

End of Life Treatment Decision Making

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1. Introduction

Every human being has a personalized life and generates meaning which is subjective and depends on cultural facts, beliefs, faith and biographical experiences. End of life could mean a long period of a human life, but end of life decisions are near death decisions. Death is the loss of biological life and it can be verified. Nevertheless it can be seen as a mystery and is open to different points of views. What is unquestionable is that our human life is finite and therefore it will always come to an end. Death is not only inevitable but a part of each individual life or the last chapter of each personal biography. To be conscious about one's own life's finitude is a unique quality of the human person as a historic and temporal entity. To comprehend its intrinsic dignity and to find deep meaning to human life, it is important to internalize and accept life's finitude and the certainty of death. When this is achieved, it may be easier to die in peace. Callahan says that end of life and death should be more acceptable for those who have accomplished their personal life projects and moral obligations (Callahan, 1995). It is still socially inappropriate to talk about end of life or death. This also holds for physicians and other health care professionals.

Death and dying are not the same. Dying is commonly not a instant but rather variable, complex and frequently lengthy. End of life may take place at any age and may occur because of a variety of physical conditions, chronic or acute illness, degenerative diseases or accidents. Many times dying occurs with much pain and suffering, with a personal emotional and spiritual crisis, anxiety and moral distress. This generates various questions and problems for those who are leaving life and for their loved ones. No matter what their personal beliefs might be, everyone faces the mystery of life and death with doubts or questions that have no definitive answers. This is a perennial issue that is not expected to change with 21st century technology, hence this chapter will not focus on technological aspects of the ethics of end of life.

Most patients at the end of life receive health care, but it is commonly provided without clear objectives and with insufficient knowledge of their wishes and hopes. Care givers are usually very able in their technical skills but confused about what is the best for each particular patient. We are all aware of the many changes in medicine in the 20th century, from earlier when nothing very effective in treating illness could be done, to our days when we are able to cure many diseases and to prolong life for days, months or even many years, although the disease has not been cured. This progress has led medicine to focus on curing

and to neglect its historical mission of caring for those who suffer and for those who are in their dying process with the exception of palliative medicine. Many authors have analyzed this divergence of the efforts for curing and for caring. One of the more clear-cut studies was the Hastings Center project to re-establish the goals of medicine (Hanson & Callahan, 1999), where two of the four are: *....cure and care of those with a malady, and the care of those who cannot be cured ... andthe pursuit of a peaceful death* A high proportion of patients at the end of their lives receive treatments that do not benefit them in terms of healing, relief of suffering or personal wishes achievement, and their distress and agony are extended. It is not clear why it has been so hard to improve health care at the end of life.

Situations that patients, families and care givers have to deal with when they care for patients who are at the end of life are numerous and variable. Relevant issues are the need for controlled pain, anxiety and other symptoms; how to know the patient's wishes, fears and hopes; which is the best way to respect his or her values and advance directives if they exist; how to respond to emotional and spiritual needs; how can family and other loved ones be supported; and how can care givers be helped in relation to their own distress. Each one of these and related issues require specific answers and difficult decisions have to be made. There are no easy, precise or general answers. The aim of this chapter is to analyze the complexity of end of life decision making and to suggest some ways to improve it, so that it can benefit patients and their relatives. Four representative situations will be described, to be kept in mind while reading this chapter. Then different types of decisions and related challenges will be discussed, as well as by whom and how they should be made (euthanasia and medically assisted suicide will not be considered in this discussion). Suggestions on how to improve end of life decisions will be made. The underlying assumption here is that the topic is in part an ethical matter as end of life decisions commonly involve conflicts of values, such as prolonging life vs. reducing suffering.

2. Four representative cases

The following situations that are presented raise questions about the end of life decisions that had to be made and the problems that health professionals, patients and family members had to face. Readers should keep these situations in mind while reading through the rest of this chapter.

2.1 Situation 1

A 68-year-old patient who suffered from gastric cancer diagnosed eight months earlier presented multiple peritoneal and hepatic metastases, despite several rounds of chemo and radiotherapy. He was an independent professional, married with two sons, two daughters and eight grand children, all of whom were very close. He understood his disease and accepted his near death based on his strong religious faith. After his last admission to hospital, he decided to be cared for at home and his general condition quickly deteriorated. He was nearly emaciated, despite being on partial parenteral feeding. Four years earlier, due to cardiac arrhythmia that was refractory to medication, the patient had a cardiac pacemaker implanted, regulated to go on if his own frequencies fell below 70 beats per minute. Given the patient's terminal status, some in the caring team expressed their doubts about the pacemaker's effects during his dying process. The patient had mentioned his intention to donate his pacemaker after death, but had not asked for its deactivation. The cardiologists were not sure about the effect of the pacemaker in a possible prolongation of

the patient's final time. Nevertheless, they opposed deactivation, which they considered as ethically uncertain. The family was initially in favour of the deactivation, but ultimately decided against it because of the specialists' uncertainty. The condition of the patient progressively deteriorated into a state of stupor and later into a coma. This moribund phase lasted for ten days, with a cardiac frequency invariably fixed at 70 beats a minute, which is explained by the action of the pacemaker. Although physicians and family members decided based on what they felt was the best on clinical and ethical grounds, the patient had an artificially prolonged agony and the family suffered deeply during this period.

2.2 Situation 2

A 46 year old previously healthy industrial manager had a severe car accident while driving alone on a highway. After emergency measures were carried out at least one hour later by the rescue ambulance personnel, he was transferred in extremely poor conditions, unconscious and with visible multiple fractures to a small community hospital. He was intubated and after initial hemodynamic stabilization he was transferred by helicopter to a tertiary care hospital. At admission he was unconscious, with very low blood pressure, severe metabolic acidosis, and rapidly developed multisystemic failure needing mechanical ventilation. His fractures were immobilized and two days later he was connected to dialysis. His neurological assessment demonstrated deep coma, some occasional seizures, and the serial CAT scans showed extensive demyelization lesions and cerebellum and basal ganglia lesions, all of them secondary to a prolonged ischemic encephalopathy. After five days with no change, the neurologists made clear that the patient's recovery would not be possible and that in case of survival he would go into vegetative state or another similar condition.

