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THEME ISSUE
END OF LIFE ISSUES
AND ADVANCE DIRECTIVES

BRIEF WORDS FROM THE GUEST EDITOR

When I received - and promptly accepted - the invitation to serve as guest editor to this theme issue of Medicine & Law, I knew we were going to deal with a subject that is, at the same time, controversial, exciting and challenging.

Controversial, because it involves not only legal concepts, but also personal beliefs, religious dogmas, and an endless number of ethical and philosophical questions that have been haunting mankind for centuries.

Exciting, because we are living in a time where science is developing faster than in any other period of history, bringing advanced technologies to medical devices, and creating the possibility to artificially postponing death but, at the same time, bringing along the questions: should we (?); and who gets to decide.

Challenging, because by discussing it over and over again, we have the opportunity to observe the issues under new parameters, discovering that sometimes we don't need to focus on the answer, but on reformulating the questions.

As a result, we deliver to you a theme issue with no less than fourteen papers, from all over the world. Fourteen different views, proposals and experiences that - combined - will provide an excellent source for research and discussion, hopefully breeding new ideas, provoking new debates, and delivering alternatives and ways to balance ethics, human dignity, science and law.

And without any further delay, I hope that your reading experience will be fruitful and positive.

With my warmest regards,

Eduardo Dantas
Warsaw, May 2013

ADVANCE DIRECTIVES AND LIVING WILLS: THE ROLE OF PATIENT'S AUTONOMY IN THE BRAZILIAN EXPERIENCE

Eduardo Dantas*

**Vice-President World Association for Medical Law
President Brazilian Association for Health Law**

To violate a person's autonomy is to treat that person merely as a means, that is, in accordance with others' goals without regard to that person's own goals. Such treatment is a fundamental moral violation because autonomous persons are ends in themselves capable of determining their destinies.¹

Abstract: This paper aims to discuss the development of the notion that the patient has the right to refuse treatment, and how the Brazilian legal system is dealing with bioethical dilemmas, such as the possibility of exercising autonomy through advance directives. The paper discusses the lack of legislation to regulate important issues in the end of life healthcare, and what ethical guidelines exist, providing physicians with ethical and legal parameters to deal with the patient's will.

Keywords: Autonomy; Living Will; Advance Directives; End of Life; Informed Consent; Brazilian Law

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1 Beauchamp and Childress, *Principles of Biomedical Ethics*, 1994, 4th ed., p. 125.

1. INTRODUCTION

All over the world, one of the more controversial ethical issues is how to deal with the patient's wishes in a scenario surrounded by the approximation of death. Physicians are trained to postpone death at all costs, but sometimes the patient's will is to avoid senseless pain when staying alive is not viable anymore (or when life cannot be lived with dignity).

So many questions arise from this conflict: Until when a patient is competent to decide? What are the limits of the patient's autonomy? What are the limits of medicine, and at what point the thin line of saving a patient's life and making him suffer for no reason other than keeping him alive is crossed?

And more: in a society where medical issues are brought to the courts in a speed that challenges even common sense, and where the law and statutes can't keep up to the pace of medical development, what are the limits to what is legal, what is acceptable, what is moral, what is ethical and what is right?

Medicine has evolved in such a speed in the last six decades, that now it is possible to keep a patient artificially alive for years, even against what could be called "the laws of Nature". There are huge debates over the purposes of postponing death at all costs, even if it means leaving the patient alive and suffering in a vegetative state, just to satisfy the family's wishes. For some, this is a natural response (and obligation) of medicine. To others, it is just playing God beyond the limits of science.

There is no easy answer to these issues, but a consistent solution is under construction in different parts of the world, leading towards the respect of the patient's will, and recognizing the importance of obtaining the patient's consent, whenever it is possible, respecting autonomy and choice.

2. DEFINING CONCEPTS, OR UNDERSTANDING AUTONOMY IN END OF LIFE SITUATIONS

Informed consent is the authorization given by the patient to undergo treatment, based on the knowledge of the nature of a medical procedure, and be submitted to risks, side effects, possible complications, benefits and alternatives to the proposed treatment. In other words, it is the acceptance of the services to be delivered by a healthcare professional, after understanding what is being consented to.

A long time has passed from the days when physicians told patients what they needed and patients agreed without question. Although some patients still have an “I will do whatever you say, doctor” attitude, they’re in the minority. In today’s world, different people react to proposed treatments or tests differently, often as a result of their varied backgrounds, financial status, values, attitudes and perspectives.

