

Original article

# Health care for terminal patients: between medical practices and religious beliefs<sup>1</sup>

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## Abstract

The new Brazilian Code of Medical Ethics, which became effective as of April 13, 2010, addresses terminal and irreversible clinical situations. In such cases, doctors are advised to provide appropriate palliative care for patients under their responsibility instead of performing unnecessary diagnostic and therapeutic procedures. The Code's process of approval is examined in this article, as well as the changes occurred in Brazil within a few decades regarding health care for clinical profiles considered as terminal or out of the therapeutic chances of cure. Although the terms orthothonasias, dysthanasia and euthanasia are not used in the new Code of Medical Ethics, they are addressed in this article together with the different points of view of religious groups on the process of dying. A "good death", with dignity, or the production of a humanized death has received the attention of palliative caregivers, who postulate the need to provide spiritual assistance to ill patients and their families. Surveys with palliative care teams and the medical ethics new code's text are the background for the debate over the dilemmas faced by all those practically involved in the process of dying. Finally, focus is placed on the doctor/patient/family relationship in this recent kind of care, because such interaction is intertwined with power relations, where different values and religious beliefs can be seen.

## Keywords

doctor-patient relationship; spiritual assistance; palliative care; health-illness process; life-death.

As of April 13, 2010, a new Code of Medical Ethics became effective in Brazil and its standards particularly address ill people diagnosed as terminal or without therapeutic chances of cure. Article 41 of Chapter V, which is about the relationship with patients and family members, states that the doctor is not allowed to "shorten the patient's life, even if requested by either the patient or his legal representative"; and the sole paragraph makes it clear that "in cases of irreversible and terminal illness, the doctor should offer all the palliative care available without adopting useless or obstinate diagnostic or therapeutic actions, rather to consider the patient's will or, if not possible, his legal representative's will".

Under the perspective of health care, such principles and norms reflect an opposition to practices that can yield an inhuman process of dying. The new standards of medical conduct are geared towards producing a good death, with dignity, capable of avoiding interventions that may cause the ill patient to suffer, designated as obstinacy, futility or therapeutic cruelty. Such terms are associated with prolonging life when there is no longer hope for cure or control of the illness, with interventions that cause the ill patient to suffer. Therefore, it is about providing *orthothonasias*, defined by doctors as the natural process of dying, without using resources to hasten or postpone death. The inclusion of such norms in the new

document ruling doctors' ethical conduct results from criticism to an markedly curative model, where death was – and still is, at times - seen as failure by health professionals (HERZLICH, 1993).

Determining the end of life – and how it should happen – depends on historical, social and cultural context. Living/dying have always been influenced by laws and religious values. Nowadays, it depends on the debate and the standardization that builds near the fine line dividing being alive from being dead. In the modern western society, two spheres influence the definition of the beginning and the end of life: the scientific and the religious spheres. The former has been associated, since the 18th century (FOUCAULT, 1994), with the statute of producing "truths", guiding the creation of criteria for the person's conditional existence. As regards the second sphere, in each context positions and demands of religious groups emerge, in view of new possibilities to intervene in the beginning and the end of life and to decide over them.

Since the beginning of this century, practices such as euthanasia and the interruption of fluids, food and/or treatment have caused increasing controversy in many countries as the claims to make those procedures legal grow (MENEZES, 2009). In Brazil, there are groups both for and against the formulation of norms and laws, as was the case of the new Code of Medical Ethics.

This article aims to examine the process whose result was the formulation of the standards which refer to the condition of terminal patients, and the recent type of care provided in this situation. Surveys conducted in public units of palliative health care and interviews with doctors devoted to palliative care<sup>2</sup> have contributed to the debate on the practical dilemmas faced by all the people involved in the process of dying. The Code of Medical Ethics was chosen as a reference to examine these issues not only because it is the document that regulates and sanctions the medical conduct, but also due to the fact that the Brazilian Medical Council plays an extremely important political role in Brazilian society. As stated on the website of the Council, it is about "defending people's health and the doctors' interests"<sup>3</sup>. Moreover, it is common knowledge that creating and approving standards which refer to life and death are not only based on technical criteria, but also influenced by religious values and beliefs. Another aspect is the centrality of the forms of knowledge related to the health-illness process, to the medical institutions, and to health professionals in the modern western culture<sup>4</sup>. In other words, one can observe the increasing importance of this reference in people's everyday life, in the views and the habits concerning oneself's care.

