ETHICS AND SEDATION AT THE CLOSE OF LIFE

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SUMMARY

1. PRESENTATION

David Callahan[1] tells us that one of the two main objectives for 21st century medicine is to help people to die in peace. Sedation is generally considered one of the existing means - albeit extraordinary and, in many instances, a source of anxieties, but still a means - of securing this objective.

Recently, both the Sociedad Española de Cuidados Paliativos[2] and the Colegio de Médicos de Barcelona[3] have drawn up a number of guidelines on the practice of sedation intended for the clinicians that have to deal with stubborn symptoms in patients close to death. However, as Couceiro[4] points out, in one in three patients in an end-of-life situation, it is possible to predict whether they will be sedated or not on the basis of which hospital is caring for them. Is such fluctuation admissible?

Furthermore, in a recent study carried out with 151 consecutively dying patients attended by 23 palliative care teams in Catalonia, with a psychologist in them, almost a third of the calls on this expert's time were desperate or last-ditch efforts by the team. Why, one might ask, were the patients not screened in good time for their risk level and resources, so that the gelling of emotional situations difficult not to say impossible to control could be foreseen at least in part?

Our intention, in structuring this seminar, was to advance, if only a little, in our knowledge and good practice of sedation, to ease the work of the clinicians. Thanks to support from the Víctor Grífols i Lucas Foundation we have been able to bring together a good number of professionals who represent, taken together, a pool of experience and multidisciplinary perspectives from many different fields: experts in palliative care, oncologists, internists, surgeons, health administrators, journalists, psychiatrists, psychologists, nurses, legal and bioethical experts. Apart from the personal enrichment that this seminar will have supposed for each of those who attended, readers will be able to judge for themselves the magnitude of the problems and the unknowns which have yet to be resolved, from the contributions made, and included in the present volume.

The seminar was structured in the following way:

a) First of all, two speakers of recognised prestige and experience in the field of sedation, Josep Porta and Azucena Couceiro, had 45 minutes each for their presentations.

b) After the break, there followed an open-ended debate, moderated by Ramon Bayés and lasting three hours and a half, on questions arising out of the two talks. It should be pointed out that the 22 invited participants were given transcripts of the two talks that make up the core of this publication several weeks in advance.

c) After the seminar had been completed, those taking part were asked to send the Foundation a maximum of 5 pages of comments, facts or opinions on the subjects covered, plus indication of the aspects, if any, that proved particularly interesting. They were asked to do so within a maximum time limit of two weeks.

The contributions made in this way have been included in the present publication.

RAMON BAYÉS

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2. FIRST PAPER

CLINICAL ASPECTS OF SEDATION IN PALLIATIVE CARE

Josep Porta

Introduction

Ever since the article by Enck was published in 1911, when the term Terminal Sedation was coined many studies have been written on clinical aspects of sedation in Palliative Care. In the last decade a substantial debate has arisen concerning the need for Terminal Sedation. There are those who think that, as a procedure, such sedation is seldom necessary in Palliative Care and when it is, that it should be given solely for physical reasons[2]. And, on the other hand, other writers postulate that Terminal Sedation is a relatively frequent practice that can be considered not only for physical reasons, but also for emotional distress[3,4,5]. Possibly, both stances may be seen to be right at least in part, where it is possible to accept the premises of their reasoning.

In this presentation we set out to summarise the clinical information available in the literature on the use of sedation in Palliative Care. Inevitably, however, in the part referring to practical aspects, what will be presented will be common practice and the particular experience of the writer; these latter in any case in accordance with the published recommendations of the Sociedad Española de Cuidados Paliativos[6].

When referring to sedation, it may be difficult to draw a clear dividing line between clinical aspects and those having to do with correct application. When talking about good or correct practice, an ethical connotation is always present. This is all the more so in the administration of sedation to those near death. For that reason, while this text sets out to deal exclusively with clinical aspects, questions of a clearly ethical nature will naturally arise.

1. Basic Aspects

The *Diccionario de la Real Academia Española de la Lengua* defines the verb to sedate as "pacify, ease, calm". The *Diccionario Enciclopédico de Medicina* defines sedatives as "substances which lessen the sensation of pain, or more exactly, the arousal of the central nervous system. The sedative action of such medication is related to its analgesic, tranquillising or hypnotic properties, and the type of action effected will depend on the dose administered". This means that the tranquillising or hypnotic effect obtained from the administration of a sedative, for the same patient, will depend on the dose given. But the response obtained for the same dose will vary depending on the patient in question, so that doses have to be individualised to achieve the desired effect. There are many medical drugs that are able to affect the functioning of the brain, but not all can be classed as sedatives. In fact, Martindale's Extra-Pharmacopoeia classifies only the following substances as sedatives: alcohol, antihistamines, general anaesthetics (propofol, ketamine and barbiturates), neuroleptics, benzodiazepines, scopolamine and the opioid analgesics.

The use of sedation as a therapeutic procedure is certainly not new in medicine; in fact, sedation has for long been used as a measure to prevent obvious and predictable pain. For that reason, sedation is employed routinely in distressing or painful procedures. Thus, in Intensive Care, sedation is used to minimise agitation, promote synchrony with the respirator and help alleviate anxiety related to the surroundings, often seen as hostile by the patient[7]. In psychiatry it is not deemed poor practice to sedate a patient who is extremely agitated or having panic attacks. In medicine, in general, and in Palliative Care in particular, sedation may be used to lessen both physical pain and emotional distress. Not to provide a patient with adequate sedation when undergoing a painful or distressing procedure could be considered malpractice. Furthermore, it is widely known and accepted that sedation in a seriously ill patient in for example an Intensive Care unit[8,9], could induce certain risks, even death. No one would accept that the decease of an extremely ill patient in an Intensive Care unit, after being administered a sedative, could be construed as homicide – on the contrary this would be considered a secondary effect, or if you will, a potentially foreseeable and calculated risk.

The administration of a sedative does not necessarily mean the permanent suppression of consciousness. Even in Intensive Care, the habitual aim of the sedation is to adjust its level by means of controlled administration of sedatives, in accordance with the objectives set for each patient, permitting relaxation and ease of rousing[7].

Part of the controversy that arises in discussions on sedation in the context of Palliative Care seems to stem from the fact that not all writers mean the same when they talk or write about sedation, both from the conceptual and procedural points of view. Given this disparity, I shall, with a view to making the topic easier to understand, avail myself of descriptions of clinical situations, and then go on to look at conceptual aspects. All clinical situations mentioned below should be seen in the context of patients with advanced and terminal illness.

2. Clinical situations

A typical situation could be one in which a patient is confronted with a painful procedure (e.g. manual removal of a phaecaloma or the tending of a painful ulcer). In this situation, the habitual procedure is the administration of benzodiazepine (by any route) with the objective of guaranteeing minimum discomfort during the carrying out of the painful or distressing procedure. It is considered good praxis to explain to the patient and his or her family the purpose of the medical procedure and the reasons for administering a transitory sedative. Where patients are autonomous it is considered essential to obtain their consent, or alternatively, and where not, the consent of the patient's family, but consent from one source or another is usually necessary. Patient's consciousness will diminish as the need to ease the discomfort becomes greater, reaching a point where level of consciousness is zero. The details of the sedation should be noted down in the clinical records to ensure correct decisions, as well as the appropriate completion of procedures and recording of results obtained. The kind of sedation referred to above is termed Transitory Sedation. This does not in fact differ from sedation that may be used in other specialities, and thus does not necessarily need to be designated by a separate term.