The paradox of contemporary medicine is that a constant expansion of therapeutic options makes decoding these options increasingly difficult. In legal terms, this new situation has been transposed into a growing demand for patient participation in decision-making which seems to express the notion that anxiety caused by being subjected to some kind of medical dictatorship creates the need to even out a relationship which is by essence asymmetrical. To this recent culture is added a growing trend to judicialisation² which challenges medicine to respond to two contradictory imperatives: to give the best possible care, but within mandatory limits and constraints, or to be confronted with hostility.

When it comes to end of life situation, another piece of human drama is added: the patient - as a corollary of the principle of respect for human dignity, has the right to be informed about his situation, the prognosis and the possible or expected outcome, and then be an active player in the decision-making process.

In other words: in a terminal situation, the patient has the right to refuse treatment, if there is no possibility of staying alive without suffering or a minimum standard of quality, and opt to receive just palliative care, leaving life to follow its natural course, without artificially postponing death.

One of the biggest problems in accepting this decision is that some segments of society still thinks that refusing treatment is the same as authorizing euthanasia.

Euthanasia is the act of provoking, or facilitating the death of another person who is suffering from a serious and, for the most part, painful illness. It depends on a clear act, such as the application of high doses of sedating, or lethal substances to a terminal patient, which differs from the assisted suicide,

2 On this topic, DEMICHEL’s “*Au nom de quoi? Libre propos d’une juriste sur la médicalisation de la vie*”.

because in the latter, the help to die is explicitly requested by a patient who is no longer able to move, or to act on his own in this regard.

The orthotanasia, is the suspension, reduction or withdrawal of medication, equipment, or procedures that serve to artificially prolong the life of a patient, abbreviating his suffering, and allowing life follow its natural path to extinction. Not resuscitating one patient who is suffering a cardiorespiratory arrest seems to be a good example of it.

In a diverse path follows the dysthanasia, which is prolonging life of a patient without any viable prospect of cure or improvement by artificial means.

The treatment of terminally ill patients, and the postponing of end of life issues, has always been one of the greatest dilemmas faced by doctors, who were trained and taught to face death as a defeat, and the prolongation of life as the only acceptable procedure.

Just recently, the issue has become subject of legislation in different countries, strengthening the idea that the patients needed to play a major role, regulating thus how autonomy could be exercised, in order to bring legal safety to the decisions, pushing liability and criminal responsibility away from the doctor-patient relationship.

3. THE DEVELOPMENT OF THE PATIENT'S CHOICE - ETHICAL AND LEGAL ASPECTS

Refusing treatment is always an event situated at the centre of a profusion of concerns. The need for recognition is probably one of the most significant of them. This need for recognition that Paul Ricoeur³ analyzed with great precision exists in both patient and doctor.

Patients want doctors to recognize their individuality and their complexity. Refusal can be an expression of this need and a request for euthanasia is frequently a call for help rather than evidence of any real desire to end life.

But doctors also need recognition from patients, not so much in the form of gratitude, but in terms of recognition for their competence, their sense of responsibility and the legitimacy and specificity of the values which the medical profession upholds.

3 P. Ricoeur, *Parcours de la reconnaissance*, Paris, Stock, 2004

To these two components could probably be added the expression of a need for social recognition, recognition of a need expressed by a public call for help from both protagonists in the act of caring. One specific characteristic of caring is the statement of an act of solidarity so that the “private” dialogue between patient and physician is frequently part of a quest for social harmony. When these demands are claimed by both parties, it is easy to understand that the two (or three) recognitions may not coincide. This may be the case when a sick person entertains iron-bound convictions that do not allow him to take account of the concern for professional - not to mention legal - responsibilities that inhabit the doctor, or a doctor who is excessively infatuated with some therapeutic project and resents criticism from the patient.

Or it could also be a recognition in the medicine as a culture that finds it unacceptable for traditional beliefs it considers as irrational to be allowed to challenge their modern practices backed by scientific evidence. As can be seen from all these examples, solving the issues on a pragmatic case by case basis is not the way to developing guidelines.

One answer lies in the fact that the way many of us can expect to live, age and die has changed dramatically over the past quarter of a century. In many countries, advances in basic living conditions, healthcare and medical technology mean that *most* of us are living to a good age, and that *many* of us are living to a very good age in spite of the illnesses or fragility which ordinarily beset us. When in the past we had good reasons to fear an *early* death, today many of us fear living *too long*, and we fear that medical interventions will unreasonably prolong our dying as well. When in the past we had good reasons to fear a painful and uncomfortable *aging* and *dying*, today with advances in the management of chronic illnesses and palliative medicine, we are more likely to be fearful of *living* not with pain and discomfort, but instead with the perceived degradation of physical dependence or mental incompetence.

Boundaries of this subject are yet to be discovered. In *Old Law, New Medicine*⁴, Sheila McLean points out:

“The fundamental taboos which surround the very subject of death permit the perpetuation of an approach to it which may have a number of consequences. First, those who actively choose death may be regarded as irrational or lacking legal competence.

