

END OF LIFE CARE

La muerte es una vida vivida. La vida es una muerte que viene.

Death is a life lived. Life is death to come.

Jorge Luis Borges (1889-1986). Argentine writer

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In memory of Mati Ezquerro Lezcano, who was an associate of the Ethics Group since its inception.

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These **“Reflections on everyday practice”** are intended to provide food for thought for their readers (essentially family physicians), to assist them in cultivating the ethical dimension of the care they provide to the citizenry. It is not our intention to establish standards of conduct or to define strategies for medical professionals to avoid potential legal issues. In any case, the members of the Ethics Group believe that, given the uncertainties of our profession, practices that are ethically proper are tools not only for doing things better, but also a way to prevent legal issues from arising.

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AS REAL AS LIFE ITSELF... ¹

Peter, 64 years old, has been diagnosed with hepatocellular carcinoma (HCC). He has suffered from hemochromatosis for years, entailing frequent visits to the hospital for treatment, testing, phlebotomies, etc. When being diagnosed with HCC, his family thinks it is better for him not to know the full extent of his disease, as they feel he has suffered enough already and he will not be able to cope with it. His daughter, who is very persuasive, has visited his GP at the Primary Care Center in many occasions in order to make sure that, in his father best interest, nobody says anything about his real disease. She has even asked for a medical report where the word "cancer" has not been mentioned. All home visits have been supervised by the daughter. In the end, when the disease is already quite advanced and Peter can hardly talk, he starts an acute fever episode. At this point, the family decides to bring Peter to the emergency department, where he is admitted. He dies two hours later.

Joseph, 52, has a pancreatic neoplasm for which he has undergone palliative chemotherapy, to little effect. He is aware of his diagnosis. A joint decision for palliative care has been made between Joseph and his doctors. It is mainly for pain control. The pain is under fairly good control (3 out of 10 on a pain rating scale, allowing him to sleep. It flares up occasionally, when an extra morphine dose is added). A practitioner in a different field has recommended taking gabapentin, but he doesn't want to because "the cure is worse than the disease" (it causes dizziness so he is unable to leave home as he has done so far). However, the doctor recommends he should take it....

Josephine is 99. Up to now she has managed on her own at home (she lives alone) although she is unable to walk outdoors (she needs a wheel chair when she goes out) because of a degenerative joint disease of knees and hips. All she takes is paracetamol. This morning she presents persistent precordial chest pain, like a vice, with vegetative symptoms, which still persists at 3 a.m. when she arrives at the emergency room. The doctor on duty does not give her case priority although she is still in pain because, "she's 99 years old!".

James has just died at home after a struggle with cancer and his relatives call the Primary Healthcare Center. The duty doctor tells them "This is not an emergency" and that his GP will see to them tomorrow, "and she'll take care of all the formalities".

¹ We especially recommend to watch the short "The lady and the reaper", accessible at: <http://www.theladyandthereaper.com/>

Peter has just been diagnosed with an advanced stomach cancer. The gastroenterologist has told the family that this has no cure. Once the symptoms get worse, Peter may need to be admitted at the hospice for palliative care. His daughters are very upset. They want their father to know all the information he needs to know, but it is very difficult for them to explain that he will need to go to a place where he has always believed: "it is where you go to die"...

Adelaide suffers from an advanced respiratory disease due to COPD. She is 87 years old and is bed/chair house bounded. She is being treated with bronchodilators and oxygen at home. In her medication she also has a phlebotonic or venoactive drug, alendronic acid and calcium tablets for treatment of her osteoporosis with an asymptomatic old vertebral crush.

INTRODUCTION

Throughout history and in every culture, men and women have always worried about death (and what happens after). The certainty of its existence does not relieve the anxiety, especially when we think about our own death.

In our society, it is hard to talk openly about the meaning of death, especially if we have to deal with our own death. It is difficult for health care professionals to deal with our patients' death too. It seems as we live apart the age, the suffering or the death. These facts seem to be a mistake in a scientific and technologic world. Many people, including doctors, think death is a failure of medicine. Only those who have reflected on the topic are prepared to look after those who are dying. Regardless of age, as health care professionals we should be prepared to deal with death at the same level of care and concern with which we address other conditions. Discussing this issue is difficult for professionals, as the medical literature reflects, which evidences the need for basic training.

When treating patients with a prognosed short life expectancy our responsibility goes beyond the usual aspects (what do I do, how and when). We need to know how to address the emotional (accepting limitations, managing our own and others' emotions), social (who will care for whom, how and where) and spiritual (transcendence, beyond its religious meaning) dimensions of the person.

By the same token, to accompany someone at the end of his or her life is a very intense experience. It gives us the opportunity to become fully aware of our own mortality. It is a key moment for showing our respect for a person's dignity, in accordance to their preferences, and for developing a constructive dialogue, without deception but hopeful. Always seeking to ease and comfort the person up to the last moment.

As GPs, the longitudinal care we provide throughout life places us in the appropriate position to become the best provider of care at the end of life. We have technical skills, we know patient's history either medical, social and family history, including their values, preferences and expectations. We have a relationship of trust built up over many years and many different situations.

Nonetheless, it is not easy to look after people at the end of life. It requires solid training in technical and ethical issues. We find ourselves faced with a difficult and unstable balancing act: commitment to the patient and good medical practice require us to give up unsuccessful treatments and to recognize reversible conditions, in a context where prognosis is presumably short, either because of the patient's age and/or illness.

It is clear that the work environment (busy agendas, little flexibility, etc.) can improve or deteriorate our care. However, in this paper we want to reflect on our own responsibility, on the principles that must guide us as GPs.