Another situation would be where a patient persists in presenting a distressing symptom, such as dyspnoea or anxiety. When distress continues for more than a reasonable period, even after trying all available treatments, the medical team will begin to accept the intractability of the symptom and prescribe sedation. The objective in such instances is the reduction of mental distress arising from perception of the threat. In the examples given, dyspnoea may lead to a perception of suffocation leading to death, and anxiety arise from loss of control in the situation the patient is undergoing. While the circumstances may be very emotive, the team should be capable of explaining to the patient and their family in a comprehensible, reasonable and sensitive way, the need for the change in strategy, and obtain consent. Where the patient is not autonomous, obtaining of the family's consent is highly recommended. Where patients do not have a family, or the latter feels incapable of taking such decisions, the team should proceed in the best interests of the patient to secure his or her well-being. It should be remembered that decisions have to be made, and final responsibility rests with the medical team[10]. Obviously enough, as with other procedures carried out in medical practice, processes of decision taking have to be noted in the clinical records, along with details of the medication administered and the result of the sedation (anxiety level and level of consciousness). The dose, route and rate of administration of the sedatives can vary with the clinical needs of the patient, so that some patients require sedation on particular occasions or only at specific times of the night or day, while others require continuous administration. As is already usual practice in Palliative Care, liquids and solid foods should be offered to the patient in a form in accord with their ability to ingest them and their wishes. Even though patients may not be on the threshold of death, their medical condition is usually extremely fragile and serious. Thus, their general condition usually deteriorates after several days or weeks, either as a result of the progression of their illness or of their metabolic situation (e.g. hypoxemia, fluid and electrolyte disorders, kidney or liver failure). This will generally mean that patients appear more and more lethargic and drowsy until death takes place. This type of sedation we call Palliative Sedation.

Patients with acute problems, or ones that are unexpected or life-threatening, are usually sedated rapidly. Such situations are considered paradigmatic, but in fact are not so frequent as generally thought. Thus, for example, sedation as a result of massive haemorrhage of whatever origin represents less than 10% of cases of sedation[5,11,12]. Clinical experience teaches us that when acute or profuse bleeding, or any similarly cataclysmic situation occurs (e.g. massive pulmonary thromboembolism), the patient often dies before sedation can be attempted. In acute situations such as these, clinicians are obliged to see to the comfort of their patients; this overrides the need to obtain permission, which will be virtually impossible to obtain. More clearly subacute situations will normally allow controlled sedation with consent, in the way described above, and despite the fact that death may be soon in occurring. In such cases, where patients cannot communicate their desires or have not done so previously, consent is frequently given by the family, always bearing in mind the medical team’s responsibility.

Lastly, another situation is where the patient is close to death, undergoing what is commonly known as death throes. It is very common at these times for any member whatever of the team, the family, or the patients themselves to see that death is imminent, certain and inevitable - and this happens more often than is generally supposed. What frequently happens is that patients facing the last days or hours of their lives are not cognitively functional, have pain, difficulty in breathing, or agitated delirium. In such circumstances, the time frame for the taking of decisions is so reduced that symptoms can be considered to have become refractory (intractable), since there is not time enough to attempt any treatment other than (superficial or deep) sedation; in such cases it is recommendable to involve the family in decision taking and obtain their consent. The clinical situation of the last days means that some patients have cognitive problems, or problems of communication. Yet the Palliative Care team should seek to discuss with patient and family aspects related to the patient's wishes and values, not only to guide them to possible sedation, but to be able better to attend to them over the course of the illness. Not unexpectedly, patients in this situation die in a matter of a few days or hours.

Sedation given during the period of dying is known as End-of-life Palliative Sedation, or simply End-of-life Sedation. In a broad sense Palliative Sedation is to be understood as sedation used for palliative reasons and End-of-life Sedation is that applied in patients close to death. In our opinion, and others'[14] the term "Terminal Sedation" is confusing, in that it can be interpreted as referring to sedation which ends the patient's life, so that it is better to use End of Life Palliative Sedation, or simply End of Life Sedation, since these are more descriptive terms.

At this point, it is crucial to bear in mind that the clinical objective of sedation is to obtain a mental state of calm, a certain indifference toward a distressing situation, and not the issue of the life or death of the patient, and that the result of the sedation can be measured using one of the sedation scales. A secondary effect of the sedation is the patients' loss of capacity to communicate, but not their death. This applies all the more in the case of highly fragile patients with illnesses at an advanced or terminal stage, where death is not a distant if approaching event. Instead it is a situation that can arrive at any time, influenced by multiple factors, and rarely under the team's control. It should be remembered, also, that any action or medical procedure can be wrongly used, either through malice or ignorance, or simply be abused (e.g. Caesarean section) but that does not mean that sedation should be accorded special consideration or status beyond that which we wish to confer on it.

3. Clinical aspects

As we mentioned earlier, sedation is a variable concept[15,16]. Three levels of classification for sedation can be established: depending on the objective, the time scale, and the intensity.

With respect to the objective, sedation is considered primary when the desired effect is reduction of level of consciousness, e.g. administration of benzodiazepine to relax an anxious or agitated patient. Sedation is considered secondary when the lowering of level of consciousness is a secondary effect of the medication, e.g. somnolence after the administration of antihistamine. Terms arguably more appropriate for designating secondary sedation would be somnolence, drowsiness, sleepiness, but not sedation. In the clinical context the term sedation is restricted, by definition, to lowering of level of alertness sought as the therapeutic effect of medication.

From the point of view of the time frame, sedation can be intermittent or discontinuous or can involve periods of alertness while the level of consciousness is maintained constantly low. Lastly, with respect to intensity, sedation can be superficial when the patient's state allows some kind of communication, verbal or otherwise, and deep when the patient is unconscious and cannot interact with their surroundings.

As a therapeutic procedure, sedation in Palliative Care has its indications and methods of application. In general there is no great controversy with regard to Transitory Sedation as described above. Ethical problems arise with Palliative Sedation, particularly when used in the death throes stage. Ethical "doubts" typically appear when an uninformed observer sees a nurse enter a dying patient's room, give him or her an injection, and possibly a few hours or days later the patient dies. Under such circumstances it is quite likely that the observer will think: euthanasia[17]. No one outside the medical team can know the reason for the injection, to alleviate suffering or to terminate the patient's life. For that reason, it is absolutely essential that the entire decision-taking process should be shared by the team as a whole and recorded in the patient’s clinical history. Noting down the process of decision-taking regarding sedation is not just a matter of ethics, but a clinical matter also.

Following the above reasoning, the prescription of Palliative Sedation is conditioned by certain clinical considerations for its correct use: a) the existence of intractable or refractory symptoms, b) the aim of reducing distress or suffering, c) the reduction in level of consciousness proportionate to the need to alleviate distress or suffering, d) obtained consent, and in the case of End-of-life Sedation, e) life expectation should be a matter of a few days or hours. All the previous points should be borne in mind and recorded in detail in the patient’s clinical records.

The concept of refractory (intractable) symptom was defined by Cherny and Portenoy[18] in the following terms: “the term refractory should be applied when a symptom cannot be adequately controlled despite aggressive efforts to identify a tolerable treatment which will not compromise the patient’s consciousness”. For this definition to be operative, “aggressive efforts" need to be placed in a time frame. Otherwise, keeping a patient in a situation of distress for longer than a “reasonable period of time” in an attempt to come up with a form of alleviation, is not easily justifiable. The “reasonable period of time” depends on the clinical situation and the patient; for example, in the case of dyspnoea or agitated delirium in a patient in the throes of death, “reasonable period time” may be just a few minutes; in a patient not so close to death, however, a “reasonable period of time” could be hours or days. It is difficult to advise on when more than a reasonable period of time has elapsed, but in this complex clinical context the best clinical judgement should be drawn upon, as well as the patient’s opinion in instances where this is possible. A distinction should be sought and made between refractory symptoms and difficult symptoms, since there are symptoms that may appear to be refractory but which become difficult ones in the hands of an experienced team, and can respond to treatments that do not compromise the patient’s level of consciousness[19].