The patient's wife, his two adolescent sons and his mother were informed about the almost impossible chance of recovery and about the prognosis in case of survival. The possible courses of action, including withdrawal of treatments, were discussed with them and with the neurologist in an ethics consultation meeting. There was neither a living will nor other expressions of the patient's preferences in case of being near death with risk of severe neurological damage. His wife said that she was convinced that if he could choose he would decide to stop all treatments because he would not want to live with such severe neurological damage. The critical care medical staff, although very uncertain about withdrawing treatments, agreed to her demand. After some hours, and giving his family some time to be with him privately and for the administration of sacraments by a catholic priest, mechanical ventilation was discontinued.

2.3 Situation 3

A 60 years old woman was a widow with only one daughter who was married with a two year old son. She had severe disseminated lupus that started many years before, with progressively worsening recurrences. She also had poorly controlled celiac disease and was undernourished. She lived alone and had to sell her small clothing industry as she was not able to run it anymore. Her physical condition had deteriorated because of generalized muscle and joint pain, weakness and extended skin lesions. She became a very isolated person, in spite of having good medical care, well controlled medication, psychological support and the necessary domestic assistance. She had a good but not very close relationship with her daughter, and she had not established a good bond with her grandson. She was admitted to hospital with severe lupus relapse, with pneumonia and in initial renal failure with some signs of encephalopathy. After her dehydration and metabolic state were

stabilized and the infection had been controlled she developed progressive renal failure that required dialysis. She was informed that this was a necessary procedure now, which was possibly indefinite in time, and that dialysis could be done as an ambulatory service three times a week. She apparently understood the information but did not agree and refused dialysis. The attending physicians were disappointed, regarded her decision as a result of mental confusion and asked her daughter to decide. The daughter made clear that her mother had for a long time considered her quality of life as very poor and was not willing to accept more treatments, although she had never written a living will nor formally assigned a proxy. She also said that the only other family member that could know the patient's preferences was her brother, but accepted that it was she who had to represent her mother's wishes. She said that she believed that one should fight to be alive but that life cannot be forced by others as an obligation, and that she thought that her mother shared this idea. She consulted with her uncle and the case was submitted to an ethics consultation. Finally she decided to support her mother's refusal of dialysis or any other new treatments, allowing the progression of disease. She said that although it was extremely difficult and sad for her, she had to respect her mother's wishes even if she didn't entirely agree with them.

2.4 Situation 4

This was a 2 ½ year old female infant on mechanical ventilation since her first day of life because of a generalized hypotonia with no muscle reflexes, no swallowing capacity and no spontaneous breathing movements. She could only move her eyelids. She was conscious and could establish eye contact when she was awake. She was fed by a nasogastric tube and several weaning trials had failed.

She was the first baby of a young couple of low socioeconomic and educational level, but they had enough understanding about their daughter's unrecoverable condition. They had established a close attachment and visited her every day in the Children's Hospital ICU.

First muscle biopsies revealed a generalized muscle fiber atrophy which is suggestive of a mitochondrial myopathy. The ethics committee was consulted about treatment limitation and suggested repeating the muscle biopsy in order to have a complete genetic diagnosis as an essential requirement. The committee recommended that only then could a treatment withdrawal be decided with both parents, to allow the baby's death under proper sedation and to provide support for her family. The parents declined consent for further invasive studies or treatments, arguing that they only wanted to avoid all suffering for their baby, that they were not prepared to stop assisted ventilation, and that they ultimately expected a miracle.

3. End of life decisions

Advances in medicine, medical technology, diagnostic procedures, antibiotic therapies, life support treatments and other interventions in critical care medicine in the last few decades have produced many new possible decisions and problems that physicians have to face when they are dealing with terminally ill patients. For each possible intervention or treatment and for each problem patients go through, there are concrete decisions to be made. This is not only a problem in critical care medicine or in the treatment of acute or terminally ill patients, but also when care givers deal with chronic or degenerative diseases at any age, or when elderly people come close to their final stage in life.

In order to consider clinical decisions when a patient appears to be entering the final stages of his or her life, clarity is required in relation to diagnosis and prognosis. After these have been clarified, it becomes necessary to determine if the patient has no real possibility to recover and therefore is in his or her final stage. Only then should end of life decisions be made, focused on what can be regarded as the best for the patient or, in other words, trying to find out what would be the patient's best interest. This is a difficult question to answer as there are many possible ways or courses of action that can be regarded as good and legitimate ways to benefit these patients (recognizing the primacy of patient choice when known).

For each patient who is facing possible death, the amount of care decisions may be numerous, from nursing care and diagnostic procedures to the more complex management or procedures in intensive care. Although a great majority of end of life care decisions involves limiting intensive care or treatments in order to avoid prolonging suffering, we will first note other decisions that should take place before that. The first is the need for clear information provision to the patient or surrogate about his or her condition, diagnosis, prognosis, chances of survival and possible handicaps or extended rehabilitation time needed if he or she survives. This is a problem in itself as it has to be a truth telling process but it also has to be compassionate and appropriate to the patient's emotional and cognitive capacities that are sometimes diminished. In bioethical terms, information provision should balance the patient's right to know and comprehend his or her situation with the physician's duty not to harm him or her by increasing stress or anxiety through inadequate or unnecessary information. Some patients may prefer not to be informed, which should be respected as their right. Occasionally, if the patients are emotionally fragile or partially incapacitated, family members should be asked before informing him or her, at least in some cultures. In other words, this requires kind and proficient communication. Family members or relatives may also have to receive information, but not necessarily the same as the patient. Biographic facts that are private should be confidential but sometimes some family members need to know more details or exact information in order to make their own decisions. Often patients are incompetent because of their prior condition, or as part of the acute state of their disease or treatments, including due to sedation. Sometimes, incapacitated patients will not have appointed somebody as a proxy with a durable power of attorney. Therefore information frequently has to be given to their families as surrogates, as in situation 3, or in relation to pediatric patients, as in situation 4. A complex decision is to establish who can best substitute the patient for his or her decision making. This means establishing who would best know and respect the patient's values and wishes. For this decision it is necessary to be acquainted with the family, with its dynamics and the roles of each of its members, which is commonly unknown when there is no family physician who has known the patient and the family for long.

