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Argumentation for the Withdrawing or Withholding of Artificial Nutrition by the Mobile Palliative Care Team

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Abstract

Introduction: Palliative care practice confronts us with the dilemma of «equitable care», namely: when to treat, by what means and, above all, when to stop. The issue of artificial nutrition is the perfect example. The present study was conducted to identify the arguments used by the Mobile Palliative Care Team to discuss the introduction or withdrawal of artificial nutrition and compare these arguments according to the advice given.

Methods: A descriptive, historical cohort-type epidemiological study was carried out on all medical files of patients followed by the mobile team of the Metz-Thionville Regional Hospital in 2013 and for whom a discussion had taken place regarding artificial nutrition.

Results: The most commonly mentioned arguments were general patient condition (68.4% of cases), estimated life expectancy (67.3%) and the palliative nature of care management (55.1%). Advice for the withdrawal or withholding of artificial nutrition formulated by the mobile team was followed in 75.9% of cases while the advice for the introduction or continuation of artificial nutrition was followed in 93.3%.

Conclusion: The decision to withdraw or pursue artificial nutrition is based on a body of arguments and a multidisciplinary evaluation with discussion encompassing an ethical dimension involving the patient and his/her relatives.

Keywords: Artificial Nutrition; Collegial Discussion; Ethics; Palliative Care

Abbreviations

SD : Standard Deviation

Introduction

In palliative care practice, the caregiver is faced with the dilemma of «equitable care», namely when to treat, by what means and, above all, when to stop [1] of all the resources used, artificial nutrition is of particular importance. Indeed, through its symbolism, it especially affects the patients, the families but also the caregivers. Some consider artificial nutrition as a form of care that is both essential and the patient's rightful due [2], while others see it as a classical treatment [3] that should be employed with expertise and whose indications are to be discussed. Nevertheless, there are very few recent articles in the literature addressing the medicals objectives arguments for deciding on whether to pursue or withdraw its provision [4-8]. In the Standards, Options and Recommendations [4], dating back to 2001, a series of discussion arguments are outlined for artificial nutrition (low level of evidence in the absence of randomized studies) including nutritional status, functional scores (WHO, etc.), quality of life, complications related to artificial nutrition, etc. These arguments should be compared and synthesized in order to arrive at a decision to initiate or withhold artificial nutrition. The most recent articles on artificial nutrition often deal with the symbolism of treatment and the representation that caregivers have of its practice [9,10] and not the clinical determinants of this treatment.

In its daily practice, the Mobile Palliative Care Team is called upon to meet many patients at the request of their referring physician and, if necessary, to give a reasoned advice regarding the initiation or withdrawal of artificial nutrition, advice that will or will not be followed by the medical teams when making their decision.

In light of the above, we conducted a study whose main objective was to identify the medical arguments of discussion used in the advice pertaining to the introduction or withdrawal of artificial nutrition and to compare these arguments according to the advice given by the mobile palliative care team. The secondary objective was to assess the extent to which the mobile team's advice was followed by the requesting department.

Material and Methods

Population Study Sample

The present descriptive, historical cohort-type epidemiological study was conducted from medical files. The 550 medical files of major patients, seen by a physician and/or a physician-nurse tandem of the mobile team, were reviewed as part of palliative care management within the Metz-Thionville Regional Hospital (CHR Metz-Thionville) in 2013. All patients for whom a discussion was initiated regarding the withdrawal/withholding or continuation/introduction of artificial nutrition were included.

Excluded from the study were patients hospitalized for resuscitation and for whom a discussion was held in view to limiting or discontinuing treatment, due to the specific nature of the arguments used in these situations. The arguments used to justify the withdrawal of artificial nutrition cannot be dissociated from those used to justify the discontinuation of life-support treatment.

After application of the selection criteria, 98 medical files were selected. All 98 files were ultimately analyzed.

Data Collection and Analysis

Given the absence of an available validated tool, a compilation grid was developed for the purposes of the study based on the existing literature and guidelines for patient with cancer and patient in palliative care [4,5,11,12] and with the help of an epidemiologist from CHR Metz-Thionville. This grid included all of the medical arguments extracted from the recommendations and was thereafter completed after being tested on a first series of ten medical files.

