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THERAPEUTIC OBSTINACY AND FUTILITY OF CURES

I. Introduction

The patient in vegetative state (VS) offers a unique opportunity for an ethical reflection on the concept and the practice of therapeutic obstinacy (TO) and the futility of cures (FC). In no other clinical situation must doctors substitute with so much of their own sensitivity and rectitude the lost autonomy and capacity to communicate of their patient. The VS patient demand from his or her doctors and nurses, besides a qualified professional service, a peculiar response: a deep respect for human vegetative life.

In common parlance, TO conveys the image of an irrational compulsion to treat, whilst FC appears as the result of an evidence-based reason to suspend therapy. TO and FC are frequently presented as opposite attitudes, peculiar to the technological bent of contemporary medicine. But we must bear in mind that TO and FC are not a product exclusive of present-day medicine. They portray two rival attitudes - interventionist and abstentionist - present along the history of medicine, as exemplify the clash of heroic medicine and therapeutic nihilism of the Romantic period, or the more recent disputes between psychotropic hedonists and pharmacological calvinists at the advent of tranquillisers.

The psychological frame of both TO and FC is the result of complex processes, where hopeful and irrational expectations coexist with feelings of cruel frustration. TO can result from the blending of two medical attitudes: the rejection of death as the ultimate professional failure, together with an optimistic trust in the power of advanced technology and intensive care medicine. The mentality of last ditch fight against death can induce a state of mind where treatments are doggedly tried making use of therapies in increasing dosage or applying senseless and unproven interventions. Doctors' heroic attempts to try anything emerge apparently from an intrinsic professional need to postpone death, as shown by the wide acceptance in the

Code of Medical Ethics from many countries of the compassive use of unproven medicines or the application of heroic measures.

FC, on its side, emerges from the disillusionment of doctors and nurses with the finitude of life and the failure of medical interventions so evident when incurable patients are treated. The harvest of lives lost, together with the uniformly poor clinical results, the negative economic outcomes, the emotional abrasion of dealing with unresponsive patients, and the conscience of their own efforts uselessness induce a state of resignation if not of pessimism very close to abandonment and indifference. TO and FC are, therefore, concepts and attitudes heavily charged with subjective whims and emotional tension.

The treatment of patients in VS puts to the test the psychological and spiritual stamina of carers. It marks the limits of medicine, the borders of professional courage, and the inexhaustible strength of charity. As the last resort, the patient in VS is a creature made in the image of God and endowed by Him with the gift of life. Ordained to a spiritual destiny beyond this world, the VS patient is of equal worth as any other person in the eyes of God and his or her vegetative life participates intensely on the sanctity of every human life. His or her apparently inert and unresponsive body is still the temple of a human soul.

II. Therapeutic obstinacy (TO)

The Holy Father John Paul II has provided us with definition of TO. Speaking to the participants at an International Congress on Assistance to the Dying, he said that TO "consists of the use of methods, which are particularly exhausting and painful for patients, condemning them, in fact, to an artificially prolonged agony." It is clear from the words of the Pope that, in common conditions, it belongs to the patient to decide which and when treatments become exhausting and unbearable painful. But not so with the VS patient who lacks the capacity to make such a judgement. Then, a surrogate, with the help of the carers, must bear the weight of deciding what the patient would have found an exhausting suffering, an unbearable agony.

Only at the end of their life, when some severe clinical event announces a change towards a hopeless prognosis, VS patients are candidates to incur into the risk of TO. Then the simple, safe, an inexpensive care they have been receiving must be substituted by complex, risky and costly aggressive therapies. Frequently, as time goes on, new and more intensive and intruding treatments are added to the previously instituted on account of the refractory character of symptoms or the emergence of multiorganic failure. Insensibly, the limits between sound and sanctioned medical practice and TO efface, and the critical evaluation of every procedure becomes more and more difficult.

There are some objective ethical criteria to judge if a clinical treatment is obstinate, such as its uselessness (it does not make any difference in the end), its capacity to induce or prolong suffering (the remedy is worse than the disease), its stubborn lack of rationality (the patient is placed in a humiliated and tortured condition), its disproportionate cost. Every doctor must know that the human body cannot endure too much medicine; that obstinate medical interventions tend to follow the law of diminishing returns, so that at some point they become counterproductive and cause more harm than good.

