

Towards death with dignity in the XXI Century

Maria Julia Kovács

Abstract

This article aims to outline some questions about death with dignity in the XXI century. To do so, five items are considered: 1. Death portraits in the XXI century: Interdiction death, over exposure death and some examples of undignified deaths nowadays; 2. Patients' needs at the end of life, and how the concept of terminal patient promotes generic care; 3. Definitions, clarifications and bioethical issues involving euthanasia, dysthanasia and orthothanasia; 4. Living wills and Anticipatory Guidelines of Will are presented as a possibility of rescuing patients autonomy and a tool which facilitates families decisions about treatment when patients are not able to; 5. Reflections about ways to promote death with dignity in the XXI century, emphasizing the development of palliative care programs in Brazil.

Key words: Death. Dignity. Palliative care. Bioethics.

Resumo

A caminho da morte com dignidade no século XXI

Este artigo objetiva traçar reflexões sobre a morte com dignidade no século XXI. Para tanto, cinco itens são considerados: 1. Retratos da morte no século XXI: morte interdita, morte escancarada e algumas formas de morte indignas presentes na atualidade; 2. Necessidades do paciente no final da vida e como o conceito de paciente terminal torna genéricas as formas de cuidado; 3. Definições, esclarecimentos e questões bioéticas envolvendo eutanásia, distanásia e ortotanásia; 4. Testamento vital e diretivas antecipadas de vontade são os documentos apresentados como possibilidade de resgate da autonomia dos pacientes e instrumentos que facilitam a decisão de familiares sobre tratamentos, na incapacidade do paciente; 5. Reflexões sobre os caminhos da morte no século XXI, enfatizando a importância do desenvolvimento de programas de cuidados paliativos no Brasil.

Palavras-chave: Morte. Dignidade. Cuidados paliativos. Bioética.

Resumen

A camino de la muerte con dignidad en el siglo XXI

En este artículo se pretende esbozar algunas reflexiones acerca de la muerte con dignidad en el siglo XXI. Cinco ítems se consideran: 1. Los retratos de la muerte en el siglo XXI: la interdicción de la muerte y la exposición exagerada y algunas formas de la muerte indigna hoy presente; 2. Necesidades del paciente al final de la vida y como el concepto de paciente terminal componen formas genéricas de atención; 3. Aclaraciones y cuestiones bioéticas que implican la eutanasia, distanasia y ortotanasia; 4. Testigos de voluntad y Directrices Anticipadas de Voluntad se presentan como la posibilidad de redención de la autonomía y de los instrumentos que facilitan la decisión de la familia acerca de los tratamientos, frente a la incapacidad del paciente; 5. Reflexiones sobre los caminos de la muerte con dignidad en el siglo XXI con énfasis en el desarrollo de programas de cuidados paliativos en Brasil.

Palabras-clave: Muerte. Dignidad. Cuidados paliativos. Bioética.

Lecturer mjkoarag@usp.br – Instituto de Psicologia da Universidade de São Paulo, São Paulo/SP, Brazil.

Correspondence

Departamento de Psicologia da Aprendizagem, do Desenvolvimento e da Personalidade – Instituto de Psicologia/USP. Av. Mello Moraes, 1.721, Cidade Universitária CEP 05508-900. São Paulo/SP, Brazil.

They declare no conflict of interest.

Portraits of death in the XXI Century: forbidden, open and re-humanized death

I'm very afraid of dying. It may be accompanied by pain, humiliation, apparatus and tubes stuck in my body, against my will, unless I can do nothing, because I am no longer my own master: loneliness, no one has the courage or words to, with hand in hand to me, talking about my death, fear that the passage is delayed. It would be good if, after the announcement, it happened gently and without pain, away from hospitals, amid people who you love, amid visions of beauty¹.

Banning the death is related to the advancement of medical technology, fascinating patients, families and health professionals. There is the displacement of the place of death: from houses to hospitals. Currently, medical error is linked to the loss limits, to prolong the process of dying with grief. Death became distant, aseptic, silent and lonely. If death is seen as failure or unworthiness, the professional finds himself losing battles and defeated. The patient who survives is warrior, but when he worsens, he is seen as a loser.

Death can become solitary moment out of space for the expression of grief and rituals. The caricature that represents it is that the patient who cannot die with tubes in orifices of the body, with the pointers as company and noises of machines, expropriated from his death. Silence reigns, making activity of professionals with critically ill patients painful. Prolongation of life and disease expands the interaction between patients, families and care staff with stress and risk of collapse.

The incapacity to avoid, delay death or relieve suffering can bring to the professional experience of his limits, finitude and impotence². Physicians should make decisions about treatments and they often feel alone and with difficulty to address family members who inquire about his evolution. Feelings of failure and frustration are frequent, seeing death as an opponent³.

With the advancement of medical technology, professionals are concerned with the maintenance of life, with the duty to take care of pointers and lights that monitor vital functions of patients. Talk, listen to feelings and emotions are not priorities of the battle against death⁴. Professionals are bombarded with technological innovations that difficult decisions to be made about treatments. Doctors and nurses, overworked, perform procedures with which they do not always agree. Although deaths

occur in hospitals, it is also there that it is realized its banning⁵.

