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The Unresolved Issue of the “Terminal Disease” Concept

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1. Introduction

1.1 Prefatory remarks

“I have already told you with what care they look after their sick, so that nothing is left undone that can contribute either to their case or health; and for those who are taken with fixed and incurable diseases, they use all possible ways to cherish them and to make their lives as comfortable as possible. They visit them often and take great pains to make their time pass off easily; but when any is taken with a torturing and lingering pain, so that there is no hope either of recovery or ease, the priests and magistrates come and exhort them, that, since they are now unable to go on with the business of life, are become a burden to themselves and to all about them, and they have really out-lived themselves, they should no longer nourish such a rooted distemper, but choose rather to die since they cannot live but in much misery; being assured that if they thus deliver themselves from torture, or are willing that others should do it, they shall be happy after death: since, by their acting thus, they lose none of the pleasures, but only the troubles of life, they think they behave not only reasonably but in a manner consistent with religion and piety; because they follow the advice given them by their priests, who are the expounders of the will of God. Such as are wrought on by these persuasions either starve themselves of their own accord, or take opium, and by that means die without pain. But no man is forced on this way of ending his life; and if they cannot be persuaded to it, this does not induce them to fail in their attendance and care of them: but as they believe that a voluntary death, when it is chosen upon such an authority, is very honourable, so if any man takes away his own life without the approbation of the priests and the senate, they give him none of the honours of a decent funeral, but throw his body into a ditch.”¹ Sir Thomas More (1516)

In 1977, Leon Eisenberg suggested a distinction should be made between the terms “disease” and “illness” (Eisenberg, 1977): *“The dysfunctional consequences of the Cartesian dichotomy have been enhanced by the power of biomedical technology. Technical virtuosity reifies the mechanical model and widens the gap between what patients seek and doctors provide. Patients suffer “illnesses”; doctors diagnose and treat “disease”. Illnesses are experiences of discontinuities in states of being and perceived role performances. Diseases, in the scientific paradigm of modern medicine, are abnormalities in the function and/or structure of body organs and systems. Traditional healers also redefine illness as disease: because they share symbols and metaphors consonant with lay beliefs, their healing rituals are more responsive to the psychosocial context of illness...When physicians dismiss illness because ascertainable “disease” is absent, they fail to meet their socially assigned responsibility. It is essential to reintegrate “scientific” and “social” concepts of disease and illness as a basis for a functional system of medical research and care.”.*

¹ Direct quotations appear in italics.

Allan Young (Young, 1982) draws a further distinction between “disease”, “illness” and “sickness”: *“DISEASE retains its original meaning (organic pathologies and abnormalities). ILLNESS is essentially the same, referring to how disease and sickness are brought into the individual consciousness. SICKNESS (...) is redefined as the process through which worrisome behavioral and biological signs, particularly ones originating in disease, are given socially recognizable meanings, i.e. they are made into symptoms and socially significant outcomes. Every culture has rules for translating signs into symptoms, for linking symptomatology to etiologies and interventions, and for using the evidence provided by interventions to confirm translations and legitimize outcomes. The path a person follows from translation to socially significant outcome constitutes his sickness. Sickness is, then, a process for socializing disease and illness”*. These ideas were later reinstated by other authors and publications, such as The Hastings Center Report: The Goals of Medicine. Setting New Priorities (Callahan et al., 1996). In this document, “disease” is defined as a physical or mental dysfunction, based on a deviation from the statistical standard, which causes impairment or increases the probability of an early death; “illness” is understood as an individual's subjective perception that his or her physical or mental wellness is either altered or absent, affecting the ability to perform normal daily activities as a consequence; “sickness” is the social perception of an individual's health status, usually, an external perception that this individual has physical or mental difficulties.

The different realities of patients, their families, physicians and society at large, which will be discussed below, lead us to consider an anthropological perspective in which the medical point of view of **terminal disease** is integrated with another that takes into account the suffering patients and their families undergo (**terminal illness**) and with the polymorphous interpretation made by the family and society (**terminal sickness**).

If we consider that the meaning of a word is made up of the set of relations (both situational and paradigmatic) reflected in that word, and that those relations are built all through the history of mankind and each individual's own history, we should understand that it is not possible to provide univocal answers in the case of such an expression as “terminal disease”, which carries multiple meanings with it.

The medical description of terminal disease, the suffering patients and their families undergo, and the view society holds are often mutually and internally contradictory. The situation arising out of this is both complex and dynamic, hence the need for a dialogue focused on the suffering endured by the “protosufferers” (patients and next of kin) when it comes to making decisions involving them.

The meaning of terminal disease should ultimately be a single, non-reproducible, contextualized construction, one which embodies the dialectic contribution made by the various agents involved.

The purpose of this paper is to question the pretended univocity of the definition of terminal disease as it is understood from an exclusively unidimensional approach (the medical one), definition which, from a functional point of view, turns out to be a rigid concept that imposes itself over the needs of patients, their families, and even healthcare workers.

It should be borne in mind that the definition of terminal disease is not intended to be solely descriptive, but, as it is later observed, it has a determining functional nature. Based on it, it could be determined whether a particular treatment is futile or not, or if therapeutic

obstinacy or neglect is evidenced, or whether those who are close to the patient (next of kin, caregivers and therapists) are respectful of the patient's dignity.

It could be said that decision-making from a functional perspective frequently fails to overtly specify whether a given disease is terminal or not. However, an in-depth look into the matter reveals that it does so implicitly, in so far as it considers whether the implementation of measures which will unnecessarily prolong life and/or the suffering of patients and their families is unsubstantial or not.