Before describing specific decisions, it is important to note general decisions that patients and families face. In a terminal or near death situation, should the patient be admitted to a hospital, nursing home, another kind of institution, or stay at home with appropriate care. These are crucial decisions that involve social features, resources and family care and all of them should be based on patient wishes. It is far easier if he or she decides, or when they are incapable if they have formally expressed their wishes through advance directives. In many social groups and cultures, the usual situation is that patients' wishes are unclear or unknown and that their relatives have to express what they think the patients would have

chosen. At this stage, physicians are not part of this decision, but they do have the responsibility of treatment planning e.g. if the decision is to care for the patient at home.

The particular decisions to be made at the end of life of patients are mainly related to what is known as "treatment limitations". The first and clearest of these limitations is the patient's refusal of treatment, which is frequent in cases of cancer with metastasis, organ transplant or even kidney failure, when these conditions are experienced as an end of life situation. Patients' rejection of treatment should be considered as right and therefore should be fully respected, based on the principle of Autonomy, unless their capacity is unclear or impaired. The rationale of limiting treatments is to avoid what is known as "treatment obstinacy", which is the approach of doing everything possible to prolong life and avoid death, regardless of its burdens, suffering and costs (Real Academia de Medicina de Cataluña, 2005). Treatment limitation is based on futility and proportionality judgments, which conclude that more interventions will only prolong the dying phase, extending agony and increasing suffering. In different ways, this was the main problem in all four cases presented above. It means not starting any new treatment or procedures, or withdrawing some of them. This cannot be decided in bloc, as each treatment, whether more or less complex, has its own purpose and therefore should also require a particular decision. In these highly sensitive conditions, minor interventions such as an intravenous line, a feeding tube or a biochemical test acquire special meanings for patients and family members. Often, physicians are not aware of these meanings and of the great anxiety that they can produce. It is also important to note that these kinds of decisions are not to be taken as one single and definitive decision, because this is a continuous and evolving process where the patient's condition, symptoms and needs may change every day and even within hours. During the course of this stage, both patients and their families require physicians' and other professionals' support and guidance.

The decisions of treatment limitation usually begin with a Do-Not-Resuscitate order, which means not to do what is routinely established as emergency protocols in cases where the heart stops beating. Another limitation decision, if the patient is already in hospital, is to decide not to admit him or her to intensive care units. Other decisions are to not perform surgical procedures, either major surgeries or minor ones such as gastrostomy or tracheotomy, and not to start vasoactive drugs, antibiotics or other treatments. In these cases, a consistent decision should be to also not perform more laboratory or imaging tests. Other decisions, such as not starting hemo-dialysis or assisted ventilation, are usually more difficult to make, both for professional caregivers and for family members. All these decisions have been described as withholding treatments, but they also can be decisions to stop or to withdraw these or other life support treatments. For many of those involved in end of life decision making, it is more complicated and stressful to decide to withdraw rather than to withhold treatment. Even if the intention of both are in the patient's best interest, and we know that there is no significant moral difference between them, withholding and withdrawing treatment decisions are experienced as different. Perhaps the most difficult (withdrawing treatment) decision is to stop mechanical ventilation, because death may occur shortly after it is performed, and inevitably many will feel it is the cause of death. This was the hard problem faced in situations 2 and 4. Discontinuing assisted ventilation is associated with many fears and myths, such as that it is a sort of euthanasia, or that it is illegal or risky for physicians who could be taken to court for it. In a similar way the deactivation of cardiac pacemakers is a complex and difficult decision as occurred in situation 1. Another special situation that has been widely discussed after the Terri Schiavo

and Eluana Englaro cases is the withdrawal of artificial nutrition and hydration (A.S.P.E.N., 2010). These procedures are perceived as a mandatory duty of basic humane care by some or as an unnecessary technical intervention by others.

The decisions described above do not mean abandonment of the patient or that "there is nothing to do". Decisions of treatment limitation can be part of actions that favor the patient's wellbeing, in order to make possible a peaceful death. Therefore, end of life decisions include the planning of efficient symptom and pain control plan with all the necessary medication and sedation.

Other kinds of decisions are related to the patient's spiritual needs, as severe illness and the state of being near death cause a personal spiritual crisis that is frequently unrecognized. Spirituality is understood as the compilation of hopes, fears, faith and values that guide one's plans and meaning of life and death. It involves the spiritual or existential suffering that includes hopelessness, feeling like a burden to others, loss of sense of dignity and loss of will to live. It includes but is not restricted to the patient's religious needs (Chochinov & Cann, 2005; Sulmasy, 2006). The patient's spiritual needs have to be defined by him or herself. But physicians and other health care professionals have the responsibility to make sure that these needs are recognized and evaluated, and that patients are offered the appropriate responses to them. To include spiritual and emotional support as a substantial part of end of life medicine centered on the care of the patient and his or her family will considerably facilitate the patient's peaceful death.