LEGAL FRAMEWORK

Law 41/2002, 14th November 2002 concerning regulatory basis for patient autonomy, rights and obligations with regard to medical information and records. BOE 274 (14-11-2002). Jurisdiction: Spain. It legitimates people's rights to autonomy. For this, it is necessary to have enough information: informed consent, including the advanced directives form. The right to information (art. 4) covers information about a person's own health, respect for the desire to not be informed, dialogue as the primary and fundamental means of communication and the obligation to keep a record of both procedures and the communication process. Parts of Article 18 should also be highlighted:

1. Art. 18.2: "The right of patients to access their medical records may also be exercised by a duly accredited representative"
2. Art 18.4: "Health centers and individual physicians shall only allow access to the medical records of a deceased patient to persons who are related to him, either as family members or personal representatives, unless expressly prohibited by the deceased and accordingly ascertained. ... No information shall be provided that affects the privacy of the deceased or the subjective impressions by the health care professionals, nor any that would adversely affect third parties".

1. *Organic Law 10/1995 23rd November 1995, Criminal Code (art. 143).* The term murder with mitigating circumstances is used to refer to euthanasia. This is defined in point 4 "a victim who suffers from a serious illness that would necessarily lead to their death, or that causes serious, permanent suffering which is difficult to withstand. Anyone who causes death or cooperates in causing it shall be tried for murder with mitigating circumstances". It is understood that by using this turn of phrase, the legislator wished to acknowledge that the author might have committed this act out of compassion. However, this is not explicitly stated.
2. *Law 21/2000, dated December 29, 2000, concerning rights to information regarding a patient's health and autonomy, and to medical records. DOGC 3303 (11/01/2001). Catalan Parliament* Article 8 regulates the advanced directive (AD). The AD is a document that is addressed to the physician in charge, in which a competent person gives instructions to be taken into account when the person is in a condition that does not allow him to speak for himself. Section 3 makes reference to provisions contrary to the law or to good clinical practice. In such cases, a note explaining the rationale must be entered into the medical record.

3. Decree 175/2002, 25th June 2002, that regulates the advanced directive registry:

Available at:

<http://www20.gencat.cat/portal/site/canalsalut/menuitem.af261f715269a25d48af8968b0c0e1a0/?vgnextoid=e6aab812a341d210VgnVCM2000009b0c1e0aRCRD&vgnnextchannel=e6aab812a341d210VgnVCM2000009b0c1e0aRCRD&vgnnextfmt=default>

This decree manages the conditions under which an AD is valid. It also justifies the necessity of keeping a record of existing ADs easy to access and to consult. In addition, it defines the figure of the legal representative, LPA (lasting power of attorney) a person designated by the patient who will take responsibility for decisions when the patient is no longer able to decide.

Not only that, it is also legally valid to have documentation on the patient's medical records about advanced decisions to refuse treatment done with the patient on with his power of attorney.

DEONTOLOGICAL FRAMEWORK

The physician's conduct when confronted with the end of life is contained in Articles 68-70 of Chapter VII of the Deontological Code of Ethics of the Council of Medical Associations of Catalonia (2005):

- Art. 68. "Every individual has the right to live with dignity until the moment of their death, and the physician must ensure that this right is preserved. The physician should bear in mind that the patient has the right to refuse life-extending treatment. It is also doctor's duty to help patients to accept death in accordance with their beliefs and what has given meaning to their lives. When the patient's condition is such that he is no longer able to decide for himself, the doctor will accept the decision of the next of kin who are responsible for the patient, but will point out their duty to respect what would have been the patient's opinion".
- Art. 69. "If a patient has an advanced directives document, the doctor must respect and heed the instructions in it".
- Art. 70 "The aim of end of life care is neither shorten nor extend patients' lives. Otherwise, promoting their quality of life to the highest possible standard. Treatment of the dying patient should seek to avoid needless suffering and distress".

Although not in force in Catalonia, we consider several of the articles from Chapter VII of the "Deontological Code of Medical Ethics of the General Council of Medical Associations" (2011), which make reference to end of life care to be worthy of interest:

- 36.1 "A physician has the duty of cure or improve the patient's condition whenever possible. When it is no longer possible to do so, there is still an obligation to implement appropriate measures to ensure patient's well-being, even when the consequences of such measures could be to shorten life."
- 36.2 "A physician should not initiate or continue any diagnostic or therapeutic action without a benefit for the patient, useless or obstinate. The doctor must take into account the patient's explicit desire to refuse life-prolonging treatment. When the patient's condition does not allow him to make decisions, the physician will consider any prior instructions as well as the opinion of the next of kin or legal representatives who are responsible [for the patient]."
- 36.3 "A physician will never cause intentionally death of any patient, even if specifically requested to do so".
- 36.4 "A physician is required to honor the patient's wishes as expressed in the AD, unless they go against good medical practice".
- 36.5 "Palliative sedation is scientifically and ethically appropriate only if symptoms are unresponsive to currently available therapies and with implicit, explicit or delegated consent of the patient".

ETHICAL FRAMEWORK

The principles

Beneficence

At the end of life, the principle of beneficence makes us redirect the goals of care, according to the stage of illness and to face it without hiding anything. When, technically speaking, there is no possible cure or the suffering involved in a proposed treatment makes no sense, it is our duty to do our best to provide well-being and comfort. If the principle of autonomy is essential to correctly understand beneficence in any medical act, the relationship between the two is specially close when a patient is in the last stage of his life. The use of the words "well-being" and "comfort" only make sense subjectively. There is a largely objective component in "healing". The objective component in "providing comfort" is much more reduced.

Helping to integrate the experience of being ill into people's lives is an active task that requires specific training in order to do so without manipulating or imposing one's own beliefs.²

Autonomy

Up until a few years ago, respect for patient's beliefs, values, attitudes and behaviors was applied mainly to decisions such as treat or not treat, place of death, preferred physical and emotional environment and so on. However, for some years awareness has raised. Patient's concerns at the end of life are now reflected in issues related to the meaning of death, reconciliation with oneself and with others and so on. As these concerns can only be partially confined to their psychological or emotional aspects, they are named transcendental or spiritual. They are present in people with or without religious beliefs. It is therefore necessary to have the skills to identify and address these needs by helping the patient and guiding him according to the personal resources of the health care professional, the patient's own beliefs and the community resources.³

Nonmaleficence

To try and gain good control over the symptoms and avoiding therapeutic obstinacy are the basic standards of end of life care. Disregarding them causes unjustifiable harm to the patient. So, it is necessary to consider them as standards of non-maleficence.