As we mentioned earlier, the objective of sedation is to diminish the degree of distress generated by the symptom, and to do so by decreasing arousal of the Central Nervous System. Strictly speaking, sedation does not set out to modify the underlying cause of the symptom but to mitigate or palliate the distress produced by the symptom. In other words, sedation is a clearly palliative measure, rather than an etiological one. This concept validates the use of the term Palliative Sedation.

With the objective of guaranteeing alleviation of the distress produced by a symptom in particular instances *without* diminishing consciousness more than necessary, clinicians should monitor response to sedatives. As happens with much medical treatment, the right dose is the minimum which will obtain the desired pharmacological result. In Palliative Sedation the relevant parameters to evaluate and monitor are anxiety, agitation and the level of consciousness.

There are many scales that can be used in Intensive Care, but for simplicity of use and reliability the Ramsey scale can be considered one of the most useful[7,20] (see table 1).

Table 1. Ramsay Scale[21]

Level	
1	Agitated, anxious
2	Calm, co-operative
3	Wakes suddenly with verbal stimulus or glabelar percussion
4	Sluggish response to glabelar stimulus
5	Response to painful stimuli
6	No response

It is important to note, with respect to consent, that this should not be taken to mean consent communicated in writing. In the Palliative Care context this would not only be difficult to obtain, it would be insensitive, inopportune, and even harmful. Verbal consent should be considered enough, but it certainly is essential to have this consent recorded in the patient's clinical record[22]. In a published study[5], 50% of patients were able to participate in the decision-taking process, despite the fact that the average period of survival of the sample was 2.5 days. The clinical reality of such situations makes it quite impractical to wait for all patients to give their consent, but that does not mean that no patients will be able to give their consent. When a patient's consent is impossible to obtain, the consent of the family should be obtained[23] and this should be based on knowledge of the patient's values. Consent is considered valid[24] if after receiving honest information on the current clinical context of the patient, the latter is capable of understanding its relevance and consequences (that is, reduction in degree of consciousness). The team should respect the patient's refusal of sedation, and accept delegated consent or tacit consent. If the patient is not competent, the family should take the decision in his or her place (surrogate judgement).

It is nothing less than essential to remember that sedation is a medical procedure proposed by the team as the result of careful clinical deliberation. If it is the patient who requests sedation, this will generally indicate there is great distress. The request should therefore be listened to attentively, sensitively and professionally, regardless of whether sedation is afterwards indicated. Sedation of a patient ought never to be considered as a response to the family's distress; on the contrary administering of a sedative should indicate the need for greater attention on the family's part.

Despite the fact that many patients will never need a sedative at the end of their lives, any Palliative Care team should be capable of exploring beforehand the values and desires of the patients. Better knowledge and comprehension of these aspects will give us greater opportunities to look after patients in accordance with their wishes, instead of leaving this knowledge for hypothetical use in future sedation.

As regards prognosis of survival, in Intensive Care there are different models, but when we find ourselves dealing with the very end of a patient's life, the clinical impression is still useful. Clinical studies show that there is a tendency to overestimate[28,29], so that the risk of thinking that patients are going to live less time than they finally do (underestimating) is very low. A relevant observation here is that almost all patients are unconscious when they pass over, but that does not mean that all are sedated.

4. Definitions

A number of definitions are given in the literature. Fondras[30] defines sedation in Palliative Care as "the administering of psychotropic agents, in most cases benzodiazepines and neuroleptics, with the objective of controlling physical symptoms (insomnia, anxiety attacks, agitation) or to bring about unconsciousness in a patient in certain dramatic situations (e.g. sudden haemorrhage). It can be used to put a patient under where that person requests it, but also without their knowledge". This definition describes some of the circumstances in which the level of consciousness could be reduced in Palliative Care. Despite the fact that the use of psychotropic drugs is mentioned for the alleviation of physical symptoms, the examples given by the writer lead us to think that he is also considering emotional or psychological stress as a reason for sedation. The definition does not make it clear whether the patient's unawareness is due to the clinical situation or is to be considered part of normal practice.

Chater *et al.*[31] proposed another definition for "Terminal Sedation": "Terminal Sedation is defined as the intention to induce deliberately and maintain a state of deep sleep, but without deliberately causing death, in particular circumstances: a) for the alleviation of one or more intractable symptoms when other possible treatments have failed, and the patient is perceived to be close to death, or b) for the alleviating of deep (possibly spiritual) anxiety which is not manageable with psychological, spiritual or other types of intervention, and the patient is perceived to be close to death". The authors make it clear that this is not applicable to patients with delirium or to transitory sedation.

Within this definition, Chater also considers physical and emotional reasons as motives for administering sedation, although sedation is only considered in its deep, prolonged form and other possibilities are not mentioned. Sedation is also excluded as a means of control in the management of delirium, which in any case is the most frequent cause for its administration.

Based on the study by Chater *et al.*[31] a multi-centre (multi-hospital) clinical study was performed[5] and a consensus meeting with respect to "Terminal Sedation", proposed a new definition[32]: "The term Terminal Sedation is understood to mean the deliberate administration of drugs to produce a sufficiently deep and predictably irreversible reduction of consciousness in a patient whose death is seen to be fast approaching, with the intention of alleviating physical and /or psychological suffering not attainable with other methods, and with the explicit, implicit or delegated consent of the patient." Comparing this definition with the one in Chater *et al.*[31], it is stated that sedation is not just the intention but actually the administration of sedatives. In fact the word "deliberate" includes and encapsulates various meanings: a) to do something intentionally, b) having weighted the pros and cons of the decision carefully, c) having discussed the options with others, that is, having shared the decision. The reasons for the rest of the definition have already been touched upon.

Recently, Broeckaert[33] put forward the following definition for Palliative Care. "The intentional administration of sedatives in the doses and combinations required to reduce consciousness in a terminal patient to the extent necessary to alleviate adequately one or more refractory symptoms". This is a very worthwhile definition because it recognises the need for proportionality in the reduction of consciousness level.

The Sociedad Española de Cuidados Paliativos (SECPAL)[6] recently adopted and put forward the following operative definitions: Palliative Sedation: “By palliative sedation we mean the deliberate administration of drugs in the doses and combinations required, to reduce consciousness in a patient with advanced or terminal disease, both where necessary to alleviate sufficiently one or more refractory symptoms with their explicit, implicit or delegated consent" and Terminal Sedation: "By terminal sedation we mean deliberate administration of drugs to achieve alleviation, not attainable by other means, from physical and/or psychological suffering, through sufficiently deep and irreversible diminishing of consciousness in a patient whose death is seen to be very close, and with explicit, implicit or delegated consent". It is mentioned in the original text that terminal sedation is the palliative sedation used in the death throes or end-of-life stage.

5. Clinical studies

In a recent review[34] all studies mention "Terminal Sedation" and none provides information on Palliative Sedation in other circumstances. All the information given below refers to Terminal or End-of-Life Sedation.

5.1. Frequency of use

Frequency mentioned in the literature represents a very wide range indeed, ranging from 1% to 72%, with an average frequency of 25%. Analysis of the literature shows that the reported frequency may be influenced by the research design of the study in question (see table 2). Frequency reported almost triples when sedation is tailored to the needs of the patient, as defined by the SECPAL. When the practice of sedation is more in accord with the definition in Chater *et al.*[31], in other words inducing and maintaining a drug-induced coma until death occurs, the frequency falls below 15%. In Spain frequencies as low as 6% have been reported, if sedation is only understood as such when it is deep and continuous[20].

