

## Ethical implications of care in terminally ill patients

### *Implicazioni etiche nella cura dei malati terminali*

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It was in the mid XX century when medicine began to consider having a real and effective control over death. Scientific and technological progress in those years got what until then had not been possible: preserving artificial vital functions. This brought about profound changes in the social, economic, legal and, medical areas; such as: increased life expectancy, rising health care, and criteria for determining the death of a person, etc. This being said, it is not surprising that bioethics has emerged in this context due to the core moral problems. For example, deciding whether or not keeping a person alive is beneficial or not; and asking questions such as: do limits exist on the use of techno-scientific progress, and if they do indeed exist, what are they? Bioethics provides health care professionals with criteria to help them make ethically correct decisions involving terminally ill patients. In this article the authors will attempt to do a bioethical analysis of the ethical implications involved in the care of terminally ill patients, keeping in perspective human dignity.

**Key words:** Palliative care, human dignity, excellence, terminal illness

*Era la metà del XX secolo, quando la medicina ha cominciato ad avere un controllo reale ed efficace sulla morte. Il progresso scientifico e tecnologico di quegli anni ha ottenuto quello che fino ad allora non era stato possibile: mantenere artificialmente alcune funzioni vitali. Questo ha portato profondi cambiamenti nel campo sociale, economico, giuridico e, naturalmente, medico; come ad esempio: aumento della aspettativa di vita della popolazione, aumento di assistenza sanitaria, nel criterio per determinare la morte di una persona, ecc. In questo senso, non sorprende che la bioetica è emersa in questo contesto, perché i principali problemi morali, successivamente, cercano risposte che facciano sapere, in primis, se mantenere in vita una persona è qualcosa di vantaggioso o meno, vale a dire, se ci sono dei limiti sull'uso del progresso tecnico-scientifico e, in ogni caso, quali sono questi limiti e, in secondo luogo, stabiliscano quale posizione prende la medicina rispetto a quei pazienti per i quali prolungare la vita non è qualcosa di vantaggioso, ergo, cosa ci si aspetta dalla medicina sui malati terminali. In questo lavoro gli autori intendono fare un'analisi bioetica delle implicazioni etiche della cura per i malati terminali dal punto di vista della dignità umana.*

**Parole chiave:** Cure palliative, dignità umana, eccellenza, malattia terminale

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## Introduction

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In many cultures and civilizations, the man of power was and still is in some places, the doctor. This being because unlike many professions, the doctor has scientific knowledge as well as a concrete reality of the vulnerability of a person due to their physical weaknesses. Today, the power of the doctor has increased thanks to the development of medical advances. Bioethics is in favor of not using invasive procedures to prolong life in patients who have been diagnosed terminally ill using the techno-scientific advances; it also tries to raise awareness among physicians and the society in general. While many continue to view medicine only as curing the ill, it is not only limited to that, it also can accompany the ill, relieve their pain and suffering. Thus, palliative care arises. It is paradoxical; while scientific and technological advances have enabled the control over the dying process, it has also led to medicine discover the ethical boundaries.

In this article, the authors will attempt to do a bioethical analysis of the ethical implications involved in the care of terminally ill patients, keeping in perspective human dignity. To do this, first we introduce the three essential conditions of the man: suffering, disease and death so we can later discuss the ethical problems involved. Secondly, we compare intensive care and palliative care. Traditionally, the division has been made between intensive/critical care and palliative care. In the work field, can one distinguish between the two? Are they two areas of medicine that although they have different objectives, they can be complementary? This article will also mention relevant dates in order to analyze palliative care. It will also describe the way palliative care in medicine has evolved, and that challenges it faces today. In the core of the article we will analyze hospice/palliative care and its relation to human dignity making reference to situations in which the person should be the

center of discussion, analyzing the medical aspects beyond what is the pathology and sickness of the person. The idea of excellence is proposed in the care of terminally ill patients, with ethics at its base. Finally, some practical ethical principles will be discussed in medical care.

## 1. Illness, suffering and death: unavoidable traits in the human condition

Every human being lives their own existence facing continuous instability, as a subject of needs and privations, in their bodies and souls. Man possesses a dynamic existence that leads them to be passive and an active subject of different circumstances, sometimes being pathological. Illness, suffering and death are proper realities that happen, unescapable in human lives. They are unavoidable conditions in every human being, when facing physical limitations of living in an interacting world.

There are no exceptions to the limited and temporal nature of human life conditions that let us avoid their consequences. The way we face them is what changes and gives a different sense to pain, experience, suffering and death through all believing cultures and societies in history.

“Modern society consigns illness and death to an anonymous state in hospitals, this topic is never discussed with dying people. Nobody learns how to face death, and it is common that people face death for the first time, when they face their own (Spaemann, 2005)”<sup>1</sup>. Learning to die and helping others facing their own death is a relevant task of health care team these days.

The physician is the one that must take over the treatment, when there is still a favorable prognosis, and when there are no good expectations, he must direct the patient to those who can care holistically and assume the delicate part of helping them learn and face the end with the proper care and attention.

However, it has been a difficult goal to achieve in modern health care systems, in what has been called “industrialized medicine”, where the sick are taken care wholesale, not as humans, they are impersonalized. This then may lead them in to a rather pathetic situation, inhumane one might say, the task of attending the ill's final days.

<sup>1</sup> Primitive society surrounded death of a ritual ceremony. Dying does not mean being passive attitude but being able to have given fullness to a role in society. There, the medicine man or quack doctor had his part, the task of curing with herbs and conjurations, but at the same time he had the aim of fulfilling a magical ritual, that made something deeper make sense. The patient was a part of a drama. Nowadays the medicine man is the clinical researcher, who is mainly interested in illness, but less in the sick person. The physician is situated between the quack doctor and the researcher. On the one hand, he uses the power of his science and his own experience to cure; on the other hand, he states with the patient a personal contact that smooth the suffering situation and integrates an active relation. (Spaemann, 2005)

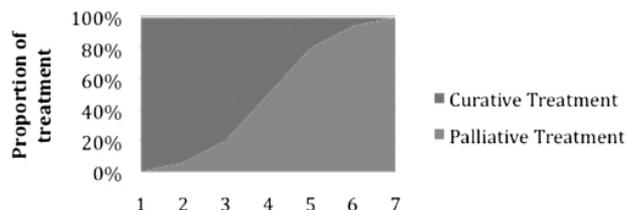
How to avoid medicine that is dehumanizing? To answer this question is a symptom of an isolated man, who is feeling vulnerable and unprotected, like being alone before the silence of infinite space that stated by Pascal. The human subsistence, exposed in the terminally ill persons, who face suffering when approaching death, becomes present as an identity who claims for itself the respect for their dignity (Ferrer, 2007), but also claims in favor of others, of those who serve and those who also become more valuable when applied to care.

