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Opinion paper

Nutrition, Ethics and Cancer, “To name things wrongly is to add to the misfortune of the world”

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SUMMARY

Medical nutrition therapy is a full-fledged treatment such as antibiotics, antidiabetics or mechanical ventilation. Like any medical procedure, evidence-based medical nutrition therapy (from its indication and introduction, to the eventual interruption thereof) goes along with ethical dilemmas, especially in the most extreme situations such as old age, end of life or critical care. But more than any medical intervention or therapeutic act, nutrition and food carries specific sociological and anthropological representations, and, therefore, a heavy symbolic and emotional burden. For several reasons, cancer is at the intersection of all these dimensions: the disease and its treatments severely affect the nutritional status; end-of-life situations in oncology are still frequent, leading to thorny ethical dilemmas. The difficulties in withholding and withdrawing nutrition and food due to the symbolic and emotional burden as well as the social function are at the forefront of said dilemmas. If nutrition is still struggling to find its rightful place, isn't it also because it struggles to be well named?

The aim of this article is to analyze the ethical dilemmas, thought a socio-anthropological approach, that arise when it comes to feeding the cancer patient and to reflect on how the human based right approach can support the decision-making process in nutrition. The summarized case of Delphine G. is exemplary of these questions and will serve as the common thread of this analysis.

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Introduction

The access to nutritional care has recently emerged as a human right. This means that the patient should “beneficiate from the right to be screened and diagnosed for disease related malnutrition, to receive regular hospital diet, therapeutic diet (i.e., food modification and supplements) and evidence-based medical nutrition therapy (i.e., Artificially administered nutrition and hydration, AANH) administrated by an interdisciplinary team of experts, and the government has the duty to guarantee it” [1]. This implies, for the health care professionals, the recognition of a set of core ethical guiding values that ensure a patient-centered approach, where the needs and rights of the patients are of the most significant importance [2]. In medicine, medical nutrition therapy is a full-fledged treatment such as antibiotics, antidiabetics or mechanical ventilation. Like any medical procedure, evidence-based medical nutrition therapy (from its indication and introduction, to the eventual interruption thereof) goes along with ethical dilemmas. Most of all, in extreme situations such as the old age, end of life or critical care, and the lack of evidence-based data makes ethical reflection, enlighten by the legal framework, more important than never [3]. But more than any medical intervention or therapeutic act, nutrition and food carries specific sociological and anthropological representations, and, therefore, a heavy symbolic and emotional burden [4].

For several reasons, cancer is at the intersection of all these dimensions: the disease and its treatments severely affect the nutritional status; end-of-life situations in oncology are still frequent, leading to thorny ethical dilemmas. The difficulties in withholding and withdrawing nutrition and food due to the symbolic and emotional burden as well as the social function are at the forefront of said dilemmas.

In this article we will analyze the ethical dilemmas that arise when it comes to feeding the sick person and will focus on the vulnerability of the malnourished cancer patient. We will not analyze the ethical issues of artificial hydration as their are different and needs a specific reflection. We aim to reflect on how this approach can support clinicians to make evidence-based decisions in the best interests of their patient. The summarized case of Delphine G. is exemplary of these questions and will serve as the common thread of this analysis.

Clinical case

Delphine G, a 91-year-old woman, has a history of breast and stomach cancer, treated respectively with surgery, radiotherapy, hormone therapy, and surgery, chemotherapy. In early 2021, Mrs. G. underwent surgery for adenocarcinoma of the transverse colon. In the postoperative follow-up, the signs of disorientation present before the intervention increased. No adjuvant treatment was necessary, but faced with insufficient food intake, parenteral nutrition was undertaken. Cognitive functions worsened despite returning home, where Delphine fell several times. In March, the central venous catheter was torn off in a fall. Mrs. G. was more fatigued since stopping parenteral nutrition. Her daughter, the home nurse and the physiotherapist asked for a new catheter. But the insertion of the catheter was made impossible by major agitation. Due to the repeated requests of the daughter and the caregivers at the patient's home, a second attempt was made: it was a failure. Geriatric specialists and then the Ethics Committee were solicited. The geriatricians concluded that there was no indication of artificial nutrition, that any attempt to place a catheter under stress was deadlocked, and they suggested a “pleasure diet”. The Ethics Committee, taking up the cardinal principles of bioethics, concluded the same thing, but at the insistence of the patient's daughter and with the agreement of her oncologist, the patient was transferred to a nearby hospital for nasogastric tube placement. Her agitation made the installation difficult and the tube had to be repositioned several times. While enteral nutrition was started, the patient pulled on her tube, and following vomiting of digestive fluid and diet, inhaled