Recently, an interesting international multi-centre (multi-hospital) study was published[35], in which four units took part, two in South Africa (Durban and Cape Town), one in Israel and one in Spain (Madrid); the study analysed sedation in the last week of life. The reported frequency was 15% (Israel), Duran (29%), Cape Town (36%) and Madrid (22%). Carefully examining the results in the original (see figure 1) it can be observed that while figures may appear superficially similar, the Madrid patients are less somnolent and more alert than their counterparts in the other centres. As one might expect, the majority of the patients pass the last two days of life unconscious. This study illustrates, rather well, the difficulties there are in accepting that the low sedation figures are good and the high figures are bad, as some writers have chosen to insinuate. Thus, frequency in End-of-Life Sedation should be analysed with due caution, taking into account the procedures used.

Table 2. Factors influencing reported frequency of End-of-life Sedation.

Factors	%
Research design	
– **Prospective**	**37,2**
– **Retrospective**	**21,1**
Place	
– **Home**	**29,7**
– **Hospital**	**28,1**
Type of sedation	
– **Proportional**	**38,2**
– **Sudden**	**14,5**
Reasons for sedation	
– **Solely physical**	**27,5**
– **Physical and psychological**	**25,0**

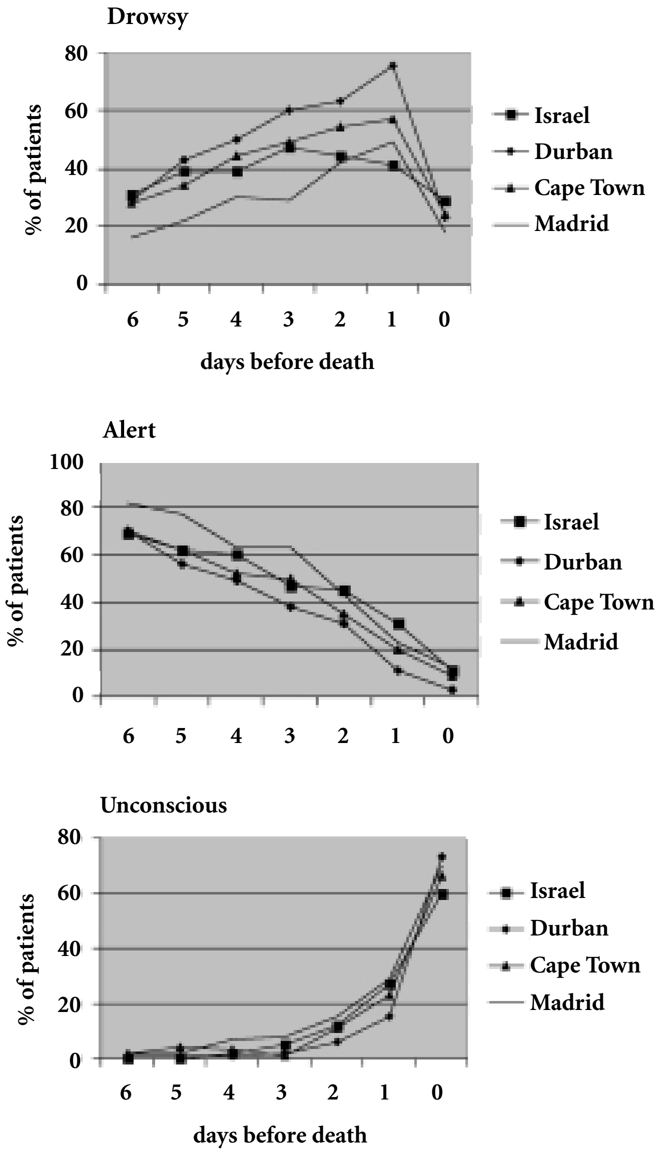
5.2. Causes, drugs and results

In most studies the three main reasons for sedation are delirium, dyspnoea and pain. A summary of the causes frequently communicated in the literature is shown in table 3. If the hospitals are beginning to recognise delirium as one of the main causes for End-of-life Sedation, we should recognise that the definition given by Chater *et al.*[31] needs to be modified or adapted.

The frequency with which symptoms present varies depending on the research design[34]. In prospective studies dyspnoea is a greater factor than in the retrospective studies (40% compared with 26%), while in the case of delirium the opposite is found (prospective studies indicate 22%, retrospective studies 50%). This radical variation in figures in clinical studies gives an all too fuzzy picture of the reality, so that it is vital to have a prospective study that provides an operative decision before the fact, both for general Palliative Sedation, and End-of-Life Sedation.

From the pharmacological point of view, the most frequently used sedatives are Midazolam, Haloperidol and Morphine (see table 4). It appears that physicians in Asia prefer Haloperidol over Midazolam, the latter being the preferred drug in Europe and America. That is very interesting, owing especially to the fact that the drug action that the two substances have is very different. Haloperidol has a powerful antipsychotic effect and yet is not very

Figure 1. Percentage of patients who are drowsy, alert or unconscious during last week of life.



sedative, while Midazolam is a benzodiazepine which lacks any known antipsychotic effect, but on the other hand is powerfully sedative. The fact that morphine appears as one of the most used drugs is due to the fact that it is prescribed for pain, but is an admittedly poor sedative, as some of the authors of the studies themselves recognise[36]. In the majority of the studies that give information on the results of End-of-Life Sedation, this drug was considered successful in more than 80% of cases[5,23,35].

6. Clinical practice

The choice of drug depends essentially on the reason for which the sedative is indicated. Thus, in patients suffering from delirium, after administration of Haloperidol, the next drug to be used would be Levomepromazine and not Midazolam, owing to the fact that delirium tends to worsen with benzodiazepines[37]. In other indications, the medication of choice continues to be Midazolam. In patients that have not been treated previously with benzodiazepines the initial anxiolytic dose recommended for Midazolam is 0.4-0.8 mg/h in Continuous Subcutaneous Infusion (CSCI)[38,39]. Generally an induction dose of 5 to 10 mg/SC[40,41] is recommended, with the possibility of extra or rescue doses of 5 to 10 mg/SC. Calculation of the daily dose needed depends on the total dose that had proved necessary in the previous 24 hours. If Midazolam is given in the form of continuous infusion SC or IV, bolus effects can be avoided and the physician retains greater control of the sedation. The rate of the infusion can be modified as needed in accordance with clinical needs. It is considered that doses of between 160-200 mg/day of Midazolam are capable of saturating the Gabaergic system producing paradoxical agitation[19]. In this case the addition of another sedative or changing to another sedative is recommended. When rapid, deep sedation is indicated, 5 mg of Midazolam IV may be administered as an induction dose, followed by an infusion of Midazolam 10 mg in 100 cc of saline, until the patient is deeply sedated (in all instances under direct medical supervision), the latter being generally achieved in 3 minutes[20].

Some authors[19] consider Levomepromazine the next-step alternative when Midazolam fails. It is recommendable to reduce the Midazolam dose by a half when beginning the neuroleptic stage. This is to avoid a withdrawal syndrome which would worsen the situation or cause agitation. An initial dose of Levomepromazine of the order of 25 mg/SC every six hours or CSCI of 100 mg/day is frequently well tolerated. Rescue doses will therefore be 12.5-25 mg with calculation of the total daily dose based on the rescue doses needed. The maximum dose is considered to be 300 mg per day.

Barbiturates like Phenobarbital or Thiopental can be considered if sedation with benzodiazepines or neuroleptics fails. Phenobarbital is a long-life barbiturate with an elimination half-life of 2-5 days. It should not be combined with other drugs and when its use is considered, the recommended induction dose is 100 mg IM[19,42]. The initial infusion dose of 25 to 60 mg, CSCI or 2-3 mg/kg/IV, with subsequent increases of 100 mg/SC as needed, are usually sufficient to alleviate distress in most patients. Doses in excess of 1600 mg/day are not usual.