## 2. Epistemic Analysis of illness

To be able to distinguish between chronic and acute illness, from the epistemic point of view<sup>2</sup>, it is important to understand the application an efficacy of special care to terminally ill patients. An ethical analysis starting from that distinction will be of significant use as a guide in this paper to address discussion of ethical, medical and legal problems in the oncological patients.

The distinction between the two is established in *Corpus hippocraticum*, when the Hippocratic's realized that there were two different types of diseases. The first disease was characterized by its abrupt onset, but amongst all things, its quick resolution. On the other hand, the second disease was generally resolved slowly. They used two Greek terms to call them by, *krisis* which means change; sudden change and *lysis* which means solution. These terms, were translated with precision into Castilian as "resolution" and "solution". Thus, there are diseases that end in resolution and others that end in dissolution. Both translations, may be positive or negative; meaning that either can lead to be healed or death<sup>3</sup>. Furthermore, the prognosis and treatment will be different for each of the diseases.

Chronic disease usually begins gradually and progresses, and it generally ends in dissolution. The lysis of chronic diseases makes patients enter in what today is known as "terminal phase", a term mainly used in oncology. Once a patient is diagnosed "terminally ill", it is necessary to initiate a new strategy in their management. The medical attention isn't directed towards the cure, it is directed at the palliation of symptoms, to provide the most comfort possible. The shift in strategy gives rise to what is now known today as "palliative medicine", a term coined by a Canadian on-



**Figure 1.** As the disease progresses, the curative treatment decreases and leads way for palliative treatment. Although for some time the treatments coincide, towards the final stages of the disease, the palliative prevails.

cologist, Balfour Mount, in 1975. "Palliative care" is given specifically in the final stages of chronic diseases, but they may begin at any point in any pathological conditions. As the pathology increases in severity, the curative treatment decreases and palliative care increases progressively. As shown in the Figure 1 below.

Terminal illness is an incurable, progressive and advanced disease in which the patient is not able to respond to specific treatments. There is presence of numerous problems and/or symptoms which can be severe, multiple factors that can involve a huge impact on the patient, family and therapeutic team; it has a prognosis of life less than six months<sup>4</sup>.

By palliative care, it is understood total, active, continued assistance of its patients and their family members by an interdisciplinary team<sup>5</sup> when their expectations include no cure. The primary goal is provide quality life to their patients and their family members without trying to prolong their life. Palliative care must meet their patients and family member's needs: physical, psychological, spiritual and social. If it be necessary, the support should include the grieving process<sup>6</sup>. This issue will be discussed further in the end of the chapter.

The acute disease arises suddenly and its duration is short and limited; it also ends by resolution. The crisis in this disease leads to what is called "critical situations" whose management is addressed by "critical care" or "intensive care". The intensive care generally uses treatment to sustain life.

Intensive care is also known as critical care. Rubi Gomez<sup>7</sup> defines it as the part of medicine that deals with patients whose pathological and functional impairment has

<sup>2</sup> The distinction between chronic and acute diseases aims to facilitate the bioethical analysis in this chapter, to establish such a difference in practice is difficult because chronic diseases may require entering a patient in the Intensive Care Unit (ICU); as evidenced below, the target of intensive care medicine is not restricted to heal the sick or keep him alive; therefore in ICUs each day are more common palliative care.

<sup>3</sup> The causes of death can be classified in a practical way in two major pathophysiological groups: sudden or unexpected deaths, and terminal or expected in the final process of life deaths (Trueba, 2007).

<sup>4</sup> Definition of the Spanish Society for Palliative Care (SECPAL).

<sup>5</sup> Namely: a doctor, a pain management specialist; a nurse, a psychotherapist, a social worker, a thanatologist, a psychiatrist, among others.

<sup>6</sup> The European Palliative Care Subcommittee of the European Economic Community in its meeting held in May 1991 in Stockholm with the participation of 11 European countries, the definition is established Palliative Care. (SECPAL, 2009)

<sup>7</sup> Juan Antonio Gómez Ruby is one of the pioneers of intensive care in Spain has also driven in the strongest terms the development of bioethics in that area of medicine. His collaboration input is valuable to this work not only for the reasons I have expressed it; also by his own experience as a patient in the ICU for six days after a complicated surgery to replace the liver.

reached a level of severity that can danger their life but is susceptible to recovery. These patients get admitted in the hospital into a special area known as the Intensive Care Unit (ICU). Its aim, therefore, is the diagnosis and treatment of patients who meet two conditions: 1) A critical situation, which can potentially cause suffering and complications and put at risk their lives 2) Potentially reversible pathological process, discarding patients that are terminally ill; incurable (Gomez, 1991)

Shoemaker states that intensive care medicine is “something more” than the sum of the other specialties that deal with life-threatening situations. That “something else” is the holistic form of evaluating the vital organs and the development of therapeutic programs and life support systems that can battle efficiently with life-threatening situations (Shoemaker et al., 1984).

Rubi Gomez believes that life-threatening situations have a common link: the sharp decrease in oxygen delivery and the immediate risk for cellular metabolism. Although many diseases exist, each has a different way in putting life at risk and is very limited. For example: respiratory failure, problems in circulation, and deterioration in the mechanisms that maintain the consistency of the eternal environment<sup>8</sup>. According to Gomez, the patient needs to meet certain criteria’s: 1) Existence of a life-threatening problem, different from the terminally ill, potentially recoverable. 2) The need to have monitors at all times to evaluate their vital signs and have analysis taken periodically to detect and monitor organ failure. 3) The use of life support (Gomez, 2002).

There is no consensus whether or not to refer a critically ill patient into an ICU. It is common to use expressions such as: “life support care” or “life-sustaining treatments.”

According to the *Hastings Center*, the life-sustaining treatment is any medical intervention, technique, procedure or medication that is administered to a patient to prolong, life this type of treatment, is directed towards underlying disease or biological process (Monzón, 2009).

For Gomez, the procedures that prolong life artificially to “buy time”, or any medical treatment (be it surgical or treating the underlying cause of the disease), or the evolution of the disease (processes that are used only to keep the patient alive for emergency care) must be able to reintroduce the sick back into the society under the same conditions as before the sickness.

The following are some types of end of life care procedures/treatments: cardiopulmonary resuscitation (CPR),

<sup>8</sup> Although there are many diseases and pathological process, the ways in which any of them can lead to death are limited, they are called “common terminal pathways”. The pathophysiology of these final common pathways, recognition of the evolutionary changes produced by them and the domain of drugs and technology that forms the doctrinal body interferer as of intensive care medicine as a discipline. (Gomez)

mechanical ventilation, renal replacement systems, vasoactive drugs, artificial nutrition and blood products.