massively and developed acute respiratory failure. Because of the therapeutic limitations collectively stated, it was decided not to intubate. Mrs. G. Delphine received oxygen at high flow, increasing sedation, and finally died 48 hours after the placement of the gastric tube. A few days later, Mrs. G.'s daughter filed a complaint with the hospital for “loss of chance”.

Why is Mrs. G.'s story illustrative? Because Delphine had advanced cancer, because she was old, because she was at the end of life. But also because the indication of the withdrawing of artificial nutrition has been at the origin of acute ethical dilemmas (about refusal of care, autonomy ...), and subjective and emotional representations of both the family and the oncologist irrupted in the decision. Perhaps only pain is invested with such a symbolic weight that goes beyond the medical dimension. No other treatment, not even mechanical ventilation (though depository of the breath of life), would have crystallized so many medical, moral and social issues.

Through this story, we will successively examine the ethical implication of considering nutritional care as a human right for cancer patients, the social and cultural role of food, and the position of caregivers.

Nutrition: a physiological role, but above all a cultural and social one

In 2016, the ESPEN guideline on ethical aspects of artificial nutrition and hydration highlighted the importance of both nutritional and social aspects: “When independent ingestion of food and liquids is disturbed, nursing and medical procedures serve to cover the individual's vital need for nutrition as well as to fulfill these natural requirements with the purpose of enabling the individual to participate optimally in his/her social environment” [5]. Like philosophers, sociologists or anthropologists, doctors have pointed out the complex role of food in humans.

We cannot understand the ethical issues related to nutrition if we do not consider its symbolic function. According to Aristotle, nutrition is the main function of the general organization of the living and one of the main functions of the soul. In fact, according to this philosopher, the fourth part of the soul is the ‘nutritive soul’. But above all, the nutritional function is associated with reproduction: “The nutritive soul is the first faculty of the soul and the most common, the one by virtue of which life belongs to all. [...] It includes both the assimilation of food and reproduction. The same faculty of the soul is both nutritious and generative.” The close link with life and fertility underlines this function of perpetuation of the person, but also of the species.

The act of feeding and eating and the surrounding environment therefore define man in his ecosystem, a full member of the species and an eminently social animal. This social function of food and meal is widely described: “Food is both an encounter of the subject with himself and a collective act” [6]. The French sociologist Pierre Bourdieu recalls that man makes the “meal a social ceremony, an affirmation of ethical dress and aesthetic refinement” [7]. In some cultures, eating is instituted as an art of living: being prevented from doing so, by disease or poverty, becomes thenceforth a double condemnation. For Delphine's family and her caregivers, the impossibility to receive artificially administered nutrition was perceived as a double signal of abandonment by the world of living beings.

Moreover, man as a social object is also defined in his environment by his feeding characteristics. Bourdieu recalls the role of “habitus” in our practices and even our tastes, “a choice of destiny, but a forced choice, produced by conditions of existence” [7]. When dependence on nutritional therapy occurs because of the disease, or when, conversely, the diet must finally be stopped, it is much more than a treatment that is introduced or stopped: it is a real social uprooting.