4 (1999), London, Pandora, p. 140-141.

This is particularly so when medicine can offer hope of a cure or palliation of symptoms.

...

Second, some individuals may be so afraid of a life without prolonged quality that they choose suicide as an option. Angell, for example, has noted that: 'The very high suicide rate in older Americans is due partly to their being concerned that they will not be able to stop treatment if hospitalized... Some people now fear living more than dying, because they dread becoming prisoners of technology.'

...

Finally, medical advances require resolution of the question of what is to be done in respect of the person who is incompetent, with no hope of recovery and with no clear advance expression of wishes. Strict adherence to the principle of the sanctity of life results in such individuals being maintained in an insentient form for what, in some cases, may be a very long time. Without clear justifications for the termination of treatment, life which has no quality for the person living will be prolonged merely because the technology to do so exists."

The discussion about patient's autonomy is neither new nor original⁵. But it is interesting to see that all movements made, both in the legal and ethical fields, lead towards the same conclusion. Different jurisdictions, with completely unrelated legal backgrounds, eventually end in finding the same solutions.

Historically, the ability to force treatment on unwilling patients derives from a need-for-treatment justification. This approach started to change in the 1960's, mostly in the United States, when there was a gradual move toward the "dangerous patient" justification-unwanted treatment could be imposed only if, or when, the patient presented a significant risk of harming himself or others. Under this new system, patients' advocates began to press for the patient's right to determine what is to be done to his own body, creating instances in which the committed patient could decline treatment with medication. As these matters began to make countrywide legal appearances

5 Regarding the historical background on this issue, I refer to my paper entitled "When consent is not enough: the construction and development of the modern concept of autonomy", published by *Lex Medicinæ* (Portugal, vol. 15, 2011, p. 101-112).

in the U.S., virtually every involved court recognized some substantial patient interest in a right to refuse treatment⁶.

In 1989, deciding a case in the British courts⁷, Lord Donaldson MR stated in his ruling that:

“The ability of the ordinary adult to exercise a free choice in deciding whether to accept or refuse medical treatment and to choose between treatments is not to be dismissed as desirable but inessential. It is a crucial factor in relation to all medical treatment”.

In 1997, Article 5 of the Oviedo Convention (European Convention of Human Rights and Biomedicine), clearly stated:

“An intervention in the health field may only be carried out after the person concerned has given free and informed consent. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequence and risks. The person concerned may freely withdraw at any time.”

Very similar to that, and just a few years later, UNESCO's Universal Declaration on Biomedicine and Human Rights (2005) recognized the same principle of respect for autonomy, also in its article 5:

“The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected”.

In 1994, the United States Congress acknowledged patients' overall rights to refuse medical treatment in certain circumstances, even if such refusal would result in death, enacting the Patient Self Determination Act⁸ (the "Act") in an effort to encourage patients to exercise their common law rights to refuse treatment. The Act applies to licensed health care facilities which receive Medicare or Medicaid program funds. The Act requires hospitals, nursing homes and hospices to furnish certain information to the patient/resident at the

6 In the same sense, see *Vacco v. Quill*, 117 S.Ct. 2293 (1997) or *Washington v. Glucksberg*, 117 S.Ct. 2258 (1997).

7 *In Re F (Mental Patient: Sterilisation)* (1990) 2 AC 1.

8 (a.k.a. the "Danforth Act") See 42 U.S.C. §1395cc (1994).

time of admission. This written information concerns the patient's rights under State law and the written policies of the provider regarding implementation of the patient's advance directives. The facility must also document in the patient's medical record whether he holds an advance medical directive. The provision of the patient's care may not be conditioned upon execution of an advance directive.

In France, the patient's right to advance directive and to appoint a person to act as proxy (not necessarily a relative, but someone who will be entrusted on enforcing the patient's will in case of unconsciousness, or inability to speak for itself) is regulated by the law of March 4th, 2004 (commonly known as *Loi Kouchner*).

Recently, Portugal enacted the Law 25/2012, which regulates advance directives, living wills and healthcare proxy and creates a National Registry of Advance Directives.

All of this combined represents a quick but comprehensive view on the complexity of the situation, and how seriously the debate over autonomy and the patient's right to decide his own fate when facing a terminal disease is.

In the precise words of Kristinsson⁹,

“Personal deliberation might be valued for its ability to bring out, express, and create the distinct point of view of the individual in question, and for making it possible for the individual to steer the course of her life according to that distinct point of view. An individual's “point of view” is a complex, dynamic outcome of emotions, judgments, beliefs, desires, habits, and character, and all of these are in turn affected by upbringing and other contingent circumstances”.