Technical development in healthcare creates inhuman environment, leaving the dignity in the background. There was condemnation of death in the modern era, people away from their dying process, in a flagrant loss of autonomy and awareness⁶. Prolonging life, not considering the limits of treatments, can lead to fear and suffering, supported in the intensive care unit (ICU) in the company of machines and without the presence of family and friends⁷.

There are significant changes in the ratios of death, especially in relation to the duration of the process, due to the prevalence of chronic diseases, heart diseases, cancer, neurological diseases and AIDS. Fear is not the attention to certain symptoms like pain and the inclusion of invasive procedures, which prolongs death – which may be grounds for debates on euthanasia and assisted suicide⁵.

In the United States of America (USA), medical care late in life is expensive: 25% of the costs involve patients with advanced disease. The treatments are sophisticated and difficult to break. The ICUs are occupied by people over 80 years old suffering from irreversible chronic diseases for a long time under invasive and costly treatments. Family asks for the maintenance of these treatments for lack of clarification, promoting poor quality of death⁸. In Brazil, we observe similar situations with high hospital costs for elderly people with chronic and degenerative diseases⁹.

Although it is not specific topic of this article, the open death invades the lives of people with violence, unexpectedly, making the elaboration of mourning difficult. It creates situations of vulnerability without protection or care. There is the trivialization of death on TV, flooding homes with images of death, either in the news, soap operas or movies⁴. It is the portrait of the twenty-first century undignified death. Among unworthy open deaths we include: murder, suicide and accidents. They are collective, anonymous deaths and with mutilated bodies, complicating the farewell process.

A humane death is approached by Kübler-Ross and Saunders, who wrote about care to patients and families in the approach of death, accepting the suffering. The patient returns to the center of action, rescuing their dying process^{10,11}. The development of thanatology, as the study area proposed by Kübler-Ross, discusses death as signifier of existence, so it is treated with respect, humility, without trivializing or banishment. Death is counselor, and the professional is her apprentice.

This author was also well known for the description of the five stages through which passes when the patient is diagnosed with poor prognosis disease: denial, anger, bargaining, depression and acceptance. These are not coping models, but they can help the practitioner to be aware on the lived experience of the patient ¹¹.

Saunders – who graduated in nursing, medicine and social services and in 1967 founded St. Christopher's Hospice, which is reference in the area of palliative care ⁴ – suggests the scientific study involving relief and symptom control, present in palliative care programs in which the concern is not a cure, but the patient and their needs, being offered multidisciplinary treatment

Patients with advanced disease and their needs

The aging population grows exponentially and currently exceeds the number of elders of the children. In 2030, one in eight people will be over 65 years old and in 2050 5% of people will have more than 85 years old ¹². Longevity increases the incidence of complex and high costly diseases. Illnesses which had acute outcome became chronic. There is a growing number of people with 90-100 years. Specialty care is provided to patients with cancer in its various forms, also in palliative care programs.

Brazil follows the global trend. Data relevant to 2010, the Brazilian Institute of Geography and Statistics (IBGE) show significant increase in the population aged over 65 years old, from 4.1% in 1991 to 7.4% in 2010. By 2020, it is expected that Brazil will be the sixth largest world population, considering the population of elderly ⁹.

Critically ill patients are stigmatized, named terminals associated with “nothing more can be done”. There is the expectation of suffering and pain in death, coupled with diseases such as cancer, which is partly true. Patients may be isolated. There is fear of contagion by suffering and powerlessness and they may resent the distance from the family, the work; live financial, autonomy and healthy body loss. They are afraid of addiction, pain, degeneration and uncertainty; they experience a period of mourning the loss of themselves and those around them.

Serious patients go through stages of consciousness and perception of death; social adjustment and personal preparation; information to people about the disease situation; delegation of responsibilities to family, friends, professionals and goodbyes ¹³. De-

pendence forward to everyday activities frightens more than death. Dementia is difficult to be cared for, prevents the understanding of disease and treatments, requiring simplified explanations.

The disease process involves somatic problems, isolation, feelings of abandonment, lack of meaning, dependency for daily activities. They are situations of distress for patients and families. Older people feel “disinvested” by people nearby, they consider that they ever lived and that care should be aimed at young people, who have the existence ahead.

The specialized care for sick elderly with mental disorders also have high costs in Brazil ⁹ On the bound, one can speak of “economic euthanasia”: who have financial possibilities is cared. Few hospitals are equipped to care for patients with chronic diseases. For elderly, hospitalization involves separation from family, strange place that do not respect old habits. The ICU receive elderly with poor prognosis, offering treatments that often do not provide quality of life ⁵.