The expression of social differences through food remains attached to the sick until the end of their lives. Thus, according to their socio-professional categories, access to food exceptions or wine will or will not be tolerated by caregivers, in the name of both hygienic and moral preventions. However, “it is more what we have always loved, always had the habit of consuming, that is important to maintain as permanence, when the serious illness forces a ‘change of pace’” [6]. Ethical issues are again at the forefront, between respect for autonomy and the desire not to harm. ESPEN's recommendations are not mistaken: “Other needs like the enjoyment of food and social aspects of feeding including humane attention are not satisfied by these routes of food supply, and should not be neglected as such” [5]. There is a dimension here, “food/drink pleasure”, which is usually only found in the category of comfort care; however, nutrition is a treatment, whose place is singular. This is probably why, when

geriatricians and the Ethics Committee concluded that “only” a “pleasure diet” was mandatory for Delphine, the patient’s daughter and the oncologist considered that the notion of pleasure was not compatible with the fighting spirit needed to survive. This last point is central because the distinction between treatment (i.e. cure) and care (comfort and pleasure according to patient’s criteria) is in constant tension in clinical nutrition practice. This underlines the crucial need of early shared-decision making, advance care planning and end-of-life discussions, in order to avoid futile obstinacy when the end-of-life approaches.

If the place of nutrition is so remarkable in oncology, it is also because cancer and its treatments primarily attack the digestive organs and functions of nutrition. Anorexia, hypermetabolism and the consequent weight loss and sarcopenia testify to its severity; chemotherapy and radiotherapy are toxic to the entire digestive tract (mucositis, nausea, vomiting, functional disorders, etc.); disorders of taste and smell, food disgust, sometimes functional impairments of swallowing alter the quality of life and ability to eat under the effect of treatments or the course of the disease. Aristotle already noted this phenomenon five centuries before our era: “Healthy people judge healthy foods that are truly healthy, while the sick judge quite differently” [8].

In a situation of good health (while being aware of the relativity of “health”), food is therefore a vital need, a pleasure and a social act (in terms of productivity, food to work; and in the sense of a social bond). In a situation of disease, such as cancer here, all these functions remain true, but with distortions of these roles and of the perception of their necessity according to the stage of the disease. Nutrition becomes a full-fledged treatment: it is therefore part of the mandatory arsenal at the beginning of and during the course of illness. “Artificial nutrition and hydration are a medical intervention, requiring an indication, a therapeutic goal and the will (consent) of the competent patient [...]” [5]. However, in an imminently dying situation, because of its treatment status, nutrition, and with it hydration, can be stopped, unlike other therapeutics or supportive care that are continued until the end of life (analgesics, anxiolytics, physiotherapy). Whether you are in the beginning or in the final phase of the disease, the principles of bioethics apply to nutrition as well as to other treatments [9]. These are the principles of beneficence, non-maleficence, autonomy, and justice.

A vital need, a fundamental right: the right to the benefit of nutritional care

“I will serve according to my power and my discernment a diet to the relief of the sick” (10). As art and science, Hippocratic medicine was based on two dietary imperatives: adapting healthy foods to human nature and adapting the diet to the condition of sick patients in order to avoid suffering and death. The imperative to provide for the nutritional needs of all, in an adapted and thoughtful way, therefore dates back to antiquity [4,10].

Recently, nutritional care access has been considered to be a human right linked to the right to food and the right to health. This implies that cancer patients should ideally have access to screening, diagnosis and assessment of malnutrition and the administration and monitoring of food and evidence-based medical nutrition therapy including artificial nutrition and hydration [1]. It is important to highlight that recognizing that nutritional care access is a human right does not imply there is an obligation to feed all patients at any stage of life and at any cost. From an ethical point of view, conversely, this right implies that the best decision for the cancer patient must be made and this may include, under certain circumstances, the decision to withdraw or withhold nutrition. Our patient, Delphine, was successively in both situations: as required, she benefited first from assessment and the onset of artificial nutrition, and several months later she was ordered to stop nutrition.