## Death and dying in modern western society

The process which originated the increasing penetration of referents arising from biomedical knowledge into everyday life – designated as medicalization of society – was and has been investigated by several authors, among which one can highlight the pioneering studies by Michel Foucault (1979, 1994), Philippe Ariès (1981, 2003) and Norbert Elias (2001). Published from the 1960s onwards, these studies analyze the emergence of the general hospital and the concurrent transformation in knowledge that established the anatomo-clinical rationality, which came to structure modern medicine. Before the 18th century, hospitals were essentially institutions assisting the poor, managed by religious denominations, with no resemblance to contemporary hospital medicine (FOUCAULT, 1979). Hospitals not only offered shelter to the poor and the socially excluded but also protected other people from contamination danger. They were places associated with assistance, separation and exclusion. It should be noted that members of the clergy relied on other people's help, especially women's, to care for the poor admitted into hospital in order to save their souls. Those helpers were people considered to be sinners; they did not aim to cure the ill, but to save themselves on the day of the Last Judgment.

At the end of the 18th century, pathogenic elements are reorganized, and medicine starts to produce a scientific speech about the individual, his health and illness. Hence, the origins of the medicalized hospital lie in the adjustment of two closely connected processes: care shifts from clergymen to doctors, and the disciplinarization of the institutional space shows in specific architecture and functioning, so as to become itself a means of intervention upon in the ill patient. An important character has emerged from the core of this type of intervention: the hospital doctor. Trust in this social actor by groups, communities or societies is the result of a long process that took place in the modern western culture. According to Daniel (1999), trustworthiness acts as a mediator not only in the doctor-patient relationship, but also in the articulation between a professional category and society.

From the 18th century, the definition of life and death was incorporated into the medical knowledge grounded in science, and in biology, in particular. At least ideally, secularization and medicalization of society (MENEZES, 2004) shifted the definition and the determination of the limits between life and death from religion to science. The organization of a highly rationalized logical structure to produce "truths" about the universe became the prominent axis (FOUCAULT, 1994; CAMARGO Jr., 2003). Thus, illness and death started to be

considered natural events, caused by recognizable diseases. The end of life was reconstructed and resignified: from a spiritual passage to a medical phenomenon (WALTER, 1996). Biomedical knowledge became the hegemonic reference as regards health and, at the same time, hope while coping with dying. As a result, hope was medicalized and secularized.

As medicine and medical doctors became crucial to manage illness and dying, new standards had to be formulated, especially with the advent of innovative medical technologies geared towards creating, prolonging or maintaining life. During the 20th century, particularly the second half of it, new equipment was manufactured - for example, mechanical ventilators - presenting new ways to intervene in the body. In a few decades, technologies for transplantation of vital organs (LOCK, 2002) and assisted reproduction (LUNA, 2007) were created and disseminated and the transplantation . Moreover, life could be prolonged with specific life-sustaining equipment and therapies.

The emergence of such new possibilities required new standards. There is debate over new criteria to define death, especially as regards the profile of patients considered to be in "irreversible coma" (LOCK, 2002). Definition of death starts to adhere to two conditions: "traditional" cardiopulmonary death and brain death. This definition was produced by a committee at Harvard Medical School (in the United States), and became a criterion for most western countries in the 1980s. The committee focused on the social meaning of death: at stake were the definitions of person, process of dying and brain functions. A new statute for the person and life itself is created, wherein personal identity is centered around the mind (LOCK, 2002). The criteria used by this committee to set the limits between life and death became prevalent in the United States and Western Europe, where the belief in medicine is nearly hegemonic

On August 8, 1997, the Brazilian Medical Council passed Resolution CFM nº 1.480, which defined new criteria to determine brain death (FRANÇA, 2004). Determining the boundary between life and death involves legal aspects which can be subject to different interpretations and interests. The decision to terminate artificial means of life support causes great controversy when there is no consensus among members of the patient's family or the medical team over the procedure.