Being able to distinguish between acute and chronic disease and palliative care versus intensive care, allows us to make a classification amongst the sick, divided into four levels, shown in Table I.

Some authors have developed more specific category groups<sup>9</sup>. For our purposes, we will focus on levels 3 and 4, which generally require specialized palliative care, as shown in Table I.

**Table I.** Classification of diseases according to the support and type of care.

TYPE OF DISEASE	Level	TYPE OF SUPPORT	TYPE OF CARE
Acute Diseases	LEVEL 1	Full support.	Intensive Care
	LEVEL 2	Full support and an evaluation every 24 hours.	
Chronic Diseases	LEVEL 3	No type of life support.	Palliative Care
	LEVEL 4	Suspension of curative measures.	

### 3. Relevant information for analysis and understanding of palliative care

Throughout clinical research, there has been much talk about palliative care and its importance and need of holistic medical attention for the patient, especially those patients that find themselves in terminally ill phases of life. There has also been much emphasis on medical and social needs to improve medical practice instead of choosing an easier, faster and economic option involving actions such as euthanasia and physician assisted suicide.

<sup>9</sup> Albert R. Jonsen, Mark Siegler and William Sinsale published in 1982, a handbook of ethics in which ethical problems cataloged in four axes coordinates: medical indications, patient preferences, quality of life and socioeconomic factors. In the first, the authors distinguish three types of disease: guinea pig (Acute, Critical, Unexpected, Responsive, Easily Diagnosed and Treated), CARE (Critical, Active, Recalcitrant, Eventual) and COPE (Chronic, Outpatient, Palliative, Efficacious). Diego Gracia looking for some acronyms that translate into Castilian allows this classification. First, ACRE are acute diseases, reviews, reversible and effective diagnosis and treatment; ie critical illness and are reversible, those in the intensive care are perfectly justified so pose no undue ethical problems. Second are the CID conditions: reviews, irreversible and deleterious they, unlike the previous ones, is that cause the greatest number of ethical problems. Finally there are CEPA diseases: chronic, effective symptomatic treatment, outpatient palliative and these are the diseases that accompany the individual throughout his life, having a slow onset and resolution. According to the four levels of patients, the disease ACRE correspond to the first level, the CID to the second, and the third CEPA. The study and classification made by Gracia detect specific ethical problems and propose alternatives much more real and practical solutions.

With that being said, palliative care is understood as on-going assistive care for patients and their family members by an interdisciplinary team when medical expectations don't intend to cure the patient. The primary goal is to provide quality of life for patients and their family without trying to prolong life. It must cover physical, psychological, spiritual and social needs of patients and their families. If necessary, the care should also include the grieving process<sup>10</sup>.

Javier Barbero, a clinical psychologist and bioethicist, believes that palliative care arises to give terminally ill patients the best wellbeing possible in their final stages of life and that their families and friends can receive support if needed. An expression that is banned in palliative care is "There is nothing left to do", even if the person has no chance of being cured. There is always a way to provide some type of care, one can give and provide the best means to make the most out of final stages of life possible.

The shift from a curative to a palliative attitude does not happen drastically. The binomial cure-care does not have a sharp cut-off point, even though the objective may be fundamentally at first healing the disease, care is always indicated; similarly, when the dynamics of hospice care prioritizes and does not exclude that they can cure various problems that become symptoms that cause significant patient discomfort<sup>11</sup>.

Palliative care is focused on the patient that is suffering and dying, but also includes their families. The family isn't just subject to care for the sick member; they also become part of the core of palliative care. Their participation in the care for their sick family member is not only instrumental, but also affective and existential. It is evident that palliative care plays a dual role. At first, its care is holistic directed towards the patient and their family, secondly, its care get directed towards giving the family support during the moaning/grieving process after the death (Barbero, 1989). In order for palliative care to be considered excellent, it must cover these two points.

Due to the fact that symptoms vary in intensity and pain from patient to patient, it is important that palliative care explore each patient's unique situation and symptoms (biological, psychological and social). Each patient perceives different threats to their existence and physical/psychological integrity. The sensation of helplessness entails the terminal illness to be subjective and therefore one can include suffering as well. Thus, one can conclude that palliative care is based on the life experience of each patient's life. Barbero argues that psychological support and establishing appropriate levels of therapeutic communication will be essential. Limiting cases of psychopathology specialized counseling is a misunderstanding of the impact of the dying process limiting a fundamental perspective of palliative care emotional disorders: prevention of the suffering that can be avoidable. He further argues that the edge technology is in hospice interdisciplinary work (Barbero, 1989).

When a patient enters the ICU, we cannot solely base criteria on the type of pathology, palliative care cannot be generalized on the type of care and support for all patients. The theme of the accompaniment (Sanz Ortiz, 2004) of the patient is essential not only in palliative medicine but in the practice of medicine in general, especially when one is facing the last moments of his life.

In this sense, four options have been established that can adjust care: abandonment, struggle, completion and accompaniment. The last one is opposed to the previous three: "Cure sometimes, relieve often, always accompany". The active lends itself to a certain "struggle" looking for a benefit for the patient, but this is where it is desired to find a reasonable limit not to exceed nor fall short. The passive, consists in "being there" without participating, influencing the evolution of the process or to get involved. Unable to harmonize the accompanying and giving end. The accompanying attitude is not limited to a period, if so; it would become the threshold of abandonment or covert or even system completion hospice appearance abandonment.

The dying process is unique and different in each person. Criteria, protocols and recommendations are not a

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tive option or significant prolongation of survival once a patient diagnosed as terminal. (Núñez, 2004)

<sup>10</sup> SECPAL. History of Palliative Care in Spain. Op. Cit. In 2002 SECPAL formulated the "Declaration on the medical care at the end of life" in which the goals of care in advanced and terminal illnesses are noted. According to the statement, the basic principles and goals of care are to promote a high quality of life, dignity and autonomy of patients taking into account their physical, emotional, social and spiritual needs, considered the patient and his family as a unit treated. (Universidad de Navarra, 2009) In this regard, David Callahan believes that death should not be the enemy to defeat but pain, disability and poor quality of life prior to death. Callahan, D. "Death and the research imperative." (The New England Journal of Medicine, 2009). WHO refers to palliative care as a way addressing advanced, incurable disease that seeks to improve the quality of life of patients facing illness and their families through the prevention and relief of suffering by means of early diagnosis, appropriate assessment and prompt treatment of pain and other psychosocial problems both physical and spiritual.