Applied together, human rights and health care ethics are closely linked as they support and complement each other [11]. According to E. Hirsch, human rights concepts “characterize and illuminate the issues of an ethical requirement in the fields of care and research.” [12] Consequently, when it comes to feeding the sick cancer patient, respect for human rights and dignity are not abstract values, but take on a practical dimension “which defines a social order and places us under mutual obligations towards each other” [12]. Recognizing the right to nutritional care as a human right establishes a commitment to a very important ethical responsibility that must be based on the respect of the four ethical principles (autonomy, beneficence, non-maleficence, and justice) as well as other principles

such as vulnerability, equality and equity [3,4]. Moreover, recognizing nutritional care as a human right implies the ethical duty of feeding the ill person in conditions of dignity.

Cancer occurs, and food often takes a back seat: the paradox of cancer nutrition

As a treatment, nutrition obeys the laws of right prescription and ethics. The first statement of international recommendations by Espen says: “Prerequisites of artificial nutrition and hydration are 1) an indication for medical treatment, 2) the definition of a therapeutic goal to be achieved and 3) the will of the patient and his or her informed consent.” [5] Nutrition is a part of the therapeutic arsenal in the same way as chemotherapy or surgery (and is not a vaguely humanitarian option, left to the care of volunteers or the family that brings food). Everything should contribute to place food at the heart of these concerns: its essential social and anthropological place, as seen above; its status of “basic need”, as defined by Virginia Henderson [13]; the nutritional aggression of cancer and its treatments; its proven effectiveness, natural or artificial, to improve the prognosis [14].

However, we still often observe a paradoxical phenomenon when caring for a cancer patient: diet and nutrition take a back seat, sacrificed to the war against cancer and the will to heal. Because of its dual status (both physiological and socio-cultural), is it secondary and vaguely superfluous? Does being such an “object of pleasure” give food, taste, senses, a hint of guilt compared to the priorities of chemotherapy or surgery? This negligence is not the responsibility of doctors alone: oncologists, but also the patients themselves, obsessed with the imperative urgency of treating the cancer disease, focus all their efforts on heavy treatments, with etiological aims, relegating to second place a treatment that has become a simple support. Yet, what doctor would treat pneumonia with antibiotics alone while forgetting about oxygen? The fundamental right to be fed in a correct, adapted and thoughtful way [2,15], is therefore often abused. It is only much later, as life slips away and the clinical benefit of food wanes, that eating and drinking return to the forefront of human concerns; we will come back to this.

A triangular relationship

While cancer primarily affects nutritional status, there is a frequent discrepancy with the poverty of nutritional care (screening and diagnosis for disease-related malnutrition, etc.). Three players meet: the patient, the oncologist, and the nutritionist.

The patient, at this stage, is the prey of many paradoxes where representation plays a key role: “eating makes cancer grow”, anti-cancer diets, fasting or alternative therapies, as shown in breast cancer patients [16]. Thus, we often hear that “not eating well in the hospital is normal” or that “weight loss is inevitable when you have cancer.” [17]. Priority is given to the fight against tumors, going as far as sacrificing some aspects of quality of life (including eating well). However, many patients, confide regret a posteriori of putting their quality of life on hold.

The oncologist also gives priority to etiological treatment. Among toxicities, they pay more attention to immunological damage (more worthy of interest?) than to digestive toxicities, for example. The problem of loss of taste is rarely addressed. And if they integrate the importance of nutrition, the oncologist is less concerned by the intrusiveness of parenteral nutrition. Moreover, oncologist referrals to providers and programs of nutrition and increased physical activity are infrequent [18].

The nutritionist, finally, tries to limit the consequences of disease-related malnutrition or toxicities, in a sometimes solitary and thankless role. They know the loss of chance of not taking care of sarcopenia. They know that everyone's sensory equipment is unique, and that we cannot categorize people according to predefined criteria: the personalization of care is essential here.

Ethical issues of particular magnitude

The ethical challenges are identical to other fields of medicine: sharing information and decisions respecting the autonomy of the sick person, while ensuring the principles of beneficence and non-maleficence [9]. “Personal health care [...] has to take into account the “overall benefit”, the possible results of the treatment in regard to the disease, the quality of life and the psychological and spiritual

well-being [5]. The goal is for professionals to have a holistic approach to the patient; the patient's values and preferences must help them to do so.