Thiopental is a barbiturate with action over a very short period. It should only be used intravenously, and must not be mixed with other drugs. The usual induction dose is 50 to 100 mg/IV, with maintenance dose by infusion of 5 to 7 mg/kg/day. Larger doses usually need mechanical ventilation.

Propofol, finally, is a very attractive drug since it acts rapidly and produces very manageable sedation, and after infusion is halted, the patient rapidly regains alertness. It should be administered always and only intravenously. The recommended induction dose is 0.5 to 1 mg/Kg. Initial maintenance dose is 1 mg/Kg/h, with rescue doses at 50% of the dose required for induction. In my opinion, this drug is preferable to the barbiturates, given its safety and versatility, when the patient has an intravenous line already set up and is in a hospital environment[43].

Table 3. - Reasons for sedation (%)

Reason/Study	Ventafridda 1990	Fainsinger 1991	Morita 1996	Stone 1997	Ojeda 1997	Faisinger 1998	Morita 1999	Porta 1999	Faisinger 2000	Chiu 2001	**Media**
Dyspnoea	52	–	49	20	74	9	41	23	27	23	**35**
Pain	49	6	39	20	6	–	13	23	7	10	**19**
Delirium	17	26	23	60	37	91	42	21	62	57	**44**
Nausea/Vomiting	8	–	10	–	3	–	2	6	9		**6**
Haemorrhage	–	–	–	–	8	–	–	9	3		**7**
General deterioration	–	–	38	–	–	–	–	2	–		**20**
Psychological distress	–	–	–	26	–	–	2	36	11		**19**

Table 4. - Drugs and forms of drug-delivery in End-of-Life sedation. % (mean-mg/day)

Drug / Study	Turner 1996	Morita 1996	Stone 1997	Fainsinger 1998	Porta 1999	Morita 1999	Fainsinger 2000	Chiu 2001
Midazolam	88(25)	55	80(22)	61(29)	79(38)	31(7)	75(26)	24
Haloperidol	–	33	37(5)	–	25(14)	31(3)	19	50
Levomepromazine	–	–	33(64)	–	5(197)	–	5	–
Morphine	80(66)	55	–	100(79)	64(74)	37(5)	–	12
Hyoscine	–	13	–	–	9(3)	10	–	–
Via	**sc**	**sc**	**–**	**–**	**sc**	**sc/ev**	**–**	**vo/sc**

7. Conclusiones

Sedation in Palliative Care can be used in different scenarios. One is transitory sedation, which is practised to alleviate brief distress, for a limited time. This type of sedation is indistinguishable from that practised by other medical specialities. Palliative Sedation is a therapeutic manoeuvre prescribed by the team attending the patient, after all possible measures to alleviate at least some of the symptoms or clinical situations have failed. The ultimate aim of Palliative Sedation is to relieve mental distress generated by the symptoms. When Palliative Sedation is considered or indicated the patient does not have to be close to death, but the clinical context habitually associated with such sedation is advanced or terminal disease. When Palliative Sedation is prescribed in the clinical situation of imminent death, that is, in the throes of death (formerly termed Terminal Sedation) the general clinical procedure and the associated ethical considerations are the same as in Palliative Sedation when patients are not in their death throes. However, the differences between the two clinical scenarios should be clearly recognised. In order to distinguish them we propose to use the term Palliative Sedation to refer to the general procedure and End-of-Life Sedation to denote sedation where the patient in question is in the last days of life. It is important to remember that sedation is a therapeutic manoeuvre prescribed by clinicians and that the sedation that is sometimes requested by the families or patients may involve other considerations. It is also relevant to point out that despite the fact that most patients die when they are unconscious, this does not mean that all have been sedated.

The requisites for good practice in Palliative Sedation include: a) the existence of one or more refractory symptoms, b) with the objective of lessening distress, c) proportionately lowering the level of consciousness, c) with consent. And, when End-of-Life Sedation is considered, d) life expectancy of merely days or hours. The process of decision-taking and monitoring of the sedation should be recorded in the patient's clinical record. Misuse of Palliative Sedation, either through ignorance or malice does not justify glib comparisons of sedation with euthanasia. Best practice of sedation ought to be based on better training in both clinical and ethical aspects.

The clinical studies currently available refer exclusively to end-of-life sedation. The average incidence of such sedation observed was between 20% and 25% of the total, but with wide differences, since each writer understood something different by sedation. If we take it that the level of consciousness should be reduced enough to alleviate the patient's distress and that deep sedation is not always necessary, frequency of End-of-Life Sedation is above 25%. Where only the cases in which pharmacological coma is induced are considered, the frequency drops to 10%. Even though these studies show a wide range of differences, the most frequent reasons for sedation are delirium, dyspnoea and pain, and the three most used drugs are Midazolam, Haloperidol and Morphine. In all studies good to satisfactory results are recorded after sedation.

There are still enough areas or questions that are not well enough understood to justify more research into sedation. What is the real frequency of Palliative Sedation and End-of-Life Sedation respectively? Which is the most recommendable set of guidelines or protocol? Can one identify at-risk groups among the population vis-à-vis sedation? And if so, is it possible to design some kind of strategy to eliminate or reduce this risk? As usually happens, the future will continue to bring us new questions as the ones facing us now are answered.

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3. SECOND PAPER

SEDATION OF PATIENTS IN THE CONTEXT OF PALLIATIVE CARE

Azucena Couceiro

1. Introduction

In the last decades of the 20th century we saw an unprecedented growth in what today we call palliative care, but that does not mean that this has been achieved easily, or even that this development has been completed. This area of medicine, or rather this paradigm of approach to the patient, is still immersed in its own process of growth and maturity.

Nor is it easy to find a clear explanation of the struggle that palliative care has had to be recognised as a proper branch of medicine, and not the back door or a last resort to turn to when the situation is hopeless. Why should this be so? I think there are two reasons, at least. The first has to do with the epistemological status of present-day medicine, the daughter of 19th century scientific positivism, which fosters knowledge of disease within the scientific method. In terms of this paradigm, what is really important is the scientific perception of reality by means of direct observation, technical measurement and due application of the experimental method, so that the facts can later be interpreted using a rational and plausible system of reference. Certainly, this is the framework that enabled medicine to come of age as a science, and which developed technical capability that, by the 19th century, had so wrapped up human beings that it determined not only their life ways, but also the manner of their dying.

"Where the technical prevails, in the very greatest of senses, there is danger", observed M. Heidegger. The danger is both physical and metaphysical, because it can threaten life and because in a very real sense it can impair our ability to see in depth what things are. "But -Heidegger adds- where the danger is, there is that which saves". Never a truer word. With our technical advances we save lives, but we also prolong death; with technical advances we can add years to our lifespan, but on occasions what we gain in quantity we lose in quality. Ever since medicine became technological, society has expected the physician to cure illnesses, and all that is incurable is felt to be a professional failure.

This approach to clinical activity is a way of being, a way of living in and relating to a world which is in what L. Boff terms the "work-mode", characterised by the use of analytical reasoning, calculating and objective, imposing itself on things in order to dominate them. This type of reasoning demands objectivity and therefore imposes a certain distancing from reality in order to study it objectively. The process of transformation of human beings and human nature is wrought by means of a subject-object relationship, a control relationship. And when this control fails, one talks of failure. In this framework, the palliative philosophy does not fit.

But there is another way of being in the world which is mediated through care. Care is not contrary to work, to the modification of the environment, or the patient's condition, but it sheds a different tonality upon it. The relationship is not one of domination control over someone but of co-habitation, and the core of this relation is no longer occupied by the logos or reason, but by pathos or feeling[1]. Hence it is possible to understand that the responsibility for human beings and the link that is set up with the dying creates obligations with this other person, and that looking after, caring, is to recognise the dignity and difference of the other person[2]. Caring has to be seen as more than just another attitude, since it designates a basic phenomenon, the phenomenon that makes it possible for human existence to be human[3].