The concept of terminal disease will be discussed all through this paper; however, it is convenient to clarify *ad initio* that, in fact, there are no terminal diseases but terminal patients, and this is precisely the main guiding principle behind this work. Reification of the concept of terminal disease, disregarding the terminal patient, frees many from the burden of disentangling the complex, dynamic nature of each situation in particular and the commitment which that entails.

2. Terminal disease, terminal illness and terminal sickness

2.1 Terminal disease or the medical point of view

The definition of terminal disease is seemingly simple, clear and univocal. The Spanish Society of Palliative Care (Sociedad Española de Cuidados Paliativos [SECPAL, n.d.]), for example, provides the following definition:

"In the case of terminal diseases, a number of elements should be present. These elements are important not only to consider a terminal disease as such but also to determine the most suitable therapy.

The key elements are:

1. *Presence of advanced, progressive, incurable disease.*
2. *Reasonable unresponsiveness to the specific treatment.*
3. *Presence of multiple, changing, severe symptoms or problems of multifactorial origin.*
4. *Great emotional impact on the patient, the family and healthcare workers, closely related to the implicit or explicit immediacy of death.*
5. *Life expectancy of six months or less.*

This complex situation requires the uninterrupted provision of appropriate care and support.

End-stage CANCER, AIDS, motor neuron disease, specific organ system failure (kidney, heart, liver failure, etc.) meet these criteria to a greater or lesser extent. Traditionally, providing adequate care to end-stage cancer patients has been the raison d'être of Palliative Care.

It is ESSENTIAL not to consider a potentially curable patient as terminally ill."

Some of the controversial aspects of this definition will be discussed below. It is worth pointing out, however, that this definition is not to be rejected entirely. In fact, it could be accepted as a guideline, but not as a dogma that should be asserted over concrete decisions.

2.1.1 How advanced, incurable and progressive a disease should be to be considered terminal

2.1.1.1 Advanced disease and life expectancy

An 84-year-old male patient has a 10-year history of dementia. For the last three years, he has been bedridden, unable to walk, with incontinence of bowel and bladder. His ability to communicate is nearly lost (he occasionally answers "yes" or "no" to questions), he does not

react to simple commands, and he rarely recognizes loved ones. He does not present swallowing difficulties but is unable to feed himself (he requires help from a caregiver). Could this patient be considered terminally ill?

In his statement for the Association of Alzheimer Disease, SG Post expresses that *"the advanced stage of dementia includes a loss of all or nearly all ability to communicate by speech, inability to recognize loved ones in most cases, loss of ambulation without assistance, incontinence of bowel and/or bladder, and some weight loss due to swallowing difficulties. The advanced stage is generally considered terminal, with death occurring on average within two years."* (Post, 2007).

The preceding definition extends life expectancy from the maximum of six months, as stated by the Spanish Society of Palliative Care, to an average of two years. This evident inconsistency of criteria shows us that the definition of the concept from the medical perspective is not univocal.

At the age of 42, Stephen Jay Gould, the famous paleontologist, was diagnosed with an abdominal mesothelioma and was informed that the median mortality after discovery was 8 months. In his article "The Median isn't the Message", Gould explains why it is the variance more than the mean, or the median in his case, what should be taken into account to establish a disease prognosis. The reason he gives is that the most common statistical measures of central tendency (either the mean or the median) are useful only to define a Platonic state but not the hard reality of the dispersion of results (Gould, 1985). Gould died at the age of 62.

Defining how advanced a disease is by establishing a period of time which is not only arbitrary but dubious as an estimate seems to be far from functional when it comes to making the kind of decisions we are concerned with. In other words, as it was once expressed by Sir William Osler (Osler, n.d.), *"Medicine is a science of uncertainty and an art of probability"*.

2.1.1.2 Incurable, untreatable and disease-modifying drugs

In medicine, it is well-known that incurable is not synonymous with untreatable. Also, for certain diseases, there are therapies which, without being necessarily palliative, modify disease progression without curing it. In other words, disease progression in a group of subjects receiving a new drug may be statistically better relative to a particular aspect when compared to an untreated group.

The fact that a disease is incurable but its progression may be slowed down creates a grey area between "curable and incurable". Disease-modifying drugs are useful but they do not cure.

Furthermore, certain measures considered therapeutic or even curative in some cultures are not accepted in others. A clear example is the rejection of blood transfusion by Jehovah's Witnesses.

2.1.1.3 Lack of primary injury progression is not synonymous with lack of disease progression

Non-progressive secondary injuries may put a patient at such a risk that, in the event of complications, they may cause his or her death.

Patients with severe sequelae, such as irreversible permanent vegetative state following anoxic or traumatic brain injury, who exhibit no progression of their primary brain injury, may be maintained in that state through intensive care procedures. These procedures are usually implemented to prevent the occurrence of complications or to reverse them if they

occur. Yet, in settings with less sophisticated means, patients are expected to progress towards death. Anencephaly could be mentioned as another example of nonviable disease, possibly comparable to an irreversible vegetative state; it is terminal but it does not meet the progressiveness criteria required in the definition.

In spite of the lack of primary injury progression, there could be modifications which may improve or worsen the clinical condition, thus challenging the univocal definition of the term “progressive disease”.

Furthermore, there are dimensions in the progression of a disease which cannot be seen from an exclusively biological perspective, such as the social and psychological impact that failure of recovery has on patients, their families and even the community (and this impact can certainly be progressive). In other words, there may not be an “unfavourable” progression in biological terms but there could be one from a psychological and/or social point of view.

