Surrendering to or Inducing Death: Artificial Feeding as Paradigm

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Marie Frings

Euthanasia because of loneliness, because of unappeasable suffering, because of the inadequate training of caregivers, because of the lack of personnel, because of family neglect, etc. Euthanasia, presented as THE solution, disguises the real questions that underly this act of death. Once “bandaid” euthanasia is carried out, the miseries remain.

Didier D. (close friend)

Western societies are confronted increasingly to the dilemma of euthanasia. However, as we enter the public debate, we find ourselves in a Tower of Babel of sorts because it is almost impossible to reach a consensus on the definitions of key-words and terms. It is also true that this specific question should not be separated from the larger picture of all other ethical questions related to end-of-life realities. In such a context, I opted to withdraw from the sterile “conceptual” disputes surrounding this essential issue. I returned to my practice of palliative care and looked at these issues through a concrete clinical questioning, the one around tube feeding either in terminal illness or at the *limits inherent to age with its multiple pathologies*.

The subject of tube feeding may seem highly specific and a selective study; it actually reveals itself as a paradigm of all “end-of-life” ethical questions: therapeutic obstinacy, vs. unreasonable and coercive therapies, euthanasia, assisted suicide, abandonment of the sick, informed consent, difficulties with the loss of autonomy, advanced directives, and/or designation of a legal proxy (living wills), quality of life concepts, chemical or physical restraining methods, the subtlety of the act leading to double effect, with unintended consequences.

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The very question at the core of this debate is: what is the cause of death? Did we want to induce it or did we surrender to it as ineluctable? How can we distinguish between “surrendering to death,” i.e., accepting it as part of our human condition with its limits, and “inducing the dying process,” i.e., to kill or to let someone die intentionally, transgressing the prohibition of murder, either in an active and direct way or indirectly by neglecting the positive correlate of the prohibition which is to assist any person in a time of danger. How can we answer? How can we elaborate a path to find a response to these essential questions? Or if we speak of the right to die, how can we distinguish, in clinical practice, between the right to die with human dignity and the right to kill (self or others) on one’s own terms.

But before we reach these existential thresholds, we need to investigate and evaluate the clinical dimensions of the question.

6.1 Framework of this Reflective Study

I have conducted this research on artificial feeding and hydrating in end-of-life cases for many years. In my medical practice in palliative care units and long-term facilities, I was often confronted with what appeared to me as forced feeding. I saw old people in end-of-life situations, literally sated *ad nauseam*, who needed to have the injected liquids pumped back out because they were immediately rejected; some of these old people were restrained in their chairs or beds to prevent them from pulling the feeding tubes away from their nose. As I watched these practices, I came to question their rationale. But, on the other hand, I was debating mentally whether it was possible not to feed a patient, and to forego these feedings. Was this not inducing the death of this patient and therefore engaging oneself in a process of euthanasia? These questions represented a terrifying onus because they had never been part of the academic curricula nor included in any practical training I had received in medical school. What was to be done then? As many others, I started questioning the now common recourse to these feeding tubes. A thoughtful reflection prior to the placement of the feeding tube would have offered the option not to keep it indefinitely on the patient thus sparing all involved from the harrowing questions surrounding the therapeutic scaling back.

I then sought the advice of a geriatrician friend, Dr. Veronique Latteur. She worked in an acute geriatric medicine ward. There, her experience was as frustrating as mine, yet for a different reason: she was appalled by the number of elderly patients undernourished due to the neglect of this basic health issue. She bitterly deplored the lack of teaching in this important field of nutritional support. She was outraged as she observed the patients’ sufferings, and even more scandalized that many caregivers were so unaware of this. She was determined to fight and create a new awareness to address the nutritional needs of the elderly population, as well as to train the caregivers in this field in which the negligence and the indifference were as rampant in the wards as were the damaging therapeutic obstinacy I described earlier.