Patients in agony phase mainly need comfort, not invasive treatments. Signs of agony are, among other multiple symptoms, confusion, agitation, cold extremities, respiratory noise, blurred vision, decreased urine output, hallucinations, severe weakness. When these signs are present, it is essential to maintain proper medication mainly for the comfort and relief of symptoms, and suspend treatments with side effects, which increase the suffering. You must ensure these measures at home and open access for 24 hours of connection or hospital palliative care programs ¹⁴.

Euthanasia, dysthanasia, orthotanasia, assisted suicide – bioethical issues

Medical technology is present in the diagnoses and treatments, allowing significant progresses in healing of diseases and life extension. However, it should be considered eventual effects of prolonging the life of sick people. In this context, bioethics combines the path of technical and scientific knowledge of health sciences and philosophical knowledge ¹⁵. There are possible dialogues with clinics and ethics with reflection and deliberation, with many viewpoints.

Hellegers, from Joseph and Rose Kennedy Center for the Human Reproduction and Bioethics, Washington, created focus groups with physicians, philosophers and theologians of many beliefs to discuss issues arising from the progress of medicine. Clinical bioethics aims ethical discussions applied

to the care of sick, reflecting on dilemmas involving diagnosis and treatment. We seek to respect for human dignity and their personal values¹⁶, expressed in the exercise of autonomy.

Schramm believes that the first systematic formulation of autonomy was postulated by Kant. The existentialist concept of freedom understood by Sartre leads to responsibility, to respond to the situation without subterfuge. Foucault denounces submission of people in repressive institutions and highlights the importance of respecting subjectivity and autonomy. One must consider the complexity of this idea, given the diversity of human beings and cultures in the exercise of freedom and responsibility¹⁷.

Diseases can be threats to patient's autonomy, facilitating the exercise of paternalism and over-protection by family and health professionals. Important part of care at end of life is facilitating the exercise of autonomy and decisions of sick people, who bring with themselves their biography. What is observed is that with increasing age and worsening of the disease, decisions about life and death are no longer allowed to patients⁴.

Bioethics of autonomous reflection seeks to emphasize the autonomy and plurality of beliefs and feelings in a deep respect for human beings. Recognizing the presence of conflict, it seeks to discuss it with reason and emotion in a multidisciplinary setting¹⁸. Without separating emotion, sympathy, empathy and compassion before painful feelings, it considers that act in society must involve personal characteristics, freedom and possibility of choice, demonstrating that the plurality of ideas is the wealth of bioethical thinking.

Among the main goals of clinics the search of dignity, respect for the values of the person and the reduction of suffering are included. Suffering is only intolerable when it is not cared, leading to self-destructive processes¹⁹. Currently, we observe discussion on the humanization of care. This is at least a semantic paradox. How to search humanization when we are talking of care to humans? Why have medicine and other health areas lost the quality to deal with what is human?

What underlies this discussion is the need to replace the person at the center of the process, favoring the dignity and autonomy of their choices, the sense of belonging – arrangements which become even more urgent when it comes to vulnerable people. Humanization involves solidarity, compassion, respect and approach.

Issues about the end of life – reflections and debates

Euthanasia

Euthanasia was, in the original sense, the good death. Then one wonders why euthanasia is currently labeled as acceleration of death and it turned crime? Why the good death, pursued as balm, relief, rest has become murder? Euthanasia is legalized in three European countries: the Netherlands, Belgium and Luxembourg. Even with proper legal support it is always a conflict situation for the patient, family members who accompany them and professionals that perform it.

People with degenerative diseases or multiple symptoms may express a desire to die. It is necessary to clearly differentiate whether we are dealing with request for euthanasia, orthotanasia or not dysthanasia.

Requests to die may have a variety of reasons, including the consideration that this is the end of existence. It may also be the complaint that there is unbearable suffering or that it is sought to save the family. When the person asks to die, they wait to be heard in their reasons and the commitment of professionals to take care of what is needed. What it does not mean killing this patient²⁰.

Sedation used in palliative care programs is proposed procedure when symptoms are not relieved by other treatments. It is indicated in specific cases and may be used only upon authorization of the patient and family²¹.

The stolen death, by unauthorized sedation or without explicit request of patient, may be because their suffering assaults who takes care of it. This procedure stops the contact, goodbyes and sharing of feelings, which the proximity of death demands. Hospitals are places where the stolen death is most practiced²².

So why do we observe nowadays so many debates about euthanasia in the media of mass communication? May they be demands of relief of a meaningless life with much suffering and, as happened with Ramon Sampedro, whose book *Letters from hell* inspired the movie *The Sea Inside*?²³

Would they be related to the prolongation of life, without concern for its quality?²⁴ There would be fewer requests for euthanasia if patients did not feel lonely and in pain, being welcomed on their needs²². Healthcare professionals can struggle to relieve pain and other disabling symptoms, moving

away from the moment of death, feeling that they are not doing their best.

Maybe for that reason treatments that prolong life are proposed in an attempt to alleviate the feeling of helplessness before death²⁵. Paradoxically, trying to preserve life at all costs may cause one of the biggest fears of the human being nowadays: having their life maintained with grief in solitude in the ICU, in the company of tubes and machines – the portrait of dysthanasia, dysfunctional death with pain and suffering¹⁹.