2.1.2 Discussion

While a two-valued logic provides us with safe, clear definitions (advanced vs. not advanced, progressive vs. non-progressive, incurable vs. curable), our patients' individual situations, seen from a medical perspective, challenge us to adhere to a multi-valued, even fuzzy, logic, in which “things are to the extent they are, and things are not to the extent they are not”, and in which “nothing exists by itself but in relation to other things”.

If we understand that there are no diseases but patients, that there are no absolute, timeless realities but concrete, historical circumstances in which individuals live, get sick and die, the criteria to define a disease as advanced, progressive or incurable vary, and, as we have already mentioned, they need to be specified by medical professionals considering each individual case.

2.2 Terminal illness or the patient's perspective

Recently published news articles in Argentina (Carbajal, 2011a, 2011b, 2011c, 2011d, 2011d), described the situation of a 19-year-old girl (MG) who had been diagnosed with neurofibromatosis type I (Von Recklinghausen disease). The girl considered she had an “advanced” form of the disease. She was bedridden and had severe shortness of breath; however, she was in full possession of her mental faculties. *“It is not fair to live like this. Nearly all of my body is numb, and whatever I feel is painful. I can't even hold a cup in my hand, and I'm forced to lie down all the time. I choke, I can't breathe. This is not a life worth living; I don't want to go on like this. But they don't understand, they think one can always pull through. But I can't bear it any longer, I simply can't”*, one of the articles transcribed. Despite her medical condition, MG was lucid and was very clear when expressing her position. Physicians considered that hers was not a terminal disease; nonetheless, the patient wanted to be given sedatives to induce unconsciousness and stop feeling pain.

The case became known to the public. Melina, that was her name, was apparently sedated in the end, and died a few days after the media published her case (Carbajal, 2011e, 2011f).

Ramón Sampedro was a patient who was not considered terminal from a medical point of view. He was quadriplegic due to a traumatic cervical spine injury, and was bedridden for more than 30 years as a consequence of this. In his “Letters from Hell”, where he claimed to be living in, he expressed (Sampedro, 2004), (translation is mine):

“To no avail, I say to them: No!, I am dead!,

*I tell them I can't speak like them
Because it is absurd to speak as human beings do
And they don't let me be, either dead or alive
These crazy, freaked-out nuts"*

A different situation is that of Stephen Hawking's, who could find his purpose in life despite having a progressive disease and being severely disabled. Yet, no comparison between these two patients' moral values is intended, this last example has been introduced to show that personal experiences with a particular medical condition vary greatly.

In his 1845 short story, "The Facts in the Case of Mr. Valdemar" (Poe, 1845), Edgar Allan Poe presents a visionary metaphor of today's intensive care units with their intervened deaths which is worth commenting on. Mr. Valdemar, who is "*in articulo mortis*", accepts to undergo an experimental hypnotic technique and he is suspended between life and death for a period of seven months. During that time, he is not allowed to die but he cannot be awakened either. The objective of the investigator carrying out the experiment is to find out up to what extent or for how long, the hypnotic process would be able to prevent death from occurring. During the 7-month experiment, Mr. Valdemar is visited by physicians and friends and receives continuous nursing care. All through this process, however, Mr. P (the mesmerist) is unable to make decisions. It is Mr. Valdemar himself who, given the investigator's inability, begs: "*For God's sake! -quick!-quick!-put me to sleep-or, quick!- waken me!-quick!-I say to you that I am dead.*".

In light of a helpless but grandiose medicine, which does not allow either to live or to die, it is the undead who demands changing the status quo.

JV, a 38-year old male patient who suffered from amyotrophic lateral sclerosis, was fully aware of his disease and its prognosis. Percutaneous gastrostomy for enteral feeding was suggested when he was still able to undergo the procedure, but he rejected it. He also expressly refused in writing to receive invasive or non-invasive ventilatory support of any kind. He was later hospitalized due to an infectious complication. At that moment, he was unable to express himself orally (he communicated what he wanted to say by pointing at letters on a sign with his right index finger). To our surprise, when his wife asked him whether he still rejected ventilatory support, despite not being dyspneic at that time, he reproached her for such a question because it seemed to suggest she wanted him to die. Then, he indicated that he obviously wanted to be provided with ventilatory support if it was required. A few days later, it was necessary to implement the support. The patient survived 4 months in the intensive care unit and finally died.

In 2008, the case of a 13-year-old girl named Hannah Jones became known to the public. She had previously suffered from leukemia and refused to have a heart transplant to treat a chemotherapy-induced cardiomyopathy (BBC News, 2008). Her attending physicians sought court intervention to force her to undergo surgery. The media informed that physicians recommended the transplant as the only solution available, but they could not guarantee survival after the surgery. And, if she survived, her leukemia could relapse and her new heart would last ten years at the most. Hannah decided that she had suffered long enough and told her physicians that she preferred to spend the rest of her life without having to go through another traumatic treatment. Her parents were supportive of her decision, but the hospital where she was being treated in Herefordshire interfered with Hannah's decision. Physicians warned Hannah's mother, Kirsty (a nurse), that they would apply for a court order at the High Court in London to remove the child's

custody from them. The following day a child protection officer visited Hannah at home. Nobody knows what Hannah said to the officer, but, a few hours later, the Hospital Legal Department withdrew the legal action. *"The girl is firm in her decision to refuse surgery"*, said the child protection officer. *"It is incredible that such a young person who has gone through so many things has the courage to defend her rights"*, her father Andrew proudly said.

Hannah did not have what in medical terms would be considered a terminal disease; however, she made the decision to refuse the suggested treatments with apparent autonomy and competence. She had already decided that her illness was terminal. She could have been wrong, but so could have been her physicians thus prolonging her suffering.