In addition to brain death, another condition is required, as stated in the new Brazilian Code of Medical Ethics: irreversible or terminal situations. Diagnosed as lacking therapeutic chances of cure, such cases have received considerable attention of health care teams since the emergence of a new

type of care offered to dying patients. Palliative care or *hospice philosophy* emerged in England and the US in the late 1960s as a response against a prevalent type of care considered inhumane, whereby a physician would exert excessive power over ill patients. In order to explain the origins of palliative care, it is necessary to introduce the process that culminated with the formulation of the concept of a normal or natural death - in other words, orthothanasia.

The end of life has been investigated by social sciences ever since the beginning of the 20th century, especially by French and English scholars (DURKHEIM, 2000; MAUSS, 2003; EVANS-PRITCHARD, 2005; RADCLIFFE-BROWN, 1940). English ethnographic studies describe death rituals in detail. However, these studies have solely focused on non-western cultures. In the second half of the 20th century, social sciences have produced an increasing number of studies on the process of dying. According to some authors devoted to this issue (ARIÈS, 2003; Herzlich, 1993), the increased interest was due to the realization of relevant changes in attitudes, practices and representations concerning death and dying. With the realization of such social changes, the end of life – mainly as a result of a chronic and degenerative disease – was food for thought about the fragility of social bonds, the increasing institutionalization of health care, the routinization of health care for the ill as well as the concealment and social exclusion of those who are approaching the end of their lives.

In order to obtain a historical understanding of the origins of this typical death management model from the second half of the 20th century – known as the "modern dying" model - Ariès (2003) conducted a pioneering investigation on the changes in the collective attitude towards dying. His study covered a long historical period ranging from the Early Middle Ages to the 20th century. His approach is based on the conception of a progressive degradation of the relationship with death, established by individuals and societies. Ariès is particularly critical of the modern period, which set the final stage of ill people's life apart from daily life, while turning that into a taboo.

During the 20th century, the technical progress of medicine managed to reduce some mortality rates, especially child and neonatal rates – and extend life expectancy, thus changing the way death was dealt with. Concurrently, by adopting prevention measures and exerting social control of health and illness, medicine itself played a major role in keeping death away from individuals' consciousness. The awareness of some natural processes' inexorability is then softened by a notion that somehow they can be controlled.

Several authors (GLASER, et al., 1965, 1968; KÜBLER-

ROSS, 1969; SUDNOW, 1967) have investigated the modern model of dying, managed by biomedical knowledge and medical institutions. The core issues addressed by such studies are the process of depersonalization of patients admitted to hospitals; the increasing power of doctors; the dehumanization, subjectification or objectification of the ill, especially the moribund. In this type of management of dying, the patient is in the hands of the doctor and has limited possibilities to access knowledge of what is happening to him and hence, knowledge of possible alternatives and choices for therapies. The ill person is silenced and has no participation in decisions about his life, illness, suffering and death. In this model, the social actors involved in the process of dying have no chance to express their feelings and wishes (ELIAS, 2001). For the hospital and the health care team, death represents, above all, the expression of failure of medical intervention: thus, it is convenient that death loses its central importance and stops demanding resources and energy.

The paradigmatic image of dying in this model is that of an ill person admitted to an intensive care unit (MENEZES, 2006), whose body is lonely, isolated, and connected to equipment. This profile is designated as *dysthanasia*, as a result of futility, obstinacy or therapeutic cruelty. These expressions depict a profile where the doctor opts for medication or surgery without consulting with the patient and his family, despite the large body of evidence that there is no cure for the illness or the possibility to control it. This medical conduct means not only prolonging the ill patient's life but also causing him and his family to suffer. On the other hand, the religious perspective of prolonging life is also ambiguous, as one "cannot use it as one pleases" because life is a "gift from God's love", as stated in the Declaration on Euthanasia by the Catholic Church.