Dysthanasia processes are performed with severely ill patients to avoid what is erroneously defined as euthanasia, understood as the acceleration of death. When the dying process is extended, it promotes dysthanasia. But avoiding dysthanasia is not euthanasia. Fighting death with futile treatment causes some of the unworthy deaths of our time, prolonged, with suffering, and lonely⁷.

Sometimes, patients who should not be in ICU, which is an intended place to patients in critical condition, require intensive treatments, which may not be the case of patients with advanced disease, with no possibility of recovery. Many families believe that the ICU is the best place for the patient, even in this condition. It should be clarified that this unit may not be the best option in these cases and that the patient would be better served by palliative care programs.

Orthothanasia

As the opposite of dysthanasia, orthothanasia is not euthanasia, although sometimes it can be mistakenly understood as acceleration of death. The difference between them, however, is significant: if the main aim of euthanasia is leading to death to shorten the pain and dysthanasia consists of preventing death at any cost, orthothanasia seeks death with dignity at the right time, with pain control and physical, emotional symptoms as well as issues relating to social and spiritual dimensions. Because of its multidisciplinary nature it is sought to provide family support in the preparation of anticipatory grief and post-death. Orthothanasia is therefore an attitude of deep respect for the dignity of the patient.

It is essential to clarify the terms and ethically correct attitudes as orthothanasia and incorrect as dysthanasia. Besides the confusion between orthothanasia and euthanasia, there are debates whether the latter should be legalized or not. Those who condemn it fear that it is used without parameters, causing the futile death the same way they accept

futile procedures to maintain the existence at any cost. In this context what is missing is depth discussion on dysthanasia procedures that occur by way of preserving life, causing dysfunctional death with suffering and indignity²⁰.

The ICU, when it is not indicated for patients with advanced disease, with no possibility of improvement, can make death an undignified and lonely process; it can become cruel when depriving the subject of his own death. U.S. Statistics show that 63% of physicians overestimate the service life of patients and 40% suggest treatments that they would not recommend to themselves⁸. Additionally, the artificial prolongation of life leads to hypermedicalization of death²⁶.

Palliative sedation is a treatment option when other procedures are not effective, or cause so many side effects that should not be used. Its goal should be informed to the patient and family: decreasing the patient's consciousness and thus bringing relief to refractory symptoms. Most sedation occurs in hospitals and approximately 52% of agonizing patients need it. The survival time of agonizing patients undergoing sedation is not lower when compared to patients who continue with the treatment that they had been receiving²⁷.

It is also essential to observe the difference between euthanasia, assisted suicide and palliative sedation. The philosophy of Edmund Pellegrino, cited by Rocha²⁸, indicates that euthanasia and assisted suicide are not considered beneficence, even when there is request for death by the patient, associated with not cared suffering. There are moral invariants related to the sacredness of life that can never be traded. He advocates the established trust in the doctor-patient relationship in palliative care programs. Care may be excessive or inadequate and therefore they should always be refurbished for life. If orders to die are related to depression, it should be treated carefully.

Sedation also has the character of beneficence and euthanasia has the character of malfeasance, the latter because death is seen as a proposal for relieving suffering. Sedation leads to drowsiness, decreased awareness and suffering. Conscious life is finished, but not the biological life and the biggest goal is always the welfare of the patient, the relief of suffering by preventing the feeling that the best was not done²⁷.

Sedation should not be seen as a generic situation, its character is exceptional. Preventing therapeutic obstinacy, ensuring comfort and minimizing

suffering, even without eliminating it completely, is a fundamental task of care at end of life.

Living wills, advance will directives: documents to orthotanasia

The so-called living wills were originated in the U.S. in 1969, established as the right to refuse medical treatment aimed at prolonging life in cases of a terminal diagnosis or persistent vegetative stage²⁹. It is a written declaration, which must be delivered to the doctor, relatives or legal representatives. It is related to the refusal of treatments realized as therapeutic obstinacy.

The cases of Karen Ann Quinley, Nancy Cruzan and Eluana Englaro sparked discussion about when to prolong life, involving several court battles. In the U.S., the Patient Self Determination Act was voted in 1990, proposing the determination of the patient to refuse or accept treatment, based on the record – in writing – of his will.

In Brazil, it was decided by advance will directives (DAV), which although they are not a law, they have the support of the Resolution 1.995/12 of the Federal Council of Medicine (CFM), recognizing the right of the patient to express their will about medical treatments and designate representative for such purpose, and the duty of the physician to fulfill it. In this document there is the forecast in order to detail, in writing, the desires and values that should support medical decisions about patient treatment²⁹.

In Brazil, the Code of Medical Ethics, of 1988, records that the doctors should never abandon their patients. Euthanasia, in any case, is prohibited. In 2006, CFM launched CFM Resolution 1.805, which allows the physician *to limit or suspend procedures and treatments that prolong the life of the terminally ill patient, with serious and incurable illness, respecting the wishes of the person or their legal representative. The patient will continue to receive all necessary care to alleviate the symptoms that lead to suffering, assured full assistance, physical, psychological, social and spiritual comfort*³⁰.