Dr Tony Calland, chairman of the British Medical Association's ethics committee, is quoted in the same BBC News article: *"a child of Hannah's age was able to make an informed decision to refuse treatment"*. Dr Calland said he understood why a doctor might have taken this action. He said: *"I think some doctors take the view that they must intervene and they are making that decision in what they see as the best interests of the patient. But of course best interests of patients is not just the best medical interests - it's the overall holistic interests of the person in general."* He added: *"I think obviously a child of 13 with these circumstances should be perfectly capable of making the decision and particularly when supported by the parents."*

In the city of Mar del Plata, Argentina, a patient was admitted to the General Acute Care Hospital (Hospital Interzonal de Agudos) with a history of diabetes and gangrene in the right foot. Above-knee leg amputation was performed on August 9, 1995 after obtaining consent from the patient (he had denied consent previously). On August 16, 1995 he was diagnosed with necrosis of the left first and fourth toes, cellulitis and edema involving the entire foot were also observed. On August 23, 1995 he was diagnosed with vascular ischemia of the left lower limb. Below-knee amputation was indicated, but the patient refused to undergo this procedure. The following was documented with respect to his refusal: *"The patient refuses to receive treatment, his decision being entered into his medical record. Considering that the patient is lucid, we deem it advisable to notify the Direction in the event of a legal issue."* The patient was perfectly lucid and fully aware that he was putting his life at risk. The Hospital Ethics Committee stated that patient autonomy should be respected. However, court intervention was sought, and the judgment was granted in favour of the patient and his decision (Hooft, 1995).

As we have already mentioned, a typical example in which the concept of "terminality" differs between patients and physicians is that of Jehovah's Witnesses. A Jehovah's Witness patient who presents with hemorrhage caused by a treatable condition prefers to refuse blood transfusion and die rather than violate his or her religious beliefs for a treatment not considered as such.

Autonomous and competent patients who refuse a particular treatment and put their lives at risk when making such a decision provide their own concept of "terminality", different from their physicians' concept.

The poet (Victor Jara) expresses *"life is eternal in five minutes"*. A few days or hours stolen from death may be enough for some patients to reconcile with their loved ones or to say goodbye to them. Conversely, a few minutes or hours, or sometimes months or years, may be tormentous for other patients because of the physical, mental and/or moral suffering they have to endure during that time. Those who find meaning in the agony of the last moments of life are no better than those who no longer find a reason to go on living.

2.2.1 Discussion

In any case, patients themselves are the ones who have to endure suffering. Our role as family members, friends and healthcare providers is to cooperate with them in the construction of their own meaning of life and death, as long as they allow us to do so.

2.3 Terminal sickness or the perspective of the family, caregivers, next of kin, society and the state

There is a large number of well-known cases published in the medical literature or by the media in which patients and/or their families have spent long years in distress struggling to have an illness recognized as terminal in order to allow the sufferer to die with dignity and loved ones to mourn their loss.

The hegemonic line of thought, however, considers death as a failure that should be delayed as long as possible. Sufferers (patients and/or their families) are thus severed from the decision-making process, and medicine, the courts and religious institutions are allowed to exercise their power over other people's bodies even if, after a long pilgrimage, sufferers are granted what they have asked for.

We have already commented on situations in which patients refused treatments which they considered futile or required measures to be taken so that they could die with dignity. We also examined the case of a patient who, having an illness which his physicians considered had reached its end-stage, first refused and then asked for support measures.

Greater is the complexity of the cases in which patients are unable to express themselves and it is their family who ask for withdrawal of life-sustaining measures in the absence of the patients' explicit statement of their will to do so.

Patients in an irreversible permanent vegetative state are not considered terminally ill in the applicable definitions. Due to their brain injury, these patients have neither self-awareness nor awareness of the surroundings. They do not feel pain but they are able to breathe autonomously. They may have some reflex activity, including eye movements, grimacing and grunting. They are unable to take food or fluids by mouth and they require tube feeding for nutrition and hydration. The sleep-wake cycle is preserved and, if they are provided with adequate care, they do not look critically ill at first sight. A distinction should be made, however, between the irreversible permanent vegetative state and the potentially reversible persistent vegetative state. After coming out of a coma due to brain injury, a patient progresses to a vegetative state if sufficient sparing of the brain stem allows for preservation of his or her autonomic functions. Recovery from a vegetative state is unlikely after three months if brain damage is anoxic or a year if brain damage is traumatic; in those cases, the vegetative state is said to be permanent. "Vegetative" does not mean that the patient is a vegetable but that the so-called vegetative functions are preserved (breathing, heart rate, body temperature control, blood pressure, gastrointestinal motility, etc.) (The Multi-Society Task Force on PVS, 1994a, 1994b). The vegetative state must be distinguished from the minimally conscious state, in which the patient shows minimal self-awareness and awareness of the surroundings.

Our purpose is to show that these medical conditions are seen from different perspectives by families, physicians, the courts and society at large. Some of them consider that these patients are terminally ill and that they are being subjected to futile treatments, whereas others see them as living patients who are comparable to other disabled individuals and whose life should be sustained regardless of their families' wish or the wish they may have expressed when they were competent.