<sup>11</sup> When the issue was addressed in the LET (Limited Therapeutic Effort) was concluded that intensive care and palliative care are not exclusive but concurrent; in other words, curative and palliative treatments are not mutually exclusive. For Jose Manuel Núñez, the choice of a particular treatment should be determined by a suitable identification of the stage at which the disease is found (curative, palliative or dying); further progress of medicine constantly changing the boundaries between these phases. The conflict in the choice between curative and palliative treatment can occur for several reasons: Ability to obtain identical results for the control of symptoms with both types of treatment; ability to prolong survival with one of the two treatments although this is not the main objective; diseases for which the best options for controlling symptoms in the terminal phase reside mainly in active / specific / curative treatments, eg AIDS, neoplasms, certain types of heart failure, etc .; difficulty recognizing the curative option transition between phase and phase palliative option in the course of the disease and the individual patient; need to rethink a cura-

constraint to understand, understand and care for the patient (not the disease) in the last days of their lives. One must try not to assume, but to take into account the idiosyncrasies of each person, their particularity, the subjective perception of what is happening inside or living experience. No patient is alike; dying cannot be generalized nor protocolled for everyone<sup>12</sup>.

For Spanish bioethicist Azucena Couceiro, it is necessary to recover excellence as a professional *ethos* of medicine especially where human activity is to help the other. “The pursuit of excellence should be part of palliative care because helping others is not only technical but also human, and is at the heart of clinical activity. There is no doubt of the moral goodness in the concern of one human being to another that is in the terminal phase of his life, but that does not mean that from there all that follows is permitted. The relationship between the doctor and a suffering patient is not of domination but of coexistence; the center of that relationship is not occupied by the *logos* or reason, but by the *pathos* or feeling. In exercising care for the rational calculation of the patient’s situation and its possibilities, as the practice of feeling closeness and empathy with patients is very fundamental. Nothing is unethical per say; therefore, palliative care is unethical for them, as they need a lot of knowledge, specific skills, and the development of deliberation on each and every one of the problems that arise in clinical practice” (Couceiro, 2004).

One of the first and most important problems of palliative care has been and continues to be to clearly define what the specific goods they provide to society. When such goods rest on a series of technical facts, as is the case of the surgeon who operates an appendicitis, things seem clear, but when concepts with a strong evaluative context get meshed in, things get complicated. One should at least be aware that what we take as objective often contains a strong subjective burden<sup>13</sup>.

As pointed out by Barbero, palliative care affirms that each person has dignity and autonomy; therefore he continues to believe that the active and decision maker of what is happening and active protagonist is the patient. It is not to develop therapeutic targets “for” them, but “with” them.

<sup>12</sup> We can ask whether all patients at the end of his life is subsidiary to be treated by specific palliative care teams, the answer is no. There will be patients for their clinical complexity or psychosocial maladjustment will require the participation of teams specifically palliative. (Barbero, 1989) Each is an individual with individual needs, desires, hopes and unique circumstances, therapeutic approaches should be based on evidence but individualized (Núñez).

<sup>13</sup> When diseases are acute is the most important principle of non-maleficence, but in the case of chronic diseases, particularly in the terminal phase where human relations are of another kind and longer, the integration of disease in the patient’s life project takes on primary importance, so that the professional should neither act maleficently, has an inescapable obligation to promote charity (Couceiro).

If we can see life in positive states and if death is not seen as a failure but as a normal human condition inherent in the process, it is easier for the therapeutic approach to be positive. There are many things one can do to accompany and treat the patient in the terminal phase, it can be done as good and not just as a lesser evil.

The term “control of symptoms” is often used in palliative care which refers solely to pain control. But there are also several symptoms that may affect to a greater extent patients quality of life. In regards to this, it is necessary to state two things: It is not accurate to say that controlling pain is diminishing suffering as the pain and/or other symptoms may be masking even more suffering for the person; additionally symptom control is not an end in itself but an important mean to achieve the objective of the sick person to reach the highest level of satisfaction and well-being desired by him.

Palliative care requires a respectful, tranquil, and communicative environment. This depends on the doctor, the patient, and the patient families’ attitude. It does not imply that dying at home or in a hospice would be best but rather, make sure where ever the terminally ill deems appropriate that it be tranquil, calm and peaceful (Barbero)

Richard A. Parker, from Harvard Medical School, mentions two fundamentals that should be applied in the attention of the terminally ill patients. The flexibility and ability to communicate. Flexibility to face a variety of situations that produce attention. The ability to communicate to get to know the patients values and morals, and to be able to respond to the patients and their families worries (Parker, 2002).

Care ethics comes from the idea of verticality of human relations based on the binomial authority/submission or commandment/obedience. On the contrary, for the responsibility ethics, the consequences are important to moral life, that’s why it is necessary to achieve an agreement between principles and consequences. For this reason, palliative care assume from its origins some treats of the conviction ethics, but little by little, it is following the proper models of responsibility ethics.

An ethics that does not put attention towards its consequences is not responsible. These ethics are complementary; there is no responsibility in its convection. In this way, the circumstances that a person faces, in their last days of life are very important to determine the type of care that should be offered. Principles without consequences are blind, and consequences without principles are empty.

Today’s bioethics is oriented towards responsibility. Palliative care gives light to principles that should be kept in mind meanwhile accompanying and caring for the person. that the person suffers, and is dying.

Although establishing concrete rules in palliative care, some authors have proposed some principals to consider when taking clinical decisions in critical situations involving terminally ill patients.

José Manuel Núñez propose five steps to take clinical decisions in a patient that need intensive care because of a clinical abnormality:

1. To delineate the potential problems and adverse effects of clinical abnormality being studied that may influence the quality of life of patients.
2. Assess the degree of suffering associated with the specific problem within the constellation of symptomatic patients, knowing that the same symptoms can be seen with a different relevance over the course of the disease.
3. To identify potential problems caused by the correction of clinical abnormality and how the correct attempt can influence the quality of life of patients.
4. Assessing risk/benefit ratio of the advantages/disadvantages of not intervening in the patient.
5. Develop a consensus with the patient, the family and other team members on what actions must be taken (Núñez).

Whenever the principal axis is the dignity of the person there should be respect.

#### 4. Brief Itinerary of Palliative Care

In the beginning of 2014, World Health Organization published a Manual of Palliative Care. It constitutes a complete and precise compilation of palliative medicine up to date. The definition of PC maintains the same elements since 1992: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2014). Although twenty years of experience have brought a strong improvement, in many countries, specially in defining the specific elements to be considered for attending and preserving what the patient consider a dignified live, specially in their last days.

Caring for the terminally ill was named palliative only recently. For centuries it was not institutionally organized, not even considered a part of health attention (García, 2011). The milestones that have marked the history, according to the work of García, up to date, are the following:

In the beginning of the fourth century, Fabiola, a young noble roman, who had been disciple of Saint Geronimo, founded in Ostia, a port near Rome, a huge hospital, where many sick people from Africa and Asia came looking for physical and spiritual care. The attention was for free. It was the beginning of institutional health care (Centeno, 1988). That was the type of care that was developed then. Later, in the middle ages, hospices appeared in all Europe. Not for Palliative care. Their objective was not even to cure, but charity, to give home and food to the beggars and homeless.