The data were extracted from the files of the mobile team as well as reports prepared by the mobile team for physicians requesting its intervention. The reports included the following information: names of the interveners, medical examination and summary report of the interview with the patient and his/her family, if applicable, as well as the team's conclusions and proposed therapeutic course.

The data were anonymized and processed in accordance with the ethical and legal regulations in effect in France.

The recommendations only propose the initiation of artificial nutrition when the patient has an estimated life expectancy of more than 3 months [5,11]. In the case of a life expectancy of less than 3 months, the benefits in terms of quality and quantity of life are estimated to be nil or insufficient to justify this cumbersome treatment. Differences between the medical files were hence made based on this threshold, with the starting point being the day on which the mobile team's advice was rendered.

The data were analyzed using the SAS® 9.3 software package. Qualitative variables were compared using exact Fischer tests while quantitative variables were compared using Student's t-tests when normality conditions were met, or with Wilcoxon's nonparametric tests in other instances. The threshold of significance was set at 5%.

Results

Studied Population

Table 1 presents the characteristics of the population included in the study. Of the 53 patients with cancer as primary diagnosis, 21(40%) were of digestive origin and 17(32%) of pulmonary origin. Of the 7 patients with organ failure as primary diagnosis, 3 had a cardiac impairment, 3 had a pulmonary impairment and one patient had a hepatic impairment. of the 23 patients with neurological impairment as primary diagnosis, 19 had a neurovascular disease, 3 had post-anoxic encephalopathy, and one patient had a neurodegenerative disease.

The discussion regarding artificial nutrition was initiated by the mobile team in 63% of cases, by the department in 15% of cases, the family in 1% of cases, while the initiator was not specified in 21% of cases.

Characteristics	N (%)
Age (years)	75.6* (SD=12.5)
Gender (female)	48 (49)
Available oral route	49 (50)
Available enteral route	13 (13.3)
Available parenteral route	91 (92.9)
Main Diagnosis	
Cancer	53 (54.1)
Organ failure	7 (7.1)
Dementia	6 (6.1)
Sepsis	8 (8.2)
AIDS	1 (1)
Neurological impairment	23 (23.5)

Comorbidities	
Dementia	11 (11.2)
Sepsis	9 (9.2)
Progressive cancer	9 (9.2)
Second progressive cancer	8 (8.2)
Organ failure	7 (7.1)
Occlusive syndrome	3 (3.1)
Suspicious lesion of an undocumented neoplasm	3 (3.1)
Stroke	3 (3.1)
Age	2 (2)
Uncontrolled epilepsy	2 (2)
Lymphoma	2 (2)
Hepatic encephalopathy	2 (2)
Carcinomatous Meningitis	2 (2)
Confusional syndrome	1 (1)
Advanced MS	1 (1)
Psychosis	1 (1)
Pulmonary embolism	1 (1)
Hemorrhagic shock	1 (1)
*Mean SD: Standard deviation	

Table 1: Characteristics of patients for whom withdrawal/withholding or continuation/introduction of artificial nutrition was discussed. (N=98).

Medical Arguments Put Forward in the Discussions Regarding Artificial Nutrition

The most frequently cited medical arguments were the preserved or altered nature of the patient's general condition in 67 cases (68.4%), the estimated life expectancy in 66 cases (67.3%) and the palliative nature of care in 54 cases (55.1%). The medical arguments cited in the advice of the mobile team are detailed in Table 2.

In 43 cases (43.9%), the discussion highlighted the presence of comorbidities. The latter are detailed in Table 1. The most common findings in the files were dementia, sepsis or a progressive cancer.

Assessment of nutritional status was utilized in 29 cases. In 69% of cases, this assessment was based on laboratory data: albumin assay in 18 cases (mean value 26.2 g/l, SD = 5.3) and pre-albumin assay in 4 cases (mean value 0.11 g/l, SD = 0.05).