In 1975, 21-year-old Karen Ann Quinlan suffered a cardiopulmonary arrest after ingesting a combination of alcohol and tranquilizers. She subsequently went into a permanent vegetative state and was placed on mechanical ventilatory support. Hers was the first case in which parents requested withdrawal of the ventilator. Physicians turned down the request, so Mr. and Mrs. Quinlan resorted to the courts. New Jersey Supreme Court authorized the family's request relying on the substituted judgment standard, which is intended first to determine the individual's own needs and wishes and then to decide on how to proceed once his or her personal value system is known. In Quinlan's case, the court sought to protect the autonomy of an individual who was unable to defend it on her own by honouring her parent's opinion (Beauchamp, Childress, 1999). Additionally, as Annas clearly recalls: *"Since the court believed that the physicians were unwilling to withdraw the ventilator because of the fear of legal liability, not precepts of medical ethics, it devised a mechanism to grant the physicians prospective legal immunity for taking this action. Specifically, the New Jersey Supreme Court ruled that after a prognosis, confirmed by a hospital ethics committee, that there is 'no reasonable possibility of a patient returning to a cognitive, sapient state,' life-sustaining treatment can be removed and no one involved, including the physicians, can be held civilly or criminally responsible for the death."* (Annas, 2005).

Once ventilatory support was withdrawn, Karen continued breathing on her own and lived for another 9 years (10 years since she had suffered the cardiopulmonary arrest) still sustained by tube feeding. Her parents did not consider requesting discontinuation of artificial feeding (Kinney et al, 1994), which could mean that Karen's parents considered that the need for ventilatory support indicated that her condition was terminal, while the other life-sustaining measures placed her in a different situation.

Nancy Cruzan's case provides us with another context. Nancy was in a permanent vegetative state as a result of a car accident she had had in 1983 (Annas, 1990). She required tube feeding but not ventilatory support. When her parents were certain that she would not recover, they requested discontinuation of the treatment stating that this was Nancy's desire as expressed by her in the past. Physicians did not accept treatment withdrawal, but the trial court authorized it. On appeal, the Supreme Court of Missouri reversed the trial court judgment and so did the U.S. Supreme Court (it was the first time that the U.S. Supreme Court had heard a case like this). Among the reasons provided, it was stated that even though a patient had the right to refuse treatment, the same decision made by surrogates on behalf of a previously competent patient could not be accepted. It was also expressed that the State should in principle favour the preservation of life and that the patient's decision as to the withdrawal of treatment should be practically indubitable (halfway between what society considers in that situation and what the law considers beyond any reasonable doubt). This last requirement limited the decision-making capacity of Nancy's parents, who loved her beyond doubt.

A new petition was submitted to the Supreme Court of Missouri, and the court rejected it again stating that there was no clear and convincing evidence that Nancy would have refused tube feeding had she been alive. It was also added that artificial nutrition and hydration were considered ordinary treatment procedures which should be provided under any circumstances, and that the State's interest in preserving life was absolute and unconditional. The State Court also expressed that although the patient is in an irreversible vegetative state, *"She is not dead. She is not terminally ill. Medical experts testified that she could live another*

thirty years"² (Cruzan vs. Hamon, 1989). The U.S. Supreme Court, in turn, pointed out that tube feeding was **an extraordinary treatment procedure which could be discontinued** and that if there was enough evidence of the patient's wishes, artificial feeding could be removed. It also expressed that even though the State of Missouri should set the standard to discern what the patient's wishes were, it did not have the absolute right to deny refusal of treatment. In light of new evidence provided by Nancy's friends and acquaintances with respect to what her wishes would have been in her situation, the Court of Missouri authorized the removal of artificial nutrition and hydration. The treatment was discontinued on December 15, 1990 and Nancy died 12 days later (Cruzan vs. Director, 1990).

Although the definition of terminal disease was not the main discussion in this case, as seen above, it is explicitly mentioned by the Supreme Court of Missouri: *"She is not terminally ill"*.

Dissenting opinions as regards Nancy's state were expressed by the U.S. Supreme Court Justices and the President of the Supreme Court of Missouri, which are worth transcribing (Cruzan vs. Director, 1990).

Justice Brennan from the U.S. Supreme Court, with whom Justices Marshall and Blackmun joined, expressed the following (bold emphasis is mine):

*"Medical technology has effectively created a **twilight zone of suspended animation where death commences while life**, in some form, continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity."*

*"Nancy Cruzan has dwelt in that twilight zone for six years... The Court would make an exception here. It permits the State's abstract, undifferentiated interest in the preservation of life to overwhelm the best interests of Nancy Beth Cruzan, interests which would, according to an undisputed finding, be served by allowing **her guardians to exercise her constitutional right to discontinue medical treatment**. Ironically, the Court reaches this conclusion despite endorsing three significant propositions which should save it from any such dilemma. First, a competent individual's decision to refuse life-sustaining medical procedures is an aspect of liberty protected by the Due Process Clause of the Fourteenth Amendment. **Second, upon a proper evidentiary showing, a qualified guardian may make that decision on behalf of an incompetent ward**. Third, in answering the important question presented by this tragic case, it is wise "'not to attempt, by any general statement, to cover every possible phase of the subject.'" Together, these considerations suggest that Nancy Cruzan's liberty to be free from medical treatment must be understood in light of the facts and circumstances particular to her. A grown woman at the time of the accident, Nancy had previously expressed her wish to forgo continuing medical care under circumstances such as these. Her family and her friends are convinced that this is what she would want. A guardian ad litem appointed by the trial court is also convinced that this is what Nancy would want. Yet the Missouri Supreme Court, alone among state courts deciding such a question, has determined that an irreversibly vegetative patient will remain a passive prisoner of medical technology -- for Nancy, perhaps for the next 30 years."*

Justice Stevens, in turn, extensively quotes Judge Blackmar from the Supreme Court of Missouri who explained that decisions about the care of chronically ill patients were traditionally private: *"I would not accept the assumption, inherent in the principal opinion, that, with our advanced technology, the state must necessarily become involved in a decision **about using extraordinary measures to prolong life**. Decisions of this kind are made daily by the patient*

² Hereinafter bold emphasis is mine.

or relatives, on the basis of medical advice and their conclusion as to what is best. Very few cases reach court, and I doubt whether this case would be before us but for the fact that Nancy lies in a state hospital. I do not place primary emphasis on the patient's expressions, except possibly in the very unusual case, of which I find no example in the books, in which the patient expresses a view that all available life supports should be made use of. Those closest to the patient are best positioned to make judgments about the patient's best interest."

