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Chapter 9

**QUALITY OF LIFE X QUANTITY OF LIFE:
THE RIGHT TO DIE WITH DIGNITY
PROTECTED BY THE ADVANCED
DIRECTIVES INSTITUTES**

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ABSTRACT

In the last century we have witnessed a great development in medicine. New drugs and sophisticated surgical interventions present the proposal for a long life, almost as a product available on the market. Facing death as a natural process is increasingly distant from people's lives nowadays. Quantity of life does not mean quality of life. In cases of incurable diseases, the best treatment is to accept the condition and offer

palliative cares to ensure the quality of life that still remains. It cannot be forgotten that behind all the medical techniques in development there are human beings who ought to be at the center of the medical-patient relation and have their dignity and autonomy respected. There is a juridical mechanism called “Advanced Directives,” popularly known as “Living Will,” which is a public document to register all the medical directions regarding health care treatments and procedures that the patients do not wish to be submitted to, that can be used to ensure that the patient’s wishes concerning his life will be respected when he may not be able to express his will. The advanced directives defend the dignity of every human being and the palliative cares rather than the pursuit of a cure.

Keywords: health, quality of life, quantity of life, advanced directives, living will

1. INTRODUCTION

M.A.S., 67 years old, smoker and a long time hypertensive patient, had a cerebrovascular accident by an ischemic stroke, resulting in a motor sequel, with an inability to ambulate and a possible permanent sequel due to the severity of cerebral lesion, despite the efforts undertaken by the doctors.

At hospital discharge, the patient received all guidance for treatment, including therapeutic and prophylactic measures in order to rehabilitate the motor part, bringing psychic health to face and overcome this condition and preventing new ischemic events and new possible complications such as infections and pressure ulcers, always seeking the highest quality of life possible.

Six months later, she suffered a new cerebral ischemic event, which made her stay in the hospital for three months until discharge, this time with greater cognitive sequel, no longer being able to understand and keep contact with the environment as well as suffering pain. In this case, doctors had to make use of vital signs as a way to realize any hassle in the patient’s body even if unconscious.

During the last hospitalization the patient developed different infectious diseases, including pneumonia, urinary tract infection and ulcers of the pressure acquired by immobility and muscle atrophy. It was necessary to use antibiotics almost continuously as well as several surgical interventions in order to remove necrotic eschar tissues, often having exposed bone.

This medical intervention lasted about three months and during this period of time, for several times the patient's family tried to find the best way to face the dilemma prolonging life versus quality of life, also questioning the medical group about the sorts of intervention in terminally ill patients.

Accepting this situation was a very difficult moment for the family, but they realized that there was really nothing more to be done medically. As M.A.S. had not proceeded to prepare her living will and never expressed herself about the medical treatments that she would accept or not in a situation like this, the only solution for this medical case was having the hospital's medical staff inform the family of the terminal illness and explain that a choice should be made between extend the medical and hospital procedures indefinitely to keep the patient alive or adopt palliative care to prevent suffering and let the disease take its natural course.

It was decided by the doctors and the patient's family that it was better to keep a continuous sedation and analgesia without proceeding with such aggressive treatments that proved, after great investment, inefficient. Orthothanasia was the choice for this clinical case, considering the best interest of the patient and quality of life during the life time left.¹

The quoted case above is quite common and represents similar situation concerning the end of someone's life, which individuals might have to face at some point in their life. The most diverse diseases can end people's lives in a very similar way to this case.

When there is someone affected by the disease with psychological conditions, sufficient knowledge and information about his or her health condition, the person is then able to plan consciously the way doctors and family members should proceed.

Otherwise when the patient is not able to determine the medical conduct towards his or her disease, as with M.A.S. and also as still happens with most people, the decision to proceed with medical treatment or not is up to the family which is a situation quite uncomfortable, complicated that often causes many intrigues and family problems once decisions need to be taken at a time when family members are feeling especially vulnerable, fragile and moved by feelings of faith, love, fear and compassion.