Arguments	In favor of Withdrawal/ Withholding N (%)	In favor of Continuation/ Introduction N (%)
Overall patient assessment		
Altered general condition	62 (63.3)	0 (0)
Preserved general condition	0 (0)	5 (5.1)
Palliative nature of care management	54 (55.1)	0 (0)
Estimated life expectancy less than 3 months	54 (55.1)	0 (0)
Estimated life expectancy greater than 3 months	0 (0)	12 (12.2)
Presence of comorbidities	41 (41.8)	0 (0)
Nutritional status	29 (29.6)	0 (0)
Karnofsky Index <40%	8 (8.2)	0 (0)
Karnofsky Index > 40%	0 (0)	1 (1)
Performance status ≥3	2 (2)	0 (0)
Significant weight loss	4 (4.1)	0 (0)
Symptomatic evaluation of the patient		
Complications due to artificial nutrition	47 (48)	0 (0)
Symptoms related to undernutrition	8 (8.2)	1 (1)
Absence of hunger	2 (2)	0 (0)
Feeling of hunger	0 (0)	2 (2)
Sufficient oral intake	1 (1)	0 (0)
Insufficient oral intake	0 (0)	37 (37.8)
Factors limiting oral intake	0 (0)	36 (36.7)
Feeling of thirst	0 (0)	1 (1)
Evaluation of artificial nutrition		
Ineffective artificial nutrition	17 (17.3)	0 (0)
Complications related to technical access route	31 (31.6)	0 (0)
Specific ongoing oncological treatment	0 (0)	8 (8.2)
Complications related to oral nutrition	0 (0)	4 (4.1)
Impact of nutrition on the patient and his or her environment		
Alteration of quality of life	38 (38.8)	0 (0)
Wishes of the patient	6 (6.1)	4 (4.1)
Disruptions in social relationships due to excess medicalization	6 (6.1)	0 (0)
Wishes of loved ones	4 (4.1)	3 (3.1)

Insufficiency of the host/ housing structure	3 (3.1)	0 (0)
Wishes of the departmental staff	1 (1)	5 (5.1)
Impairment of body image by invasive techniques	1 (1)	0 (0)

Table 2: Medical arguments raised for withdrawal/withholding or continuation/introduction, found in discussions relative to artificial nutrition (N = 98).

In 36 cases, the factors limiting oral intake were used as medical arguments, the latter of which are detailed in Table 3. The most common findings in the discussions were swallowing disorders (19 cases), alertness disorders (7 cases), anorexia (5 cases) and nausea/vomiting (4 cases).

Factors	(N=36) n (%)
Swallowing disorders	19 (52.8)
Alertness disorders	7 (19.4)
Anorexia	5 (13.9)
Nausea/Vomiting	4 (11.1)
Asthenia	2 (5.6)
Xerostomia	2 (5.6)
Dyspnea	1 (2.8)
Hemoptysis	1 (2.8)
Mucositis	1 (2.8)
Patient refusing to eat	1 (2.8)
Gastric stenosis	1 (2.8)
Oral ulceration	1 (2.8)
Hemorrhagic ulcers	1 (2.8)
Food aversion	1 (2.8)

Table 3: Factors limiting oral intake found in discussions regarding withdrawal/withholding or continuation/introduction of artificial nutrition.

Five patients underwent a calorie intake count with an average of 400 kcal/d (SD = 800). Symptoms related to undernutrition, an argument used in 9 cases, were pressure sores in 5 cases and cachexia in 4 cases. Complications linked to oral nutrition, mentioned in 4 cases, were either inhalation pneumonitis (3 cases) or vomiting (1 case).

Complications induced by artificial nutrition, an argument reported in 47 cases, were bronchial congestion (32 cases), edema (22), inhalation pneumonia (3), as well as inhalation of nutritional fluid (without superinfection), cholestasis and phlebitis (1 case each). Technical complications, an argument stated in 31 cases, were the absence of perennial access (long term access as implantable ports) (27 cases), infection of the implantable catheter chamber (3) and Percutaneous Endoscopic Gastronomy (PEG) ablation due to an abscess (1).

Advice Rendered by the Mobile Team

Advice in favor of the decision to withdraw or withhold artificial nutrition was rendered in 83 cases (85%), and advice in favor of its introduction/continuation was rendered in 15 cases (15%) by the mobile team. In the 15 cases where advice in favor of continuation/introduction was rendered, nutrition by enteral administration was proposed in 7 cases and parentally in the remaining 8 cases. Figure 1 details the decisions made by the requesting services based on the opinion of the mobile team. In 12 instances, there was no mention of the decision taken by the requesting services in the medical records. Advice for withdrawal or withholding of artificial nutrition was followed in 75.9% of cases and advice for its continuation /introduction was followed in 93.3% of cases.