### Palliative care: a new social organization of dying

The criticism of both scholars and society in general inspired new models to manage death. In the 1960s/1970s, in the United States, advocacy groups for ill people's rights and civil organizations claimed for issues ranging from the right to die with dignity to the regulation of euthanasia. Finally, there emerges a discourse proposing a new assistance model that was to change the power relationship for the practice regarding the end of life. In 1967, Cicely Saunders sets up the first hospice<sup>5</sup>, an exemplary institution of the innovative model of assisting terminal patients: palliative care. Around fifteen years later, given the HIV/AIDS epidemics and the

development of techniques to fight degenerative diseases, especially cancer, and the pain and symptoms these illnesses cause, other palliative care units were founded, at first in Anglo-Saxon countries and then in other countries.

Rather than silenced, hidden or denied, the concept of dying started to be debated. The diffusion of this new form of care for terminally ill people, at the beginning of the epidemics, was partially due to the ones having AIDS: politically, ideologically and socially committed young people from social classes with great visibility. It should be noted that in 1986 the World Health Organization published the manual *Cancer pain relief and palliative care report*, which was translated into nineteen languages and distributed in several countries. This manual echoed the concern with the comfort and well-being of terminally ill cancer patients.

Basically, the palliative care team aims to assist the moribund until the end of his life, by minimizing his discomfort and by providing spiritual and emotional support to his family. In other words, palliative health professionals advocate good death and believe that the dying person should have control over the dying process, that is, he/she should be able to make decisions based on the information provided by the doctor about techniques and possible therapies. Their motto is the straightforward communication among health professionals, patients and patients' families: all the stages of the treatment should be discussed by all social actors involved. In opposition to the essentially curative "modern dying" model, which deprives the patient of his voice, the new assistance model takes into account the will of the ill person.

Dialogue among the social actors involved in the process of dying is crucial in the palliative proposal: once the limits of the doctor's actions and the patient's choices are clear, decisions can be made about particular procedures to follow and people to say farewell to, with support being given by a multi-professional team. The core principle of palliative care is to humanize dying and to offer dignity to it. Such conception has a religious bias, as it postulates care for the "spiritual-biopsychosocial wholeness" of the patient and of those related to him.

It is about the incorporation, by health professionals, of a dimension of life so far not in their range of intervention. It can be stated that the palliative proposal is supported by the junction of three logics: the medical, the psychosocial and the religious spheres. This new discipline's theoretical body (Palliative Medicine) legitimizes a new field of professional intervention aiming not only at the ill patient but also at his relatives and friends, and considering the patient's religiosity and beliefs.

The belief in eternity, the soul, the spirit, the afterlife – among other possibilities – especially regarding the process of dying, was eclipsed by medicine in the modern western culture (WALTER, 1996). Palliative care teams should develop skills whose purpose is to "learn about and acknowledge the spiritual needs of terminal patients" (STANWORTH, 2004). Ideologists of palliative care see the end of life as the last opportunity for a person to develop, when he can harmonize his faith and the construction of meaning for life and death. Along these lines, there appear proposals for group intervention - the ill person and/or their family - and individual appointment, aimed at achieving "spiritual peace" (BREIBART, 2003).

Types of spiritual assistance advocated by palliative care teams are context-dependent. In England and in the United States, emphasis is given to the use of meditation and visualization techniques, similar to those of the New Age. In France, a country with a strong influence of psychoanalysis, the situation experienced by the terminally ill patient tends to be interpreted psychologically and palliative care teams often pose some resistance to accepting religious practices (CASTRA, 2003).