² Couceiro A. Ética profesional y cuidados paliativos: En busca de la excelencia. A: Couceiro A. (Ed.): "Ética en cuidados paliativos". Triacastela. Madrid. 2004. (p 41)

³ An interesting document is the report by the group focused on the spirituality of palliative care at SECPAL, available at: http://www.osakidetza.euskadi.net/v19-hbas0005/es/contenidos/informacion/hbas_ad_noticias_novedades/es_hbas/adjuntos/guia_espiritual.pdf

The diagnostic process must also be included in patients' care. Discerning the origin of the symptoms is essential in order to provide appropriate treatment. For example, patient's distress may arise from different causes including the proximity of death, the absence of someone who is especially dear to the patient, the growing burden the disease places on the family, the family's welfare after his demise and so on. So, treatment may not involve any pharmacological therapy. However, it may also be due to an organic problem, such as faecal impaction or dyspnea that we also need to evaluate and treat.

Although providing comfort to the terminally ill is a priority, there are times when intercurrent processes or complications make it necessary to act, although the purpose of the intervention will be palliative. For example, it may be decided to perform surgery in the case of bowel obstruction in advanced neoplastic disease in a patient whose general condition is good. The intention is palliative, in order to prevent complications of obstruction and to give comfort. If it is not performed, it will be maleficent. The benefits and drawbacks must be weighed, though sometimes deciding which risk or inconvenience will be greatest is not easy in such situations.

Justice

Justice, understood as a concept that speaks to us of equity in the distribution of resources, obliges us to organize ourselves in such a way that we find enough time to attend to patients who are in the process of dying and their families, as it is at this time that they most need it.

The difficulties inherent in teamwork cannot be an obstacle in patient care: communication between professionals, different ways of approaching health care, lack of knowledge about the skills of other disciplines (social work, psychology, nursing, palliative care specialists). Training of multidisciplinary teams in end of life care must arise from the need to provide good care and not because of a protocol or a guideline.

Care for people from different cultures or social backgrounds cannot be a factor for discrimination in giving care. In any case, and under certain circumstances, positive discrimination should be considered: for example, in the case of a recent immigrant with little knowledge of our country and little social support.

Justice is what causes us to demand the necessary organizational flexibility in our jobs in order to provide quality care to a person in the last moments of life when their desire is to be in their own home and their family circumstances allow it. Our failure to provide support cannot be the main factor when deciding where to die.

Every patient should be able to choose where they want to die. Very often, home conditions, lifestyles and family expectations determine decisions despite the professional best intentions.

The patient's circumstances determine needs to provide services: give more to those most in need, protect the helpless. In practice, making a careful assessment of needs means appropriate use of resources.

Some standards

As GPs, the considerations for our patients requires us to know their values, to know what gives meaning to their lives and to help to encourage it, to discuss care plans and to respectfully consider their decisions even when they are different from those we might have taken for ourselves.

Professional values collected in the *Compromís ètic del metge de família*⁴ (GP's ethical commitment) are also a good guide for end of life care. In particular, we wish to point out some values that must be put into play in an atmosphere of cordiality and trust.

Respect

We must see the patient as "someone else" and not to confuse what we would wish for ourselves with what the patient wants.

In another sense, respect for privacy results in the preservation of information entrusted during the physician-patient relationship. The expectation that the family may need some of the information about the patient once he has died, implies that we must discuss with them which information is essential for them to know (for example, for payment of the insurance among others) and which information should be preserved by professional privacy.

Proximity

As a fundamental value in the practice of family medicine, it also implies accessibility to attend patient out of hours. Set up strategies that allow us to make home visits at any time during our working hours makes effective the standard of proximity.

⁴ Available at: http://compromis.camfic.cat/Carta_eng.aspx

Proximity is also related to sympathy and compassion. Genuine concern for the patient is necessary in order to understand properly what they want. In what Emanuel and Emanuel called interpretive and deliberative physician-patient relationship models, proximity appears to be a default value.⁵

Serenity

Serenity, in these cases, is sensitivity to speak out without relieving the hope. Serenity is to understand suffering and fear, default against unavoidable or the loneliness felt even when accompanied.

The professional will have difficulty having a calm attitude unless he has been able to come to terms with his own finiteness (or he has made the personal preparation about his own finiteness). Serenity will allow him to show compassion without being an obstacle to effective care.

Prudence

Contributes to the insight necessary for assessing adequately every situation and determining the most appropriate course of action. We have to be specially cautious using medications or procedures that have not been approved by health authorities but we may think are useful for the patient.

Fidelity

Understood as a continuity of the responsibilities inherent in a physician-patient relationship, fidelity results in continuity of care even in the most difficult times and helps in the integration of emotional, contextual, social and cultural aspects of care. It also implies telling the truth, both about the clinical situation as well as the treatment options.

⁵ Emanuel EJ, Emanuel LL. Cuatro modelos de la relación médico paciente. In: Couceiro A. (Ed.). Bioética para clínicos. Editorial Triacastela. Madrid, 1999. (p.109-126). There is a catalan version (two parts) available in Annals de Medicina de l'Acadèmia de Ciències Mèdiques de Catalunya i Balears: Annals de Medicina 2010;93(3):133-36 i Annals de Medicina 2010;93(4):180-84. Available at: http://www.acmcb.es/files/499-60-FITXER/sense_amnesia2.pdf <http://www.acmcb.es/files/499-74-FITXER/sense3.pdf>

DAY-TO-DAY MATTERS

Relationship with the patient at the end of life

As always, we need to focus on patients at the end of life by keeping in mind their extreme fragility and enormous dependency that may have at the end of life. This places them in a situation of imbalance with social relationships as well as their relation with health care professionals. However, person's values and dignity do not change.