In 2009 there is implied ratification of orthotanasia as a dignified death without pain and suffering (...) *in the irreversible and terminal medical conditions, the doctor will avoid performing unnecessary diagnostic and therapeutic procedures and allow the patients under their care all appropriate palliative care*³¹. The Code of Medical Ethics of 2010 prohibits euthanasia as a perspective for death with dignity³². It proposes orthotanasia in irreversible

clinical situations linked to the quality of palliative care offered, by presenting items on terminality of life and palliative care, emphasizing the importance of doctor-patient relationship.

The Code also spoke against dysthanasia: *In cases of incurable and terminal illness, the physician should offer all palliative care available without undertaking diagnostic or therapeutic useless or willful actions, always taking into account the expressed wishes of the patient or, in their absence, of their legal representative* (Art. 41, Sole paragraph).

The DAV suggested that patients should actively participate in the termination of treatments which they do not want to be subjected. What is still in debate whether the patient is competent to make these decisions. In São Paulo, the state law 10.241, of 17 March 1999, better known as “Law Covas”, regulates the right of the user to refuse painful treatments which only offer precarious and burdensome prolongation of life³³. This is not suicide, denied assistance or euthanasia, but respect for autonomy and patient choice. However, this law is not yet aware of the general population and should be disclosed in several instances.

On 31 August 2012 CFM Resolution 1.995 was published in Official Gazette of the Union³², setting the DAV about care and treatment that the patients wish or do not wish to receive when they are unable to express freely and autonomously their will. It is the ability to register in advance their desire in writing, delivering this document to their reliable doctor or designating a representative of their relationship, from family or not.

The DAVs are performed when the person is conscious and speaks or delegates to family or trusted person their decision. The directives are anticipated, because there are doubts whether patients with advanced disease are able to decide on their lives. Hence the importance of this topic is spread amongst patients, families and care staff. The primary objective is to emphasize patient autonomy, and the respect for the values and choices of the person. The document also supports the medical practice in conflict situation, protecting professional from prosecution of denied assistance or euthanasia, and one should register in the medical record the procedure performed according to ethical principles of the profession.

Decisions at the end of life are complex, often taken when the patient’s reasoning ability is impaired or impossible. When death is close, two paths may occur: measures to prolong life – fighting

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death in a futile way – or measures that allow the dying process with a minimum of pain³⁴.

The patient's wishes may, at first, involve cure or survival. With the worsening of the disease, it may seek to maintain the functionality, quality of life and independence. The comfort becomes a priority. When death is close there are worsening of symptoms, cognitive deficits, and metabolic diseases – deepening the vulnerable situation. However, family denial of death does not change this situation³.

Therefore, living wills and advance directives seek to increase communication among physicians, patients and families. These measures are proposed to prevent families decide against the wishes of the patient, considering that they may not be prepared to make decisions about treatment or its discontinuation.

The way of death with dignity in the XXI century

Each season has parameters which is the good death. In the Middle Ages, deaths occurred with different ways of current ones. At the time, large amounts were the dying planning, with the proximity of family, sharing wills, promoting continuity of desires and distribution of goods – the sudden isolated and death was feared¹⁰. Nowadays, due to prolonging and isolation that many patients are undergone, the desire for a quick and painless death, preferably in a familiar environment, resurfaces with intensity. Dignity is dying with affirmation of values and beliefs in one's life⁴.

When approach or intimacy with death is sought, the differences among trajectories of diseases should be considered. Neoplasms have certain predictability when their aggravation occurs. Chronic diseases can be complicated, leading to death, unexpectedly. When there is cognitive impairment with dementia or mental confusion, decisions about the end of life become difficult²⁷.

The concern is transferred from death to the dying process that, despite technological advances, or because of it, can occur with suffering. Depriving the being of his humanity in favor of the technique is not the best way to dignify human existence^{4,35}.

Death is a fundamental part of existence, and it may be planned and self-determined – a controversial point that still requires discussion. People have different desires and expectations: some prefer the proximity of family and friends; others need

to be alone, asleep or awake, feeding themselves or not. We advocate the need to talk about death itself, to inform people about upcoming desires, leading to a final planning of existence⁴.

The principles of palliative care programs, published by the World Health Organization in 1986 and reaffirmed in 2002, are: a) promoting the relief of pain and other disabling symptoms; b) reaffirming life and see death as a normal process; c) do not accelerate or postpone death; d) integrating psychosocial and spiritual aspects with care; e) supporting the patient in order to live as actively as possible until death; f) supporting the family throughout the illness trajectory. They should be initiated early, in conjunction with other procedures, promoting better understanding and management of symptoms³⁶.

In July 2010, about the quality of death, *The Economist* published an article whose title we translated as "Quality of death". "Scaling care at end of life around the world"¹². Article presents a study conducted in 40 countries, including Brazil. Topics related to care at end of life and the integration of palliative care programs for seriously ill people were considered. Pioneer and reference in this area, the UK tops the list for having doctors who honestly communicate prognosis, conduct effective analgesia and prioritize palliative care at end of life. Brazil is at 38, what triggered discussions on the subject in our community.