From all this comparative background, it seems that there is no doubt that we are heading towards the recognition of the patient's right to exercise autonomy, not only during treatment, but also deciding when it should finish.

9 KRISTINSSON, Sigurdur. Autonomy and informed consent: A mistaken Association? *Medicine, Health Care and Philosophy*. DOI 10.1007/s11019-007-9048-4, Springer, 2007.

4. THE BRAZILIAN SCENARIO - THE ACTIVE ROLE OF THE FEDERAL COUNCIL OF MEDICINE

The Brazilian situation regarding advance directives is very peculiar. While other countries have long been discussing the subject, either in court or through legislation, the issue has been solemnly ignored by politicians, leaving a void in legislation, and thus creating insecurity for the health care professionals.

There is no provision in Brazilian law, regulation or establishing guidelines for the use (and even validity) of advance directives in a terminal situation. Physicians have to rely on the interpretation of various codes and legal norms in an exercise of legal interpretation they are not used (or trained) to.

According to the Federal Constitution, based on Article 5, section II, which states that nobody can be forced to do, or be compelled not to do something against his or her will, unless determined by law, a patient has the right to refuse medical treatment,.

In the same sense, according to sections VI and VIII of the same article, which guarantees such freedom, medical treatment can be refused in respect for the patients' philosophical convictions and religious beliefs. In other words, it's a constitutional right that the patient's will prevails over the therapeutic options chosen by the doctor, even if technical and professional arguments are ignored. Being a conscious decision, taken by a competent patient, after proper information, the patient's will must be respected.

References to the patient's right to refuse treatment are scattered all over Brazilian legislation, without a specific legal act. The Civil Code states, in Article 15, that "*no one can be constrained to submit, with risk to life, to a medical treatment or surgical intervention*".

The terms of the article are imprecise, because the expression "with risk to life" may lead to the false conclusion that, if there's no risk of dying, the patient could be constrained, or forced, to accept treatment or surgical intervention, which is not the spirit of the law.

The new Civil Code, enacted in 2002, presents a twist in medical responsibility, changing what was considered the main physician's obligation - saving human lives by all means - and giving powers (and, as a consequence, responsibilities) to patients and legal surrogates, letting them interfere and decide their own

fate, according to the bioethical principles of autonomy.

In the same spirit of law, Article 17 of the Elder's Statute (Estatuto do Idoso) guarantees to people of more than 65 years of age, which are sound mind and sane, the right to choose what they consider to be the most favorable health treatment.

The aforementioned Statute does not make any reference to risk of death as a condition to carry out the right to choose a therapeutic option. Regardless of his clinical condition, the only possibility of restraint for the patient is to be insane and lacking mental integrity. In this situation, the doctor can only proceed his own personal option of treatment if: a) the patient cannot express his will; b) the relatives or legal surrogates cannot be found; and; c) there is immediate and real risk of death.

Another expression of the patient's autonomy in the Brazilian legal system is contained in Article 10 of the Statute of Organ Donations and Transplants. This Article favours, the patient's consent in any situation, in spite of the doctor's decision, demanding the express consent of the receiver, after counseling about the risks of the transplant procedure. That means that, even in real and immediate risk of death, the patient can decide to submit or not to the risks of transplantation.

The same reasoning, though, can be applied to radical surgical procedures, administration of medicine, chemotherapy and blood transfusion, considered by many as a form of "transplantation"

It is perhaps worth mentioning, at this point, a law enforced by the State of São Paulo¹⁰, which guarantees to the State's health service users the right to receive clear and adequate information on therapies and therapeutic procedures, in respect for ethical and cultural values.

Two other States - Paraná and Minas Gerais - also passed laws for public health services users' protection¹¹, stressing patient's autonomy as a principle to be observed and enforced.

It is clear then, that these modern pieces of legislation take into consideration the patient's will, in spite of his clinical state and condition, presenting legal

10 State Law n. 10.241/1999 - São Paulo

11 State Law n. 14.254/2003 - Paraná and State Law n. 16.279/2006 - Minas Gerais

mechanisms to enforce his right of choice, rejecting medical or judicial impositions and respecting the principles of dignity of the human being.

Another conclusion that can be reached is that the bioethical principle of Beneficence must be interpreted under the patient's view, since he is the addressee of medical intervention, and even if the Medical Ethics Code guarantees the physician (Article 22) discretionary action in a life and death situation, this discretion cannot oppose constitutional rights.

There are, though, winds of change, provided not by legislators, but by physicians themselves. By August 2012, the Federal Council of Medicine approved a new resolution (CFM n. 1995/2012) allowing doctors to withhold procedures or withdraw treatments designed to keep a terminal patient alive, provided the patient or his legal surrogate expresses the wish to do so.