"Judge Blackmar then argued that Missouri's policy imposed upon dying individuals and their families a controversial and objectionable view of life's meaning: "It is unrealistic to say that the preservation of life is an absolute, without regard to the quality of life. I make this statement only in the context of a case in which the trial judge has found that there is no chance for amelioration of Nancy's condition. The principal opinion accepts this conclusion. It is appropriate to consider the quality of life in making decisions about the extraordinary medical treatment. Those who have made decisions about such matters without resort to the courts certainly consider the quality of life, and balance this against the unpleasant consequences to the patient. There is evidence that Nancy may react to pain stimuli. If she has any awareness of her surroundings, her life must be a living hell. She is unable to express herself or to do anything at all to alter her situation. Her parents, who are her closest relatives, are best able to feel for her and to decide what is best for her. The state should not substitute its decisions for theirs. Nor am I impressed with the crypto-philosophers cited in the principal opinion, who declaim about the sanctity of any life without regard to its quality. They dwell in ivory towers.""

"Finally, Judge Blackmar concluded that the Missouri policy was illegitimate because it treats life as a theoretical abstraction, severed from, and indeed opposed to, the person of Nancy Cruzan, adding that "the Cruzan family appropriately came before the court seeking relief. The circuit judge properly found the facts and applied the law. His factual findings are supported by the record and his legal conclusions by overwhelming weight of authority. The principal opinion attempts to establish absolutes, but does so at the expense of human factors. In so doing it unnecessarily subjects Nancy and those close to her to continuous torture which no family should be forced to endure."

Justice Stevens, in turn, pointed out that "It is perhaps predictable that courts might undervalue the liberty at stake here. Because death is so profoundly personal, public reflection upon it is unusual. As this sad case shows, however, such reflection must become more common if we are to deal responsibly with the modern circumstances of death. Medical advances have altered the physiological conditions of death in ways that may be alarming: Highly invasive treatment may perpetuate human existence through a merger of body and machine that some might reasonably regard as an insult to life rather than as its continuation. But those same advances, and the reorganization of medical care accompanying the new science and technology, have also transformed the political and social conditions of death: People are less likely to die at home, and more likely to die in relatively public places, such as hospitals or nursing homes(...).The trial court's order authorizing Nancy's parents to cease their daughter's treatment would have permitted the family that cares for Nancy to bring to a close her tragedy and her death. Missouri's objection to that order subordinates Nancy's body, her family, and the lasting significance of her life to the State's own interests. The decision we review thereby interferes with constitutional interests of the highest order(...).It seems to me that the Court errs insofar as it characterizes this case as involving "judgments about the 'quality' of life that a particular individual may enjoy. " Nancy Cruzan is obviously "alive" in a physiological sense. But for patients like Nancy Cruzan, who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is "life" as that word is commonly understood, or as it is used in both the Constitution and the Declaration

of Independence. The State's unflagging determination to perpetuate Nancy Cruzan's physical existence is comprehensible only as an effort to define life's meaning, not as an attempt to preserve its sanctity(...)."

In their words, these judges forestall several of the theses put forward in this document: the irreducibility of life to its mere biological nature, the need to consider such aspects as quality of life, the ability to stop the progression of a severe medical disease through technology (a disease which would be otherwise terminal) but, at the same time, the inability to reverse the condition, the fact that these cases are usually settled in a different way when decision-making occurs within the family circle (Nancy's case reached the U.S. Supreme Court because she was hospitalized in a state hospital).

A very different case (the reverse of the preceding one) is that of Helga Wanglie, an 86-year-old patient who died after being in a vegetative state for more than a year (Miles, 1991). At the age of 85, she was hospitalized with symptoms of shortness of breath caused by chronic bronchiectasis. She required emergency intubation. During hospitalization, she acknowledged discomfort and occasionally recognized her family. Five months later, she was referred to a chronic care facility after several unsuccessful attempts to withdraw ventilatory support. A week later, she experienced a cardiopulmonary arrest, from which she was successfully resuscitated. She was then transferred to an intensive care unit, where she was diagnosed with hypoxic-ischemic encephalopathy. Physicians suggested removing the ventilator first a month and then two months after diagnosis. They did not believe that ventilatory support would benefit the patient in any way. The family, however, rejected this suggestion saying that doctors should not play God and that Helga would not be better off dead. They also added that she had not expressed any decisions with respect to such a situation. Ten months after her first admission and five months after the cardiopulmonary arrest, Helga was still unconscious and supported by a ventilator. A medical consultant whose opinion was requested at that time considered that the patient was at the end of her life, and that mechanical ventilation was not beneficial for the patient, that it would not cure her lung condition and that she would not survive without it. However, because ventilation could prolong life, it could not be considered futile. The conflict between the family and the hospital, which held that it was not obliged to provide non-beneficial medical treatment, was finally taken to court. It was first determined that the hospital had no financial interest in withdrawing treatment since expenses were covered by Medicare for the first hospitalization and by a private insurance for the second one. The trial court also appointed the patient's husband as the person who could best represent her interests. In the light of uncertainty about its legal obligation, the hospital decided to continue providing the treatment. However, Mrs. Wanglie died of septicemia three days after the court ruling.

