bickering, "healthy death" or a "dying well" (Byock, 1996; Field, 1996; Callahan, 2000; Neuberger, 2003; Chochinov, 2006).

We also find spontaneous stories in our daily work and in the media that portray this exemplary journey: "He is a hero;" "He is a fighter;" He died as a hero;" "He was a warrior;" "He fought his disease bravely;" "He will win this battle;" "He fought a dignified and courageous fight against cancer" (Seale, 2001; Henig, 2005).

In all these "ways of dying," we find the constitutive elements of a path of struggle against the disease. This path is identified with the social characteristics of acceptance and welcoming. Regardless of the names that are suggested by various authors, what is behind these constructions is a set of characteristics that form expectations of more "gentle" medical methods for suffering alleviation, unconditional acceptance, respect for the decisions of the dying, and a process of dying that can be faced by the patient and can be socially ritualized (Floriani & Schramm, 2010). There are metamorphoses of the processes historically identified in familial and communal death in peasant societies and in the ethical and aesthetic journey of the Greek *kalós thánatos*.

For some, these models of "good death" would be the expression of an attempt found within the present-day hospice movement, a focus not only on compassion for those who stand out while dying, which is fundamental to the origins of the movement. Instead, it would show that what is most important would be how one dies, or rather, the process of dying itself (Bradshaw, 1996).

FINAL CONSIDERATIONS

The social ritualization of a process of dying and death, inserted into a journey that expresses the patient's fight in a medical scenario identified with the persistent and growing use of technology, places the modern hospice movement in the delicate position of being the flag bearer of a certain way of dying. In other words, a model of dying considered dignified and beautiful, full of meaning, and appropriate to those that are on this journey: the *kalothanasia*. Behind the various constitutive characteristics of the "good death" defended by this movement, one can perceive it as an ethical and aesthetic death.

The institutionalization of the "good death" in the modern hospice movement is a reality. It is this theoretical framework that mobilizes an expressive segment of the professionals involved with this movement. In fact, the hospice movement has identified the need to offer a model of assistance that assumes, if fully followed, to be the most adequate for someone at the threshold of death, leading to a "good outcome."

The modern hospice movement intends to be an important locus of a specific style of care within healthcare system in which, quite frequently, there is a medical practice at the end of life that is characterized by excessive intervention, abandonment, or both.

Insofar as it is introduced in the traditional healthcare system, the "good death" may be able to demonstrate its strength and weaknesses. Both of

them will depend, to a great extent, on how people at the threshold of death will have their needs heard and their decisions respected, i.e., the means adopted so that those who are dying can take ownership of the dying process in which they are involved. Herewith, they become subjects of their lives and deaths, an essential aspect of their existence.

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