The patient, who is the owner of information, will always have the leading role. The patient chooses the information needed, he takes his own decisions and which ones he wishes to delegate. The doctor should discover and not presume patient's needs and wishes.

The physician is also responsible for the people looking after the patient (often family members). They need our help too. Their cooperation is essential. Very often we need the help from family members (or others close to the patient) to find out patient's needs and desires, especially when the patient loses the ability to communicate.

The right to information

Accompanying the patient at the end of life makes us understand information as a process within the physician-patient relationship. It leads us to promote a dialogue that is not only mindful of words but also of silences. The use of silences in communication is a powerful skill. It allows us to receive valuable information from the patient's worries and concerns.

Deception is not acceptable under any circumstances. It breaks doctor-patient relationship due to distrust. At the end of life we have to face medicine limitations for healing. Relentless proximity of death should be known. Truth acquires a special meaning. We should always keep in mind that our communication is not only words, non verbal communication plays an important role as well. Through non verbal communication we are able to tell patients the truth but also the lie.

Veracity, even when it comes to the prognosis, is a part of fidelity.⁶ To tell the truth, however, does not imply having to abandon: perhaps we have no cure, but we can alleviate, give support. Telling patients the objective truth about irreversible situations must always be accompanied by a commitment not to abandon them.

⁶ "giving you clear and sincere information about your health problems, possible options, the risks, benefits and my advice, attending to your needs and beliefs." (My commitment as the family doctor, CAMFiC: http://compromis.camfic.cat/Carta_eng.aspx)

Not to lie does not mean to cause hope to be given up (that would be maleficent): For example, there is no need to give an exact date or way to die (we do not exactly know it!), we must live the present (what do you need now?), continue supporting patient's journey. Medicine does not always cure: we haven't beaten death! Yet, healing is not the only (or perhaps even the primary) purpose of medicine. Good professionals not only try to heal, they also soothe and offer support.

Patients have a right to know and also to not know, to choose what they want to know or not. Many of the signs from patients are not explicit (patients often do not tell us clearly what they want to talk about). However, if we pay attention, a roadmap of the information that needs to be given will take shape. We will remain faithful to the truth and loyal to the patient even though not everything that could be said will be said, not even the information that, as professionals, we sometimes think would be beneficial for the patient.

It is useful to make notes of anything outstanding in the medical records.

To summarize, the patient has a right to know the truth, but he is not required to be informed of the whole truth!

The conspiracy of silence

In our cultural milieu, family frequently wants to protect the patient by hiding diagnoses with a poor prognosis. The whole family "conspires" to prevent the patient from finding out the truth, to avoid the infliction of excessive suffering on the patient.

When dealing with a relative who asks us to conceal the truth from a patient, our attitude should not be one of rejection but rather of empathy and understanding, although that does not imply that we are in agreement. We need to help the family understand the disadvantages of keeping the patient in the dark: they will feel isolated (they often know or suspect the truth already), they will not be able to take care of outstanding matters, they will be unable to say goodbye, they will not be able to decide about their care, etc. We will try to convince the family to provide the patient with the needed information. Ultimately, our first loyalty is to the patient and if needed, we will have to express to the family we can not deny the patient an information that belongs.

Respecting the wishes of patients

Respect for the patient's will is a fundamental element of their autonomy. When it is foreseeable that the development of the disease will limit their ability to make decisions, it would be wise to know in advance about their wishes and instructions. Medical records are a good document source, where we should document patients' decisions during their disease.

Current law allows us to prepare a document that will reflect patients' preferences at the end of their lives. The advanced document is a legally recognized format to express these preferences, but it is not a legal requirement and it is not even needed to provide assistance consistent with patient values. Over time, communication with the patient will provide us with the most current information we need concerning his wishes. As with information, respecting the will of the patient becomes a dynamic, changing process. In the communication process, the family can help the professionals to know the patient's wishes, especially when they lose their capacity to do so themselves.

The primary purpose of an advanced document is to ensure that treatment adapts to the conditions the patients desire when they are being treated in a place where their values, expectations and beliefs are not well known.

After having received adequate information, the patient is entitled to decide that he wishes not to apply (or to discontinue the application of) pharmacological measures or other sorts of treatment. As in any situation throughout life, we must respect their decisions as long as they have capacity. The advanced document, the documentation on their medical records, knowledge of the patient's values and directions from the people who are close to them will help us to know what the patient's desires are when he loses his capacity to decide for himself. In this type of situation it will always be important that each one asks himself (professionals and family): what would the patient have wished for in this situation...?

Confidentiality after death

The duty of confidentiality towards the patient does not come to an end when the patient dies. Respecting patient privacy, we must preserve confidentiality even after the patient's death.⁷

Current law is somewhat contradictory, allowing access to patient's medical records to family and people close to the patient.

⁷ See the document "Confidencialitat, el dret a la intimitat" CAMFiC Ethics Group:
http://www.camfic.cat/CAMFiC/Seccions/GrupsTreball/Docs/etica/confidencialitat_cat.pdf

Loyalty commitment forces us, beyond the law, to protect patient's privacy in any event, just as we have done in life even in front of his family. One question to consider before giving out any information can be of great help: what information (and to whom) would the patient have granted permission for to be given or explained? The final sentence of Article 18.4 of Law 41/2002 (see section regarding legal framework) can support our decisions in benefit of the patient, "No information shall be provided that affects the privacy of the deceased or the subjective impressions by health care professionals, nor any that would adversely affect third parties."

Obstinacy

Obstinacy, a term often used to mean therapeutic obstinacy, consists in the use of diagnostic or therapeutic measures that either produce no benefit or produce benefits that are so limited that they may be considered futile. In fact, it can happen during aging, long before the approach of death.