However, as we have seen, patients themselves are subject to unusual cognitive biases and representations conducive to sacrificing this autonomy. Emotions, heuristics and “limited rationality” are in the foreground here [19–21]. If they remove their paternalistic costume, oncologists could restore the conditions of this autonomy by not unilaterally privileging one objective (the administration of specific treatments) to the detriment of others (control of sequelae, information on loss of taste, digestive damage ...); the goal of non-maleficence must balance that of beneficence, especially if it is not shared. However, the decision-making regret reported by many patients proves the negative impact of insufficient respect for autonomy. More generally, compliance with good nutritional practices should be part of the overall framework of respect for human rights.

Malnutrition, a visible mark of a progressing disease

At the ultimate stage of cancer, more than any other pathology, the advance of the disease deposits its stigmas on the entire body: the contours of the face, torso, thighs and hands deepen and disappear before their time. Sarcopenia clears muscles and reduces forces, physical dependence affects the essential and common acts of life. Does the patient look at himself in a mirror, and no longer recognize himself? Death has already depersonalized him. “Active and destructive death arises in the imagination to the point where the ‘dead already dead’ and the moribund who will be dead become themselves indistinct” [22]. After the destruction of the body in its physical representation, dependence will come to proclaim a widespread feeling at the end of life, that of lost dignity. The cruelest act of dependence will be help to feed oneself: from an act of major social and symbolic significance, marker of being in the world and belonging to the society of the human beings, eating little, or the impossibility of eating alone, becomes the sign of exclusion, already, from the world of living beings. What could be more natural, then, than to cling to the memory of this body and its fading strength by nourishing it, whatever the cost, overcoming the disgust of food, the appetite that disappears, swallowing that becomes painful? And if necessary, by using artificial means.

Artificial nutrition has become a part of palliative care, with the potential to increase survival and quality of life, as well as assessment and treatment of pain and other physical, psychosocial and spiritual problems [5]. Long term home enteral and parenteral nutrition programs may be considered, in order to foster and sustain an optimal quality of life. Parenteral nutrition may be a part of palliative care in cancer, allowing increased survival in far-advanced cancer cases without gastrointestinal access to patients who would have died from starvation and not primarily from their malignant disease [5]. However, the patient's point of view is essential when considering quality of life, and according to Amano, most patients with advanced cancer do not wish to receive nasogastric tube feeding because of the psychological and social impact [23].

The dilemma of advanced palliative feeding

As a full-fledged treatment, nutrition can be stopped for futility. The paradox described above at the beginning of the cancer still exists, but it is reversed as the cancer progresses and the end of life approaches: starting as necessary, nutritional therapy becomes optional or even deleterious, while patients or families become more and more attached to it ... “As the patient approaches the end of his life, the administration of food - specifically adapted to his needs in terms of calories and nutrients - becomes increasingly insignificant” [5]. For Delphine, while the right to be adequately nourished after surgery was materialized through total parenteral nutrition, the non-obligation to prescribe artificial nutrition at the end of life made it possible to stop the prescription without altering the prognosis. But the obstinate insistence of Delphine's family to continue artificially administered nutrition by hook or by crook testified to the symbolic attachment to feeding when life ends. In cancer patients, the benefit/risk ratio is first balanced, then it is reversed: the beneficial effects of nutrition (artificially administered in particular) disappear in the face of the catabolism of far-advanced cancer, while the toxicities of artificially administered nutrition appear and accumulate (peripheral edema, overload, aggravated by hypoalbuminemia). Delphine experienced another type of iatrogenic adverse event with the

malposition of her nasogastric tube leading to a massive aspiration. At times initially neglected by the oncologist, nutrition becomes the ultimate crutch for failing chemotherapy. As a full-fledged treatment, nutrition can then fall into the category of unreasonable obstinacy, and as such may/must be stopped (or not be undertaken because of futility), just like artificial ventilation, adrenaline or chemotherapy. Nutrition goes from being a vital need, to becoming an artificial support for keeping a patient alive! The objective is clear: “Prolongation of life may never be the sole goal and always has to be factored in relation to the wellbeing of the patient. Prolongation of life must never turn into prolongation of the dying phase” [5].