Some of them were sick or dying people. In a certain way the people who run those hospices give a kind of integral care, looking for their hostess in all dimensions (Del Río, 2007).

Many centuries later, the word "Hospice" was referred to a place dedicated to terminally ill care. It was in Lyon, France in 1842 (Figueredo, 2011). A lady named Jeanne Garnier established houses for attending sick people, she called hospices<sup>14</sup> in several French cities. The Hospice founded in Paris in 1971 it is called Maison Medicale "Jeanne Garnier". It is still nowadays a prestigious institution dedicated to palliative treatment of patients with advanced cancer (Jeanne Garnier). Following the work of Jeanne Garnier, Anne Blunt Storrs, founds in 1899 the Calvary Hospital in New York. These Calvary's (another word for hospice) main patients are advanced cancer adults (Calvary Hospital, 2007). Other relevant institutions of PC in the nineteen century were Kaisererth Foundation, in Prussia; Our Lady's Hospice in Ireland; Saint Luke's Home and other protestant small places. In the beginning of the twentieth century, it was founded, St. Joseph's Hospice and Saint Christopher Hospice in London, with the same objectives in care.

Cicely Saunders, born in 1918 has been the leader of contemporary Palliative Care in England. She first studied Politics, Economy and Philosophy. Later she graduates in nursing and later in Medicine. Her main interest was to help the patients to dye with dignity. Between 1958 and 1965 she worked directly with terminally patients, at the same time she did research at the St. Joseph's Hospice, in London. There she learned to listen to what the patients had to say, taking care of the sick with a new integral vision, considering the personal needs as well as medical ones. In 1967, Saint Cristopher Hospice incorporates Dr. Saunders ideas, to practically PC: a total, active and continuous aid to terminally ill patients and their families by a multidisciplinary team, not pretending prolonging life unnecessarily, but keeping life's quality, having all the patient's needs covered.

Dr. Saunders brought the hospice idea to the Unites States, to the Yale University, where she pronounced these brief but insightful words: "You matter because of what you are. You matter until the last moment of your life and we will do whatever we may, not only to help you dye with peace, but that while you are still alive, you live with dignity" (García, 2011).

In The EEUU, palliative care had been developed mainly in the patient's houses. The Domiciliary Programs work principally with teams of officially certificated nurses. They must be able to offer medical care services and bring the ill the opportunity to be entered in a hospital if needed (García, 2011).

<sup>14</sup> She called "Calvaries". The main objective was to comfort and relieve terminally ill patients.

The other outstanding woman in the palliative movement is the Swiss professor Elizabeth Kübler-Ross. She started in the EEUU a treatment for terminally ill patients. She has published a book in 1969 about death and the dying people, which had been a Bible for learning to face death. She reaffirms the ideas of Saunders, but added the concept of domiciliary palliative care (Kübler-Ross, 1989).

In England in 1980's there were developed the first specialized support teams to control symptoms, in several general hospitals and cancer centers in the National Health System. These teams develop an important work as consultants for other hospital services in which patients with advanced cancer were addressed. In addition to working with existing curing treatments, they began to take the responsibility for beginning the PC (SECPAL, 2012).

In Canada, the term "palliative care" arose. It is what best describes the philosophy of care terminally ill patients, Hospice (Cecily Saunders) seems more related to the physical structure of an institution should be granted (SECPAL, 2012). It was proposed in the Royal Victoria Hospital in Canada in 1975 by Mount Balfour. Indeed, in other European countries and in Latin America, this is the term that has been accepted and used today. Palliative Medicine in 1987 and is recognized as a specialty in the UK. Subsequently it has also been admitted as a specialty in Canada and Australia and Poland. In 1991 it was established formally, at a national level, the Canadian Palliative Care Association (CPCA). Ten years later, in 2001, it was named Canadian Hospice Palliative Care Association. A year later they published a relevant Guide of PC, based on general principles and practical directions for special care orientation.

On March 20/21 in 1993, took place in Brussels a meeting sponsored by the European Society for Palliative Care (EAPC) and the European School of Oncology (ESO) program of the European Communities "Europe Against Cancer" financed with funds from the European Community. These meeting were directed by Derek Doyle and Robert Twycross, with the participation of 30 experts and specialists of the twelve EU countries. Common consensus document for all EU countries reflects the inclusion of content in Palliative Medicine in the curriculum of the School of Medicine and health professions occurs (Sanz, 1989).

"Palliative care in Italy is considered a young discipline; developed as a result of the "Hospice Movement" influence. In our country it originated around the 1980s thanks to the work of non-profit organizations which worked on a voluntary basis and had begun to respond at a homecare level to the complexity and ever-changing needs of the terminally ill and of their families, who at the time did not find any answer to their needs in the health care system and especially in hospitals. Only in 1999 palliative care has been officially recognized and included in our National Healthcare System. Since then it has had an exponential growth and nowadays there are more than 250 centers scattered throughout

the country, which offer both residential and home care services (Casale and Calvieri, 2014)". Ventafridda jobs in Milan on the treatment of cancer pain, the establishment of the European Association for Palliative Care (EAPC) and the development of institutional policies by some governments, have been some of the determinants of development milestones.

Countries of Eastern Europe came to join the last decade's vigorous development of PC, just thank to the political changes. Perhaps the most outstanding country was Poland. Luczak jobs since 1986 are quite relevant. Poland has recognized palliative medicine as a medical specialty in 1995 for a population of 30 million is up 30 Inpatient Units, hospital support teams 20 12 day centers and over 100 home care teams. Two thirds of these programs are owned by the public health system (Sanz, 1989).

In Germany, discussions about end-of-life practices have been almost taboo for over half a century, but now intense debate is underway as professional bodies review their guidelines to physicians caring for the dying. The concept of hospice had not been well understood yet, but recently there have been some improvement in the interest of German physicians in order to qualify health workers to help in better ways dying patients (Schildmann et al., 2010).

When The Netherlands began looking forward to attending their terminally ill patients, it had to learn from other countries experiences. Because of "using euthanasia", Palliative Medicine was not developed. It will take time to develop PC at the same rate as other countries. Zylicik was the first to attend and developed this kind of discipline in Arnhem.

In Austria, in 1997, in nursing schools, PC was integrated as a scheduled obligatory subject. In the 2000, Palliative Care was incorporated to a national plan for developing specialized attention in critical hospitals. Graz University also incorporate a program on PC, in the clinical center as well as in the medicine and nursing programs.