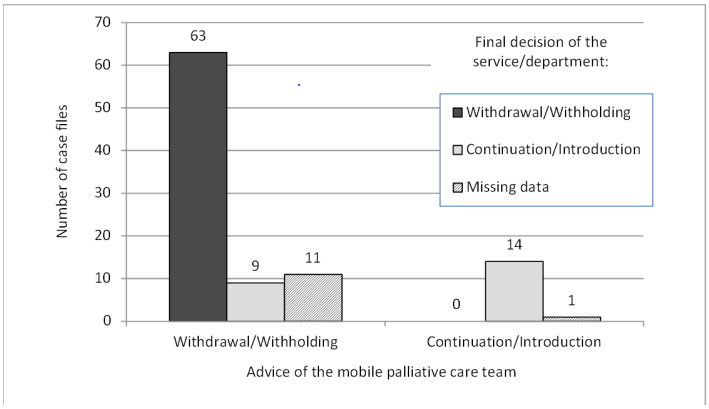

Figure 1 : Final decisions of the requesting service/departments based on the advice of the mobile palliative care team with regard to artificial nutrition (N=98).

Sixty-nine patients (70.4%) died within 3 months with an average life expectancy of 14.6 days (SD = 17.3) while three (3.1%) died after 3 months with an average life expectancy of 131.7 days (SD = 34.7). Twenty-six patients (26.5%) were lost to follow-up having left the establishment and it was not possible to obtain information regarding their outcome.

The mean life expectancy of the 83 patients for whom advice was rendered in favor of withdrawing or withholding artificial nutrition was 12.4 days (SD = 27) while that of the 15 patients for whom advice was given in favor of its continuation/introduction, the average life expectancy was 24.6 days (SD = 38.8), this difference being not statistically significant (p = 0.11).

No statistically significant relationship was found between the main diagnosis and the advice rendered (p= 0.46).

Adequacy of The Advice Rendered and The Medical Arguments

The medical arguments cited in the medical files were in line with the opinion rendered by the Mobile Palliative Care Team in over 80% of cases (i.e. medical arguments in favor of artificial nutrition were associated with advice of continuation/introduction and the medical arguments disfavoring were associated with advice for withdrawal or withholding), with the exception of «insufficient oral intake» arguments (adequacy in 27% of cases), «factors limiting oral intake» (28%), «wish of the requesting department/service to continue artificial nutrition» (40%), «wish of the patient to continue artificial nutrition» (50%) and «specific ongoing oncology treatment» (62%).

Discussion

Our Study Presents Several Biases

This is a retrospective study conducted from medical files which necessarily implies a loss of data compared with the initial situation. Conversely, performing the same study on a prospective basis would expose to another bias, since the medical staff would then be more attentive to the study, which would alter usual practices thus leading to a distortion of the results.

Some of the medical arguments, likely used in discussions regarding patients included in the study, were not taken into account because they were not entered in the mobile team's reports. It is well recognized that oral transmissions are often a source of error and approximation, and it is from this problem that arises the importance of written transmissions. As a result, the decision ultimately taken sometimes appears, erroneously, to be based on very few medical arguments. This bias was also highlighted in the study by Denoyel, et al. [13] revealing a lack of written record of such discussions in a certain number of files, underscoring the importance, in this type of decisions, to record the entirety of the medical arguments in the patients' files.

A similar study with larger population samples could perhaps reveal other statistical relationships not highlighted in the present study due to lack of statistical power resulting from the small size of certain subgroups.

Due to the absence of published reference standards on the average population of patients encountered by mobile teams in France, we are unable to draw comparisons with our study population. It is therefore possible that our data cannot be extrapolated to all mobile teams and their patients.

In our sample, patients rarely had an enteral administration route and frequently had a parenteral route. This can be explained by the fact that our patients were often provided with peripheral or central venous access lines, such as an implantable post, notably in cancer diseases, whereas the enteral route was most often used in the presence of obstacles in the digestive tract or in instances of swallowing disorders.

Cancer accounted for slightly over half of all major diagnoses, indicating that palliative care was not limited to oncology but also encompassed other specialties such as geriatrics and neurology [14,15].