In Brazil, there is a strong spiritist frame of reference: several of the health professionals who participated in this study mentioned that they believe in the afterlife and in spirits who aid the ill patient in their "passage" (MENEZES, 2006). The belief in spirits is part of the network of meanings commonly found in Brazilian society (VELHO, 2003). Many of the Brazilian palliative health professionals interviewed (MENEZES, 2009) state that "there is life after death", regardless of their self-acknowledged religious orientation. Palliative care teams believe it is crucial for the ill to rescue pending material, relationship and spiritual issues so that they can have a good death. Palliative ideas prescribe a path to be followed towards a good death. Practical decisions have to be made concerning retirement, pension or will. Quarrels with friends and/or relatives have to be resolved, preferably with forgiveness for wrongdoings being achieved. Finally, the ill person should let go the life and the people he is related to, so as to focus on another type of existence, at another level. Some palliative health professionals believe that spirits aid in the process of dying, along the journey towards another level, and mediate the encounter with enlightened entities (MENEZES, 2009). Although recurrent among Brazilian palliative professionals, the idea of life as a "passage" to another level is not hegemonic. Some professionals, especially physicians, reject such interpretation of dying hence neither considering nor proposing any kind of spiritual

assistance. Rather, they focus on relieving and controlling the patients' pain and symptoms, and providing physical comfort. Moreover, they are concerned with the subjective elaboration of mourning by the team and family members, and by the patients themselves (grief anticipation).

Palliative caregivers provide assistance for dying patients based on an ideal model and trajectory formulated by the proponents of this type of assistance and developed by different teams in specific contexts. In that sense, it is a normalization of the death process, whereby spiritual resolution and deep connections between biomedicine and religiosity are proposed. Although these issues cannot be addressed in detail in this article, some questions may raise, as the following: what is the purpose of producing a good death by incorporating a religious frame of reference? When one understands that there is a non-confessional modern religious ethos (DUARTE, 2005), one can consider that medicine integrates a cosmology that works like a religion, without introducing itself as one. When coping with the body and health decay, one needs to produce meaning for life that is still possible. Thus, death requires a new meaning that palliative care sets out to produce, in a comprehensive and sophisticated project where values and beliefs which are prevalent in each context are eventually reaffirmed.

### Controversy over orthothanasia

In curative medicine, when a patient is clinically diagnosed as "hopeless", the physician ceases both responsibility and efforts on him. The patient is merely the occupant of a bed. The new assistance model, however, is about providing a "good death", or orthothanasia, seeking to avoid dysthanasia. These terms, in addition to euthanasia, are present in the debate about care in the end of life, especially for patients with chronic degenerative diseases such as cancer. In Brazil, orthothanasia is defined as the decision not to artificially extend the process of dying beyond natural standards, while dysthanasia means the opposite, being synonymous with the term therapeutic cruelty.

Euthanasia can be active or passive; voluntary or involuntary. Active euthanasia involves the participation of a doctor by administering lethal medicine; passive euthanasia refers to withdrawing resources such as medication, food and fluids (HOWARTH *et al.*, 2001). Then, a dilemma emerges: how can passive euthanasia be distinguished from orthothanasia, which is supposed to accept the "natural" course of the dying process?

Voluntary euthanasia happens when the patient requests action to be taken to end his life, whereas involuntary

euthanasia is when a patient's life is ended without his knowledge and consent. Another category is found in the debate over interrupting someone's life: assisted suicide, which differs from euthanasia by the fact that the ill patient himself ends his life with drugs prescribed by the doctor for this purpose. The Netherlands was the first country to legalize euthanasia in 2001, followed by Belgium in 2002. Euthanasia is illegal and considered to be a crime in Brazil.

Proponents of palliative care – mainly health professionals who provide it – oppose to euthanasia because they believe that terminal patients only resort to euthanasia when they are given precarious health care (HENNEZEL, 2004). Concurrently, movements based on religious beliefs condemn euthanasia and affirm the holiness of life. Their arguments center around the idea that if involuntary euthanasia becomes acceptable, especially in the case of the elderly – economic pressure will make it feasible after a while (DINIZ, 2006). However, the Catholic Church officially accepts orthothonasias, which undoubtedly contributed to the directions of the recently approved Code of Medical Ethics.