This is when we started discussing some of our patients' cases. I feel compelled to present some of these cases here below, as "narrative ethics" is becoming more and more relevant in clinical ethics.

6.1.1 Case #1—Madame B. 73 Years Old

This patient is suffering from Alzheimer's disease; she lives with her only daughter, a widow. Mrs. B was diagnosed five years ago, and she has been coming to this geriatric day center six months ago because she is more and more disoriented and she cannot any longer be left alone in the house while her daughter who is a nurse is at work. One morning, Mrs. B. was found in a coma and was rapidly admitted to the hospital. She was diagnosed with an acute cerebral hemorrhage that could not be operated on. She remained in a coma over the next few days and in the absence of any likely recovery, she was transferred to a palliative care facility near her home, but with a feeding tube and, despite the coma, a subcutaneous pump with morphine and sedatives to ensure a continuous sedative state.

What is the meaning of this situation? What can be done for Mrs. B.?

6.1.2 Case #2—Madame F. 90 Years Old

Mrs. F. is quite alert for her age. She is suffering from arthritis and hypertension. She prudently opted to move to a nursing home six months ago to avoid being hospitalized in an emergency and having to endure unwanted therapeutic obstinacy. But then she had a stroke that left her hemiplegic, aphasic, and having troublesome deglutition. She had to be hospitalized. After a month-long treatment, having made no significant progress, she was sent back to her nursing home with a feeding tube. Four months later, her feeding tube "fell off" three times within a week, and was put back in place each time, till her son intervened and refused to let the nurses replace the tube.

What can be done in this case? We know the patient is conscious and most likely understands what is going on, yet she cannot communicate and express herself?

Are we not here with a case of nutritional therapeutic obstinacy? Why? Who decides these treatments? And regardless of who and why, let us ask: "how can we face such a situation?"

6.1.3 Case #3—Madame J. 68 Years Old

"A 68 years old patient is not a geriatric patient," the geriatrician thought as she was on her way to the Emergency Unit of the hospital to take charge of a new patient. This patient was suffering from acute pneumonia, but more worrisome was her weight registered at admission: 31 kilos, or some 68 pounds. The file revealed a complex and dire medical past: the patient had suffered from polyarthritis for the past twenty years, had taken cortisone drugs for years, and her condition had worsened because of the many side effects of the disease and of the treatments over the years. And yet this thick file showed no mention of her weight, nor did it contain any notes on her nutritional status. The doctor fortunately had a solid background in nutritional therapies and addressed immediately and aggressively the

many causes of her patient's undernutrition. Even if her polyarthritis was not curable, the patient was fed through a feeding tube for six weeks. This allowed this woman to gain ten kilos or 22 pounds in two months, and recover a functioning autonomy she had lost for the past two years. This patient was then able to take care of her own daily hygiene, get dressed without help, and even go briefly on a few errands. To imagine that she could have just as well landed in the palliative care unit of the hospital, located next to the geriatric ward, because of her state of severe malnutrition, and would have died a few days after her admission, is indeed food for thought.

These clinical narratives illustrate the multiple questions we must raise, from the most fundamental to the most pragmatic—and in fact, a doctor will always address the latter ones first. It must be restated that the majority of problematic clinical cases concern dependent individuals, having lost their autonomy, and relying on other people to make decisions in their name. This reality creates a vulnerability that places these patients' safety and rights in jeopardy. Confronted with the incapacity of the patients to express their will, the caregivers may at times be tempted to over-protect their patient whom they legitimately want to assist to the best of their ability.

Regarding the clinical questions, I will only treat those linked to tube feeding, and I will set aside the issues related to malnutrition.

6.2 Why Use Feeding Tubes? What Criteria Prevailed? How Efficient Are they? How Did we Come to Adopt these Protocols?

Dr. Veronique Latteur and myself shared our experiences and went on to explore the existing medical publications that revealed a multitude of clinical studies. First, we discovered papers published between 1985 and 1995, on the pros and cons of intravenous artificial hydration in the last days of life, mainly in terminal cancer patients, where palliative care originated. Then we continued to read the research published after 1995, on artificial feeding, its advantages, and the other questions around it, for other medical populations, particularly in geriatrics because palliative care was then extended to other palliative groups and not reserved anymore for terminal cancer patients.