The majority of discussions regarding the withdrawal of artificial nutrition were initiated by the mobile team, although in 5 cases, the mobile team considered the wishes of the staff of the requesting service as an argument in favor of the continuation/introduction of artificial nutrition. Several plausible explanations could be proposed. It is possible that the mobile team, having an outside view of the case, may feel that a situation is already highly advanced and that it has become necessary to discuss the relevance of artificial nutrition. Indeed, following patients on a daily basis can sometimes lead to lack of hindsight.

Artificial nutrition can also be considered to hold a particular symbolism in that it refers, in each of us, to values that are more fundamental than mere drug therapy [16-24]. Finally, certain caregivers regard artificial nutrition as basic care to be irrespectively given to the patient [2] which may impede them in their approach to this type of situation.

In most instances, the medical arguments put forward by the mobile team were in favor of withdrawing artificial nutrition. This can be explained by the palliative nature of patient care management in the sense that, in order to be considered as «palliative care» by the medical community, the patient must either have had a long medical history with failure of numerous specific treatments, or that the disease was discovered at an already very advanced stage, thereby precluding the proposal of a specific treatment due to the patient's altered general condition. In both instances, the course of the disease is often pejorative on the short or medium term and in which artificial nutrition loses all its relevance.

This hypothesis is furthermore supported by the medical arguments stated in the medical files. Indeed, patients often had an estimated life expectancy of less than 3 months along with a very poor general condition. This latter medical argument, which may appear at first glance as a simple subjective evaluation, is in fact a reflection of the assessment of the overall condition of a patient by trained and experienced physicians. It incorporates a number of medical arguments such as the Karnofsky Index or Performance Status (little used as standalone arguments), functional signs such as asthenia, the autonomy of the patient or even sarcopenia.

Comorbidities contributed to the increased frailty of our patients, greatly affecting their prognosis and quality of life, which in turn reduced the relevance of artificial nutrition. The presence of adverse effects linked to artificial nutrition, often associated with

overload-related phenomena, is a medical argument frequently invoked at a stage of the disease where the theoretical objective of protein-energy renutrition conflicts with the practical necessity to ensure the patient's overall comfort. These adverse effects reflect the fragility of the patients encountered by the mobile team, who are unable to withstand the large volumes that would need to be provided for artificial nutrition due to impaired cardiac or renal function.

The most commonly-used medical arguments in favor of the continuation/introduction of artificial nutrition were directly related to the physical condition of the patients. Inadequate oral intake was particularly common in patients followed by the Mobile Palliative Care Team and was accordingly in keeping with factors limiting oral intake. Many of our patients presented swallowing difficulties, alertness disorders, nausea or simply anorexia, symptoms which could be attributed to the treatments or course of the primary disease.

Although oral intake was often deemed insufficient, there were only a few cases where a calorie count was duly noted in the files.

Inadequate intakes, coupled with frequent hypercatabolism (cancer, infection, etc.), necessarily result in undernutrition, invoked in one third of the patients. Among these, over two-thirds underwent a biological assessment. It is possible that certain laboratory measurements were carried out but not entered in the file of the mobile team. Of note, the advice of the mobile team being only in an advisory capacity, there are cases where even if these measurements were in fact suggested, they were ultimately not performed. One can also raise the question of the relevance of these measurements, the kinetics of albumin being of greater interest than its actual numerical value. In the study by Dupire, et al. [24], there was a lower reliance on the biological assay of nutritional index markers (30%) than in the present study.

One may ponder as to the low emphasis of the patient's opinion in the discussion, although in many instances (90% of cases), it appeared that the patient did not express a strong opinion in one direction or another. After discussion with the referring physician on the benefits and risks of artificial nutrition, the patient often followed the medical advice. As showed in another study [25] patients lack knowledge concerning artificial nutrition mainly concerning benefits and risks. It seems important for physicians to assist the patients in such a difficult choice.

The lack of a statistically significant relationship between mean survival and the advice rendered can be explained by high number of missing data due to patients lost to follow-up or to a lack of power due to the low sample size of advice for the continuation/introduction of artificial nutrition. Notwithstanding the latter, survival time was twice as long in the group with advice for continuation/introduction than in the group with advice for withdrawal/withholding of artificial nutrition.