In Brazil, the debate over a medically managed good death favored the approval of Resolution nº 1. 805/2006 by the Brazilian Medical Council (CFM), as of November 28, 2006, which states that "At the terminal stage of serious and incurable illnesses, the doctor is allowed to restrict or withhold procedures and treatments that extend the ill patient's life, thus ensuring that he receives the necessary care to relieve symptoms that cause him to suffer, within the perspective of full care, as long as the patient's will or that of his legal representative is respected".

This decision generated debate in the media. For example, the issue of Brazilian newspaper *Folha de São Paulo* published on December 4, 2006 quotes the favorable position of the National Conference of Brazilian Bishops (CNBB): "affirming that the practice of orthothonasias, as long as conducted with good judgment, represents the acceptance of human condition before death". Nevertheless, in spite of the clear position of the Catholic Church, in November 2007 the Federal Justice of the Brazilian Federal District revoked by injunction the resolution by the Brazilian Medical Council. According to Judge Roberto Luis Luchi Demo, who conceded the legal appeal, "orthothonasias, as well as euthanasia, seems to characterize homicide, as expressed in article 121 of the current Brazilian Criminal Code" (*Folha de São Paulo*, November 27, 2007). He also states that although this Resolution meets the expectations of physicians and other professionals, decisions on this issue must be made according to a law passed by the Parliament<sup>6</sup>.

On December 18th 2007, the denial of the injunctive relief filed by the Brazilian Medical Council was published in the Section II of the Brazilian Federal Court official newspaper, *Diário da Justiça da União*. When justifying his decision, Federal Judge João Batista Moreira explained that "suspending the regulatory appeal could yield an irreversible outcome, unlike maintaining it, which aims to preserve life. [...] I deny the request for suspensive effect."<sup>7</sup>

In the opinion of Dr. Roberto D'Ávila, from the Brazilian Medical Council, orthothonasias does not anticipate the moment of dying, as is the case with euthanasia, but rather allows the ill patient to die within the natural course of time, by avoiding using resources that prolong his suffering and that of his family's. In its turn, the new Code of Medical Ethics encompasses orthothonasias in its provisions although the term itself is not used.

The news on the approval of this document was considered by the media and by doctors in general as advancement in health care due to the fact that it officially incorporates palliative care. Major Brazilian magazines, for example *Veja* and *Época*, have published an increasing number of articles on health care for terminally ill patients and related aspects such as palliative health care units, interviews with physicians, terminal patients and their families. A story with photographs of terminal or deceased babies held by their mothers contains personal accounts praising the neonatal intensive care unit, which offers palliative care<sup>8</sup>. This new way of coping with dying enables parents to let go of their children in a humane manner, supported by a team comprised of doctors, nurses, psychologists and social workers who can assist them with bereavement. When the babies are diagnosed as terminally ill, these health professionals speak to parents and stop diagnostic or therapeutic interventions. The goal, thus, shifts towards the newborns and their families' dignity.

As for adults with chronic illnesses such as cancer, some issues emerge as the one recently described in a Brazilian magazine<sup>9</sup>: sometimes some doctors – in mutual agreement with their patients – hasten the process of dying by administering analgesic and sedative medication. Although this practice can be penalized in Brazil, no doctor has been convicted for it, because it results from an agreement between the patient, his family and the doctor.

There are other situations where doctors make choices, without consulting or obtaining permission from the patients and their families, which can either postpone suffering – when there is no perspective of curing or controlling the illness - or hasten the process of dying. Such cases are hardly ever documented, debated or publicized. The case of a

92-year-old lady during the 1990s is an example: blind for many years and suffering from dementia, she was admitted to the Intensive Care Unit of a large private hospital in Rio de Janeiro because of pneumonia. The costs of her admittance were covered by her health insurance; thus, there were no restrictions as to the interventions doctors might consider necessary. The patient had four daily sessions of physical therapy as recommended by the doctor. During the sessions, she moaned and cried in pain.