The items considered in the study were: 1) the importance of palliative care programs for the quality of death; 2) training of health professionals for the relief and control of symptoms and to overcome the taboo around death, allowing non-prioritization of innocuous curative treatments and prolonging life at all costs. The study proves to be essential to seek a new vision of palliative care as active treatments and not as withdrawal or second-line procedures¹².

Public debates on euthanasia and assisted suicide, while in the latter the patient performs the final act, raise awareness about deaths and indirectly open discussion about palliative care. The availability of opioids is fundamental to dealing with the pain, which undoubtedly influences the quality at the time of death. It is necessary to change the mentality about palliative care, associated with death and dropout and not the quality of life. Even among professionals there are those who still relate, erroneously, palliative care to euthanasia or assisted suicide. Palliative sedation is not a euthanasia procedure, because the main goal is to relieve suffering, which is refractory to other measures. The DAV and orthotanasia are measures of deaths with dignity.

According to the above study, public money is intended for care at the end of life only in a few countries. Funding for palliative care programs in most countries studied comes from sources such as donations or philanthropy. Palliative care as a priority need to be integrated into public health policies and professionals must have expertise in the area. Of the 40 countries studied, only seven have policies for palliative care: Australia, Mexico, New Zealand, Poland, Switzerland, Turkey and United Kingdom. Austria, Canada, Ireland and Italy are providing tools for developing such policies. Others do not have public policies, although they have palliative care programs. Brazil is not included in countries with good quality of death index.

The limits on treatment should be informed and clarified to avoid dysthanasia processes. Note that there is limit to treatments and not for care in the various dimensions of human suffering. There is no remedy for death, but one may help to die well, with dignity.

Care at the end of life involves solidarity, commitment and compassion and not authoritarian and paternalistic positions. The great challenge is to enable people to live with quality death itself. Patients who were able to speak with their physicians about end of life were more likely to die in peace and take control of the situation. Their family also managed to better elaborate mourning.

To have dignity it is fundamental: to be aware of the approach of death, control; privacy and intimacy; comfort for disabling symptoms; choice of place of death; have information, clarification, emotional and spiritual support; access to palliative care; people with whom to share; access to DAV, decision-making and power to say goodbye; leaving without impediments³⁷. It is possibility to recover aspects of tamed death as a natural event and with significant people¹⁰.

Palliative care rescue death with dignity, one of the goals of palliativist professionals. The following points for the good dying are important³: with respiratory comfort; without pain; in the presence of family members; with the wishes fulfilled; with emotional and spiritual support; without hospital suffering (avoiding, as previously said, dysthanasia processes).

It is essential that a harmonious multidisciplinary team is present, with as work the full care of the person through listening and acceptance of stories, feelings, by using the senses, the look and feel. People express their final wishes that must be

met, which are important to provide comfort and dignity – but those who cannot express themselves also need to be heard and welcomed.

In Brazil, Menezes writes about the good death involving four conditions: reducing internal conflict with death; be in line with the ego; repair or preserve meaningful relationships; meet the wishes of the person¹⁴. Dying with dignity promotes important discussions to the present days. Quality of life in the dying process should not mean incompatibility, but complementarity with the maintenance of life.

The best care should also involve stopping within the limits of reasonableness. Many people ask for executing the possible treatments, because the fear, when it stops them, is that when care is left. It is important to set priorities, take care of symptoms, if the cure is not possible, avoiding surgery or invasive treatments that do not bring benefits. The goals of palliative care is quality of life, relief of pain and other symptoms, maintenance of consciousness and dignity at end of life, composing the contemporary *ars moriendi*⁴.

Care involves particularization, understanding of the meaning and personal senses³⁸. Pain and suffering have individual and cultural connotations. We live in a society that cannot stand to see and deal with the suffering that needs to be eliminated immediately, even if it is necessary to dope the patient. Caring is not only eliminating symptoms, but providing relief, comfort and well-being⁵.

Pain and suffering can become intolerable when there is fear, misunderstanding or depression. The art is to find a channel for their expression. Suffering must awaken in the professional the desire for caring, empathy and compassion; leading to estrangement, indifference or technicality, it means that something is wrong³⁹. For caring one must let themselves to be touched, open the sensitivity antenna to capture the signals emitted by those who are under their care.

It is necessary to perform the differential diagnosis of depression, which should not be naturally associated with the dying process. Dying role³⁴ includes physical and psychological burdens that need to be cared for – sometimes they are ignored by the physician and society.

For this reason, a therapy related to dignity, including tasks is proposed for this phase: blessing their beloved ones, spreading life wisdom, resuming and reviewing meaningful relationships, remembering and sharing stories and memories of life. It is an intimacy with death, as proposed by Hennezel in her

book *Intimate Death*³⁹. Some people never enter in this paper, in a culture that denies death. This is not about accelerating death, but respecting it. Preventing it by invasive treatments can be regarded as a serious side effect of medical approach.