From the point of view of the scientific paradigm, pathos is a world fraught with danger, one which has little or nothing to do with science. For that reason it is no coincidence that the first hesitant steps taken by palliative care coincided with another revolution in clinical relations, the advent of Bioethics. The latter changed the way we make decisions in the clinical setting, with the introduction of both new techniques and values for all those involved. Facts and values are not mutually exclusive, they are complementary, however difficult it may be for health service professionals, trained on the basis of scientific positivism, to grasp that. And if it is plain that all that surrounds death and terminal illness is redolent with values and anti-values, what is not so clear is whether we really know how to introduce these values appropriately in our decision-taking processes. In the world of palliative care, the assumption is more frequent than in other branches of medicine that my values and my beliefs are shared by those around me - or should be so, even if they are not. This is what Randall and Downie call palliative care's "hidden agenda", those beliefs and character traits that it seems those working in palliative care implicitly ought to have[4].

And if there are two reasons that explain the difficulty palliative care has encountered in being accepted by scientific medicine, the second has to do with the professionalisation of care. All human beings can exercise personal care, but not all are suited to carrying out professional care, which requires the acquisition of knowledge and skills which are admittedly different from those of other branches of medicine, not for that less important. For a palliativist, communication skill is as important as manual dexterity is for a surgeon, and in the same way, knowledge of the WHO analgesic ladder is as necessary to the former as knowledge of topographical anatomy is to the latter.

If the knowledge and skills are lacking, we will not be able to carry out professional care, and we will be inexpert and inefficient in the art of caring. Thus, when professionalised, the "care mode" that Boff refers to requires the integration of reason and sentiment, of logos and pathos, avoiding both the rationalist-scientist type of attitude so typical of medicine, and mere sentimentalism. In the exercise of care, rational calculation and technical knowledge of the patient's state are just as important as the praxis of sentiment or closeness and empathy with the patient[5]. And while this would seem to be all too obvious, it is something which many people still have not understood. Many people stick to the idea that most of the skills required to work in palliative care have to do with personal traits and characteristics -character, religious convictions- rather than technical knowledge. If we approach the ethical problems that arise in palliative care only from this angle, the answers will be emotional, character-orientated or religious, something which while totally respectable, will not provide us with a minimally intersubjective basis upon which to base our moral judgements, something which is essential for a plural and democratic society.

Apart from the aspects mentioned, and before going into the specific problem of sedation, we need to look briefly at the stages the development of palliative care has passed through in Spain[6]. The initial or awareness-raising phase (1975-1984) occurred at the same time as democratic habits were taking hold in Spanish society, a society in which autonomy was beginning to be timidly put in the place of the secular paternalism of the preceding regime. The second phase (1984-1992) the phase of institutionalisation, was when the palliative philosophy was introduced into oncology services and coincided with the passing of the Ley General de Sanidad (Spanish General Health Act) among other things. The latter represented the first charter of patients' rights in Spain and an affirmation of the Spanish coming of age as citizens. It might be thought that this necessarily presupposes the transition from the paternalist model to more democratic ones, but that did not really happen - precisely because oncology is where the "young paternalist" thesis has been strongest. Young paternalism treats the patient like a teenager and for that reason is incapable of engaging with serious or fundamental issues, and this has only recently begun very slowly to undergo modification[7].

The third phase or universalisation stage (1992-1998) began with the creation of the Sociedad Española de Cuidados Paliativos (SECPAL), and is slowly but surely promoting the expansion of the philosophy of palliative care within the context of the Spanish healthcare model. In this period, the autonomy and rights of citizens is something that is already very clearly perceived, both in the kind of clinical relation expected of healthcare professionals and more specifically in the ethical issues facing palliative care workers. And this is motivated to some extent by a growing change in the therapeutic relationship. At the present time this relationship is beginning to be seen as a process of negotiation between subjects that mutually respect one another in their autonomy, and hence enables negotiation of topics like the role of previous instructions, the problem of patient sedation, and even the issue of euthanasia.

Sedation of terminal patients is by now becoming the frequent object of discussion in Spanish and foreign publications on palliative care. In principle, the debate was centred on the determination of the symptoms that might, because of their negative effects on the patient's quality of life or their refractory nature, require the administering of medication to partially or completely suppress consciousness. By refractory we mean that which cannot be adequately controlled despite efforts to find a tolerable treatment that does not compromise consciousness, within a reasonable time frame[8].

Subsequently, other issues have appeared, such as the sedation requested by the patient for psychological reasons or for continuous uncontrolled anxiety. We can safely take it that people want increasingly more control over the end of their lives, and what contributed to this feeling in part was the knowledge acquired from the mass media of conflictive clinical cases, which have even been taken to the European Court of Human Rights in Strasbourg. I refer specifically to the recent ruling in Pretty v. The United Kingdom[9], concerning a British citizen with a neural degenerative disease who was not able to end her life without collaboration of others, something which constitutes a crime in the United Kingdom, under the 1961 Suicide Act. It is clear that one thing is assisting in a suicide and quite another is end-of-life-sedation of a patient because of deep distress, and that these are two clearly distinct moral problems. However, what I am getting here is that all these facts are vital for understanding such an evident reality in our present day society as the increasingly widespread wish to have more control over the end of one's life.

2. Clarification of the concepts

In the framework of palliative care, sedation is seen as the therapeutic measure when other treatments have proved ineffective, so that normally it is a response to "therapeutic failure" as far as other treatments are concerned. Depending on the aim, two types of sedation can be discerned:

a) Secondary to the administration of massive doses of drugs used to deal with symptoms, and thus not directly or intentionally sought;

b) Primary, when the main object of the intervention is to reduce the level of consciousness.

Sedation is used as a therapeutic weapon in other areas of medicine, for instance in intensive care, but with the aim of being transitory - for example where a patient connected to a respirator is sedated while this situation lasts. Here the object is to "wean" the patient off the application as soon as possible, and to use the shallowest level of sedation possible[10]. This is an application of sedation which is planned to be transitory, like many another instance in palliative care, so that the ethical problems involved are few. Where the problems appear is in primary sedation, intentionally sought by the health professional, and irreversible. In this process, the patient's conscious life is gone forever, although not his or her biological life. Life is maintained as a material biological structure, but the common attributes and characteristics such as ability to relate, communicate, experience are missing, all of these attribute that make this biological life a human or person's life. Here, then, lies the professionals' concern, arising precisely as a result of this fact. Reduction in the level of consciousness might take place at various different points of the patient's illness, and these should be clearly stated (see table 1):

- When the death of the patient is thought to be very near. This is known as terminal sedation[12], when sedatives may be administered to produce a sufficient deep and forseeably irreversible cessation of consciousness. This is carried out with the intention of relieving physical suffering - dyspnoea, delirium- and /or psychological suffering -anxiety attacks, and so on, not effectively treatable with other measures, and with the explicit, implicit or delegated consent of the patient. This is therefore a type of sedation which is carried out as the patient approaches death and enters the death throes, a situation which can on occasions last days. The most frequent indications are delirium, dyspnoea, and pain. Generally the objective here is to avoid the agitation caused by hypoxia, pain, and dyspnoea.

To avoid the confusion that can arise with use of this term, since it could be taken to mean the sedation that will bring the patient's life to an end, a substitute term has been proposed which is End-of-Life sedation, a term that better describes the palliative sedation which is carried out in a dying patient. As we shall see below, one of the most serious ethical problems here is the inclusion in the definition of the fact that patient's consent can be implicit or delegated.