When addressing the topic of end of life decision making, it is necessary to consider that these decisions sometimes have to be made when it is not possible to know the patients' values and wishes. This will always occur in neonates with untreatable conditions, but also in children when their parents have to make decisions on their behalf, as in situation 4. In incapacitated adults because of advanced Alzheimer or other neuropsychiatric diseases, decisions will also have to be made by proxies, but patients' previous values should be respected. Some patients and their families need professional assistance in communication in order that they can better understand their disease and prognosis, and then express their doubts and preferences. This is what is referred to as a guided and assisted interpretive patient physician relation model (Emanuel & Emanuel, 1992).

Decisions for end of life care are influenced by multiple factors related to patients, their families and social environment, cultures, religion, available resources, health policies and more. Decisions may change according to each patient's age, capacity, emotional condition and understanding of diagnosis and prognosis. Decisions may also change if it is a chronic or acute disease and in cases of added complications to previous conditions, even more so if they occur after prolonged admissions to hospitals. Also, decisions are dependent on family fears, hopes, guilt or interests. One should also consider differences between family members' points of views. Decisions related to similar situations may differ in different cultures, for example in Anglo-Saxon, Latin-American, European or Asian environments, where notions about meanings of human life and about death and dying can differ. Cultures influence decisions of patients, families and health professionals. Their religious thinking can determine what they want for themselves or for their loved ones when they are approaching their final stage in life. Whether they believe in eternal life or not, in reincarnation or in some form of transcendence based on their faith, has crucial influence over their decisions. Decisions also largely depend on the economic situation of patients and families, especially if they have to pay for final care by themselves without state or insurance coverage. Health policies may greatly determine the kind and amount of care

people will receive at the end of their life, according to hospital guidelines and available resources. Last, but not least, decisions of quantity and kind of care depend to a great extent on physicians and other professionals' recommendations, which are also influenced by their own cultures, values, experiences and personal sensibilities.

Another crucial issue for end of life decision making is to establish if the care and treatments given to the patient are effective or futile, and if they are proportionate or not. These determinations, sometimes defined as the likelihood of benefit cannot be established as exact determinations. Technical and medical assessment for futility can be based on medical evidence and experience, but proportionality of burdens or costs are non-medical appraisals that should also be considered.

Before describing problems of end of life decisions, it is necessary to define what we understand by euthanasia. Although it is not a focus of this chapter, it is part of an ongoing debate. Different countries and cultures have dissimilar notions, social meanings and legislations about this matter. What many people understand by euthanasia and what some European legislations have approved, refers to well defined procedures to induce death in specific circumstances of terminal patients. The terminology frequently used, of direct or indirect, voluntary or non voluntary, and active or passive euthanasia, causes confusion. Therefore, it is appropriate here to clarify that (medical) euthanasia should only be understood as procedures that intentionally and voluntarily produce the patient's death, because of an incurable disease and unbearable suffering. It is therefore direct and voluntary (Institut Borja de Bioética, 2005). This is different from accepting death as a foreseeable but inevitable consequence of limiting futile or disproportionate treatments in order to avoid suffering and therapeutic obstinacy. The ethical grounding of this is the moral difference between producing and allowing death, and the well known doctrine of double effect. Therefore, treatment limitation should not be confused with euthanasia.

4. End of life decision-making problems

Decisions related to patients who are in terminal conditions because of acute or chronic diseases, as well as to those who are ending their lives with different degenerative conditions, can be difficult and problematic. These problems concern in different degrees patients, their surrogates, physicians and other health professionals. A list of these issues is shown in Table 1. Decisions are focused on patients and their families' views about the meaning of life, the dying process and death itself. In some way, at least in the western world, we live as if we are immortal, not recognizing our finitude. Difficult as it is to admit to any serious disease, it is more difficult if its chances for recovery are rather low. In such a situation many patients go into a personal existential crisis, questioning their life achievements, developing complex fears and hopes. Some of them expect to have time enough to express their wishes, to achieve some reconciliation with family members, to express their gratitude to their loved ones and to pray according to their religion. Other patients, with the same diagnosis and clinical situation, prefer not to know about their condition, and therefore disregard information and deny the illness or its gravity. Some want to extend their lives as much as possible, while others wish to have a short disease, because they accept their death more readily or because they fear the disease and its treatments. A personal approach is required. Imagine a 68 year old male with lung cancer and initial metastasis. His younger daughter is planning her wedding to take place in two months. He will most likely struggle to be alive at least for his daughter's wedding, and

then to be able to see her with her new family, hopefully giving birth to her own children. In this situation the patient, his daughter and the whole family will have the same aspirations. In contrast, with the same diagnosis in another patient of the same age, but a widower, retired and living alone, the patient may refuse treatment and expect the course of his disease to be as short and painless as possible. A different situation is that of the parents of a 5 year old son with deep brain damage because of birth asphyxia, who now has a severe pneumonia on mechanical ventilation, with added multiresistant sepsis. Some parents would accept that death, sad as it is, may be best for their child, while others may request disproportionate therapies. Other problematic decisions are organ transplant or abortion decisions, which are influenced or determined by cultures and religions (The Lancet, 2011).