The rapidly growing number of published articles on artificial feeding could be explained by the fact that a larger number of patients were being tube fed, thanks to the improved technical tools used (mostly thanks to the introduction of the tube directly in the stomach through a gastroscopy¹). Incidentally, it is interesting to note that this technique was developed in 1979, in neonatology, for premature babies. After 20 years of increased use of this new technique, way beyond neonatology, it became necessary to evaluate the practices in this field. To understand the scope of this phenomenon we will cite an American statistic according to which the number

¹ Guided by the light of the gastroscope (the camera tube), the doctor can make an incision at the right place to create the orifice through which he will introduce the tube. The orifice created in this manner is called percutaneous gastrostomy.

of Americans over 65 years of age, who were treated with such a tube, skyrocketed from 15,000 individuals in 1988 to 123,000 in 1995, or a 10-fold increase over 8 years.²

What did we want to measure? Studies have tried to remain objective as they looked at the impact of this type of nutrition on the *span of life* gained, but also on the resulting *quality of life* during that time, two criteria that seemingly could show improvement through these feedings. A thorough study conducted on American veterans showed that lives were prolonged in an average by 7 months and a half for a group of 7000 former soldiers who had been fed through gastrostomy in the 1990s, whether in the case of a cancer, a brain thrombosis, or other medical conditions. The study concluded that most patients fed that way were in the terminal phase of their lives since the American medical corps designates the last 6 months of life as “the terminal phase!” Regarding the quality of life, the studies tried to take into account the impact on the bedsores (expected to go away thanks to a higher level of proteins), on the pneumonias caused by inhalation (also expected to disappear in the absence of troublesome deglutition) and the functional status of the patient (i.e., his or her physical and intellectual performances linked to the weight of the person, to name only one factor), all these elements being the main rationale invoked when a doctor prescribes artificial tube feeding.

The patients fed this way represent a wide spectrum of conditions. Some have been largely studied such as the geriatric population, especially the Alzheimer patients, or those who suffer from other neurological pathologies such as Parkinson’s disease, or cerebral-vascular strokes. There are also many younger patients, suffering from rare affections, such as Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND) or other neurological dystrophies. Yet other patients, also tube fed, are more rarely evaluated. It is particularly true of some poly-handicapped children (brain-impaired or suffering from syndromes called “orphan diseases”³) who are often fed this way, or persons in a persistent vegetative state (PVS) after a coma from a head trauma, a medical complication, or an operating room incident. In order to guard against hasty comparisons and avoid mixing situations up, there are other important aspects to consider such as the clinical state of the patient at the time of the placement of the feeding tube. This state can be quite satisfactory when the tube had to be placed “early on” in the disease, to nourish the patient having a troublesome deglutition, as the person was still in a good nutritional state (as is often the case in a certain form of amyotrophic lateral sclerosis); however, most of the time the tube is placed as a last resort, *when there is nothing else to be done* and the malnutrition of the person is in an advanced state, making it most often a futile recourse (with the exception of the third clinical case presented above that constitutes a counterexample). To add a further observation, the deglutition can

²The numerous references to the mentioned studies, and other texts, can be found in the book *Les alimentations artificielles en fin de vie*, Racine, Brussels, 2005.

³An orphan disease is a pathology that does not benefit from effective treatment. Most orphan diseases are rare diseases, the development and commercialization of which are not profitable for the pharmaceutical industry.

be impaired either *totally* or *partially* (still allowing an oral feeding, albeit insufficient, as is the case for Parkinson patients who need extra time to eat). The question of foregoing the tube feeding is obviously more acute in the first situations.