RESOLUTION CFM 1.995/2012 (August 31st, 2012)

Article 1 - Defining advanced directives as a set of wishes, previously and expressly manifested by the patient, about the health care or treatments he/she wants - or not - to receive in the moment he/she loses the ability freely and autonomously express, his/her will.

Article 2 - When deciding about health care or treatment of patients who are incapable of communicating, or to freely and independently express their will, the physician shall take into consideration their advanced directives.

Section 1 - If the patient has designated a proxy for that purpose, the proxy's informations should be taken into consideration by the physician.

Section 2 - The physician shall disregard the patient's advanced directives or proxy's informations when they are, after his analysis, conflicting with the principles established by the Medical Ethics Code.

Section 3 - The advance directives shall prevail against any medical opinion and against the patient's family wishes.

Section 4 - The physician will register, on the patient's chart, the advanced directives that are directly communicated to him by the patient.

Section 5 - If no advanced directives are established, nor a proxy has been designated, and if there is no family members available to decide, or if they have conflicting requests, the physician - when found necessary and convenient - shall submit the case to the hospital's Ethics Committee. If there is no such committee, the case must be submitted to the Regional and Federal Council of Medicine, to provide solid grounds in order to solve ethical conflicts.

Article 3 - This Resolution shall enter into force on the date of its publication.

Such a Resolution is not a statute, but rather than just being an ethical guideline, and facing the lack of regulation on the matter, it assumes capital importance and (at least temporarily) fulfills the legal gap, since the Federal Council of Medicine was created by a Federal Law, and among the competencies that were given to it, there is the power to enact guidelines that will oblige physicians during the exercise of the medical profession.

It is an important step towards giving the patient the possibility of regaining control over his own life, thus allowing him to die with dignity. The main result of this Resolution is to recognize that dying with dignity is the culmination of a greater scenario, which is living with dignity.

Although it may seem justifiable to state that patients may wish to be and remain at all times in complete control over matters regarding their personal health, this simple statement of principle bears little relationship to reality. People who are confronted with pain, disease or approaching death, are bound to feel diminished by the awareness of their own weakness and therefore lose some of their autonomy to the extent that they no longer know what it is they really want or can accept and are not even able to express themselves.

By their side, more often than not, facing them, are physicians or carers whose strength, despite some doubts and hesitation at times, is reinforced by their own science and who wish to accomplish their mission, which is to apply in full a treatment they consider to be the most appropriate, under the circumstances, to alleviate, cure, or delay the advent of death.

But can what is left of patient autonomy, of the notion of consent that the patient is requested to give and of the need to create conditions in which freedom of

consent - which everyone agrees must be "informed" - be exercised? Can there be consent if, as we have seen, there is no possibility of refusal?

This was the question that the Brazilian Code of Medical Ethics (another Resolution from the Federal Council of Medicine) dated 2009 attempted to answer, so as to provide patients with more autonomy of decision as regards medical care and ensure more equality in the relationship between doctors and patients.

The Code enshrines the notion that patient consent must prevail and in other words states that, in the light of information and advice supplied by healthcare providers and in consultation with them, patients are entitled to take decisions regarding their own health. Doctors must respect wishes expressed by patients after informing them of the consequences of their decisions.

When refusing to undergo or continue treatment represents a threat to life, physicians must do their utmost to convince patients that they should accept essential treatment. No medical act or treatment may be applied without securing free and informed consent from the person concerned. There is, though, a legal gap in here, since consent may be withdrawn at any time, but the criminal code forbids physicians to interrupt life-saving treatments. This inconsistency has yet to be faced by Court, since no claim has posed this issue up to now.

These are, therefore, the ethical foundations of patient autonomy and right to refuse treatment, as inserted in Brazilian Code of Medical Ethics:

Art. 41-[The doctor shall not] Shorten the patient's life, albeit at his request or at his legal representative.

Sole paragraph - In cases of incurable and terminal disease, the doctor must provide all palliative care available without undertaking unnecessary diagnostic, therapeutic or obstinate actions, always taking into consideration the wishes expressed by the patient or, in his impossibility, of his legal representative ".

Amongst the Fundamental Principles of Medicine, elected by the Medical Ethics Code, the one described in section XXII says verbatim that "in terminal and irreversible clinical situations, physicians avoid carrying out unnecessary diagnostic and therapeutic procedures and allow the patients under his care all appropriate palliative care. "

The aforementioned resolution is grounded in the claim of the defense of constitutional principles such as human dignity, and the prohibition of inhuman or degrading treatment, clearly stated in Articles 1º, III and 5º, III - of the Federal Constitution. While these effectively important principles add up to the bioethical principle of autonomy, they do conflict with the protection of life (the sanctity of life, as found in the foreign doctrine).