1. Patients' and families' views of death
2. Health professionals' views of death
3. Human life regarded as an absolute value
4. The right to refuse treatment
5. Patients' capacity
6. Surrogate's decision capacities
7. The meaning of the duty to care
8. Quality of life
9. Fears of limiting treatments
10. Specific situations

Table 1. Main issues in end of life decisions

Physicians and other healthcare professionals such as nurses, physiotherapists, and psychologists have views that influence information and guidance for patient or proxy's decisions. Perhaps our own biases are inevitable as we inform patients not only through verbalization but also through our non verbal communication. And these biases in some way determine the emphasis on prognosis, severity of the expected symptoms for the near future, quality of life if the patient survives, and available courses of action (Gilligan and Raffin, 1996). Examples are the issues presented in situations 3 and 4. It is difficult not to be directive when informing patients and their relatives. It is important to recognize that health care professionals are members of the same societies as their patients, although they do not necessarily share the same culture, religion or beliefs. Therefore they may have similar uncertainties and doubts. But it is even more challenging for health professionals, as they may experience the death of their patients as a failure, both personally and of their professions. This is why physicians often feel that even if they cannot cure a patient they have the duty to prolong his or her life as much as possible. As part of the denial of their patient's impending death and because of the difficulties they have addressing family members, intensive care residents try hard to keep patients alive, at least until the next shift. Many times physicians are not prepared to limit treatments, arguing that their role is to prevent death and that they should not play God, by shortening life (although arguably they do so by prolonging life).

Physicians and relatives often excessively prolong the agony of patients. Many end of life treatments unduly prolong suffering. This is therapy obstinacy which is not a benefit but a harm for the patient. A frequent reason to do so is viewing human life as an absolute value. The notion of the absolute does not allow any grades and therefore life should be considered a fundamental and not an absolute value. Still, if or when prolonged agony is worse than death, our moral duty is to avoid suffering rather than to postpone death.

If the above issues are clearly understood, one can recognize and respect patients' right to refuse treatment, which is contrary to the paternalistic tradition of health care. Patients' rights are based on autonomy, which is easier to understand in relation to elective treatments or to informed consent to research. It is more challenging when terminal patients, whose lives can be prolonged, refuse ordinary treatments. This may be because the patient does not want to live anymore in what he or she views as extremely poor conditions, as in situation 3. But it also may be the consequence of fears or of not having full understanding of prognosis and of the treatment, as occurred with the parents' decisions in situation 4. There may be no problem if the refusal is for non-crucial procedures, but serious conflicts might arise when it is for treatments that are considered medically necessary. Imagine patients refusing feeding tubes, drainage or oxygen masks that are simple procedures that mitigate symptoms and do not involve much risk. The conflict may be more challenging if family members agree with these kinds of refusals, but may worsen when family members refuse treatment for patients who have not even been asked about it. In some cultural environments, such as in Latin America, this occurs often because families feel that asking patients about treatment options can be a great emotional burden (to patients) that should be avoided.

Patient decisions about their treatment rely on their right to decide. This right depends on each person's capacity. At times the assessment of capacity will not result in a yes or no answer. If the patient was incapacitated long before the end of life situation, there will be no problem and all his or her decisions have to be made by their proxy. A common situation is that of partially capable patients who now may be less able to understand their diagnosis and prognosis. Other cases may involve previously healthy and normal adults who now have a critical disease with uncertain or very poor chances of full recovery. In these circumstances, although they were previously able to express their desires, they may now not be able to do so. The problem is how to establish whether the patient is permanently or even temporarily incapacitated (Drane, 1985). Capacity implies not only cognitive but also emotional qualities and patients in a critical condition may have some degree of emotional difficulty to make decisions about their end of life treatments (Gilligan & Raffin, 1996). It is necessary to evaluate capacity for each decision in itself. Sometimes patient or family requests appear to be unreasonable or may even be against the law. This would be the case if they demand to abruptly stop all treatments, transfer a patient when it is not possible because of his needed life support requirements, limit treatments when recovery is still likely, ask for the administration of lethal drugs, and other extreme demands. Asking for disproportionate treatments can also be considered as an unreasonable demand. Sometimes asking for more treatment, when there is no chance of recovery and death is likely to occur within the next few hours or days can be considered unreasonable, although it may be understandable. Examples of these situations are demanding ECMO in cases of advanced lung fibrosis, mechanical ventilation in advanced Lou Gehring's disease, or more chemotherapy in final stages of

cancer. In all these cases, the conflict between families and physicians may become severe. This should not be seen as disrespect of autonomy but as the limitation of autonomy, because of the patient's partial incapacity or because of unreasonable requirements that would compromise medical integrity.

Assessment of patient's capacity for end of life decision making is not sufficient. Decisions may rely, at least partially, on surrogate decision makers. In some cultures, a proxy can be formally nominated or designated, but in others many family members may honestly think that they have the right to make decisions for capable patients. Stress and anxiety of those who have to decide in the name of their loved ones is strong and unavoidable, which makes it easier for them to avoid treatment limitation choices. Decisions or requirements coming from a spouse, son or daughter who are in severe emotional distress are questionable. Surrogates' cognitive and emotional capacities should be assessed. Decision making may conflict with a family's values, sensibilities and interactions. Examples of these situations are common, especially when one fairly dominant member of a family, sometimes with personal emotional problems or guilt, strongly demands unreasonable treatment or procedures. This can be very common in large families, in cultures where an extended family feels that they can also participate in decision discussions, and in very dysfunctional families. In such cases psychiatric evaluation and support can be helpful.

Other issues concern physicians and other health professionals or caregivers. They all share the moral duty to care. Some of them believe that their responsibility is to always provide all possible treatment to every patient. But the real duty to care is the commitment for the patient's good or best interest, and there are situations where the best for the patient is not to prolong his or her life. Situation 1 and 4 are examples of this. The aim should be not a longer life but a better life. These situations are complex and include many emotions and sometimes severe disagreements among professionals and between them and family members.

The previous paragraph relates to quality of life. Quality of life is a subjective judgment. When somebody says I don't want to live any more, he or she may be saying I don't want to continue living in this condition or with these symptoms. Many people would initially say they would not accept chemotherapy or live with paraplegia or even with a colostomy, but most patients in these conditions want to continue to live. These and other limitations will certainly decrease their quality of life but they cannot be the only reason to withhold or to withdraw treatments. Nevertheless, there are conditions which common and reasonable people would never like to experience. Examples are a permanent vegetative state, advanced Alzheimer disease, severe neurological damage without self consciousness, and patients in unbearable pain with no response to analgesia. Quality of life, even if it is subjective, should be one of the considerations for treatment decisions at the end of life.