For the autonomy and the patient's will to be respected in situations such as the set out above, the legal sciences with the help of medicine established some legal tools that can help the terminally ill patient, also known as advance

¹ This clinical case is not real and was created by the authors of this chapter in order to illustrate the theme developed.

directives. Thus, for a better understanding of the theme to be addressed, it is necessary to make a preliminary analysis of the concepts of health and quality of life for only then to enter into the subject of the advance directives and their consequences.

2. HEALTH AND QUALITY OF LIFE

2.1. Notes on the Concept of Health

In English, the noun health means "the general condition of your body and how healthy you are" [1] or "the state of being free from illness or injury" [2]. In Portuguese the noun health has its origin in the Latin term "salute", which means salvation or preserving life. The definition of health in the dictionary of the Portuguese language is "individual state whose organic, physical and mental functions are found in normal situation" [3].

In this context it is very common to point the statement that health is the absence of known diseases and also all the criticism inherent in its limitation. A more well-known and better concept comes from the World Health Organization (WHO) that defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" [4, 5]. This definition, though advance for the time it was created (21st Century), receives several critics especially given the wide subjectivity of the term "complete well-being" and its intangibility, as well as what would be the good physical, mental and social once this definition holds an intangible and dependent perfection of subjective aspects of personality characteristics of each individual involved, which greatly hinders the development of a concept [6].

Given the contemporary tendency and aiming at extending the concept of health that includes well-being (physical, mental, social, spiritual) and quality of life, it can be concluded that the most correct is to mention health as a notion and not health as a simple concept, because notion is malleable definition of something, which allows better adaptation to each specific case and greater degree of subjectivity [7]. For this reason, the notion of health is better built in case-by-case basis and with people reached by a specific context.

2.2. Notes on the Concept of Quality of Life

When dealing with health issues, it is inevitable entering the theme of quality of life, often misinterpreted as a synonymous expression with the term “health”. Even though there is a clear interdependence of the two realities, health and quality of life, it is important to point out that being healthy does not necessarily mean having quality of life whatsoever.

The concept of quality of life is very complex. There are indications that the term first appeared in the medical field in the thirties but a widespread concept and still able to translate the reality of the term belongs to August Campbell back in the seventies, whom understands quality of life as "a vague, ethereal entity, something about which many people talk, but no one knows clearly what it is"[8]. The lack of clarity and consistency occurs both because of the difficulty of achieving a more precise definition as well as the need to maintain an adaptable setting to each reality, time and different cultures.

In this context, it is important to note that the World Health Organization defines quality of life as achieving an international and cross-cultural perspective, listed as a perception of the individual according to the environment in which someone appears, with the social and cultural context the person lives in and also considering his or her goals and expectations [5].

From the nineties it seems to have been established that the concept of quality of life comprises two necessary and relevant aspects: the multidimensionality and subjectivity. The first one refers to the fact that quality of life is created out of different dimensions that must be taken into consideration in the analysis of its meaning, especially through quantitative and qualitative notes. The second one refers to the assessment that the individual himself makes his personal situation in the sense of whether or not he has quality of life, both in relation to his health as to the non-medical aspects. The focus here is to assess what the person feels about the issue and not leave the assessment to be made by designated professionals, usually from the medical area [7].

The concept of quality of life related to health involves people affected by diseases and how the development of the disease affects the quality of life of these individuals. It is something much more specific that encompasses a select group of people. It is precisely on the situation of this small group of people that this work aims at for a much deeper analysis. The concept of quality of life related to health will be the focus now. Specifically, this study seeks to focus on people suffering from diseases that lead to the state of

terminally life, i.e., a situation where the irreversibility of the disease is certain and death becomes very close and inevitable [9].

3. QUALITY OF LIFE, QUANTITY OF LIFE AND THE ADVANCED DIRECTIVES INSTITUTE

3.1. Quality of Life x Quantity of Life

The advancement of medicine in recent decades has provided a new health experience in contemporary society. Nowadays it is possible to fight against almost all diseases that affect humans and maintain life even in subhuman conditions by means of machines and drugs that replace the functions of vital organs. The humanity has gone through periods that showed that being able to avoid death was considered a victory for the medicine area and the opposite of this would be the defeat of science along with the physician. Now humanity faces a time when it is necessary to reflect through ethical standards among the possible and appropriate choices in an attempt to humanize or rehumanize medicine. The main objective of this science field should be to provide quality of life to humans and not just taking care of diseases and preventing death.