In Hungary, PC movement began in 1991. Soros Foundation had been of much usefulness. In 1997, The Hungarian sanitary law declared palliative care as a human universal right.

Neighborhood Network in Palliative Care (NNPC), a community owned program in Kerala (India), is a project evolved out of a series of needs-based experiments in the community. In this program, initiated in the year 2000, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals. Essentially, NNPC aims to empower local communities to look after the chronically ill and dying patients in the community (SECPAL, 2012).

Hospice Casa "Sperantei" is a Romanian charity founded in 1992 in Brasov, in partnership with a British hospice based in Dartford, Kent. Its mission is to introduce and support

the development of hospice and PC for patients with incurable diseases in advanced and terminal stages in Romania. In 2002 the first Romanian purpose-built teaching hospice was opened in Brasov, hosting a 13-bedded adults inpatient unit and a six-bedded unit for children, as well as day Centers and outpatient clinics for adults and children with cancer and other life-limiting conditions (SECPAL, 2012).

The Ho Chi Minh City Cancer Hospital is southern Vietnam's largest and busiest cancer center with approximately 1,700 inpatients on any given day and approximately 9,000 active outpatients. Its leaders recognized the medical and moral imperative of adding palliation to its mission to prevent, diagnose early, and treat cancer. The leaders aimed to ultimately offer the full range of palliative care services but focused initially on training. The hospital invited the Harvard Medical School Center for Palliative Care (HMSPCC) to begin basic and advanced training in palliative care for interested medical staff members. In summer 2011, it added a model home care team designed to be sustainable and replicable by other departments and hospitals (OMS, 2014).

It was also in Canada, the dignity model for the terminally ill had been successfully developed. It will be described with more detail in the following section. It represents a further stage beyond the mere quality of life maintenance.

## 5. Is it possible to measure and preserve dignity in the terminally ill?

A new attitude towards the end of life has been developed in Canada by professor Harvey Chochinov<sup>15</sup>. The main ascertain he had was to find a relation between various necessities who live sick people at the end of life and the *sense of dignity* with whom they affront those moments. He found "distress is a significant problem for individuals who are living with cancer" (Chochinov et al., 2013), that must be well identified and understood. First of all health care people around them must be trained to help them solve distress causes, and allow them live with less grief that phase of their lives. Health care team must have a good insight on which authentic requires and needs are, which diminished the sense of dignity they have at that particular time. Patients' preferences in these areas are as dynamic and in-

dividual as their own life experiences (Chochinov, 2010). What is crucial is to determine how to solve them accurately. This is what a Palliative Care team shall do.

A small number of terminally ill patients, with a cancer bad prognosis, are channeled opportunely to Quality Palliative Care (QPC). Most of them face these circumstances without any valuable orientation. People who face an end of life situation mostly live moments of bewilderment due to lack of appropriate information about their illness; how to handle pain and suffering; reduced independence; as well as another psychosocial, existential and spiritual distress factors. These patients' and their close relatives, usually primary caregivers, go through this new situation as if they had lost inevitably what was most valuable in their lives; their usual confidence, the role they used to play in their families, their work, among others. Not only their quality of life, but their "sense of dignity"<sup>16</sup> is strongly affected by all these factors that closely go aside their illness (Mendoza et al., 2013).

It is usual that physicians and health care workers, when they have a bad cancer prognosis, center their efforts in reducing clinical symptoms and patient's discomfort by measuring life quality indirectly by a group of physical measures. But the real situation of the patient uneasiness goes mostly in the direction of feeling respected. Chochinov and his team, had been doing serious research in thousands of terminally ill patient's distress treats when facing the end of life, for more than three decades. They have achieved practical and relevant results based on direct experience of what cancer terminally ill patients think and feel about their distress conditions, providing an excellent insight on treats involved in patient's lose of sense of dignity and allows a practical approach to eliminate distress symptoms with more acuteness. He has integrated his clinical observations and brought them up in three categories in Chochinov's Dignity Model (Dignity in Care):

- a Illness-related concerns;
- b dignity-conserving repertoire;
- c social-dignity inventory.

<sup>15</sup> Dr. Harvey Chochinov, a well-known psychiatrist from the University of Manitoba in Canada, leads the research team that pioneered the Dignity Model and Dignity Therapy. In addition to holding the only Canada Research Chair in Palliative Care, he is a Distinguished Professor of Psychiatry at the University of Manitoba and Director of the Manitoba Palliative Care Research Unit, Cancer Care Manitoba. Dr. Chochinov's publications addressing psychosocial dimensions of palliation have helped define core competencies and standards of end-of-life care. He is a member of the Governing Council of the Canadian Institutes of Health Research, Chair for the Canadian Virtual Hospice, a Fellow of the Royal Society of Canada and a Fellow of the Canadian Academy of Health Sciences. (Dignity in Care, 2010)

<sup>16</sup> Dignity defines men as a being and as what he has of worth. A human being has value because he is and because he is he has value. It is what makes him be in the center of the world. A mobile center of ascending and descending ontologically. Dignity is the way to understand men. Dignity is the way in which human being shall be seen and assumed as an individual, and also a way of seeing the others, always as an ending by themselves not as simple means or instruments. This is the contemporary posture of humane dignity which is exposed and reinforced by saying that dignity is not as isolated part of one or several ethical principles, but precisely is the one that vertebrates all principles in a sort of star's constellation that lightens and complements an harmony among them. Dignity as a proper freedom to the very being of man and dignity as a condition of a self aim of man, being an end but not a mean, in summary, becoming two constitutive notes which define the very essence of human dignity. Where Kant and Pico published on this theme, have a total and question less establishment and validity. (Sánchez, 2012)

**Table II.** It resumes the three main categories of Chochinov’s Dignity Model and the 25 items of the Patient Dignity Inventory derived from it (Reproduced and modified with authorization of Dr. Harvey Chochinov. July 2014). The numbers correspond to the twenty five questions of the PDI (Patient Dignity Inventory).