The conclusions of these studies that I evoke here only briefly show that there is little clinical evidence, i.e., few clear answers to our questions. Many grey areas remain. It is also difficult to build an objective knowledge on these populations, as we encounter many problems, ethical and practical, to conduct research studies on them. We do not know for certain that tube feeding leads to the relief—or the healing—of bedsores! Yet, it does not mean this is never the case. And alas, we also observe that even with tube feeding, the patients still contract pneumonia through inhalation.

But it is clear that a patient, while still by and large healthy, suffering a first stroke with troublesome deglutition, can truly benefit from this form of nutrition in the rehabilitation phase. We are not here in an “end-of-life situation.” This is also true in the case of ear-nose-throat cancers, where tube feeding does not pose a problem unless the disease evolves towards its ultimate phase.

For the ultimate phase as such, the remaining grey areas must lead us to act with prudence. We are well inspired to speak prudently about the benefits a patient may receive from tube feeding, as much as we must exercise caution in our interpretations of the studies. The evaluation tends to be a little clearer in the case of patients suffering from advanced Alzheimer’s disease. A large number of studies concur in demonstrating that when the advantages, in life span and in quality of life, and the recurring downsides of the tubes placed on these patients, in particular the need to *restrain* the patient physically (attach the patient), are weighed against each other, the balance is clearly in disfavor of this type of feeding. It is as if the feeding problems were a sign that the disease is very advanced, even if the patient is still mobile. However, let us also remind ourselves that a general statistical data cannot ever establish an individual prognosis. Some of these studies conducted on a population suffering from dementia rightly conclude that tube feeding must not be offered to this particular group of patients, barring a specific reason brought up by the family. The *standard care* for these patients, from a professional point of view, must be *assisted oral feeding*, meaning that the caregivers could and should take the time to spoon-feed these patients, as appropriate.

This allows us to understand the current way of thinking when facing uncertain clinical situations. One seeks to weigh the pros and cons of such a therapeutic option, while referring as much as possible to the latest known objective data. This approach, based on the *ethics of principles*, i.e., on balancing the principles of beneficence and non-maleficence, of respect of autonomy and of justice, already represents a judgment on a clinical situation. This conscious weighing goes beyond ordinary clinical work, as it already implies an ethical reflection. Clinical work leads the physicians to judge a given therapy option as balanced or imbalanced in connection to the expected results (teleological perspective⁴). In other words, scientific studies and clinical experience will qualify a particular treatment in a particular

⁴Perspective taking only results into account.

clinical reality, as *obligatory or optional* (or even sometimes, *wrong*), vis-à-vis the professional obligations (through the prism of deontology⁵); hence, the coming up of more and more recommendations for the clinical practice. Presently, in France as well as in the USA, more and more *Standards-Options-Recommendations* have been published in recent years. These rational and logical approaches, based on the objectivity of clinical studies are most useful, considering the complexity of potential clinical situations and today's large offer of therapeutic options. Thus, from thinking more deeply over our clinical cases, we move on gradually to ethics.

6.3 First Approach of the Ethical Question

Let us come back to the concrete initial question: "Can we forego a tube feeding therapy?" Before all these studies even existed, a vast ethical reflection had already developed in the 1980s. Let us not forget that from the onset of this practice, tube feeding was apprehended not as some random medical treatment, but as a *life support treatment*. This was linked to its technical aspect, even though it is a very simple tool if we compare it to a ventilator or a dialysis machine. But this technical dimension implies de facto a kind of *on-and-off button* that adds an enormous emotional and moral level to the questions related to these treatments. This button turns into a *life and death switch*. Let us also mention that with the increasing number of borderline situations of this kind, linked to the progress in reanimation, a new concept appeared around 1995, that of *treatment of prolongation of the dying process*. And it is in this context that a more fundamental question came up in relation to our subject: "Is artificial feeding a *medical treatment* or a *basic care*?" Are we in a *cure perspective* or in a *care mode*?