When dealing with the existence and recognition of a patient's right to die with dignity and autonomy, Leticia Ludwig Möller shows well the conflict faced between the ethically desirable and legally permissible.¹²

“The excessive and inappropriate use of technologies applied to the medical treatment of patients in the terminal stage, leading to the prolongation of a painful end of life (often beyond what would be desired by the patient himself, disregarding his right to exercise autonomy, conforming the idea and the need to affirm the existence of a right to die with dignity. The expression "right to die" or "right to a dignified death" can now be found in studies about end of life seeking the dialogue between different areas of knowledge, such as medicine, ethics and law. The advocates of the right to die with dignity, in general, are glimpsing the patient's terminal condition that is exposed to treatments that merely extend the time of his death, bringing him no benefits, but only pain and suffering - not often wishing these authors extend this defense to the practice of euthanasia (active). Dying with dignity so often relates to the idea of dying in peace, with physical and spiritual integrity, or even, to die at the right time, with comfort and relief from suffering.

(...)

We share the understanding of Ronald Dworkin, that the way we die has importance, and in general, the right of the individual to his death is a reflex of how he lived and must be respected, that this time keeps a consistency with the values and beliefs expressed in life - especially if this is the manifest desire of the ailing, and within the limits (as stated above).”

12 In Right to die with dignity and autonomy. Ed (Publisher). Juruá, Curitiba, 2007. pages 95-98.

Another important aspect to be considered is the fact that the practice of palliative medicine is now a reality in the vast majority of hospitals in Brazil, being positive in order not to deprive the conviviality of terminally ill patient from their families. This stance, according to its advocates, meets one of the pillars of bioethics, which is the principle of autonomy, the patient's right to decide the course of their own treatment. It would still be consistent with respect for human dignity, the principle developed in the first article of our Federal Constitution.

Examining the Medical Ethics Code, Leo Pessini adds:¹³

“(...) we noticed significant change of emphasis. The goal of medicine is not only maximizing the lifetime of a person. The aim of medical attention is the health of the human being and the criterion to evaluate their procedures is whether they will benefit the patient or not (cf. art. 2nd). The commitment to health, especially if understood as global welfare of the person and not just the absence of disease, opens up the possibility for other issues in the treatment of the terminally ill, and the healing issues. Even so, it remains a steadfast conviction, also found in earlier codes, that "The doctor must keep absolute respect for human life (...)" (art. 6). This tension between benefiting the patient with palliative treatments, which may shorten his life but promote his physical and mental well-being, and the absolutism of the value of human life in its biological sense, produces a dilemma that some doctors prefer to settle in favour of prolonging life.”

From a strictly rational point of view, death is just one of many aspects of life. Nothing more natural. However, talking about death, this companion that is increasingly present from the moment we are born, causes us such discomfort, that we turned it into a real taboo. We associate it with fear, frustration, pain, suffering and despair. Trying to ignore the undeniable reality of its existence, we avoid talking about it: we deny children the understanding of the phenomenon of death and the right to bid farewell to the beloved ones; we deny ourselves share the grief with loved ones; we deny health professions students a deep discussion on the topic that would help them to better deal with the matter within their professional practice. We created an illusion of

13 In his article "Dysthanasia: some reflections from the bioethical Brazilian reality", published in the journal *Bioethics* 2004, Vol. 12, No. 01.

immortality, thus wasting the opportunity that the acceptance of our finitude gives us: the opportunity to reflect on life and the perception that the time we have is limited, and therefore precious. Live it with quality is the true translation of what it is a life well lived.

It is within this perspective of emphasis to a life of dignity and quality that the healthcare professionals who are dedicated to palliative care work. Such care seek to relieve the suffering of patients whose medical diagnostics indicate that they have no chance of healing, through symptom control (not only physical, but in different orders) and the promotion of a lifetime with the best possible quality until the last moment. It is the quest for "good death".

Inherent to palliative care is the attempt to rescue an experience more human in the relationship between the patient and the professional staff that takes care of him. Special attention is also given to the humanization of the processes of death and mourning in prolonged illnesses that are usually intense and characterized by long periods of emotional burnout and stress.

In palliative care, the person is treated, not the disease. This seemingly simple change makes a big difference. It opens space for a perception of singularities of the individual, thus leading to a more accurate understanding of their real needs. Treating the patient with respect and preserving his dignity is only possible when it is considered in its context and its nuances. This is a *sine qua non* condition, so that we can see him in his condition of human being, rather than sick and we are open to listen to their concerns, fears, desires and feelings, whether they manifest in verbal or unsaid.