MAIN CATEGORIES OF DIGNITY SENSE OF DISTRESS IN THE TERMINALLY ILL		
ILLNESS-RELATED CONCERNS	DIGNITY-CONSERVING REPERTOIRE	SOCIAL-DIGNITY INVENTORY
Level of independence (1, 2)	Dignity conserving perspectives	Privacy boundaries (20)
Cognitive acuity (9)	Continuity of self (4, 11)	
Functional capacity (8)	Role preservation (13)	Social support (21, 22)
Symptom distress	Generativity/legacy (15, 16)	
Physical distress (3)	Maintenance of pride (12)	Care tenor (25)
Psychological distress (5, 6)	Hopefulness (14)	
Medical uncertainty (7)	Autonomy/control (19)	Burden to others (18)
Death anxiety (8)	Acceptance (24)	
	Resilience/fighting spirit (23)	
	Dignity conserving practices	Aftermath concerns
	Living in the moment (10)	
	Maintaining normalcy (10)	
	Seeking spiritual comfort (17)	

**5.1. Focusing in the person, not in the illness**

The decisive idea in applying Chochinov’s Model to QPC is focusing in the person, not in the illness. The respect of each person’s dignity is what gives the health care worker an orientation to begin with the palliative treatment. Physicians, care workers, nurses, psychologist, anyone who must attend these patients should examine first of all one’s personal attitudes and assumptions regarding them. It is important not to pay attention to them as a part of a routine or generalization. Each of them shall be treated as unique. A personalized, flexible attitude by health team can have a thoughtful effect on how people face this period.

People working in QPC undoubtedly have an strategic role on helping the terminally ill patient. They shall be aware of their responsibility in this delicate and tough duty and get the opportune skills on which treats need most support in each cancer patient. The aim is find a fast solution to their critical new situation. Any instrument that may help them in this task is very welcomed. Chochinov’s Dignity Model has proved to provide the Care Team easy and straightforward ordinary aspects that may be strongly affecting the way patient feels about his sickness. Understanding these factors facilitates a hasty address of what is more appropriate for each patient as they go about their daily life.

**5.2. Principal strengths of the Chochinov’s Dignity Tools**

Chochinov had developed three main dignity measuring tools as “an attempt to provide the field with a feasible and reliable way for identifying dignity-related distress, to lessen suffering toward the end of life. Because this instrument is based on the empirical Model of Dignity in the Terminally

ill, it contains a wide range of items covering the physical, psychosocial, existential, and spiritual facets of patient experience. Even though many sources of disquietude may not be readily visible or easily articulated by sick patients, the degree to which these can shape end-of-life experience is weighty. Yet, without appropriate means of making their presence known, many sources of distress remain ubiquitous and intractable” (Chochinov et al., 2008).

A test called Patient Dignity Inventory (PDI) designed by Chochinov in 2008, has proved a very useful way to measure various sources of dignity-related distress factors among patients near the end of life. Using 25-items from the PDI help health care worker to determine significant factors which are major cause of distress, in order to focus on them in QPC psychotherapy more efficiently and help the terminally ill patients to live that part of their lives with ease and tranquility (Tab. II).

**5.3. Working with a Excellence Palliative Domiciliary Care (EPDC) team**

When the treating doctor determines that the patient does not respond to curative treatments is their duty to inform the patient, with human warmth, that is no longer need to be hospitalized and it’s best to be properly cared at home. Although the EPC can be started in the hospital, it is usually at home where they are applied from the beginning by a professional interdisciplinary team specializing in Excellence Palliative Domiciliary Care (EPDC). It prevent the patient to spend their resources making trips to the hospital, when the team can and should get where they are. The doctor must establish strategies to alleviate and control pain and different symptoms of the patient, then the psychological and tanatological party had been attended.

Elementary physical or specialized care are attended by a nurse/primary caregiver and must be carried out with the utmost care and respect for the vulnerable status of the patient. Finally, the team will train family primary caregiver and other close family members who may have to do directly with the needs of the patient to apply care with more than competence and empathy, but with real interest in the other person's situation, not afraid to show their closeness, affection, protection and support. It is essential to prevent the sick person to experience moments of solitude unsought. A person should end his life with full awareness of what is living. These elements are the ones that conferred its dignity to that time, in a better way than only preserving standard quality parameters. It must go beyond, achieving plentifully the last moments of a human being.

The Chochinov IDP is an instrument to measure the degree of anxiety that cause many factors that usually surround the patient at this stage of your life and identify those most pressing the personalized attention through the Palliative Home Care Quality (CPDC). Chochinov implemented both the model and the dignity therapy using their experience in thousands of patients, focusing on the therapeutic potential to reduce the existential pain of the patient and thus promote a more harmonious farewell to those closest to providing the patient can recover sense of dignity in the last days of his life.

#### 5.4. *Quality and excellence in the Palliative Care*

The definition from the Spanish Society for Palliative Care, gives a good framework to precise what may improves the quality of PC, a basis:

"Palliative care is based on a global, active and lively design of therapeutics, comprising the attention of the physical, emotional, social and spiritual people suffering from terminal illness; We remain the main goals the welfare and promotion of *the dignity* and autonomy of patients and their families, and therapeutic means, symptom control, emotional support and communication when we are in front of an advanced, progressive and incurable disease, no reasonable chance of response to a specific treatment and predictable short-term death, caused either by cancer, AIDS or other chronic and progressive disease" (Sanz Oriz, 2004).

Sanz Ortiz proposes some efficient and especially complete recommendations that may help achieve quality to Palliative Care attendance:

- i. incorporate death to life and stop thinking of medicine as something that make people not to die;
- ii. reduce requests for voluntary active euthanasia avoiding therapeutic futility and therapeutic useless;
- iii. the doctor is a professional trained to care for and preserve life, not destroy it. The legal benefit is always life;
- iv. the last act of life (like everyone else) should be played by the person respecting their own priorities, values and life plan;

- v. no one should die in pain and no one should die alone. Never miss the warmth of a helping hand;
- vi. avoid induced misery. All symptoms should be treated by professionals trained in palliative medicine;
- vii. attention should be paid according to the preference of the patient in home or hospital;
- viii. sedation, in difficult cases, can contain symptoms and facilitates the act of dying respecting all legal ethical standards, medical, judicial and legal standards;
- ix. modern Palliative Medicine can address the needs of the dying patient and their relatives with efficiency, effectiveness and efficiency;
- x. with 100% coverage in palliative care will not be necessary to introduce new legal forms (assisted suicide and / or voluntary active euthanasia) or by the magnitude of demand (0.3%), and the difficulty of effectively resolve the need raised.

But for excellence, a pretty more is needed. It is indispensable being outstanding or extremely good. The Ancient Greeks Aristotle and Homer had the concept of *arête*. To become EPC must be a goal that can be pursued through continuous actions of integrity.

#### 6. Why Excellence Palliative Care (EPC) proves better than Quality Palliative Care?

The relevant point in desiring excellence over quality is that excellence includes not only technical or medical efficiency, but ethical (Couceiro, 2004). To give a PC to a dying person goes beyond ensuring an acceptable quality of life. It involves specialist foresight from the perspective of the individual and respect for their values and beliefs at the time of death. It is not limited to subjective parameters of certain welfare or comfort, but rather to determine the most inner and personal needs of the patient and allow resolving a critical phase of his/her life, which must not be the toughest or distressing, but on the contrary, live these last days must become a worthy experience of an integral life near their close relatives and friends.