This question quickly placed itself at the forefront of a heated debate. After perusing these fascinating publications, and having given much thought to my own experience, I, along with a vast majority of caregivers who paused to reflect on the subject, have rallied, in a first phase, to the following proposition: "Tube feeding is indeed a medical treatment." For me, two types of arguments firmly supported this position. First, a phenomenology-based analysis of this type of feeding written by an American nurse, Jacquelyn Slomka [1], for whom it sufficed to look at this form of feeding to understand that it is part of a medical reasoning. Second, a reflection on the goals of medicine and therefore on the medical responsibility and its limits led me to the following statements: (1) there is no *obligation* to pursue unreasonable therapeutic obstinacy (deontology approach), and (2) the objective to *maintain life at any cost* is not part of the acts that define the medical profession (teleological approach). I have further reflected on this standpoint as I taught it for many years, till various new encounters and seeing other stands taken, in particular surrounding the extreme situations that are the "persistence vegetative states" encouraged me to rethink my position and, eventually, to amend my conviction.

⁵Perspective dealing mostly with the moral duties of the profession beyond the strict legal parameters.

I then adopted a more nuanced position, beyond the constructed dichotomy between care and treatment: tube feeding belongs in a *special niche* between care and cure!

De Vettere sums up the debate as follows:

"It may seem that concern over how we classify nourishment by tubes or lines is a linguistic quibble without importance. But this is not so. The moral judgment of many people is significantly influenced and sometimes determined by how they classify the procedures they are evaluating.

Thus, those classifying intravenous or tubal nourishment as medical treatment inevitably defend the morality of withdrawal whenever it seems unreasonable, and those classifying the procedures as feeding inevitably claim withdrawal is immoral as long as the body accepts the nourishment...

By not describing the procedures simply as feeding, withdrawal of the procedures will not be considered as "starving the patient to death." And by not describing the procedures as medical treatment, withdrawal will not be considered as if it were simply another case of stopping a medical treatment.

In our analysis of cases involving feeding tubes and lines, we will not classify the interventions in either of the traditional categories of feeding or treatment but in terms of a new hybrid classification that we will call "medical nutrition and hydration"⁶ or, more simply, "medical nutrition."

In avoiding in this definition to describe the procedure as simply "source of nourishment," we will not see the eventual interruption as an act aiming at starving the patient to death. And because we do not describe the procedure as a mere medical treatment, avoiding the same restriction as in the former aspect, the interruption will not be assimilated to other routine treatment interruptions." [2].

Finally, behind this proposition, a non-dichotomist representation appears that allows us to look at the situation for what it really is.

Today we do something similar when speaking of palliative care vs. curative care as we pass progressively from the first type of treatment to the second and from cure to continuing care.

This position is notably different from the one adopted in France, known as the Leonetti law considering artificial feeding as a medical treatment. But it differs also from the position defended by those who raise a caveat against the potential consequence of this law to *shorten* the life span of a patient by foregoing his/her feeding through the tube because it is deemed out of proportions and there is no more consent. Those voicing the *caveat* insist that tube feeding be always qualified as *basic care* so that it can never be foregone except in cases when it would be materially impossible to pursue it, in particular among the patients in a persistent vegetative state.

However, for the sake of pursuing our research, we decided not to focus on these extreme and over mediatized situations, also quite diverse, and most likely still poorly understood (they also represent only a slim percentage of the cases where questions of medical nutrition limitations are raised) in order to reflect on

⁶This corresponds to the choice we made in the book *Les alimentations artificielles en fin de vie* (Racine, Brussels, 2005) to speak of "medically assisted nutrition" or, when we include hydration, to speak of "artificial Hydration and nutrition".

the more common problems. Contrary to the *always basic care position*, the *median position* adopted by many allows, in effect, to keep the question open regarding the eventual foregoing of tube feeding, which may, in some circumstances, be considered as a medical treatment, potentially becoming excessive. This nuanced position also prohibits answering the difficult question of *withdrawing or withholding* of a feeding tube, in a purely medical logic. This leaning towards a more *median positioning* proved itself to be more and more necessary as we faced the large spectrum of clinical situations presented to us, a spectrum that included among others, as mentioned earlier, handicapped children and persons in a persistent vegetative state. This median correction is also helpful so that we never exclude, neither in the resolution nor in the working out of the decisions taken, the *global care, including the accompaniment*, also called *caring*, thus introducing a human dimension, indispensable and decisive, while facing any end-of-life issue.