It is often influenced by difficulty in accepting the process of dying, the "healing" environment, the lack of knowledge, the patient's and family's demands or even the need of using new technologies.

Among all the consequences, we would like to highlight the frustration caused to professionals and patients, the inefficiency due to the misuse of resources and, above all, the probable harm to the patient (i.e. side effects).

Therapeutic obstinacy has a connotation that is clearly related to technology and the hospital setting. The last stages in life in this environment are often accompanied by a significant use of human, technological and pharmacological resources. Often this tendency to "do" instead of to "attend to" spreads to the performance of Primary Care; in this case futility translates to inadequate use of hospital services, particularly emergency department. Useless drug therapies are also continued (e.g. hypolipidemic drugs). Other good examples of therapeutic obstinacy at the patient's home are etiological treatment for sudden infections or even the use of unnecessary palliative measures (such as the use of morphine in situations of well-controlled pain without dyspnea, sedating patients who have neither asked for it nor require it, etc.).

There are two types of therapeutic obstinacy. On the one hand, scientific futility can either be caused by a clinical situations not properly identified or by incorrect use of a medical procedure. On the other hand, an emotional futility induced by our own resistance to accept failure.

When the perspective of traditional success through medical technology is lost and the patient's will is to refuse futile medicalization, the role of primary care is renewed. The biographical knowledge we have about the patient in Primary Care provides a more respectful care to the patient's wishes than traditional medicine does. A family physician's commitment must be to transform excess medicalization at the end of life into care based on providing the most technically and humanly supportive assistance and companionship.

The first difficulty we face is to establish a prognosis. In addition neither do we have any reliable tools to measure the suffering of these patients. Consequently this makes it difficult to decide the best action to proceed. Few studies have evaluated short-term survival. Results suggest that severe functional impairment, difficulty in swallowing and speech impairment are generally associated with short life expectancy.

Health problems that arise in the more advanced stages of aging force us to face the technical suitability (and the ethical issue) of whether to do something about them or not. The patient's will (reported verbally or expressed through an advanced document or the opinion of those who are closest to them) will be key to guiding how we proceed. It will be very important to consider the degree of support from the family and, in particular, the burden that might be imposed on the primary caregiver. Also to be taken into account is our technical and organizational capacity to tackle the problem at home.

Frequently, the problems we face deal with nutrition and treatment of infections. In both cases the first level of decision must be whether there is a need to have the patient hospitalized. Hospitalisation must be a priority if it guarantees the complication will revert and the patient will benefit from it. However, we should advocate against hospitalization if there is no clear benefit for the patient and if the transfer and stay in an unfriendly environment will cause problems (to patient and family). Our personal interest ("I'll have less work and responsibility") should never guide this decision.

As the end of life approaches, nutrition ceases to be a priority whereas making the patient comfortable is more important (i.e. managing hydration to relieve dry mouth, the taste for pleasant-tasting foods, etc). In this sense, use of nasogastric or intravenous nutrition is highly controversial. Studies on the long-term use of a nasogastric tube indicate that it does not substantially improve either nutritional status or survival, nor does it prevent aspiration pneumonia; yet it causes an increase in inconvenience and deprives patients of taste.⁸

⁸ Finucane TE, Christmas C, Travis K. Tube Feeding in Patients With Advanced Dementia: A Review of the Evidence. JAMA 1999;282(14):1365-70

When it comes to treating an infection, it is necessary to ask oneself whether etiological treatment is right, whether the patient's condition will improve or whether it will at least make them more comfortable or if, to the contrary, any benefit will be futile or side effects may prove harmful and cause further deterioration of quality of life of the patient. In any case, notice that discomfort treatments associated with infections (e.g. fever) should never be withheld.

Research on the terminally ill

True, in current practice, research on the terminally ill takes place almost exclusively within hospitals, but we can contribute by discussing and clarifying with patients the reasons they may have for participating in research and the extent of their desire to participate: to prevent them from harming themselves and also to help them in making their decision more independently. For these reasons we must be especially careful with the feelings of gratitude and debt that patients hold towards the hospital and personnel. We must also be wary of the use of informed consent as a formula to allow research to proceed, irrational hopes of recovery and the heroic aura of so-called "experimental" treatments.

Palliative sedation

Sedation is a medical act: there are certain protocols and guidelines to be followed. Neither every patient requires sedation nor is medical treatment at the end of life the same for everyone. Each situation must be properly assessed and handled accordingly. As in any medical act, the will of the patient must be respected.

Regarding sedation at the time of death, the General Council of Medical Associations has stated that sedation, in itself, is just another therapy resource and therefore ethically neutral. What makes it acceptable or reprehensible is the result that is being sought and the circumstances in which it is applied. For example, it may not be used to reduce the burden of caring for the patient.

The boundary between sedation at the moment of death and euthanasia lies in the primary intention. The aim of sedation is to help the patient achieve a level of consciousness in which he or she does not suffer, either physically or emotionally, using the lowest possible dose of drugs, although indirectly it may shorten his life. Euthanasia seeks deliberately immediate death upon request by a competent patient (a basic requirement in the concept of euthanasia).

Good practice of sedation at the moment of death implies necessarily knowledge of the indications: refractory suffering in the time near death caused by, for example, delirium, dyspnea, pain, anxiety, panic, massive bleeding.

It is also necessary to have knowledge of the techniques: types and doses of drugs to be used. It is important that medical records include details regarding the drugs used, dosage adjustments, clinical course and treatment administered.

When its use is indicated, not to use sedation would be as ethically reprehensible (maleficent) as to not adequately anesthetize or sedate a patient who must undergo surgery.

The place of death and comprehensive care

The best place to die is the one chosen by the patients themselves or, in cases where they cannot, by the person that best knows their wishes (it can be the representative appointed in the advanced directive).