The debate that followed was largely focused on discussing that while there is general agreement that patients may refuse treatment, it is arguable whether they or their families have the right to claim for any kind of medical treatment, regardless of its efficacy, additionally bringing up the issue of fair distribution of healthcare resources into the discussion.

What was interesting about the court decision was that it asserted the family's right to make decisions on behalf of an incompetent patient (Angell, 1991). However, it did not bring into consideration the discussion about the contents of their decision and its eventual futility.

From the physicians' point of view, Helga was terminally ill. The family, however, did not seem to consider the concept of terminality as a point of discussion. What mattered to them was that the patient was alive and that her state was better than being dead.

"For the first time in the history of the United States, Congress met in a special emergency session on Sunday, March 20, to pass legislation aimed at the medical care of one patient – Terri Schiavo. President George W. Bush encouraged the legislation and flew back to Washington, D.C., from his vacation in Crawford, Texas, so that he could be on hand to sign it immediately. In a statement issued three days earlier, he said: "The case of Terri Schiavo raises complex issues(. . . . Those who live at the mercy of others deserve our special care and concern. It should be our goal as a nation to build a culture of life, where all Americans are valued, welcomed, and protected – and that culture of life must extend to individuals with disabilities." (Annas, 2005) This is how Annas describes the shock produced by the decision of the courts of Florida to authorize withdrawal of artificial nutrition and hydration from Terri Schiavo, a patient who was in a permanent vegetative state.

In 1990, when she was 27 years-old, Terri had a cardiac arrest, which was probably caused by hypokalemia induced by an eating disorder. She progressed to a permanent vegetative state due to the resulting hypoxic-ischemic encephalopathy and she required tube feeding placement. Eight years later, her husband requested legal authorization to discontinue tube feeding. A judge found that there was clear and convincing evidence that Terri was in a permanent vegetative state and that had she been able to decide on her own, she would have chosen to discontinue the treatment. The Appellate Court affirmed the judgment and the Supreme Court of Florida declined to review it. The situation was somehow similar to that after the final decision in Nancy Cruzan's case.

However, the case became more complex and sparked nationwide debate and international attraction when Terri's parents claimed that there was evidence of treatment which would help her recover from her condition. This claim was refuted by three of the five experts asked to examine the patient (two appointed by Terri's husband, two by her parents and one by the trial court judge). The Supreme Court of Florida refused to hear an appeal again on the grounds that the parents had no standing to bring it. The State Legislature, in turn, passed a bill which gave Governor Jeb Bush the authority to order the reinsertion of the feeding tube (it had been removed after the court decision), which was reinserted as ordered. The Supreme Court of Florida declared that the law was unconstitutional and the U.S. Supreme Court refused to hear an appeal brought by the Governor. The trial court judge finally ordered the tube to be withdrawn on March 18, at 1 p.m.

Amidst death threats against one of the judges, and after another unsuccessful attempt by the Florida Legislature to pass a new bill aimed at restoring Terri's tube feeding, the U.S. Congress met in an emergency session, interrupting their Easter recess, in order to pass a bill which would allow Terri's parents to bring an appeal. In spite of this, Terri's parents could not modify the court decision and Terri finally died on March 25, 2005.

In this particular case, the concept of terminal disease was not openly discussed. However, it could be said that it was implicitly present in more than one aspect of the debate. The possibility of maintaining a patient in a permanent vegetative state, "suspended" for an indefinite period of time as opposed to an advanced cancer patient, led some people to consider Terri as a terminally ill patient whose life was being artificially sustained, while others believed that she was not actually terminally ill. In the first case, tube feeding was considered futile, a measure which undermined the patient's dignity and whose withdrawal would allow for her condition to follow its natural course; in other words, it would allow the patient to die. In the second case, the treatment was deemed vital since its discontinuation would lead to the patient's death (she would be killed instead of being

allowed to die). Those who argued for the withdrawal believed that the patient's wishes, or the wishes of those who represented her interests, would be violated if treatment was withheld; while those who opposed discontinuation considered treatment withdrawal as an offense against life.

In the debate held in the U.S. House of Representatives, several of its members showed crass ignorance of what an irreversible vegetative state is. Furthermore, some members who are also physicians offered their opinions about Terri's condition without conducting their own examinations (Quill, 2005).

The media, in turn, showed people, some of them were children, trying to bring Terri a glass of water, claiming that she was being starved to death and dehydrated (this shows that most people ignored the patient's real condition – she was unable to swallow and feel hunger or thirst).

A similar case was debated in Argentina, though it did not have the same impact as Terri's case in the United States. A female patient (MdelC) had been in a permanent vegetative state under her husband's care for two years. She progressed to that state after suffering heart failure when giving birth to her fourth child (all the children were under the father's care after that tragic event). In 2000, the patient's husband (AMG) petitioned the court for withdrawal of tube feeding, but her parents objected to the request.