Nowadays, in many countries, the high number of patients exceeds the capacity of the health professionals. Few doctors in services where patients, who do no longer have a probability of cure are channeled to EPC. Besides, they are not always prepared to support the patient in these circumstances. Same with nurses. The abundance of work and lack of preparedness in this particular situation of the proximity of death leads sometimes to a dehumanized, precipitated care and mistreatment which have profound impact on the dignity of the patient and her/his family.

Few terminally ill patients are channeled to what may be called Excellent Palliative Care (EPC). Most of them, when referred to their domiciles, they have an expectancy of few months weeks, or days, face a strong state of abandonment,

confusion and stress. They and their families suffer of a serious misinformation about the situation they face, how to cope with these new circumstances, pain, suffering, fear of the unknown, lack of independence, living these leads them to physical exhaustion. Hardly have time to think calmly about the best way to prepare for death.

Excellent Palliative Domiciliary Care (EPDC) should begin at this time. A well prepared team has to assume the personal and professional care of the sick at home. It is important not to make the patient come back to the hospital, but move the interdisciplinary palliative care team to where they are.

### 6.1. EPDC Preserves and Recovers Sense of Dignity In Terminal Ill Patients

At the time the doctor realizes that there is no treatment with favorable prognosis for the patient, the wisdom is that the treating physician must channeled the patient to palliative care. No point on trying to follow unnecessary treatments, still experimental, even though the patient has the resources to afford them, or give false hopes. The situation may lead to specialists that stage risk of incurring in therapeutic futility. Not just any doctor, nurse or psychologist is able to detect how to approach a patient with terminal illness, how to support and allow him and his family to live those moments in the most dignified and respectful of their values. There is a need of an expertise team in EPDC to fully support the patient and allow him to retain his sense of dignity in facing death.

Palliative care is "one active total care of patients with diseases that are not responsive to curative treatment. Its objectives are to control (physical, psychological, social, existential) symptoms and achieve the best possible quality of life for patients and their families. Many aspects apply early next to curative treatment. Generally acts an interdisciplinary healthcare team that provides coordinated medical, nursing, psychology, social work and spiritual care (WHO, 1989).

Excellence Palliative Domiciliary Care consist of regular visits to the patient's home, in which all members of the Palliative Care team have a specific function:

- a) The first part is the responsibility of the specialist physician prescribing pain control and follow up. After that, the psychologist may begin some interaction.
- b) The second part takes goes by the nurse. Following the most basic physical and clinical care: grooming the patient, provide food, medication, organization, management, company, independence, help them go to the bathroom, among others. Here is when Dignity Patient Inventory (PDI) gives light to essential points.
- c) The nurse training the Primary Caregiver in the appropriate skills for patient's delicate and individualized care.
- d) The psychologist or tanatologist are incorporated when the patient has controlled the basics symptoms: pain

and elementary care. It usually is incorporated from the second visit to meet the emotional, loneliness, self-esteem, sense problems, family problems unsolved, among others.

- e) Subsequent visits complete treatment. Depend on how long the patient to lengthen life. Are tripping over themselves to resolve the issues that most directly identifies the patient with the recovery of the sense of dignity (CECPAM. IAP, 2007).

### 6.2. PDI: A Good Tool To Achieve Excellence In Palliative Care

The Chochinov's Patient Dignity Inventory, had proved an effective aid to EPDC in terminal patients attended<sup>17</sup>, as an accurate assistance to determine individually for each of them, which aspects need to be strengthened in the palliative treatment.

Each sick person needs, to a greater or lesser extent, solve their issues and give proper disposal to his/her concerns before leaving, so that the latter part of his/her life can be addressed with the utmost dignity. The IDP helps detect weak points of each patient, resolving efficiently and individualized elementary difficulties, allowing the dying to switch to spiritual and interior levels.

It has been proved that among the factors of the PDI with higher correlations with sense of dignity, one relevant is having lost control over his/her life (Chochinov 2008). Other aspects are: the perception of themselves as persons with low self-esteem, especially in front of their loved ones; an impression of becoming a burden to others; not having a relevant spiritual life; a significant contribution to society; an unfinished family, social or business circles; no longer have the ability to continue to play important roles: son, husband, father, grandfather. The failure to think clearly is also associated with uncertainty about their disease and its prognosis and also joined with anxiety.

When this factors are hurriedly detected and wisely solved, with the closeness and help of a good EPDC team, much will be advanced for meeting the moment of death.

## 7. Reflexive Conclusions

As a reflexive summary conclusions we propose a few ethical principles that should be implemented in health care services and palliative care units:

1. The right to health care should include access to palliative care, regardless of being a public or private institution.
2. Palliative care is not an option nor discretionary for the doctor nor the state, it is a minimum that a decent

<sup>17</sup> Research in progress. CECPAM. IAP. México. [http://www.cuidadospaliativos.org.mx/index.php?option=com\\_content&view=article&id=11&Itemid=18](http://www.cuidadospaliativos.org.mx/index.php?option=com_content&view=article&id=11&Itemid=18)

health care facility should provide to a person who is dying.

3. The fundamental goal of palliative care should provide the patient in the final stages of a terminal illness and their family, a specialized and multidisciplinary excellence care by a well trained team.
4. Care that is considered of excellence is both ethical and technical. It must provide the best quality of life including pain control, and the suffering and anguish of the family as they help their loved one go through their final stages of life and after their death.
5. Being that life is not an absolute value, death should not be considered a failure in medicine. Palliative care should not accelerate the process of dying (although, it may indirectly shorten life in treatments such as terminal sedation to avoid the pain) nor should it prolong life (although in some circumstances where certain treatment is indicated).
6. Protocols and guidelines are useful and convenient recommendations in palliative care; however, the success lies in recognizing the needs and expectation of each patient, understanding and addressing particularly the level of pain, distress and suffering, and what causes it. Excellence palliative care should not be generalized; it should be universal, but applied for everyone and their unique needs.
7. In the case of irreversible illness, it is necessary to initiate palliative treatment while the patient is in the intensive care unit (ICU). The goal of medicine is not only to fight against death in the event that the possibility exists, but fight against premature death, when the fight against death is not possible, pain and suffering should be avoided in order to obtain a peaceful death.
8. Frequently and with sufficient reason alluded to neglect of palliative care by health policies to defend the position against the legalization of euthanasia or physician-assisted suicide. The development of palliative care should not be intended to influence mainly the legislative change but to provide better care and support for the person suffering.
9. For the effectiveness of palliative care it is not necessary to contain an advance directive; however, it should be considered in having because they are part of the strategic planning of health care.
10. A way to ensure access to excellence palliative care is through the law to regulate and establish appropriate mechanisms for its organization and operation.

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