After more than a month at the ICU, the patient's profile of dementia worsened, and her daughter questioned the doctor about the need to keep her mother at the unit. She was given the following answer: "Don't you wish your mother the best? We are offering her the most comprehensive type of health care!" The patient's daughter advocated she should be transferred to a room so that her family could be closer to her. The doctor insisted that the patient was receiving the most sophisticated and state-of-the-art treatment. Eventually, after four months at the ICU, the patient passed away. In an interview, her daughter explained: "It was all very difficult for me. I avoided being present in the physical therapy sessions because she moaned and cried a lot. After a while, she stopped reacting, but I reckon she was already half-conscious. I now think she should have been taken to her room but the doctor made me feel guilty about it. At the end, before she passed away, all I wanted was for her to rest." The representations of the social actors involved in the process of dying are subject to variation according to their values and beliefs. For the doctor, keeping the elderly patient at the ICU was the best way to care for her. In such a context, it can be said the case developed towards disthanasia.

From this example and the new Code of Medical Ethics, one can wonder: When should a doctor interrupt therapy and start palliative care? Which diagnostic and therapeutic procedures are unnecessary? Under whose perspective? Which professional should make such evaluation? Who would be more able to express their views on the issue? A specialist on palliative care or a generalist, a clinical oncologist, a geriatrician or any other specialist? How can an ill patient express his views when not enough information is available about the prognosis and therapeutic options? Does every patient and/or his family wish to know the truth? Once the interaction between the doctor and the patient/family is intertwined with power relations, can the doctor possibly respect decisions made by his patients and their relatives, even when he disagrees on them? In summary, there are many implications to consider, given the new Brazilian Code of Medical Ethics and the daily duties performed by health professionals.

There are very relevant current dilemmas posed by increased life expectancy, life support to premature and/or underweight newborns, and the ongoing release of sophisticated equipment and technologies. Religious attitude is extremely important in Brazil, a "minimally religious" society (DROOGERS, 1987). Moral values and religious beliefs interfere in defining the boundaries between life and death, by influencing the proposition, acceptance or rejection of resolutions, standards and/or law bills. The Catholic Church and the American Medical-Spiritist Society are in favor of orthothanasia, which the latter considers a "method that enables disincarnation within the right time"<sup>10</sup>, while for the former it is licit choosing to withhold treatments that could only prolong life in a precarious, painful manner when inevitable death is imminent despite the means adopted to avoid it<sup>11</sup>.

There is a crucial aspect in palliative care for terminally ill patients: the moral values and beliefs which are at stake in the evaluations made by all the parties involved. Thus, when examining each situation, one should take into account the complex nexus existing between the social actors and the shared meanings they produce.

### Final remarks

The changes in the Brazilian Code of Medical Ethics mirror society's great concern with excessive medical power over the patient and his family. Reflection should be made on the complex interaction between doctor and patient, which contains issues regarding respect for life, death, pain, (lack of) hope, cure, salvation, dignity, choices, autonomy, among others, which are particularly relevant for the existence of any human being. In addition, we live in a culture which assigns great value to the physical reality of the world that can be understood by human reason. Such an elaboration lies in the basis of modern science emerging both as an idea and an instance which enunciates truth(s). In this sense, emphasis on the condition of a person's body reinforces his status in the modern western society. The privilege of individual choice, autonomy, access to the truth and the emphasis given to controlling all the stages in life – including the process of dying – highlights an ideology centered in the individual as a value (DUMONT, 1993). Health institutions and their professionals – or, in other words, the medical apparatus – are one of the pillars that support such ideology. In this panorama, all the subjects involved can produce different notions for person. Given each case and context, it is necessary to reflect upon conceptions and values for person, body, life/death, autonomy, suffering, among other categories.

While a new professional field is formed towards caring for the dying, the religious sphere – or spirituality, in palliative terms – becomes the object of intervention by a health care team. How can we understand the incorporation of a sphere of life that did not previously belong to the domain of medicine? At a first glance, one could say that religion is apparently encompassing the sphere of medicine. However, from another perspective, one could affirm quite the opposite. It is not about rendering the nexus between the two spheres as strictly hierarchical. Sharing interests between the two fields – apparently so disparate and seen as opposite poles – namely science (which is the basis of biomedicine) and religion (spirituality, religious *ethos*) reiterates the individual (value) and the need to construct him – during his life, while he is dying, and even after his death – a type of modeling that reaffirms the ideology of our western culture.