To assist patients in choosing freely we have to use the opportunities that present themselves in the course of their lifetimes to talk to them, to have them reflect upon what they want, to let them know what care options are available, in order to avoid their having to make decisions hastily and conditioned by anxiety. The serenity with which we approach the proximity of death and the confidence with which we offer them the possibility of choosing whether or not to remain at home, will make it easier for the patients thus informed to choose freely.

Should the patient decide to die at home, it is the GP's duty to ensure this happens in the best possible way, and to make use of available resources when necessary. For many patients and their families, dying at home can be an important way of sharing what is left of their lives in a familiar environment. The GP, who knows the patient and his family, can add a dollop of humanity and common sense to the care. On the other hand, the experience of supporting people and families facing their last days is, both personally and professionally, enriching: it prepares us to offer support to other people and even to come to terms with our own death. The technical and organizational preparations (and the special importance of out of hours services) to make home care possible is a responsibility that must be accepted, without forgetting to claim that the health authorities provide the improvements that are needed to make it feasible. Care at the end of life is one of the basic skills for a GP. It needs to be accepted as natural. Palliative care units and HCST (Home Care Support Team) services can provide us with support in situations that, due to their complexity, exceed our competence. Asking for their help when needed is an ethical obligation as in any other clinical situation. Frequently, all we need is occasional help; in other occasions we may need to share responsibility for the care.

In some cases another place may be best for caring for a patient at the end of life, whether it is due to a patient's choice, for technical reasons (rarely), on account of the family environment or because the home's physical features do not allow it. We must remember that in every case we are under the obligation to make it as easy as possible to transfer the medical records to whoever will take over the care and ensure support for the family. To the fullest extent possible, it is our duty to ensure that no one dies unattended in a corridor.

We must also bear in mind that the decision to remain at home may be revoked at any time by the patient or because of the family situation. We need to pay attention to any possible changes.

The responsible use of drugs

Our responsibility in the use of drugs in therapy in frail people, who are often elderly and have multiple conditions, is even greater. Knowledge of mechanisms of action, metabolism and interactions will be highly relevant.

We will have to prioritize essential drugs and stop those that no longer make sense to continue. We must avoid medications whose effectiveness has been poorly proven and the use of multiple drugs, which would increase the likelihood of maleficent adverse events and interactions.

It will also be important to ensure that the patient and/or family understand the treatment regime, especially in a situation of distress. It will be necessary to take into account cultural and educational barriers, especially functional illiteracy.

Treatment of cultural differences

To accompany people of different social, cultural or ideological backgrounds at the end of their lives creates an additional challenge for the physician. There are no perfect strategies.

Annex II provides a brief summary to different understandings of death in the different major religions such as Hinduism, Buddhism, Islam, Judaism and Christianity. However it must be noted that there can be a large gap between this theoretical approach (based on the official theoretical teachings of each religion) and daily practice or specific cases.

Refusal of treatment

When patients are competent, after sharing all the relevant information, we must heed their decision before initiating any treatment. When patients are not competent to make decisions, we must heed the opinion of their family or next of kin, and ask them to help us make a decision while bearing in mind what the patient would have wished. The advanced directives can be a useful tool when the patients lose their competence.

Patients have the right to refuse treatment, especially if it may be disproportionate or violates their beliefs. The assessment of a patient's capacity includes assessing consistency in his decisions and its stability over time. However, it is possible to change one's mind and is even to be expected, which makes reassessment necessary.

In the assessment of the proportionality of a given treatment, the following must be taken into account: patient's specific context, nature of the treatment refused, inconvenience that may result, side effects and potential benefits.

To assess the proportionality of a treatment plan (as well as that of a diagnostic test) requires that the professional undergo continuous technical training, have the ability to recognize (and evaluate) both ethical conflicts as well as conflicts between our own values and those of the patient; if the latter should be an obstacle to good care, in all honesty it would be necessary to tell the patient so and offer to refer him to another professional.

A realistic attitude is to accept death and an unavoidable part of life. Therefore we should refrain from applying measures to extend life when the final moment is inevitable. This attitude accepts human finitude. By accepting this reality we can focus on alleviating the patient's suffering and that of the people around them in the best and most reasonable manner.

The death certificate

The death certificate certifies that a person has died in order to register this fact at the Civil Registry. The law states that the physician who treated the deceased during his final illness must send a properly filled out death certificate to the Civil Registry with all the required data: identification, probable cause of death, date, place and approximate time in which it occurred. Deaths that are suspected to be caused by a violent or external cause (e.g., intoxication) are excluded; in these cases the intervention of a medical examiner is required. It is unreasonable to refuse to certify a death just because we do not know the exact cause of death.

Refusing to certify death is maleficent because it increases the family's grief and unnecessarily adds to the number of medico-legal autopsies. We are only required to certify the most probable cause of death and our suspicions that the death is not violence related. This allows any GP, even if not the patient's regular doctor, to certify the death, especially if there is access to the patient's medical records (it will be good practice that the attending GP records enough data to allow fellow doctors to make a reasonable guess as to the cause of death).

We may certify the death of a displaced person or that our own relatives (including those in the first degree).

If certification is not possible (suspicion of crime, violent death) it will be necessary to report the situation to the police court (this can be done by telephone), which will then take care of the situation. We will act in the same way should the death occur while the person is in police custody.

It is not essential to have the death certificate in order to move a dead body from home to the funeral home. For this purpose, a simple certification of death due to natural causes is sufficient. The official certificate will be required prior to burial or cremation.

It is our responsibility to facilitate the certification with maximum speed and with minimum problems for the family to avoid increasing their grief at an especially difficult time. The organization of the Primary Care Unit Team (PCT) and out of hours care team will be key. The time when certification is performed may also be a good time to assess the family's situation and to provide them with support.