Different kinds of patients may require different responses for similar situations. This is so with age differences as decisions on newborns, infants, children or elderly people may differ. Decisions when faced with scarcity of resources, also differ. Imagine deciding to refuse a potentially life saving new surgery, to stop vasoactive drugs or dialysis, to deactivate a cardiac pacemaker (Goldstein et al., 2004 & Mueller et al., 2003) or to withdraw mechanical ventilation (Campbell, 2007). One of the most challenging decisions is the withdrawal of hydration or nutrition in vegetative states. Specific end of life decisions are listed in Table 2.

Treatment limitation decisions

- Do Not Resuscitate Orders
- No more diagnostic procedures
- No more lab tests
- Withholding new treatments
- Withdrawal of hemodialysis
- Discontinuing antibiotics
- Discontinuing vasoactive drugs
- Discontinuing mechanical ventilation
- Withdrawal of artificial nutrition

Patient and family support decisions

- Analgesia and sedation
- Comfort procedures
- Companionship
- Favoring a private room or space
- Emotional support
- Spiritual support
- Family bereavement support

Table 2. End of life treatment limitations and support decisions

5. Who should make end of life decisions?

Up to the second half of the twentieth century, the question who should make end of life decisions had a simple and clear answer. Physicians had to decide, as they were supposed to know what was best for their patient. This paradigm has changed, rejecting paternalism, as patient autonomy has been endorsed. Also, decisions that were few and relatively straightforward are now numerous and increasingly complex because of the rapidly growing number of medical procedures. Nowadays it is not the attending physician who has the power and responsibility for making decisions. Decision making is now sometimes in many hands, each one with their own capacities and limitations (Karnik, 2002). The more agents take part in decision-making, the more chances of conflict which in these highly sensitive situations is difficult and distressing. A list of agents involved in end of life decision making is shown in Table 3.

The default decision maker is the patient, based on his or her right to accept or refuse treatments. This has been socially recognized and established in most contemporary health legislation as part of human rights. The bioethical basis for this is the principle of autonomy, which in health care means that everybody has a presumed right to decide what can be done to him or her, and that nothing should be done to him or her without a formal consent. However, the faculty to act with autonomy depends on capacity, on the full comprehension of the clinical condition, of prognosis and of the possible medical choices. Some patients are not autonomous since they lack minimum capacity, as occurs with infants, younger children, patients who are severely brain damaged, have dementia or are unconscious, and with those who are fully sedated. However, sometimes it may be difficult to determine the patient's capacity. Elderly patients are sometimes treated as

incompetent even if they are at least partially capable. Cognitive and emotional capacities are required, as well as freedom, which means the absence of any sort of domination or coercion which also may include some forms of intended compassionate guidance. Patients facing critical disease or terminal diseases are living a personal crisis, and many times feel alone, anxious or frightened. Therefore, their complete freedom to decide autonomously may be questionable. But that doesn't mean that they are not able to make decisions for their treatments and medical care. When they cannot express their preferences competently, other means have to be found in order to fully respect patient values and preferences in end of life care.

- Patients
- Surrogates
- Family members
- Attending and other physicians
- Other healthcare professionals
- Institutional ethics committees
- Ethics consultants
- Institutional authorities
- Judges

Table 3. End of life decision making agents

If the patient is not competent and therefore cannot make his or her own decisions, the best way to proceed is to find out if he or she has previously expressed his or her wish. Although it has been widely promoted in the U.S. and in many other countries, only a minority of people have written living wills where they make known their wishes regarding life prolonging medical treatments, and state the kind of care they would accept or refuse if not able to decide for themselves. These advance directives (living wills) should be known to family members and to caring physicians, but this does not always happen. These documents, although helpful, are not definitive, as they are not very specific and at times only state that the patient would not like to receive extraordinary life support measures or unduly prolonging treatments. Another limitation is that these living wills are established when the patient is not ill and thus is not facing the situation of approaching death. The text may have been written years before and patients could have changed their views or preferences since then. Therefore, living wills should be followed with judgment, as a guide to respect patient values and hence autonomy.

Sometimes patients might have appointed a proxy using a durable power of attorney. Such surrogates have the responsibility to assure that the patient receives end of life care according to his or her preferences. In these cases it is the proxy's responsibility to fully respect the patient's values, and to reject interventions he or she feels the patient would not

have authorized if the patient were capable to decide. A surrogate needs to be objective and unbiased, which is not easy as they are usually close friends or relatives who are emotionally involved. The capacity of the surrogate has to be evaluated. When there are discrepancies between medical recommendations and the proxy's choices, problems may emerge which have to be resolved through dialogue.

If the patient is not capable and has not appointed a proxy, then in some jurisdictions it is the family's role to represent him or her in decision making. A difficulty is that many families are large and diverse, so then it becomes necessary to decide who within the family will act as the patient's surrogate. If the patient is married, his or her spouse may substitute unless there is some clear impediment to that. For minor, parents may do so, although there are special problems when parents disagree in their choices or when their wishes are not clearly in the child's best interest (McNab & Beca, 2010). Another problematic situation is that of elderly patients with an absent or incapacitated spouse, and several sons and daughters who may differ in their opinions. In these cases, difficult as it may be to accomplish, it is best to appoint one of them as their spokesperson, making sure that all of them are involved in the decisions that are made. In all these situations, the decisional capacity of those who take part in decision making should be evaluated. Unreasonable requests that are not in the patient's best interest, or that do not respect the patient's preferences, do not have to be followed automatically and sometimes should be discussed and appealed if needed.