A long life may not be synonymous with a good and full of quality life. On the other hand, as humans are now faced with so many mechanisms to fight against death, it becomes increasingly difficult to accept it as a natural process of life. Even if the medicine is often able to overcome natural barriers and prolong life, in some cases there has to be a bioethical boundary to place limits and stop the indiscriminate use of available technological resources used in the pursuit of life at all costs.

Dying is not necessarily negative; nevertheless, it can become burdensome when it crosses the boundary from allowing life to take its natural course to fighting against death blindly without accepting that the moment has arrived. If death is a part of life, dying with respect is part of what it means to live with dignity.

People suffering from diseases such as cancer, Alzheimers, Parkinsons, cardiovascular disease, cerebrovascular accident, respiratory insufficiency, chronicle kidney failure, among many others, can reach a state of terminal illness and fail to have quality of life. Yet, the attitude of the majority of patients and their families is to avoid talking about the end of life. Their habit

is creating a fictional scenario of positiveness avoiding that death is the inevitable outcome of the terminal illness.

This type of behavior is quite typical in the western culture where society kept living for centuries with the social phenomenon called medical paternalism, which means that ordinary individuals are not able to make decisions about managing their body or their life. Instead, only a medical professional or a qualified person such as a doctor is allowed to make decisions. This kind of paternalism only began to lose strength in the second half of the twentieth century, but to this day there are still characteristic behaviors of medical paternalism, despite the clear and current intention to include the patient in the decision making processes and democratization of relations between doctors and patients [09].

Thus, it cannot be forgotten that the terminal patient, before being a sick body, is in fact a person with his/her own will to be respected. At this point there should be a medical-therapeutic limitation based on the principle of respect for autonomy [10] ensuring respect to that the terminal patient's will. It is noteworthy that autonomy in this context can be defined according to the philosophical school of Immanuel Kant, i.e., the ability of a rational individual to decide, without interference, in accordance to their own convictions based on policy, internal moral and the values deemed correct [11].

Due to the complexity and delicacy that involves any situation of terminally life, and for the respect for the autonomy of people suffering from terminal illnesses to be achieved, the health care arises directives or advance directives, better known as living will. This is a legal instrument that allows the previous manifestation of people in relation to health treatments to which they wish to submit or not in case they are affected by the diseases that extinguish their self-determination capacity or even reduce their cognition level to the point where it is no longer possible to take into consideration the patient's will.

3.2. Development of the Advance Directives in the United States of America

Historically, the first mention of the living will expression was made in the United States in 1967 by the American Society for euthanasia as a document for palliative care. After that, in 1969, in Chicago, Loius Kutner, a lawyer, drew up the first living will and advocated on behalf of terminally ill patients and their will. In 1975, in the State of New Jersey, was the first

landmark case brought to US courts, Karen Ann Quinlan's case, which after several resources could stop the therapeutic treatment having an argument based on the irreversibility of the disease, although this did not cause the patient's death. In 1976, the State of California, approved a document called the Natural Death Act, prepared by the Faculty of Law at Yale University, who was considered the first legal document to recognize the advance directives and also the Guidelines and Directives, prepared by medical associations aiming to guide physicians in the use of artificial methods to prolong life. There was also the case Nancy Cruzan, of great national impact, contributing to the creation of the first US federal law to recognize the right to self-determination of the patient, in 1991, called the Patient Self-Determination Act (PSDA) [12, 13].

The creation of the legislation concerning the advance directives boosted several US states to develop their own legislation on the subject and while there are specificities according to culture and understanding of each region, general guidelines as those established by the PSDA must be adhered throughout the country.