KEY POINTS

1. The professional's awareness and acceptance of his own finitude is key for providing high-quality care.
2. Our duty to our patients lasts for their entire lives up until the time of death and even afterwards.
3. Cooperation with other healthcare providers (e.g. home care support team, oncologists, palliative care clinicians, and so on) does not relieve us of our duty.
4. Patient's right to decide must be respected at all times. It is essential to know their wishes, whether they have filled out an advanced directives form or not. You need to start a dialogue with them so that you know what they would want in any given situation.
5. If we do not know what the patient's wishes are, it will be necessary to elicit them from the persons who know them best (usually family members).
6. The end of life should not come as a surprise: in general, a physician-patient relationship is long-lived and often has existed through months of illness. We must find time to address the issue of death and to make it easier for the patient to express his needs, fears and desires.
7. It is necessary to respect the various ways (i.e., cultural, religious) people have of facing death and make it easier for them to express themselves.
8. The right to information, which is a process, belongs to the patients. They have the right to know and also to not know and to decide with whom they wish to share this information.
9. The right to confidentiality remains in effect forever: before and after death.
10. In these situations the family is a key element in the care of the patient. We also need to care for them and seek their cooperation in fulfilling the patient's wishes.
11. We need to actively promote the idea that the patient should spend his last days in the place he prefers. The patient's own home is often his favorite place to be.
12. We need to be organized (PCU, continuous care) so that we can continue to care for patients in their own homes.
13. Rules should not be rigid in such highly complex and emotional situations: We cannot design protocols for the process of dying (we would require more arts than medical science for that!).
14. The aim is to make the patient as comfortable as possible. Obstinacy (or futile treatment) of any kind (e.g. diagnostic, therapeutic or even palliative) is to be avoided, as it is maleficent.
15. Palliative sedation can be a useful therapeutic tool, as long as it is needed and if the patient accepts it.
16. To withdraw unnecessary treatment or to sedate where needed is not euthanasia, although it may hasten the time of death.
17. The GP is usually the best professional to certify the patient's death. We will refuse to certify death only if we suspect death was due to violence.
18. After a patient's death we still have work to do: give support to the family. Giving support to the family in the moments right after death is very important. We need to make the necessary formalities easy for them. It helps to explain in advance what will need to be done and how we will proceed.
19. We need to be aware of our own feelings and emotions, which are also complex in situations such as these.

PRACTICAL ADVICE

1. Try to talk with patients before they reach the end of their lives: find out about their preferences, whom they rely on. Make the most of any occasion while they are still healthy.
2. Encourage use of the advanced directives form.
3. Whenever possible, continue to ask patients about their needs and desires. The situation changes frequently so what it is true today may not be so tomorrow.
4. If we cannot ask the patient, we have to be guided by their wishes (whether or not they have been written down) and the opinions of those who know them best.
5. Listen, clarify, explain, talk ... Always be attentive and speak the truth. Do not make a quick exit! Devote time to them: sit down!
6. Repeat to yourself, my values may be different but the patient's should always prevail.
7. Review treatment plans regularly. Reflect on whether that therapy is still helpful. If it is not, withdraw it.
8. Make patients and their families feel secure: let them know they will always have access to the best care.
9. Try to avoid that a patient is left to die in a hospital corridor.
10. Try to be accessible and keep calm in tough moments. Train yourself!
11. Determine who are the people closest to the patient and give them support: they are both the patient's and our own best allies.
12. Provide the family with useful and practical information in advance concerning the moment of death and the formalities to be followed.
13. If you are present at the time of death, do not interfere; allow the dying process to occur. Attend the family.
14. Do not hide: the moment of death is of great importance to the family. Give them support.
15. Make sure there are death certificate forms available at your institution.
16. Certify the death as long as you do not suspect any violence is involved: we do not need to ascertain the cause (we are only asked to determine the most likely cause!).
17. As in the other aspects of our profession, it is important to maintain and improve our skills in giving care at the end of life.

ANNEX I: DEFINITIONS

Terminal illness:

An advanced disease in a stage of irreversible development and with presence of multiple symptoms. It causes a huge emotional impact, loss of autonomy and little or no ability to respond to specific treatment. Life expectancy is limited to a few months and is associated with increasing frailty.

Death agony:

The period just before death occurs and it happens gradually. There is severe physical impairment, extreme weakness, high frequency of impaired consciousness and cognitive impairment, difficulty in connecting with others and in taking food and water. Prognosis of death within hours or days.

Palliative sedation:

This involves the deliberate reduction of the patient's consciousness via the administration of drugs that produce deep sedation, for the purpose of relieving intolerable suffering caused by symptoms that are unresponsive to other therapies. It is usually irreversible.

Euthanasia:

Any act (deed or omission) that is directly and deliberately aimed at ending the life of a person who has a terminal or advanced illness, at their explicit and repeated request. It is illegal in our country.

Assisted suicide:

Behavior or act by which a person brings about his own death with the help of others. The help is understood to be the providing of means for carrying out the action.

Therapeutic obstinacy:

The performance of unnecessary diagnostic or therapeutic procedures inflicting unnecessary suffering on the patient. The most common causes are: lack of professional competence and professional interests diverted to purposes other than for the benefit of the patient (scientific, political, economic or social ends) or because of unrealistic family expectations.

Therapeutic futility:

Treatment that is not expected to bring about any significant improvement in either symptoms or prognosis of the disease for which it is given. Such treatments can be expected to cause personal, family, social and economic harm due to the disproportion between benefits and risks. Therefore they are maleficent.

Refusal of treatment:

Attitude of some patients with terminal illnesses that have a poor prognosis, who forgo some sort of treatment as they consider it will provide little benefits. Refusal of treatments or measures to extend life without changing the course of the illness but only prolong the agony. Renunciation of treatment may also be understood as the denial of consent to given diagnostic and therapeutic procedures by patients (or whoever represents them). Generally speaking, this occurs when they feel the treatment is disproportionate (for reasons derived from consideration of benefits and inconveniences, or that can be economic or personal).

Limitation of treatment:

Actuación médica de limitar, retirar o no iniciar una determinada medida de soporte vital, que sólo pretende retrasar el momento de la muerte.