6.4 Distinguishing between Ordinary and Extraordinary

Historically, in the 1980s, what was at stake in the dilemma *care* vs. *treatment* was to know whether one could use, in this context, the historical distinction between *ordinary and extraordinary means of treatment*, the distinction that had been prominent for centuries in medical ethics. Indeed, it seems that care can only be interrupted by death, while in the case of treatment one can reevaluate its pursuit according to its efficiency. However, this distinction between *ordinary and extraordinary*—historical contexts are necessary in this debate—goes back to the battlefields of the sixteenth century, where soldiers with gangrened legs from wounds inflicted by a cannonball, refused to be amputated. Were these soldiers suicidal since they risked a certain death by their own choice? And were those who did not operate on them homicidal?

The question was also raised regarding nourishment, as the Canadian Ethicist, H. Doucet explains:

“Already in the XVI century, when artificial recourses did not yet exist, the Spanish theologian and moralist Francisco De Vitoria (...) wonders if a sick person who stops eating because he or she has lost the sense of taste would be considered guilty of a sin equal to a suicide. The answer of the moralist is the following. If the patient has to make herculean efforts to manage to eat because he or she is very depressed and has lost all appetite, we must accept here a sort of impossibility. The patient is therefore exempted, at least of the mortal sin, particularly if there is no hope of life to speak of.” [3].

But for the modern mind, and with the development of medical techniques, this global judgment, that was the distinction between *ordinary and extraordinary means* according to the circumstances of a particular life, was transformed into operational categories. And indeed what was then extraordinary has become ordinary nowadays. This distinction, initially so pregnant, was somehow eviscerated of its subjective and properly moral intensity, to end up being narrowed in simple

medical and technical terms. To simplify, its importance became obsolete, and as a consequence it became reductive.

It is in the purpose of reintroducing the spirit of a global judgment that the distinction was converted and renamed *proportioned*—*disproportioned*.

However, with the continuous evolution of techniques, questions keep being raised and studies will inevitably proliferate to research an objective weighing of the pros and cons, and establish the *Standards-Options-Recommendations* I mentioned earlier, which are useful to formulate this ethical judgment that I qualify as first level, i.e., the *professional level*.

I quickly realized, however, that this first *professional level* (already partly in the domain of ethics) is often so burdensome if it is done thoroughly that there is a genuine risk of omitting other ethical aspects, namely the patient's voice, the emotions of the caregiver, the role of personal convictions, i.e., *the ethical and anthropological markers* that are a significant part of all these debates, and that in reality are more important than the sole criteria of clinical efficiency. But historically, these elements were prominently present in the distinction between *ordinary and extraordinary*.

What is therefore at stake in the status of artificial feeding is making a global discernment possible that would include some medical aspects, but also moral and religious parameters, properly personal, with the weight of responsibility linked to the imperfection of any serious discernment.

To answer the partisans of a *therapeutic status of artificial feeding* by its counterpart, i.e., *the basic status*, is to remain at the level of a technique-based mentality where such considerations have no place, as Kevin Wildes of Georgetown University explains:

"With the help of family and physician, the patient is the one who weighs risks, burdens, and benefits in light of a treatment's probable impact. The distinction depends upon the patient's quality-of-life judgments. The idea of benefit, as understood in traditional teaching, is not merely the conservation of life. The benefit must be worthwhile in quality and duration. To only include the former and exclude the latter is to lock oneself in a partial and incomplete vision of medicine. The approach of modern, scientific medicine has tended to follow a Cartesian model of the human being and to treat the pathological body (res extensa) as a broken machine separate from the person (res cogitans). This mechanistic view of medicine and of the patient has increased with medical specialization and sub specialization!" [4].