A multicenter randomized study by Bouleuc *et al.* showed that supplemental parenteral nutrition was not effective in improving either quality of life or survival for patients with a median survival of 2.5 months [24]. However, it remains difficult to definitively certify the onset of the dying phase. Therefore, the withholding or withdrawing of nutritional therapy in this phase of life must always be stated in an individualized manner. Each person demonstrates a different type of behavior and different sensations until the time of death. Although patients frequently experience dryness of the mouth, an early sensation of saturation, nausea and an impaired sense of taste, they rarely experience hunger and thirst. Therefore, dryness of the mouth and thirst should first be counteracted by nursing measures such as lip and mouth care.

In cancer patients as well as in the intensive care unit (ICU), “nutrition and hydration have to be withheld or withdrawn as soon therapies are not indicated anymore (futile), from an ethical and a legal point of view.” Obviously, even when artificially administered nutrition is stopped, standard care to maintain a good quality of life to the patient must be maintained [5]. However, “there is still controversy and discordant beliefs on when to terminate AANH. This is due to the fact that there is additional emotional value attached to the provision of nutrition and hydration than for instance in continuing antibiotics or other treatments” [5]. Reactions of Delphine’s daughter and caregivers proved that this irrational resistance affects healthcare professionals, but they are not alone ...

For patients and loved ones too, return of the symbolic stake

Inevitably, distress invades the patient when nutrition and hydration are either challenged or stopped. What, being fed is no longer a fundamental human right, nor a vital need?! If it is vital and it is stopped, it therefore hastens death! Not only has dignity been lost, in terms of subjective dignity, which has already materialized in the degraded image of the body and dependence, but the social and eminently collective function of eating and drinking is in turn fading. So, at the very least, the nurse plugging in the parenteral nutrition bag or enteral tube maintained this tiny link, the right to supply this body that can no longer do it alone. Now, this ultimate bond can also be suspended: it is no longer useful to make this dying person eat and drink. What has been, in French law, an essential clarification for professionals (nutrition and hydration are a treatment, not care) [25] turns for patients and relatives into a violent act of abandonment. Painful stories (mainly for neurologic patients) have fueled the press in recent decades. In 2005, the American Terri Schiavo died after the cessation of parenteral nutrition and 15 years of vegetative coma and legal struggles. In Italy, Eluana Englaro died after 17 years in a coma, including 4 years of fighting her father and doctors to stop artificial feeding, delayed by the rifts between jurists and policymakers. After Eluana’s death, the president of the Pontifical Academy for Life wrote: “A young woman who was seriously ill but alive was deprived of food, dehydrated, exposed to great suffering and led to death.” This concern is illustrated by the debate on comatose patients, who although “non-respondents” could not be necessarily “non-sentient”.

In France, ten years of proceedings and appeals at the highest level of international justice were necessary for the “Vincent Lambert case” [26]. The harshness of the confrontation then went beyond simple physiological logic, reason and even ethical principles: the extreme solicitude of a part of the family materialized in the fear that the sick “was hungry or thirsty”, and in the symbolic weight of the break with this final link to life. It is symptomatic to note that, faced with advanced cancer, patients and families widely document their DNR orders, while they do so only exceptionally (<7%) for the issue of artificially administered nutrition [27]: because it is a blind spot of reflection at the end of life.