The decisions for withdrawing or withholding artificial nutrition were less followed than decisions for its continuation/introduction. This may signify that, despite medical arguments based on objective facts and published data, the symbolism of artificial nutrition which echoes that of food intake in the broader sense, leads the health care providers to not always follow the advice of the mobile team [8]. This finding is recurrent with mobile teams and does not only pertain to artificial nutrition. Indeed, it is not uncommon for members of the departmental staff requesting the advice of the mobile team to ultimately not apply the recommendations regarding, for example, artificial hydration or the implementation of treatment with a negative connotation, such as Midazolam.

Moreover, it has been shown that caregivers who are more frequently confronted with these situations tend to follow the advice of the mobile team, their confrontation with these questions contributing toward evolving their own representations on artificial nutrition [9].

One must also take into account that departmental staff must deal with families, whereas the mobile team does not always have the opportunity to meet the latter, although such meeting is systematically proposed. While the decision of the mobile team is based on medical principles, it is not always sufficient to have this decision accepted by the families whose representations come up against the medical decision. Frequently, they fear letting their loved ones « die of hunger » and that accepting the henceforth futile nature of this type of treatment, and thereby consenting to its discontinuation, amounts to accepting the prognosis and the patient's upcoming death. It is therefore particularly important to discuss with the patients and their relatives so as to involve them in the decision-making process, which will enable them to accept this decision with less difficulty [6,26-28]. As shown by Hwang, et al. [28] it's possible and necessary to discuss artificial nutrition to integrate it in a coherent personalized care project.

However, it should be reminded that artificial nutrition is a medical treatment and that its prescription or non-prescription ultimately remains a medical decision. While it is important to obtain the support of the family, and when necessary to take the time to discuss and «soften» the decision-making process, it should not be done at the expense of the patient, the referring physician having the right and the duty to impose on the family the decision for which he or she deems is best for the patient.

When comparing the current data with those of the literature, we note that the arguments put forward in the present study overlap those used in the guidelines on artificial nutrition [10], the Standards, Options and Recommendations [4], as well as those of

the French Society of Clinical Nutrition and Metabolism [5]. The most recent guidelines of the ESPEN guidelines on nutrition in cancer patients confirmed our results [30]. Despite the existence of several recommendations regarding the conduct of artificial nutrition, there is no simple decision tree that one can follow, the guidelines rather describing the entire spectrum of arguments that can be used during the discussions. The decisional process amounts to considering the patient as a whole with all its inherent complexity, including at the organic, psychological, ethical, sociological and spiritual levels. It is indeed the evaluation process performed within the mobile team although the entirety of these medical arguments is not necessarily found in each file. Only those that are deemed/appear relevant in light of the situation are ultimately selected and used in the discussion. This represents the main problem of the decision to withdraw or withhold artificial nutrition. Each patient is unique and it would thus seem essential that the discussion be collegial by involving, among others, competent personnel in the field that is accustomed to this type of discussion [26]. Accordingly, in the study by Denoyel, et al., the discussion regarding artificial nutrition was also described as a process unique to each patient requiring an overall assessment well beyond its organic aspect.

Conclusion

The decision to withdraw/withhold or to continue/introduce artificial nutrition is based on a set of arguments and on a multidisciplinary assessment associated with a discussion encompassing an ethical dimension involving the patient and his/her relatives. Among these arguments, some are more prominent such as impairment in general condition, an estimated life expectancy of less than 3 months, the presence of comorbidities or the alteration of the quality of life by artificial nutrition. The present findings reveal that the advice of the mobile team for the continuation/introduction of artificial nutrition is considerably more followed by the requesting departments than the advice for its withdrawal or non-introduction. It would therefore appear of interest to pursue the dissemination of this approach to medical and paramedical caregivers such that they can better appropriate the reasoning and arguments underlying the discussion regarding artificial nutrition. This dissemination requires an integration of palliative care in the medical and paramedical studies and a formation for the caregivers, which is the case with the new national plan for palliative care development [31]. It should also be necessary to improve partnership and discussion between the mobile palliative care team and the departments' staff. An inclusion of the mobile palliative care team in the collegial discussion could be a way to discuss directly withdraw or withhold of artificial nutrition with the caregivers and perhaps upgrade the rate of advices followed. To conclude we can say that the key point here is the communication: between caregivers, between caregivers and the patient and between caregivers and the patient's family. This particular point is a recurrent problem in Medicine and more in Palliative Medicine. We, as caregivers, need to improve in this field.

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