So-called *narrative ethics* are precisely contributing to the reintroduction of the nonmedical elements because they are necessary in the process of any ethical decision that deserves to be called such.

6.5 Three Levels of Ethical Judgment

This is how Dr. Véronique Latteur and myself came to elaborate and propose a three-step protocol as a reference for the caregivers confronted to difficult questions related to handling tube feeding.

1. A *professional intervention* with a judgment on the *proportionate and disproportionate*;
2. A *meeting with the patient* (or his next-of-kin or proxy) to find out his/her (their) judgment on the ordinariness or extraordinariness of the proposal resulting from the first step.
3. Finally, the conclusion of the process consisting in a *concerted decision*, with a well-formulated objective, and with reevaluation at a mutually agreed time, in order to favor a process guided with more *common sense*, rather than only by rational criteria, and also a practice including more personal elements rather than entirely dictated by a technical mentality.

Thanks to this framework, one can grasp two delicate situations. First, when a treatment is judged proportionate to the caregivers but appears extraordinary to the patient or the family/proxy. Second, when a treatment is deemed by the caregivers as disproportionate but is found by the patient or the family/proxy as ordinary. Facing that kind of divergent standpoint is very difficult. However, if all parties do listen to each other and communicate well, there are often ways out of the impasse. It does take time and it is a real process whose keystone is the quality of the relationship between the patient and the caregiver.

When the tube feeding is practiced on a long-term basis (as is the case for patients in PVS) and is then largely related to the basic care, the caregiver's conscience, even though more and more familiar with the questions and the subtleties behind all the terms used to express them, knows that he or she is almost forced to wait for a new clinical event (e.g. pneumonia) or an event of a different nature (such as the repeated fall of the feeding tube mentioned earlier), in order to be able to question anew the tube feeding's relevance. We have to recognize that any reflection on a life-sustaining treatment made *cold-bloodedly* or *at a deadline* (e.g. at the expiration date of a hospital stay), will reveal itself as pertaining to another logic. We are then not talking about a practical discernment based on one patient's reality, but we are debating about the value of somebody's life, and that kind of judgment does not honor our humanity, nor does it honor the medical profession, who, actually, has always proscribed this type of considerations in its deontology.

To come back to the distinction between *surrendering to death* and *actively or passively inducing death*, it seems to me that it is only at the end of the process described above, and after having respected each of its steps, that one will be able to speak of *surrendering to death in the respect of life*. The subtle distinction between "do we surrender to death?" or "do we induce death?" is rooted in the following. The former—legitimate—comes at the end of a global process that takes into account the sum of all the dimensions. The latter is the result of a technical conclusion estranged from the complexity of what the patient has expressed, and divorced from the rigorous clinical evaluation done by the caregivers. It is also oblivious of the social component of any human life and of the indispensable markers that are the *fundamental prohibitions*, sine qua non conditions rendering life possible in society.

So that the process may come to its full deployment, long deliberations are insufficient. It requires that some individuals be committed to face those clinical situations, bring these questions to the debate, and be ready to take a stand, by meeting all the parties concerned, particularly the patients because they should always come first.

At this point, let us reanchor these abstract concepts into concrete situations as we go back to two of the patients presented earlier.

6.6 Madame B. or the “Disproportioned Deemed Ordinary”

Despite the fact that the risk of nutritional coercion was quickly raised in the case of Mrs. B., and that a reasonable extension of the evaluation was announced, her daughter, who had a very close relationship with her mom, begged that the tube feeding be continued for her. In these circumstances, we were engaging in an unknown timeline of tube feeding and a nutrition program was proposed along with a transfer from the palliative care unit back to the nursing home, thankfully in an adjacent building. The patient continued to live in a relative stable quietude for about a year, enjoying the good weather during regular outings in her wheelchair, and in the company of her loving daughter. Then, came a pneumonia, “the old man’s friend,” as the old popular expression used to name it; it then allowed the daughter to accept her mom’s death with a reinforced palliative protocol established to that end.