The capable patient is the main agent for end of life decisions. A formal proxy or family members are substitutes for incapable patients. This does not mean that patients or proxies are the only decision makers. Historically, physicians were the main decision makers in medical care, which has radically changed in the last decades, but they continue to have an important role in deciding which treatments or procedures will be made available to patients. Physicians have not only the responsibility of providing complete and clear information but also a duty of guidance. Patients or surrogates may not have the capacity to decide by themselves based only on clinical information. They need guidance which means that attending physicians, the different involved specialists and residents, have to suggest the best courses of action. Their guidance has to be non directive and as unbiased as possible; therefore, physicians should acquire and develop these communication and guidance skills (Yeolekar et al., 2008).

There is a wide network of physicians, residents and specialists, which includes intensive care specialists, neurologists, cardiologists, surgeons and infectious disease specialists, among others. This is similar with other healthcare professionals. Nurses are specialized and teams include physiotherapists, psychologists, audiologists, clinical pharmacists, different technicians, social workers and others. Each professional has a distinct appreciation of the patient's problems and what can be done to help him or her in the best way. Not infrequently, patients and relatives establish good communication with the professionals and trust their suggestions. It is common that non medical health professionals and other care providers know more than physicians about the patient's life, hopes, fears and wishes, as well as about relevant issues. These professionals often play a significant role in the decision making process in end of life patients, and this role needs to be acknowledged, encouraged and supported by physicians.

Therefore, the decision making process involves the interaction of several agents rather than a single decision by only one decision maker. This is a crucial notion that will be

developed further in this chapter. Depending on the complexities of each situation, more decision agents may contribute to better decisions. When there is a great deal of uncertainty or doubts, and when there are discrepancies between professionals' suggestions and patients' or proxys' wishes, institutional or clinical ethics committees and clinical ethics consultation can be helpful. Ethics committees are multidisciplinary groups whose objectives are to propose guidelines in their institutions, to offer continued education in bioethics for staff, and to analyze complex situations ethically. Situations are presented to committees by physicians, other professionals, patients or families. The analyses are conducted using deliberation, and suggestions are made. The method that each committee uses may be different, but it is important that the method is specified. One of the common methods is principlism, based on how a decision respects and harmonizes the four principles of biomedical ethics: Autonomy, Non Maleficence, Beneficence, and Justice (Beauchamp & Childress, 2001). Another widely used method is casuistic analysis, which emphasizes the weight of clinical facts, quality of life, patient preferences and contextual features (Jonsen et al., 1998). In Spanish and Latin-American committees, a commonly used method is deliberation, as explained by Diego Gracia. It starts with defining an ethical referential frame and continues with the analysis of the clinical situations, the added social or contextual facts, the possible courses of action, and it ends with suggestions and their ethical reasons (Gracia, 2007). No matter which method a committee uses, their analysis should be multidisciplinary, including partners such as diverse health professionals, philosophers, chaplains, social workers, lawyers and more.

Clinical situations with ethical problems occur often in many hospitals, but only a few are presented to an ethics committee. The reasons for this may be that it is time consuming, it may be delayed, and physicians may fear being ethically judged. As a consequence, many informal inquiries are submitted to committee members, who then cannot use a proper method of analysis. As an alternative, individual ethics consultations are used, particularly in the US. Formal ethics consultations are less frequent in Europe and have only been recently reported in Latin-America. Ethics consultations are complementary to the committees and should not replace this institutional ethical deliberation entity. They constitute bed-side clinical bioethics with the purpose of helping to identify and analyze ethical problems of single situations. Ethics consultations, either realized by a single consultant or by two or three members of an ethics committee, assist in decision making in situations with ethical uncertainties, and they can also diminish the moral distress of all involved. Ethics consultation can be conducted by a single consultant or by a team on call. Consultants can analyze each situation with the involved professionals and care givers, with patient families and with patients as much as possible. This has the disadvantage of the absence of multidisciplinary deliberation. Other limitations are that consultations are extremely dependant on each consultant's communication skill, the consultant's biases compassion and tolerance. Therefore, ethics consultants' competencies have been established, in addition to the requirement to be able to comprehend clinical features (Aluisio, 2000). Clinical ethics consultants sometimes become mediators when there are discrepancies between staff, patients', and families' points of view.

Not only patients, surrogates, physicians and other health care providers, institutional ethics committees and ethics consultants have a role in decision making at the end of life. Sometimes hospitals or healthcare institutions have their own guidelines that have to be

followed. Health insurance companies may have specific policies that constrain patient care, in relation to assessments, treatment and more. In some countries, some decisions are established by each legislation and in some cases the final decision may be made by judges.

End of life decisions are practical decisions that involve moral judgments. Such applied ethics is uncertain. Some degree of uncertainty is part of many clinical decisions. This may be why clinical and ethical decisions about care are difficult and stressful. So who should make end of life decisions? There should not be a single decision maker. All parties that have been mentioned have a role in the decision making process. Some of them, such as ethics committees or clinical ethics consultants, are expected to use a specific method to analyze situations and to offer suggestions. Decisions are a matter of shared decision making based on an open and tolerant dialogue between all the mentioned parties.

6. How can End of Life decision making be improved?

The question is whether decision making can be improved and if so how. First, decisions should always be focused on what is best for the patient. This means treatment of pain, anxiety and other symptoms, together with fulfilling the patient's needs and wishes as much as possible. End of life decisions should actively pursue a peaceful death. To improve these decisions, it is important to recognize that there cannot be only one method, guideline or decision algorithm, but some suggestions will be offered here.

The focus should always be the patient's "good". This is not a scientific or technical issue. Medical facts are necessary but not sufficient for this. In order to know what is best for each patient, his or her whole biography, values, fears, hopes and preferences have to be considered. Knowledge of social, family, economic and other contextual features is also important. Involvement in decision making of all those who know, love and care about the patient is needed. The aim of end of life care should thus focus on effective palliative care. Decisions should focus on better physical, emotional and spiritual care, and by no means any sort of patient abandonment.