People with existential maturity can reach peace and die with tranquility, possibly in palliative care programs, in a process of acceptance of finitude. Those who do not accept it ask the continuity of invasive treatments that prolong life, causing suffering for themselves and family. Respect for human dignity, however, implies understand and meet the needs of each one.

More than science or law, discussions about dying seek to understand what human dignity is. A life driven by principles and values should end with them. Good care is always linked to a tuned and harmonic multidisciplinary team of which the psychologist is an integral part. The institutionalization of the good death is in palliative care programs, a counterpoint to an overly technical medicine or abandonment of the “nothing to do”.

Death with dignity is the goal of palliative care programs. One seeks to facilitate patient autonomy in making decisions about their life. One resumes the concept of good death without pain, with respect to the wishes of the patient, establishing channels of communication with family and health professionals.

The kalothanasia is related to the good death in palliative care programs, emphasizing aesthetic and ritualistic aspects. According to Floriani¹³, orthothanasia is the right, correct and on time death, kalothanasia adds cultural and aesthetic aspects to the correct death, considering the emphasis of the active participation of those who are dying, with the distribution of goods, presence of family members at the time death, farewell scenes, among other important values to ensure a good death in the perspective of patient. The term *kalós* refers to beauty, aesthetics and dignity at end of life journey with nobility, virtue and meaning..

Kalothanasia is appealing against the dysthanasia, in which the physician decides, does not inform or clarify and patients live loneliness, denial and anger, an ugly death. Tolstoy anticipates this discussion in *The Death of Ivan Ilyich*, in which shows the lies and secrets around the disease, anticipating, in the end of the nineteenth century, what some patients currently live⁴⁰.

It is essential to establish protocols for death with dignity for critically ill patients and forms of protection for dysthanasia. It is a serious breach of ethics to keep patients in the ICU for economic reasons. This attitude will never be declared openly, but in some cases is what appears when the extension of permanence is observed in these units, of people who are nearly dead or with brain death, remembering that when this occurs the patient has already the confirmed death. It is essential to clarify the family about this situation.

Discussions with the population and clarifications to family can help in detoxification of death, as the possibility of preserving the dignity and quality at the end of life. There are still quite ingrained attitudes of denial of death. The reluctance to talk about death has serious consequences when they must make decisions about treatment or their discontinuation.

It is essential to include philosophical reflections on the training of health professionals. Rubem Alves proposes a new medical specialty, “dynchrony” (“morienterapia”), involving the care with those ones who are dying, already offered by palliative care programs at the end of life, with specificities for the last hours of life⁴¹.

Far from exhausting the subject, the ideas discussed in this paper intend to open space for reflection and practices about death with dignity in Brazil, especially regarding the development and improvement of palliative care programs, so that the quality of life and death are consistent practices in our community.

References

1. Alves R. Sobre a morte e morrer. Releituras. [Internet]. 2003 (acesso 30 out. 2013). Disponível: http://www.releituras.com/rubemalves_morte.asp
2. Carvalho VA. Cuidando do cuidador. In: Pessini L, Bertanchini L, organizadores. Humanização e cuidados paliativos. São Paulo: Loyola; 2004. p. 305-16.
3. Esslinger I. De quem é a vida, afinal? Descortinando cenários da morte no hospital. São Paulo: Casa do Psicólogo; 2004.
4. Kovács MJ. Educação para morte: temas e reflexões. São Paulo: Casa do Psicólogo; 2003.
5. Pessini L. Humanização da dor e do sofrimento humano na área de saúde. In: Pessini L, Bertanchini L, organizadores. Humanização e cuidados paliativos: São Paulo: Loyola; 2004. p. 11-30.