The rejection of TO is a tradition accepted by practically all the codes of medical ethics. Over-zealous treatment denounces a lack of professionalism and, paradoxically, a loss of humanity, and oblivion of the hope-filled Christian vision of mortality and the dignity of dying.

Taken to extremes, TO is prone to fall in a dehumanised behaviour, because in virtue of its paradoxical dynamics it forgets the patient and centres all attention in the compulsive correction of symptoms. In effect, the stimulus to OT comes from the powerful analytic strength of medical technology, blind to the personal in the patient, but able to detect an infinity of abnormal biochemical and biophysical parameters. The process of dying, and particularly of dying of multiorganic failure, manifests itself in an incredible variety of derailed metabolic processes, we can obsessively detect and attempt to correct. To chase one by one these abnormalities is at the root of TO. Despite their undeniable good intentions, “obstinators” are forced to deliver their cures in a crowded and hyperactive environment by nurses and doctors whose main concern is the control of deviant parameters of illness.

The most terrible consequence of TO is the substitution of the humane care of a dying person for the compulsive correction of physiopathological indicators. The impending death of a human creature is ignored. No surprisingly, clinical records are mute to the dying process: no mention is made in them of the imminent death. Recorded data point towards the patient’s poor response to the instituted changes, incriminating the patient as a non-responder. Finally, communication with the patient or the patient's family is avoided. The spiritual and sacramental service of the dying is left aside.

The Christian attitude before TO

Section IV of the Congregation for the Doctrine of the Faith Declaration *Iura et bona* offers an illuminating doctrine on the due proportion in the use of remedies in terminal patients, doctrine that has been referred to as the principle of proportionality of care. All of us know it well, but nothing is lost by quoting some of its sentences.

First, the Declaration put us in guard against TO. It affirms that "today it is very important to protect, at the moment of death, both the dignity of the human person and the Christian concept of life, against a technological attitude that threatens to become an abuse. [...] It is always licit to be satisfied with the normal means offered by medicine"

Second, it opens the way to innovative and new therapies "made available by the most advanced medicine, even if they are still at an experimental stage and not without some element of risk."

Third, withholding of burdensome treatments is acceptable. The refusal of risky or painful cures is permissible and not equivalent of suicide. "On the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community."

Finally, the Declaration approves the withdrawal of ineffective treatments, while normal care is maintained. "When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted. In such circumstances the doctor has no reason to reproach himself with failing to help the person in danger."

III. Futility of cures

The history of the modern notion of futility of medical cures is short and complex. It has been described as a vehement dispute for authority and power between doctors, patients, surrogates, ethicists, lawyers and third party payers. They contended on how to define medical futility, how to use the empirical data, how to resolve the struggle between the autonomy of patients/surrogates and the autonomy of doctors/nurses/administrators, or how to develop a process for resolving disputes over futility.

It has not been easy to arrive to an acceptable notion of futility of cures. During a long period it could be used as an ethical trump card in the hand of the doctor to deny demands for treatment made in the name of the patient autonomy, or to disregard financial considerations in the name of medical beneficence. Technology-driven medicine has been, alternatively, the friend and foe of the notion of futility. It has disdained the old Hippocratic injunction "I will apply my treatment for the good of the patient", and opted in some moments for the uncontrolled medicalisation of human dying process, and in others for the abandonment of non-responder patients. This exclusive dominion of doctors on matters of apparent superiority of medical judgement has inhibited research on the effectiveness of medical interventions as futile/non-futile in different contexts. And has delayed also the arrival of palliative medicine, which taught us that care, comfort, pain relief and amelioration of suffering must always be provided.

But at last and after many debates, the notion of futility has acquired a wider acceptance at the price of contextualisation: futility makes sense only in relation to certain specific goals and in certain places. An intervention may be futile if its goal is to cure a disease, but it becomes effective if its aim is maintaining the patient alive. The same procedure can be considered as futile by a doctor or an administrator and held as a blessing by the patient's family. The doctors demand from the intervention efficacy and a favourable risk/benefit and quality of life ratio; the administrator attends specifically to economic efficiency; the family wants the preservation of life even at the price of poor quality. There is a marker disparity about the goals (biologic, economic or axiologic) of each protagonist. As Weijer and Elliott affirm "to pretend to reach an agreement requires to redefine a debate about conflicting values into a debate about medical probabilities. And as doctors are generally the sole arbiters of medical probability this amounts to saying to families: "Your values don't count".