Palliative care:

"The active and comprehensive care of patients whose disease does not respond to curative treatment. The basis for it is the control of pain and other symptoms as well as providing support for psychological, social and spiritual problems. The goal is to achieve the best possible standard of life for patients and their families. Many aspects of palliative care may also be applied to prior stages of the disease in conjunction with specific treatments."⁹

⁹ Bouésseau M. La muerte como frontera de sentido: fundamentos para la elaboración de una ética de la medicina paliativa. *Ars Médica* [electronic journal] 2005. [accessed 08/09/2011]. Available at: <http://www.eutanasia.ws/hemeroteca/t386.pdf>

Death with dignity:

A dignified death can mean different things to different people according to their beliefs. It is often thought that dying with dignity is dying without unnecessary physical or mental pain, with knowledge of relevant data concerning one's own clinical situation, with the power to make decisions (or to ensure enforcement of those taken previously), in comfortable surroundings and with the possibility of being provided with spiritual solace if so desired. Instead of dignified death, perhaps we should speak of maintaining a person's dignity in the dying process: to respect their will, their privacy, accompanying them and providing them with quality care.

Terms to avoid:

We find this whole article¹⁰ to be interesting and the contents of this table particularly so, in keeping with its aim to promote proper use of terms relating to death, in order to avoid dismissive, guilt-inducing or ideologically-charged use of the terms.

Terms to be avoided with regard to the word euthanasia:

QUALIFIERS OF THE TERM EUTHANASIA

Active, positive or ocision	An action to intentionally cause the death of a suffering patient.
Passive, negative or lenitive	Termination, withdrawal or omission of medical treatment that simply extends the biological life of a patient who has a terminal or irreversible illness.
Direct	Actions that cause instant death.
Indirect	Actions in which the causal link between death and the intervention is less obvious, either because the mechanism of action is unclear or because of the temporal distance between the two.
Voluntary, self-determined or at their own request	Actions performed upon the explicit request of a competent patient.

NEOLOGISMS

Dysthanasia (obstinacy or therapeutic cruelty)	Prolonging the life of a patient with a severe and irreversible or terminal illness through medical technology when the benefit of doing so is irrelevant in terms of functional recovery or improvement of quality of life. In this situation the means used are considered extraordinary or disproportionate.
Anti-dysthanasia	Ceasing to prolong biological life and allowing the disease to end the patient's life. Equivalent to passive euthanasia.
Orthotanasia	Good death, in the sense of death at the correct biological time. Etymologically speaking its meaning is the same as that of the word euthanasia, but it has been proposed as an alternative due to the negative connotations of the latter.
Cacotanasia	Deliberately hasten death without it being the patient's explicit will. Equivalent to involuntary euthanasia.
Cryptotanasia or cryptanasia	Performing euthanasia covertly, clandestinely, with or without the consent of the patients.

Adapted from Simón P.

¹⁰ Simón P. et al. Ética y muerte digna: propuesta de consenso sobre un uso correcto de las palabras. Rev Calidad Asistencial. 2008; 23(6):271-85

ANNEX II: How different religions view death

Hinduism:

In Hinduism the criteria for evaluation of moral actions concerns intention. When the motives behind an action are guided by complacency, the action lacks moral worth. However, when an action is unselfish and moved by a person's sense of duty, it is morally good, regardless of its consequences.

Buddhism:

In Buddhism suffering is considered inseparable from human existence. Release comes when all desire ceases. The desire to continue to live at any price is the result of ignorance. Therapeutic obstinacy is considered immoral. Death is considered a special point in the chain of cosmic continuity and transience of the individual. Death means the end of individual life, not life itself. Respect for all forms of life is a fundamental teaching although individual life is considered to be rather precarious and provisional. To assist someone in the last moments of his or her life is to show solidarity, while accepting the natural evolutionary process.

Islam:

Human life is sacred in Islam and must be respected and protected. Any aggression is considered the greatest of crimes. Human life is a treasure entrusted to the person by God. The end of human life is determined by one of the following two circumstances: complete and irreversible cardiac arrest, and medically verified cessation of brain function (total brain death). Limitation of therapeutic effort is acceptable and it is recommended that treatment designed to help alleviate suffering be provided. After death the body preserves the sanctity attached to it: believers must watch over it and tend to it with the required solemnity.

Judaism:

The creator not only gives life to man; He also illuminates his daily acts with the moral imperatives contained in the Revelation at Mount Sinai. Existence is a fundamental principle, despite being a passage that precedes eternal life. The meaning of life is preparation for eternity. It is the responsibility of the whole community to protect the life of every individual, both their own and that of others. To choose life and defend it is a duty. With regard to medical action, the principle of proportionality is accepted when implementing measures to sustain life. As the end of life approaches, one must be ready to deal with earthly matters as well as divine ones (Reconciliation). There are clear guidelines for caring for dying patients.

Christianity:

In Christianity, life is considered a gift from God to man, made in love. Among all creatures, only man was made in God's image and this is the origin of his true worth, no matter what the circumstances. No one can make an attempt on the life of an innocent without opposing God's love.

Pius XII made the first declarations concerning the duty to care for human life with regard to technological advances in 1957. He established two basic principles that remain valid today. When faced with an illness a person is entitled to receive whatever care is necessary for the restoration of health. The duty of care to patients requires balancing expected benefits and burdens: a distinction is made between ordinary (proportionate) and extraordinary (disproportionate). Caution and professional competence allow the physician to distinguish between what is proportionate and what is disproportionate.

Euthanasia is rejected because it would entail opposing God's plan. In the face of extreme suffering, the response is to apply all the technical, human and spiritual means intended to relieve the person who is suffering, comforting him as much as possible and keeping him company at all times.

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We remind you that this paper, like all papers issued by the CAMFiC ethics group, refers to the GPs' role, although other professionals may find these reflections helpful.