- When dealing with an advanced or terminal illness. The deliberate administration of drugs, in the required dose and combination, in order to lower the consciousness of a patient with an advanced or terminal disease with the aim of relieving sufficiently one or more refractory symptoms (with patient's explicit, implicit or delegated consent) is known as palliative sedation[13]. This type of sedation, thus defined by SECPAL[14], differs from the above-mention type in two respects: that this is not the death-throes period, since the cause or origin for the sedation is, so to speak, "biological" (refractory symptoms), and not personal or "autonomist" (intense suffering). At the outset we raised the question as to whether the principle that palliative sedation can only be considered when there is a so-called biological cause is something implicitly assumed and accepted in the palliative care environment.

Terminal sedation is a particular form of palliative sedation which is effected in the period of approach to death, or death throes, and as such should not generate more ethical problems other than those incurred in correct indication and ensuring we have the patient's consent. What in principle would seem to be clear starts to get complicated when we analyse the data published in the literature. For while the total percentage of terminal patients needing terminal sedation tends to be fairly constant, there are significant differences between studies as a result of differences in methodology (prospective v. retrospective) and the definition of sedation employed[15], making it difficult to know what the real prevalence of this type of sedation actually is.

An additional problem is the variability of criteria utilised before proceeding to sedation. In one in three patients it is possible to predict whether they were sedated or not, simply by knowing in which centre they were

Table 1. Classification of sedation at the moment when carried out.

END OF LIFE SEDATION	PALLIATIVE SEDATION
• Administration of drugs to produce a **DEEP** and predictably **IRREVERSIBLE** reduction of consciousness	• Administration of drugs deliberately in doses and combinations required to lower **CONSCIOUSNESS DEEPLY** and **IRREVERSIBLY**
• In a patient in DEATH THROES	• In an ADVANCED or TERMINAL patient
• With the intention of alleviating **PHYSICAL** suffering (dyspnoea, delirium) and/or **PSYCHOLOGICAL** suffering (anxiety, dread)	• When necessary to alleviate one or more **REFRACTORY SYMPTOMS**
• With the explicit, implicit or delegated **consent** of the patient.	• With patient’s explicit, implicit or delegated **consent**

attended, resulting in the great range in the reported rate of application[16,17,18]; and the most worrying aspect is that this great variability can also be seen within the same therapeutic team.

To establish that sedation is correctly indicated it is necessary to differentiate between refractory or intractable symptoms on the one hand, and symptoms that are difficult to get under control on the other. A refractory symptom is one that cannot be sufficiently controlled despite all the efforts to find a tolerable treatment other than one that compromises the patient's consciousness, within a reasonable time frame. Thus we should not confused the latter with the difficult-to-control symptoms. In the context of programmes with relatively little experience in palliative care, symptoms may be (wrongly) considered refractory when they are simply difficult but not impossible to control in expert hands[19]. In other words, sedation ought not to be included as a therapeutic option when symptoms are difficult to control but not refractory, as has happened in some instances[20]. The availability of "guidelines on clinical procedure" for palliative sedation can have the effect of radically modifying this tendency.

Certain ethical considerations will be discussed below, with respect to end-of-life sedation. Palliative sedation, for its part, poses its own complex problems, and the ethical considerations are not the same as those of end-of-life sedation. With the aim of differentiating and analysing these situations in depth, we will now proceed to use clinical cases which illustrate them.

3. Clinical cases

3.1. End-of-life sedation: Gastric carcinoma.

Patient aged 69. Previous history: smoker of 8 cigarettes a day, drinking 7-8 shorts/day. 28 years ago suffered an accident while at work, to the right hand, resulting in the loss of 3 fingers. Needed 3 herniorrhaphies: 2 right inguinal hernias 40 years ago and one left inguinal hernia, 1 year ago. Operated on for gastric perforation 40 years ago. Operated on for gastric neoplasm 1 year ago.

In August 2002 he entered hospital with dyspnoea. Five days previously, he had suffered dizziness when walking, that make him stop until the attack disappeared. The day before hospitalisation the dizziness was much worse, and even sitting down to rest did not completely dispel the attack. At this point he also had difficulty in breathing, which was the reason for hospitalisation. Also during the last six months the patient suffered anorexia and the loss of weight. He was an alert and orientated patient, well hydrated but cachectic. The Doppler confirmed femoral deep, superficial, and left popliteal venous thrombosis, and the patient was duly administered anticoagulants: first heparin and subsequently oral anticoagulants. The diagnosis was pulmonary thromboembolism, with secondary acute cor pulmonale and peritoneal carcinomatosis with gastric neoplasm. Patient improved and was discharged from hospital.

One month later he was rushed into hospital, suffering pain in his left side, made worse by breathing, and some dyspnoea. Haemoptoic expectoration. His general state was poor, undernourished, and with slight dyspnoea in supine. Probable episode of pulmonary thromboembolism. He was kept in, under observation. After making good progress, he was discharged. In view of his condition, he was to be monitored by the Palliative Care service, and an appointment was made with them.

Three weeks later his GP contacted the palliative unit to consult with them and explore the possibility of administering deep terminal sedation. His therapeutic objectives were clearly defined:

1. Control the physical symptoms which the patient was presenting;
2. Contact the palliative care team in the event of any doubt over control of the patient's symptoms.

3. Endeavour to respect the autonomy of a patient he had known for 18 years, and who long before the present illness had asked for terminal sedation in such a case as this;
4. Take on board this explicit necessity;
5. Work with the family in this situation.

A doctor from the palliative team visited the patient's home to evaluate the situation and the possibility of terminal sedation. The patient lived with a widowed sister with whom he got on well, and with his two nephews. He was in a strikingly emaciated, cachectic state, the doctor noted, as he had been living exclusively on diluted lemon juice for the previous two weeks as a result of the severity of his dysphagia. He sat in the living room of his house and the doctor was able to have a calm and collected conversation with him. He looked very tired. After the different options open to him had been explained, the patient expressed his preference for deep terminal sedation, and wished to have this carried out in hospital out of consideration for his sisters' feelings: he did not want to cause them unnecessary distress and alarm. His sisters shared this viewpoint and accepted the sick man's decision, although they were not clear what the difference was between sedation and euthanasia.

It was agreed to hospitalise the patient as soon as possible, having made certain that the decision was not due to unstated motives or pressures. He was taken in next day, and in the following 24 hours attempts were made to improve some of his symptoms -intense asthenia, anorexia, general ill state, epigastric pain, etc. - at the same time seeking to ensure his true wishes were reliably known. To which the patient replied that "everything that had to be said had already been talked about with his general practitioner". In the clinical record the following note appears: "Terminal patient, conscious of his situation, with irregular control of symptoms. In the case of sudden deterioration or intense suffering the patient gives his consent to sedation".

He suddenly took a turn for the worse owing to sepsis of unknown origin; no study was made to discover its provenance. There was onset of acute confusion syndrome. His general state was so poor that death was predictable within 1 or 2 days. In mutual agreement with the sister who was present, the team proceeded to sedate the patient, who died 10 hours later. In the clinical notes we read: "following day worsening of general state; awake but unable to reply. I informed him we were going to proceed to sedation. I spoke with the family and sedation was begun. The patient died ten hours later".

3.2. Palliative sedation for physical causes: Adenocarcinoma of the prostate.

Patient aged 72 years, three years ago diagnosed cancer of the prostate with good quality of life previous to that. His previous history include pleuritis when he was young, and heart attack and high blood pressure. For the last three months has had pain in the lumbar-sacral region, shoulder and neck, worse when he moves. Pain not cleared up by the painkillers prescribed by the health services of the county where he lives. Also reports blood in his stool.

As a result of all the foregoing, he sought medical attention at a health centre where, after running diagnostic tests, the latter reveal metastasis in the bones -ribs, scapulas, humerus, pelvis and left femur- and in the liver. Additionally they find severe anaemia (Hb 8.9; Htc 25.6%; red blood cells 2,810,000) accompanied by gastrointestinal bleeding, while proving impossible to locate the origin as the tests carried out -computerised tomography, barium enema and arteriography- were inconclusive.