In his critical review of the decision adopted by the courts of the Province of Buenos Aires (Argentina) with regard to this case, Dr. Carlos Gherardi clearly shows how ignorance and prejudice may lead to unfounded decisions (Gherardi, 2007). It is worth quoting what he wrote in the introduction to his review: *"We should start by transcribing the description of the patient provided by the Counsel for Minors and Incompetent Persons, which was repeatedly quoted in the relevant judgments: "I was really surprised because I did not find what I had expected. Based on the diagnosis, I thought I would find a physically impaired person, who would be completely unable to move, asleep, dishevelled, and connected to a mechanical respirator and machines controlling her heart rate, but the truth is that I found a woman with a very good physical appearance. She was breathing on her own and there were no machines controlling her. She only has a feeding tube which provides her with nutrition and hydration. I was really shocked to see her blink, she looked towards different places, she coughed and moved when doing so, and she made some facial gestures." The Counsel requested the petition to be dismissed "in limine" on the grounds of the defense of the right to life and because he considered that if the petition were sustained, it would eventually constitute neglect followed by death or aggravated homicide. In his argumentation, the Counsel makes reference to the Creator and the Parable of the Talents. He concludes that: "the hope for a Miracle should never be abandoned. Love and faith will always dwell in a heroic heart. And, waiting for God's time, which we know is different from man's time, is an act of heroism."*

This unusual account, made by the only court officer who actually saw the patient, seems to be referring to an individual in a nearly normal condition when, in fact, the patient is a person who has tragically and irreversibly lost all cognitive activity, and who does not exhibit the essential communicative skills and affective expression inherent to a person's identity. It is quite clear that this account had an impact on the judges and that it was considered reliable by them, since it was frequently quoted by the Court Attorney and some of the judges when providing the reasons for their votes. The probably erroneous perception of those who had to decide on such a complex and debatable issue may have been enhanced by the fact that none of them actually saw the patient and that they did not take into account the evidence provided by the various witnesses (family members, professionals, priests). Even though there was no procedural obligation, nothing prevented the judges from hearing

the witnesses' statements, which would have contributed to their knowledge of the case. It is hard to believe that none of the judges felt the moral obligation to see the patient or meet her husband and children to evaluate the situation of the family."

Dr. Gherardi adds that *"the patient's husband expressed that he did not know what her preferences were with respect to life-sustaining measures. However, two people who were close to the patient, one of them was a psychologist, stated that the patient had previously told them that if she had been in such a condition, she would not have wished to be kept alive. These statements were not taken into account by the judges and they were not accepted as witnesses, and neither were others who offered their testimony."*

The courts not only rejected the evidence provided by a psychologist and one of the patient's friends about her preferences, but it also based its considerations on an erroneous interpretation of the purpose of medicine ("to defend life at all costs"), the patient's medical condition, the situation the family was going through, and the suffering endured by those who took care of the patient, especially her husband. One of the judges (who never actually saw the patient) reveals an absolute lack of respect for the patient and her caregivers when he appeals to a possible miracle and calls for heroism while waiting for God's time. Should not therapeutic obstinacy be considered as an example of man's challenge to God's time?

Regardless of technological advances and the development of new goals, just as before, today's medicine will seldom cure, will often provide relief and will always have to comfort. It is not its objective to defeat death, because human beings are doomed to die. It should try to avoid early death but it should also allow patients to die in peace. And, it should not defend life at all costs since, in doing so, it would fall into such a negative value as therapeutic obstinacy. Allowing a dying person to die is not the same as killing him or her. By showing respect for a dignified death, we are also dignifying life. We dignify others when we consider them as persons, when we respect them, listen to them, watch them, talk to them. In the abovementioned case, regardless of the adopted decision, the judges showed a clear lack of respect for the patient's dignity in their failure to see or listen. With their behaviour, they ultimately showed the opposite side of therapeutic obstinacy: neglect.

3. Conclusion

We usually define "terminal disease" as a pathological condition that cannot be cured and, in spite of the treatments applied, it will end up in the death of the patient in a short period of time, i.e. 6 months. We consider that this definition is unilateral (made up by physicians). We propose that the real meaning should come up as a construction based on the dialogue between patients, their families, caregivers and healthcare workers. In addition, this process should be developed by incorporating the cultural concepts of the society in which each individual lives. The aim of this construction is to show that the meaning of "terminal disease" is not unique but multidimensional, since it can change depending on the circumstances.

4. Acknowledgement

The author would like to express his gratitude to the Ethics Committee of the Hospital Privado de Comunidad de Mar del Plata (Private Hospital of the Community of Mar del Plata) for

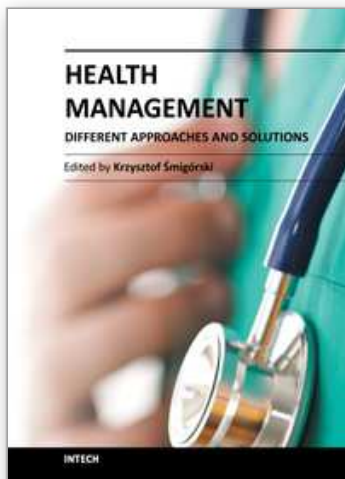
letting me be a member of it, to Dr Jorge Manzini for his teachings and his critical review of the manuscript, and to Anna Banchik for her providing me part of the bibliography. This work was financially supported by the Fundación Médica Mar del Plata (Mar del Plata Medical Foundation).

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Health Management - Different Approaches and Solutions

Edited by Dr. Krzysztof Smigorski

ISBN 978-953-307-296-8

Hard cover, 498 pages

Publisher InTech

Published online 14, December, 2011

Published in print edition December, 2011

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How to reference

In order to correctly reference this scholarly work, feel free to copy and paste the following:

Sergio Eduardo Gonorazky (2011). The Unresolved Issue of the "Terminal Disease" Concept, Health Management - Different Approaches and Solutions, Dr. Krzysztof Smigorski (Ed.), ISBN: 978-953-307-296-8, InTech, Available from: <http://www.intechopen.com/books/health-management-different-approaches-and-solutions/the-unresolved-issue-of-the-terminal-disease-concept>

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