Although popularly advance directive and living will are known as synonyms, the North American legal system recognizes the advance health care directives, i.e., advance directives as a genre which living will and the health-care proxy are the species. The living will is a document made preferably in writing or in another form and when possible it may also be deposited in a health care system intranet in order that the person makes choices related to treatments or medical interventions that wishes to receive in the future, in case of being affected by a terminal illness. The health-care proxy, durable power of attorney for health care, medical power of attorney, proxy or surrogate directive [14, 15] is an instrument used for the appointment of a proxy or representative to be responsible for making decisions about health treatment and medical procedures to which the patient intends to submit or not, supplying his will, where the person is unable to decide on his/her own as well as the representative even deciding on behalf of the patient in case of doubt, always taking into account the values and the more likely patient's choices [14].

In order to guarantee more effectively that the sick person's will is respected, the document should be written and signed by the patient and not in the form of a simple oral declaration for the family or doctor. In addition, it is worth mentioning that the living will is something independent of any durable power of attorney for health care, especially covering manifestations of will on future medical treatments; but nothing prevents, in the same document, that

the person also makes proxy directive nominating a representative. In any situation the patient should have medical advice before making an advance directive contributing to the decision of his/her family. It is also understood that legal advice might be necessary to avoid making the document on advance directives an invalid declaration.

Another important note is when a person may decide to develop your advance directive. Federal Law that regulates the issue is not clear on this point, but there seems to be no restrictions for healthy people develop living will or health-care proxy. What can be said for sure is that to develop its advance directive one must necessarily have autonomy, judgment and be free of any manipulation by third parties. In relation to the legal age, number of witnesses and other details, every North American state recognizes the applicability of advance directives and specifies their own rules [13].

It is important to point out that when the advance directives abide by the necessary requirements and are not contrary to the juridical ordainment or practices allowed by the medicine, they can be considered as a legal instrument with legal force, able to impose obligations on doctors, whom in case of non-compliance may be penalized civil and criminally [12]. Therefore, the advance directives offer legal apparatus for medical management, but at the same time requires health professionals to respect the patient's choice. If the doctor does not want to act according to the terminal patient determinations, for moral reasons and personal convictions, then the physician should transfer the case to another professional.

3.3. The Reality of other Countries Concerning the Advance Directives

Several countries in the world, especially in Europe, started to regulate the advance directives institute, each country with their striking peculiarities and traits of its culture. However it is important to point that the institute only spread after the advent of Patient Self-Determination Act (PSDA), a North American Federal Law on advance directives.

In Spain the advanced directives are called *instrucciones previas* or *voluntades anticipadas*. In that country, since 1986 there has been interest in regulating this institute, but the initial legislative work took place with the Convention of Oviedo, which was the first international legal document on advance directives able to legally bind the signatory countries. Only in 2002 was enacted the Law 41/2002, which after being regulated by Decree

124/2007, created the *Registro Nacional de Instrucciones Previas*. Law 41/2002 establishes general guidelines on the previous instructions, each Spanish autonomous community can edit specific standards. A common thread among all communities is that it can only be used in writing and must necessarily be attached to the patient's medical record [13].

Portugal can be seen as a featured country with regard to the advance directives, called in Portuguese *diretivas antecipadas de vontade*, once there has been a bill since 2006 and after several developments in 2012 this country published Law 25/2012 dealing with this matter and that determined the creation of the National Register of Will Advance Directives, also known as *Registro Nacional de Diretivas Antecipadas de Vontade (RENTEV)*, which should be consulted by the medical personnel and once there is an advance directive will, this binds the medical care at the manifested patient's will [15].

The Netherlands regulated the advance directives, also known in this country as *nontreatmentdirectives* in 1995 by creating the Act of the Medical Treatment Contract. Belgium also regulated their *declaration anticipée of volonté* in August 2002 by creating a law with 19 articles dealing with health care, demanding that the policy, i.e., the advance directive document must be renewed every five years, but admitting its revocation at any time [13].

In Italy, despite having no specific law on the subject, the country recognizes the *dichiarazione anticipata* treatment, *testamento biologico* or *testamento di vita*, and also the advance directives institute is bound in the Italian case law, also known as *giurisprudenza*. Italy has, since 2003, guidelines established by the National Bioethics Committee on this matter [13].