Pellegrino has made a critical analysis of the evolution of the concept of futility. He concludes that to obviate a number of difficulties, it appears the most reasonable to characterise futility as a prudential guide for physicians, patients and surrogates who try jointly to strike a balance between the criteria of effectiveness, benefit, and burden of cures. He proposes an approach that combines subjective and objective components of the concept, and integrates the expertise and authority proper to each of the main protagonists in the futility issues. At the same time, Pellegrino's model gives clinical expression to the classical terms of ordinary and extraordinary treatments, and to their modern variants of proportionate and disproportionate interventions.

Futility determinations cannot be made unilaterally. The choice of treatment, the determination of its elements, its quality and intensity cannot be made as a conflictive or irrational process, where the patient and his or her family on one side and the doctor on the other fight to enforce their respective inclinations. Patients, families and doctors must decide co-operatively, because each of them has something unique to contribute and each one has a specific domain of competence. In Pellegrino's words the doctor "is best equipped to determine effectiveness, the patient is the authority on benefits, and doctor and patient together share the assessment of burdens".

To cope with VS and especially with its final stage, unfortunately efficientist medicine is insufficient. In virtue of its disdain for loving care and for the old wisdom of the mere presence of family and friends at the bedside, technological medicine is destroying the capacities of many people in advanced societies to cope with suffering and death. Its message of science as salvation, that biomedical progress will make us winners over illness and death does not contain only promises of a golden future of health and longevity, but also the sad reality of terminal sedation or the final abandonment of euthanasia.

The Christian attitude before FC

We, as Catholic doctors, must be deeply persuaded that the concept of futility is predicated of means and cures, never of persons. Therefore, it is important to remind, as Pellegrino has emphasised, that each judgement of futility must take all aspects of the patient's total life into account –physical, mental, spiritual, preferences and life goals included. Futility is not an isolated, empirical yes/not test: it demands prudential assessments of a particular person in a particular experience of illness and within a particular metaphysical, theological and religious context.

Every decision futility must be finely sensitive to the individual circumstances of patients and families. It must be humane, individualised, and sympathetic to the needs and idiosyncratic likes or dislikes of the family as surrogate of the patient.

The decisions on futility must not be so rigorously taken or applied that they preclude the parting of family and friends, or the reception of Sacraments. The Anointing of the Sick, through which the Holy Spirit, mysteriously, completes in VS patients their assimilation to Christ begun in Baptism and prepares them to participate in the Paschal triumph over sickness and death. Favouring spiritual and sacramental service to his or her patients is for a Christian doctor not simply a manifestation of respect for patients' rights: it is also a feast of light and hope in the midst of his hard work.

Futility must be interpreted within a Christian context of life, death, illness, suffering and the spiritual destiny of all humans. Respect for life requires the humble acceptance of imminent death, as recognition of the creatural nature of all men. Life cannot be ended simply because curative treatment is non-existent or futile.

The Christian doctor must be faithful to the virtues of fortitude and justice, and also deeply distrustful of the excesses of compassion. Some procedures, such as terminal sedation must be considered with the utmost circumspection, since frequently and under the hypocrite cover of palliative care, hide an occult and perverse intention of terminating life. As St. Thomas Aquinas writes in his Commentary on the Gospel of Matthew, justice without mercy is cruelty; mercy without justice is the mother of dissolution.

Palliative care is founded in charity and professional competence. It must subject itself to the rules of quality evaluation and research-based improvement. It imposes on doctors and health carers a duty of humble presence and service. The Charter for Health Care Workers declares that the most important assistance is a loving and specifically medical and nursing presence at the bedside of the dying. Such an assistance gains a deep human dimension on account of the insensivity of the VS patients to the care we can offer them.

At the hour of their death, this is the singular contribution which doctors and nurses, as human beings and Christians – more than by their expertise – can and should make to the dying VS patient.

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