6.7 Madame F. or the “Proportionate Turned Doubtful (Optional) and Deemed Extraordinary”

After three “falls” or “withdrawals” of the feeding tube in Mrs. F.’s case, her son asked for a second opinion regarding her tube feeding. It is when I first met them because the assigned physician was on vacation and the substitute doctor called me for advice.

At this point, four months have elapsed since her stroke and there is no hope for improvement. The son explains to us that his mother has always said that she did not want any therapeutic obstinacy and this preference was the reason she had opted to move to a nursing home. He feels that his mom, who cannot speak, is clearly signaling this same request. A nurse’s aid/auxiliary assigned to her care shares this perception. It is as if Mrs. F. has been “pouting” at everyone for a week and no one recognizes her anymore. I went to see the patient and I tried to establish a contact with her. Being very much disconcerted, I attempted to articulate to her the question that her son and the caregivers had posed to me. I explained that we had put the tube back in place to take time to think it over. After discussing with the substitute doctor and other caregivers, I explained the nonobligatory nature of this treatment in such a clinical situation, and I invoked the available alternative of strict palliative care. In a consensus with the son and the caregivers, we agreed to meet again in two days to discuss it over. I was also told then that this lady is a faithful and devout Christian. I also learn that she has been inconsolable following her husband’s death and she yearned to be reunited with him in afterlife.

At the end of these multiple meetings, it appeared to us that this medical nutrition did not fulfill any therapeutic objective per se anymore and that strict palliative care was the most respectful way to serve the patient; we all went together to explain it to her.

Much to our surprise this lady was transformed as she heard us, she recovered her peaceful mind and was herself again. Her assent to our proposed care appeared clear to us.

We all shared a general sense of relief and we learned a lesson. A week later, following the withdrawal of artificial feeding, and within the protocol of strict palliative care, Mrs. F. faded away into her death, as the light of a candle would flicker out.

I took a risk in my discernment, calling to mind my medical knowledge as well as putting my decision to the test of my enlightened conscience “hic et nunc”, while also trying to focus on what the patient meant to convey to us. I dared speak, at my own risk; it was difficult. It is my opinion that what ensued confirmed the accuracy and justness of my discernment.

It can be said, then, that it is in accompanying the patients and their loved ones, and by articulating such questions through as honest as possible a communication, but also with the daily cares and treatments, that we can progressively discover the *just* responses to these questions however daunting they may initially appear.

6.8 Conclusion

Let us not rush immediately to the ethical questioning. Let us see first what clinical situation we are confronted with, let us evaluate the existing options, and their reasonable expectations, in the light of what science currently affords us. The accompaniment of the patient, to the best of our ability, should be our first priority.

Then, let us enter the moral debate and let us clearly distinguish the following three levels:

- The professional level: the proportionate or the disproportionate. Let us understand well that qualifying an intervention as disproportionate does not mean that the doctor is denying the patient his/her personal dignity;
- The patient's perspective: the ordinary or the extraordinary. In particular, let us look for the patient adhesion or non-adhesion in case of only nonverbal communication where doctors have a lot to learn from nurses in order to include the personal elements of the patients' lives.
- The process of working things out together with the two perspectives.

Let us not be absolute in the principle of preservation of life. This obligation must be linked to other obligations: not to harm, not to impose undue burdens, to respect other's conscience—knowing that self-respect may lead a caregiver to entrust a patient to another physician under *personal conscience clause*—and finally to consider that life is a mystery of which we only perceive a part.

It is in *active compassion* that we will find the just attitude, allowing to *surrender to death in the respect of life*, because *compassion* really means to suffer with.

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