6. Schramm FR. A questão da definição da morte, na eutanásia e no suicídio assistido. *Mundo Saúde*. 2002;26(1):178-83.
7. Kovács MJ. Instituições de saúde e a morte: do interdito à comunicação. *Psicol Ciênc Prof*. 2011;31(3):482-503.
8. Gawande A. Letting go: what should medicine do when it can't save your life? *The New Yorker*. [Internet]. 2010 (acesso out. 2013):7-25. Disponível: http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?currentPage=all
9. Gois ALB, Veras RP. Informações sobre a morbidade hospitalar em idosos nas internações no Sistema Único de Saúde do Brasil. *Ciênc Saúde Coletiva*. 2010;15(6):2.859-69.
10. Ariès P. História da morte no Ocidente. Rio de Janeiro: Francisco Alves; 1977.
11. Kovács MJ. Contribuições de Elizabeth Kübler-Ross nos estudos sobre a morte e o morrer. In: Incontri D, Santos FS, organizadores. *A arte de morrer: visões plurais*. São Paulo: Comenius; 2007. p. 207-16.
12. The Economist Intelligence Unit. The quality of death: ranking end-of-life care across the world. *The Economist*; 2010.
13. Floriani CA. Moderno movimento hospice: kalotanasia e o revivalismo estético da boa morte. *Rev. bioét. (Impr.)*. 2013;21(3):397-404.
14. Menezes RA. Em busca da boa morte: antropologia dos cuidados paliativos. Rio de Janeiro: Garamond; 2004.
15. Urban CA. Bioética clínica. Rio de Janeiro: Revinter; 2003.
16. Kovács MJ. Bioética clínica e sua prática em cuidados psicológicos e psicoterápicos. In: Siqueira JE, Zoboli E, Kipper DJ, organizadores. *Bioética clínica*. São Paulo: Gaia; 2008. p. 161-76.
17. Schramm R F. Autonomia difícil. *Bioética*. 1998;6(1):27-37.
18. Segre M, Cohen C, organizadores. *Bioética*. São Paulo: Edusp; 1995.
19. Pessini L. Humanização da dor e do sofrimento humanos no contexto hospitalar. *Bioética*. 2002;10(2):51-72.
20. Chochinov HM. Dying, dignity and new horizons in palliative end of life care. *CA Cancer J Clin*. 2006;56(2):84-103.
21. Ferreira SP. Sedação paliativa. In: Oliveira RA. *Cuidado paliativo*. São Paulo: Cremesp; 2008. p. 355-61.
22. Hennezel M. Nós não nos despedimos. Lisboa: Editorial Notícias; 2001.
23. Sampedro R. *Cartas ao inferno*. São Paulo: Planeta do Brasil; 2005.
24. Mishara BL. Synthesis of research and evidence on factor affecting the desire of terminally ill or seriously chronically ill persons to hasten death. *Omega (Westport)*. 1999;39(1):1-70.
25. Mota JAC. Quando o tratamento torna-se fútil. *Bioética*. 1999;7(1):35-40.
26. Rocha AR, Buonicore GP, Silva AC, Pithan LH, Feijó AGS. Declaração prévia de vontade do paciente terminal: reflexão bioética. *Rev. bioét. (Impr.)*. 2013;21(1): 84-95.
27. Maganto VV, Gonzalez MM. Dilemas al final de la vida. *Clin Transl Oncol*. 2005;7(7):285-94.
28. Rocha DM. Filosofia da medicina de Edmund Pellegrino e os dilemas bioéticos relacionados ao suicídio assistido. *Rev. bioét. (Impr.)*. 2013;21(1):75-83.
29. Dadalto L, Tupinambaí U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. *Rev. bioét. (Impr.)*. 2013;21(3):463-76.
30. Conselho Federal de Medicina. Resolução CFM nº 1.246, de 8 de janeiro de 1988. Código de Ética Médica. [Internet]. (acesso 30 out. 2013). Disponível: http://www.portalmedico.org.br/resolucoes/CFM/1988/1246_1988.htm
31. Conselho Federal de Medicina. Resolução CFM nº 1.805, de 28 de novembro de 2006. Na fase terminal de enfermidades graves e incuráveis é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente, garantindo-lhe os cuidados necessários para aliviar os sintomas que levam ao sofrimento, na perspectiva de uma assistência integral, respeitada a vontade do paciente ou de seu representante legal. [Internet]. (acesso 30 out. 2013). Disponível: http://www.portalmedico.org.br/resolucoes/CFM/2006/1805_2006.htm
32. Conselho Federal de Medicina. Resolução CFM nº 1.931, de 24 de setembro de 2009. Aprova o Código de Ética Médica. [Internet]. (acesso 30 out. 2013). Disponível: http://www.portalmedico.org.br/resolucoes/CFM/2009/1931_2009.pdf
33. Conselho Federal de Medicina. Resolução CFM nº 1.995, de 31 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. [Internet]. (acesso 30 out. 2013). Disponível: http://www.portalmedico.org.br/resolucoes/CFM/2012/1995_2012.pdf
34. Emanuel L, Sandrett KG. Decisions at the end of life: have we come of age? *BMC Med*. 2010;8:57.
35. Kovács MJ. *Morte e desenvolvimento humano*. São Paulo: Casa do Psicólogo; 1992.
36. Maciel MGS. Definição e princípios. In: Oliveira RA. *Cuidado paliativo*. São Paulo: Cremesp; 2008. p. 15-32.
37. Smith R. A good death. *BMJ*. 2000;320(7.228):129.
38. Breitbart W. Espiritualidade e sentido nos cuidados paliativos. In: Pessini L, Bertanchini L, organizadores. *Humanização e cuidados paliativos*. São Paulo: Loyola; 2004. p. 209-27.
39. Hennezel M. A morte íntima: aqueles que vão morrer nos ensinam a viver. São Paulo: Letras e Idéias; 2004.
40. Tolstói L. *A morte de Ivan Ilitch*. São Paulo: Publifolha; 1998.

41. Alves R. Cuidados paliativos. [Internet]. Folha de S. Paulo. 17 abr. 2007 (acesso 30 out. 2013). Disponível: <http://www1.folha.uol.com.br/fsp/cotidian/ff1704200702.htm>