In Germany the advance directives are known as *patientenverfügungen* and were regulated by the law on September 1, 2009, known as the law to the provisions of the patient's will (*patientenverfügungsgesetz*), considered a liberal law with moderate requirements for the development of the institute. Some German states, such as Bavaria, have an official template for making these documents to facilitate and secure the expression of people's will for any person who wants to have an advance directive document [15].

In Latin America, Uruguay regulates the advance directives by Law 18.472/ 2009. Argentina is the Latin American country that develops more studies on the subject and its normative regulation began on a regional basis in Rio Negro Province in 2007. In 2009 with the advent of Law 26.529/2009, amended by the Law 26.742/2012, the advance directives, also known in Argentina as *directivas anticipadas*, were finally regulated throughout the Argentinian territory [13]. In Brazil the advance directives begin to take place

in the juridical ordainment and although there is still no specific law on the subject, the Federal Medical Council (Conselho Federal de Medicina), through the Council's Resolution number 1995/2012, offered more specific guidelines for the institute to be used in Brazil. However, since 2006, after the Council's Resolution number 1.805/2006, the policies on advance directives have already been made in Brazil both through private documents and also public instruments issued by the Public Notes Registry.

4. FINAL NOTES

In the final analysis it is important to point out that the living will and the health-care proxy are not ways to implement euthanasia or assisted suicide whatsoever. The role of advance directives is to enable and prioritize the humanization of care to individuals in terminally life situation, providing palliative care for the patient that is suffering due to the disease. It is also important to register that the quality of life can exist despite the fact that the person is living with a terminally illness if the medical assistance respect the patient's will above all and practice orthothanasia, taking care of the patient and not only worrying about the disease itself so there will not be procrastination concerning the patient's suffering.

In order to make sure that misunderstandings will not be left behind, it becomes necessary to explain that orthothanasia means providing palliative care to relieve the patient's suffering and not using treatments that prolong the patient's life in an artificial and disproportional way to the process of dying. Euthanasia, on the other hand, means to shorten the patient's life with an action promoted by the doctor that will cause the patient's death [12].

The real necessity of respecting the patient's rights of self-determination and privacy is to increase the communication among the parties involved, i.e., patient, family and medical professionals. It is a way of thinking and acting together for the patient and most importantly, showing respect and understanding for the patient's autonomy.

In order to organize and regulate this matter, the advance directives must be guided by four main bioethics principles, which are: autonomy, beneficence, non-maleficence and justice [10, 12], always maintaining the focus that the doctor-patient relationship must be guided for the principles of respect for patient's autonomy and beneficence, being these principles complementary, but of equal importance.

The balance between respect for autonomy and the beneficence for the terminally ill patient implies the verification of whether or not there is the possibility of quality of life during the pursuit of medical treatments. Quality of life in the patient's individual perspective, as it has been seen, is the synthesis [16], i.e., the combination of several factors that the individual himself considers fundamental to assess his personal situation. Based on the clinical case mentioned earlier in this chapter it becomes quite easy to see that for M.A.S., the fictional patient, it was no longer possible to have quality of life after about a year of treatment, which led to the patient's family to opt for palliative care. In this case, M.A.S., the patient did not have sufficient cognition to evaluate her own quality of life after the disease took control of her vital signs. As she had no possibility to make decisions over her will or no cognition whatsoever, the decision for stopping the treatment and starting the palliative care had to be done by her relatives once the patient had lost her self-determination capacity. Notwithstanding, the family's decision is, nonetheless, a subjective evaluation about someone else's quality of life, which is something highly common in day-to-day medical hospital, once most patients admitted in hospitals do not have the knowledge or even the concern about preparing their advance directives.

Finally, as deciding on the advance directives and the terminally ill patient's future is a very subjective and personal situation, physicians should strive to respect the maximum understanding of the quality of life for each patient (or family) and never look beyond the threshold between the beneficence and the medical paternalism, because at this point medical paternalism is a great disrespect to the patient's autonomy.

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