The new area of palliative care is disseminated by its proponents as a liberating discourse which can offer social acceptance of death and inclusion of the moribund, a character who used to be socially stigmatized. By proposing that some attention is given to spirituality, palliative care professionals introduced themselves as spokespeople for a social demand of opening new horizons. However, one can question whether or not such opening can be a sophisticated way of dying where the patient must fit into the proposed standards to achieve his "salvation" or, in other words, have access to a good death.

Undoubtedly, it is necessary to standardize/normalize and constantly update the current regulations on the conduct of health care professionals, as was the case with the Brazilian Code of Medical Ethics by the Brazilian Council of Medicine, in April 2010. Innovative medical intervention technologies are devised on a daily basis - for example, the application of stem cells and new forms of assisted reproduction – and they require society and health professionals to express their positions on them. da sociedade. Hence, continuous debate and research are required on health care practices, public policies, demands from diverse social segments, as well as the proposition and proceedings of bills of law associated with such issues. It is necessary to investigate how standards are actually understood and implemented; in face of a new rule, inequality patterns may persist and power strategies may be produced, whether they are engendered by doctors, ill patients or the latter's family. The aspects discussed in this article on standards, practices and representations of life, death, autonomy and suffering, among others, suggest that defining and determining the boundaries of intervention over human existence involve conflicts and dilemmas which are - and should still be – an issue for the society to debate.

Os aspectos aqui abordados, acerca das normas, práticas e representações de vida, morte, autonomia e sofrimento, entre outros, indicam que as definições e determinações em torno dos limites de intervenção sobre a existência humana envolvem tensões e dilemas, que permanecem – e devem permanecer – na pauta de debates.

## Notes

1. I would like to thank for the suggestions and the interlocution with Jaqueline Ferreira and Edlaine de Campos Gomes.
2. Investigações realizadas nos últimos anos, em estágio de Pós-doutoramento em Antropologia Social (PPGAS/Museu Nacional/UFRJ), com suporte de bolsa PDJ do CNPq (2005-2006), no âmbito de investigação coordenada pelo Prof. Luiz Fernando Dias Duarte sobre Projeto de Leis e Valores Religiosos, com suporte do PROSARE/CCR (2007), e, ainda, na vigência de contrato de Professor Adjunto Visitante do PPCIS/IFCH/UERJ, em 2008/2009.
3. [www.cfm.org.br](http://www.cfm.org.br). Access: May 5th, 2010.
4. In the words of Luiz Fernando Dias Duarte (1999, p. 22): "It is crucial to consider the following hypothesis reasonable: that we participate in a particular system of signification that we can tentatively call 'modern western culture', which implies a certain way to observe and understand phenomena in our life and especially imagine that we can observe and understand phenomena of other cultures".
5. I use the original term in English. *Hospice means both the philosophy of palliative care and the institution providing care for terminally ill people, where emphasis is placed on the autonomy of the ill person*. In this sense, the routines follow the demands of the patients, rather than the institution's logics.
6. Available at: [www.prdf.mpf.gov.br/imprensa/news\\_item.2007-10-26.8424814261](http://www.prdf.mpf.gov.br/imprensa/news_item.2007-10-26.8424814261). Access: March 8th, 2010.
7. Available at: [www.omniware.com.br](http://www.omniware.com.br). Access: March 8th, 2010.
8. Época, April 8th, 2010 (<HTTP://revistaepoca.globo.com/Revista/Epoca/0,,ERT132195-15257-132195-3934,00ht..>); Access: April 11th, 2010.
9. Veja, April 24th, 2010 (<HTTP://www.agenciaaids.com.br/noticias-resultado.asp?Codigo=14584...>); Access: April 25th, 2010.
10. Karol Wojtyla's Encyclical Letter. Available at: [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/encyclicals/documents/hf\\_jp-ii\\_enc\\_20030417\\_eccl-de-euch\\_po.html](http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_20030417_eccl-de-euch_po.html). Access: March 3rd, 2010.

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