In a strict sense the patient's best interest should be determined by him or herself. This is not possible if the patient is entirely or partially unconscious, which is common when they are in their terminal stage. Therefore the aim is to respect as much as possible what he or she expressed when they were able to do so. When patient have written living wills or have formally appointed a proxy, there is far more knowledge of their preferences, even if the exact conditions or symptoms were not known or anticipated when they expressed their wishes. The basis of this is respect for Autonomy. Hence, a suggestion to improve end of life decisions is to promote that people write their preferences in their own way or using living wills. But, valuable as it may be to have more written living wills, it is even more important that all adults talk about death and dying within their families and, if possible, clarify the care they would like to receive if they have an incurable terminal condition and are not able to decide for themselves.

Another way to improve end of life decision making is to increase ongoing efforts to improve clinicians' communication skills. Their training at undergraduate and postgraduate levels as well as in continuous education programs should develop these competencies that are the basis for getting to know the treatments patients wish for their end of life care. Health care professionals should also be trained to provide emotional support to patients and families. Physicians should also develop their own understanding of the meaning of

death, respect the different views that patients and families may have, and acquire the necessary proficiency for symptomatic rather than curative treatment.

It has been suggested that surrogates could be supplied with empirical information on what patients in similar circumstances tend to prefer, allowing them to make empirically grounded predictions about what the patients they are involved with would want (Rid & Wandler, 2010). Relevant anecdotal reports could also be very useful for surrogates. When families take part in decisions on behalf of their loved ones, they will likely have doubts and experience stress. Therefore another suggestion for improvement of the quality of decision making is to support and guide surrogates.

A particularly helpful way of improving family participation in decision making is to provide personal counseling for those who are more involved and to conduct special meetings with the patient's family, other significant others and caregivers. Counseling and family meetings may be conducted by attending physicians or other staff and are typically led by social workers, at least in North America.

Not all end of life situations involve ethics committees or ethics consultants, but the most challenging ones may have a better outcomes if they are consulted. Therefore, a suggestion to improve these decisions in places where there are no clinical ethics committees or consultants is to train in bioethics a group of professionals in order to establish such consultations.

A special and particularly difficult situation occurs when patients who are in nursing homes have a life threatening illness. Whenever possible they should be supported to communicate how they would like to be treated. The majority of people in this situation, particularly in some countries, do not have written advance directives nor have they expressed their treatment preferences. Furthermore, their relatives or proxies may not be available when decisions have to be made. It is not the nursing home staff or caregivers' responsibility to decide what may be adequate and proportionate treatment in each situation. In such situations, it may be helpful to delineate in advance what physicians and non-physician health professionals together with the patient's family regard as the best compassionate care for each patient. If the person is partially capable, his or her capacity should be enhanced if possible, to better know what his or her preferences are. Such pre-determination addresses admission to a hospital or critical care unit, treatment of new diseases or complications, chemotherapy or surgery, artificial nutrition procedures, other support and more. Interesting tools for this purpose are the Physician Orders for Life Sustaining Treatments (POLST) forms that are offered to improve the quality of care that people receive at the end of their lives. POLST are based on effective communication between health professionals, patients in nursing homes and their families. These forms are available in different languages (Oregon POLST program).

Another suggestion to improve end of life decisions is to advocate that they be made in a timely manner, as they are often made after prolonged and avoidable suffering. In order to have these decisions made on time, the possibility of having to make them should be anticipated, preferably at the time of patients' hospital admission or soon after their diagnosis and prognosis have been established.

It is important to remember that end of life decisions are complex and that decision makers will have to take part in lengthy and/or complex processes. It is important to note that everybody involved has specific roles in these processes. Physicians have to determine the diagnosis and the possible courses of action, other health professionals share a role in support and guidance, the patient will have to consent to or refuse treatments, family

members or surrogates input the patient's values and preferences (when known), and ethics committees or consultants have expert advising and mediating functions. These are not isolated and independent roles, as it has to be a shared decision making process. End of life decisions will only be (clinically and ethically) good decisions if they are truly shared decisions that respect all points of view in order to fully address patients' best interests (assuming that is primarily determined by patients' capable choices, if known).

7. Conclusion

Advances in medical knowledge, technology, diagnostic procedures and treatment alternatives in the last few decades have produced new clinical and ethics problems, many of them related to end of life decision making. The different decisions to be made at end of life should be based on the patient's best interests, preferences, values and expressions of his or her wishes. With a benefit-burden analysis, the aim ought to be the best treatment for pain, anxiety or other symptoms, and the pursuit of a peaceful death rather than the prolongation of life if that is accompanied by agony (most religions accept reduction of such suffering).

End of life decisions are mainly related but not restricted to withholding or withdrawing specific treatments. The aim is to avoid therapeutic obstinacy and patient abandonment, and to include in end of life care emotional and spiritual support for patients and their families. The process of decision making is associated with different views about the meaning of human life and death, and with patients' and surrogates' rights. Relevant problems are related to the evaluation of decision capacities, differences between caregivers and patients or families, and diverse moral or legal concerns.

Decisions should be made by various agents, including the patient, and proxies or family members as needed. Physicians and the other health care professionals have relevant responsibilities, and ethics committees or ethics consultation have facilitation and mediation roles. The key is that it has to be a shared decision making process with respect for all points of view, addressing what is best for the patient and leaving out other interests (note that justice such as in relation to resource allocation was not discussed here).

In order to improve end of life decisions we suggest: encourage people to write their living wills; support and guide surrogates; and promote timely decision making. In health professional education, clinicians should be trained to acquire adequate communication skills, emotional and moral strength, and at least basic knowledge of bioethics.

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