Kübler-Ross points out five stages of dying, each with its own characteristics. At the denial stage, the patient uses this defense mechanism in an attempt to cope with the anxiety facing his own the death. At the stage of anger, arises a revolt against the diagnosis, the prognosis, and often against God and against those who are around him. The patient may show up aggressive toward his family members and the professionals who take care of him. At the bargaining stage, there is an attempt to negotiate his healing, doing good deeds to be rewarded for them. The fourth stage described by the author is depression, in which the patient comes into contact with a profound sense of loss and may prove to be silent and isolated from others. Finally, there is the stage of acceptance, in which the despair gives place to a feeling of peace. It is important to stress that, although these stages serve as parameters for the

understanding of the process by which the patient passes, they do not present themselves in a rigid order and the way they are experienced, as well as the duration of each, is variable for each individual. It is important to respect each of these phases allowing the patient to experience them.¹⁴

While in traditional medicine the health professional seem encouraged to turn to attempt to extend the duration of life avoiding death, medicine that resorts to palliative care is seeking to prolong what makes us human, preserving the maximum freedom of making conscious choices. Life is not only considered in its biological sense, but also includes social, psychological and relational aspects. While there is life, there is also the potential for intra and interpersonal emotional growth..

Implied to a discussion about palliative care is the issue of how human beings are perceived, because the vision of man that the healthcare professional has, directly affects his attitude and his work - whether he is aware of his ideas or not.

If the ideas of the professionals are inserted within a paradigm that assigns to the man an essence of identity, he will not be seen as amenable to changes and growth, but as someone always equal to himself, thus not affected by the other. From this perspective there is an appreciation of stability: the human conflicts are viewed negatively, taken as imbalances that must be banned for threatening stability. This man is thought of as a passive being, and therefore being incumbent to the health professional's keeping of knowledge and total responsibility for the course of his treatment.

There is, however, another paradigm that has been strengthening and which provides the basis for the changes requested by the palliative medicine: the man seen as a procedural being, i.e. a man that builds himself, actively, as he lives. This means that he never remains static or reaches the end of constructing himself. On the contrary, it lies in a continuous becoming, overtaking what is from what is about to become . The processuality of man takes place through the meeting with the other, in a dialectical relationship which affects and is also affected, being the mutual affectation the requirement for growth. The conflicts, far from being seen as negative, are the promoters of growth and they stimulate and develop the potential of adaptation.

14 KÜBLER-ROSS, E. On death and dying: what patients have to teach doctors, nurses, religious and their own relatives. Ed (Publisher). Martins Fontes Sao Paulo, 1996.

The emphasis, in this paradigmatic vision, is in the potential of human beings to make changes, to reframe their experiences and establish life projects for themselves. His ability to make conscious choices gives the possibility to seek self-fulfilment creatively and responsibly. Within this perspective, the patient is not passive towards health professionals and diagnoses received.

The paradigm that sees the patient as a whole human being has autonomy over his lifetime. So there is no space for a health professional who presents himself authoritatively: possible interventions and the implications of each of them must necessarily be discussed with clarity and directness between doctor, team, patient and family, whence the dignity of the patient is maintained and he is allowed to make choices that, in his concern, are the most appropriate, i.e. meeting his best interests. When talking about choices, we do not mean only those that involve the balancing of risks and benefits of possible treatments and medical interventions, but rather we include the resolutions of life and farewells.

To deny the patient the clarification on his actual conditions is not a way to protect him. Rather, it means leaving him alone without the chance to share his woes and feeling himself betrayed by realizing that he cannot fully rely on those whose care he is submitted to. When the family decides to keep secrets or lie to the patient about his diagnosis and prognosis, it will create an emotional barrier that will hamper the free expression of affections in relationships.

Being able to go through the end of life consciously and feeling himself valued and respected enriches the life of the patient in order to promote a greater sense of emotional strengthening. This is an important prerequisite for the establishment of clearer priorities and for a deeper connection with the loved ones.

Palliative care also fulfills the role of helping the relatives of the patient to face the process of coming across the pain of the situation impending loss of a beloved (family) member.

The familiar universe is systemic, and therefore the impact of the existence of a member in need of palliative care is impacting to each of the other members and to the family unit as a whole. The family faces a long and anticipatory mourning, since the feeling of loss is settled from the diagnosis, and the emotional issues that arise during this period of stress need to be recognized and addressed.

Being able to express the pain and share feelings promotes the individuals and his family's strengthening. Depart from the patient does not relieve pain from anyone and causes to the patient the extra pain of abandonment in life.