And always, ethical issues

Artificially administered nutrition is identified as a prevailing ethical dilemma for health professionals in their attitude toward End-of-Life care. In France, a legal tipping point was the Lambert case cited above, followed by the 2016 law [28]. Artificial feeding being a treatment, can be stopped, unlike care (pain, anxiety ...), which is maintained until the end. In terms of ethical principles, it is considered that potential harm (maleficence) comes to the forefront, for a reduced benefit (beneficence). However, this point remains debated. “The supplementation of AANH may relieve discomfort caused by dehydration, but the requirements of tubes or catheters may increase the burden for patients. Whether AANH is beneficial as a basic nutritional supplement or may become problematic due to the possibility of fluid overload in patients with advanced-stage cancer remains an area of divergent opinions among clinicians” [27]. Yet non-maleficence remains a central objective, and “the decision to administer or withhold AANH should never limit offering the best palliative care to maximize comfort and quality of life to the patient” [5]. The principle of the “double effect”, first stated by Thomas Aquinas [29], is as relevant here as is the use of morphine: “Medical treatment [may be] administered [...] for the purpose of enhancing or preserving quality of life, if necessary by accepting a shortening of the time left to live” [5]. For Delphine, the final decision gave rise to an assessment of the benefit/risk ratio, a search for beneficence (food-pleasure proposal) and non-maleficence (forced to undergo an unwanted aggressive act). The “maleficence” was already there, however, with the accidental removal of the catheter, the nosocomial risks and finally the displacement of the gastric tube with massive and deadly aspiration.

The issue of autonomy is also crucial at this stage. “Self-determination includes the right to refuse support, even if such refusal may be difficult to understand by others” [5]. Conversely, “autonomy does not mean that a patient has the right to obtain every treatment he or she wishes or requests, if this particular treatment would not be medically indicated.” Here, Delphine’s decision-making autonomy could not be taken into account, but a form of autonomy of thought (through manifestations of refusal) had at least to be heard, and the unreasonable obstinacy demonstrated by the family should not have been listened to by the oncologist. The therapeutic limitations finally took place, in a context that became very painful for everyone. Irrationality and emotion had taken precedence over reason. Nonetheless, “in all cases, the treating physician has to take the final decision and responsibility” [5]. We find here the notion already mentioned of “comfort feeding”, “pleasure food” in France. Semantics is at the heart of the acceptance of what then becomes more care than treatment: “Comfort feeding” is a term avoiding negative connotations and defining an individualized feeding care plan. Words shape our thinking, and our thoughts lead our actions. Words like “stopping artificial nutrition” are perceived as negative and raise fear although they express evidence-based fact” [5].

Finally, throughout this history, the more collective and political concern of distributive justice must also be taken into account (futile treatments, transfer to another hospital in a situation of health scarcity ...). Delphine’s case summarizes all the challenges and dilemmas of ethics and nutrition in cancer patients.

Conclusion

Life does not consist of seeking and consuming the fuels provided by breathing and eating [...]. What we live on does not enslave us, we enjoy it. [...] The paradox of “living on something” is precisely in an indulgence in that on which life depends [30].

“Food is more than a simple dish; it is language and therefore needs to be heard by the clinician” [6]. More than any other medical field (except probably that of pain management), the point of food conjures up more than medical questions: the part of representations and symbolic values (anthropological, social) is constantly in the background of the dilemmas encountered. The main ethical principles are not the sole dimension. Reason and Cartesian thinking are challenged by cognitive biases, mental heuristics and emotions, in addition to the same representation and biases due to the cancer itself.

The unique place of food/nutrition is underlined by its revealing and paradoxical status. In many countries, nutrition is a part of supportive care, as well as psychological care, pain management, palliative care or social service. Yet, while the last four are kept up in the dying phase, nutrition is

legally considered to be a treatment and can be stopped to prevent unreasonable obstinacy. Being essential to the action of other therapeutics, the maintenance of the general condition and healing at the beginning of cancer, nutrition remains insufficiently taken into account when it is most useful. At the other end of the course, in the advanced palliative phase, the usefulness of nutritional therapy fades; at that time, many patients desperately cling to this last link with life. “To name things wrongly is to add to the misfortune of the world”, wrote the philosopher Albert Camus [31]. Treatment, care, support, pleasure ... If nutrition is still struggling to find its rightful place, isn't it also because it struggles to be well named?

Declaration of competing interests

Diana Cardenas and Francois Blot declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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