To be empowered to act appropriately in palliative care, a health care professional needs some training which goes beyond the technical field. As important as the safety in knowledge acquired is personal preparation which allows coming across his own limitations and with the confrontation of doubts and anguish that the theme of death rises, and yet what we call interpersonal preparation, is indispensable when the proposal is truly monitoring the patient, taking him and his family in his afflictions and acting as facilitator of the relationship between both of them, in favor of a dignified life.

The great virtue of this resolution was to bring onto the stage the debate which hitherto remained confined to the corridors of hospitals. Science has evolved to the point of allowing to artificially prolong a terminal life indefinitely, under suffering, mechanically, without purpose and at any cost, whereby medicine is avoiding its primary objective.

5. CONCLUSIONS

It is important to recognize, however, that some people who express support for a 'right to die,' only do so in a highly qualified way. Many people who think that medicine often sustains or prolongs life unreasonably, and who feel helpless to oppose its momentum, often assert a 'right to die' when what they are really claiming is the 'right to refuse burdensome or futile treatment'. They are not interested in asserting *complete control over death*, but seek instead, to reclaim *some control over the manner of their dying*.

There is, of course, a clear and established ethical tradition describing the legitimate scope and limit of choice with respect to the circumstances and timing of death. Mindful of the dignity and consequent inviolability of human life, the Catholic ethical tradition stands with traditional Western medical ethics, in recognizing that the direct and voluntary killing of an innocent human person, at every stage and in every state of life, is always gravely wrong.¹⁵ When life-saving or life-sustaining treatment is withdrawn or withheld with the intention of ending a person's life, this is an unethical action or omission, irrespective of

15 John Paul II. *Evangelium Vitae: Encyclical Letter on the Value and Inviolability of Human Life*. Homebush: St Pauls, 1995, n. 57.

any good motive, and morally equivalent to euthanasia or suicide.¹⁶

Yet this tradition also recognizes that, sometimes, respecting human dignity and caring for patients can require the avoidance of over-treatment as well as under-treatment. Within the life of every human person there are limits to the extent to which life and health should or can be actively pursued. While there will often be good reasons to do things which protect or prolong life, there may concurrently be good reasons *not* to do so, such as great risks or burdens of various kinds for the person whose life would be prolonged or for those who would be engaged in her care.

Therefore, Catholic medical ethics describes treatments which have become, or are likely to be, *futile* or *overly-burdensome* as 'extraordinary', 'heroic' or 'disproportionate'. To forego such treatments is not the equivalent of euthanasia or suicide, but an acceptance of the human condition in the face of death.¹⁷ This is not a choice for death, but a choice about how to live while dying.

Provided that the 'right to refuse treatment' does not embrace any right to refuse treatment *precisely* so that death will occur sooner, this right is substantially different from any alleged right to become or to be made dead, by whatever means. What we are to make of this latter right - whether or not there is a specific 'natural' or 'basic human' right to have one's life intentionally shortened through suicide, assisted suicide or voluntary euthanasia - is asking 'is there a right to die?'

It is the central thesis of the common law doctrine of trespass to the person that the voluntary choices and decisions of an adult person of sound mind concerning what is or is not done to his or her body must be respected and accepted, irrespective of what others, including doctors, may think is in the interests of that particular person. To this general thesis there is an exception: a person cannot consent to the infliction of grievous bodily harm without 'good reason'. But save in this exceptional case, the common law respects and preserves the autonomy of adult persons of sound mind with respect to their bodies. By doing so, the common law accepts that a person has rights of control and self-determination in respect of her or his body that other persons must respect. Those rights can only be altered with the consent of the person

16 EV n. 65

17 *ibid*

concerned. Thus the legal requirement of consent to bodily interference protects the autonomy and dignity of the individual and limits the power of others to interfere with that person's body.

Although the law's respect for the unique dignity of every person is the same, the protection of the physical integrity which is required to preserve the dignity of one person may change from time to time and it may differ from the protection of physical integrity required to preserve the dignity of another. Differing measures of protection are required according to the physical and mental capabilities of individuals at particular times; the baby whose dignity is respected by being carried and cared for by his or her parents grows into a man or woman whose dignity would be offended by such treatment; a donation of blood by a person of full age and understanding may enhance dignity, while the extraction of blood from a person who is incapable of consenting is an invasion of that person's physical integrity. Human dignity requires the whole personality to be respected: the right to physical integrity is a condition of human dignity but the gravity of any invasion of physical integrity depends on its effect not only on the body but also on the mind and on the self-perception.

Refusal of treatment is never simply a confrontation, be it rebellion against what is perceived as the medical "order", or a claim for absolute freedom of choice or a misapprehension of the true situation. In the wings, there is always a misunderstanding, something left unsaid, on the part of the doctor, the family, or a person who may, or may not, be ailing. But perhaps it is in just such situations that the medical profession must show the true colours of its ethics.

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