During his stay in the centre (4 weeks) his condition grew progressively worse, and several blood transfusions were needed to maintain a functionally acceptable state. This patient had entered hospital under his own steam, but now proceeded to deteriorate rapidly. His doctor looked for the source of the bleeding, thinking that by eliminating the cause he could probably gain the patient one or two months of life, so that he could "get used to the idea" of his approaching death.

The transfusions were needed more and more frequently, and the anaemia was progressing, with a Hb of 7 g on the fourth or fifth day after transfusion. Also, the tests the patient was being submitted to were increasingly less well tolerated. The deterioration was impossible to halt, and without a transfusion survival would be one or two days. A maximum effort was made to control the symptoms, above all the dyspnoea secondary to the shortness of breath and the ischaemic heart disease, made worse by the calcified pachypleuritis.

The doctor, who had known the patient for some time, and who had good communication with him, explained the situation. The patient asked the doctor not to carry out more than one more transfusion, to keep the vital functions of the body and mind going long enough to be able to speak with all his family. The last days see a steady worsening in his condition and the dyspnoea increasingly less well tolerated. After saying goodbye to his family, sedation is carried out. The patient dies 12 hours later.

3.3. Palliative sedation for psychological reasons: Pulmonary neoplasm

Patient aged 71 years, diagnosed pulmonary adenocarcinoma with bilateral pulmonary dissemination. Treated with palliative chemotherapy (Carboplatin and Gemcitabine) up to August 2001, with stabilisation of the illness. In October he was admitted to hospital owing to increased dyspnoea and a cough. A chest X-ray showed a pulmonary mass in the right upper lobe, micro nodular pattern and right pleural process. The progression of the disease was noted, with secondary breathing failure, and treatment was initiated with steroid therapy and codeine, with relatively good control of the symptoms.

A month later he was admitted to hospital with persistent pain in the right side and cough, with dyspnoea at the slightest effort, and accompanying anxiety. After superficial sedation and increasing doses of the painkiller, the patient made favourable progress, and was discharged from hospital. A month later he was readmitted to hospital to control symptoms and deal with intense psychological suffering. He was aware of the diagnosis and there was no hope of a cure. He showed no sign of depression but was aware his death was near, causing him great distress. The only physical symptom was dyspnoea, which in the doctor's opinion he was tolerating quite well.

However, the dyspnoea attacks grew steadily worse, causing him fear and anxiety. All his family -wife and four children- were at this point taking turns to be with him, not leaving him be alone night or day. Physically, he was still a strong man. After a brief remittance in the dyspnoea -lasting 24 to 40 hours- the patient once again took a turn for the worse. It was clear that the relapse was deeply psychological, showing obvious signs of suffering. He repeatedly pleaded with his doctor, with whom he communicated and got on well, to put an end to it all. Faced with this situation, the doctor sought to keep him company and support him as much as possible, but the patient continued wanting to end his life. As the days passed and the suffering became more acute, various options were put before the patient, including deep and definitive (irreversible) sedation - despite the fact that team considered he might have lived several weeks more. This option was chosen.

The patient took his leave of his family and friends, and very warmly said farewell to his doctor. Sedation was initiated, steroids, antibiotics and bronchodilators were removed, and the dosage was carefully monitored to avoid depressing the respiratory centre. The patient died 36 hours later.

4. Elements for ethical analysis

4.1. The ethics of conviction, and the ethics of responsibility

Pellegrino, a noted American bioethicist, recently published an article in which he looks at the ethical problems facing palliative care[21]. Logically enough, he stated that they all revolve around two issues, the control of pain and suffering, and respect for the patient's autonomy[22]. But interestingly, he maintains that the skills needed by those working in palliative care are more "personal" than technical. In fact, he goes on, it can happen that the family or friends are much more sensitive to these very important aspects than the palliative workers themselves.

The idea that to devote oneself to palliative care one has to have particular convictions, is what has marked the palliative care movement until now. It is an "ethic of conviction", which sees the moral life as a direct application of the universal principles and moral code to each individual situation, without taking circumstances into account and consequences even less so. For example, if the principle or norm is that we should not kill, this is so always and everywhere, and circumstances should not be allowed to alter the judgement arising from direct application of the norm. The notion that moral judgements consist solely and exclusively of the deductive application of general norms is difficult to uphold, without revising the different basic ethical tenets that have emerged over the course of history[23, 24], and the statutes of applied ethics, one of whose best-known branches is bioethics[25, 26].

Max Weber, a German sociologist born into a family with a tradition of liberalism, distinguished, back at the beginning of the 20th century, two types of opposing ethic, which he termed the "ethic of conviction" (Gesinnungsethik) and the "ethic of results" (Erfolgesethik). If the first only takes principles into account when making moral judgements, the second only seeks to obtain the best results and consequences possible, without paying any attention to principles. The ethic of conviction reminds us of the excellence of duty, of rules and commandments, which are imposed absolutely. A man (or a woman) has to do what a man (or a woman) has to do, whatever the situation, and come what may. A paradigmatic instance of this way of looking at moral life is the Kantian ethic. Principles and intentions should guide moral life, and have priority over facts and situations. Its most classical expression is the maxim: "let justice be done, and perish the world!" which roundly states the unconditional nature of the moral stricture.

The "ethic of results" - says Weber- is the typical ethic of the politician, who seeks only power, and to that end uses what some members of the Frankfurt School term "strategic" and purely instrumental rationalism[27]. An example of this approach is the utilitarian ethic, which tends to approve actions in terms of the consequences that ensue. It is clear that there is an immediate confrontation between these ethical approaches, between principle orientation and consequence orientation, between the ethics of conviction and the ethics of results. As an alternative to these extreme models, Weber proposes a third, which takes into consideration both principles and consequences, and which he terms the "ethic of responsibility (Verantwortungsethik).

> Any ethically orientated behaviour can conform to one of two maxims that are fundamentally different from each other and hopelessly opposed; one can be guided by an "ethics of conviction" or by an "ethics of responsibility". This is not to say that the ethic of conviction will be tantamount a lack of responsibility, or that the ethic of responsibility will equal lack of conviction. Naturally nobody is saying that. But there is an abysmal difference between acting in accordance with the maxims of an ethic of the conviction, such as that which states (religiously speaking) "the Christian does good and leaves the result in the hands of God", or in accordance with the maxims of an ethic of responsibility such as that which warns us to be aware of the consequences of our acts [...]. When the consequences of an action carried out according to an ethic of convictions turn out to be bad, the person who carries it out does not feel responsible - instead they blame the world, the stupidity of men or the will of God that made them that way. Whenever a person acts according to an ethic of responsibility, on the other hand, they take into account all the defects of an average subject [...] They will always say that the consequences arise from the action[28].

The consequences and circumstances are important in moral life, and cannot be brushed aside in the search for a correct or ethical decision. This is what Aristotle called phronesis, or practical wisdom. The ethics of responsibility looks at consequences, but also and equally at principles and convictions: an ethic which does not pay attention to consequences is not responsible, but it should not be forgotten that there is no responsibility without convictions. For that reason, Weber takes the view that, in some sense, conviction and responsibility can be complementary, so that one can speak of "responsible conviction".

Palliative care has inclined for the ethics of conviction more than the ethics of responsibility[29]. Cicely Saunders, the founder of the Palliative Care movement, had traits that are typical of the ethics of conviction, such as the idea that religious faith was necessary, or at least very important, to be able to offer good care. It is no coincidence that palliative care came into being in many countries as a result of individual initiatives, implemented from outside the health service and inspired by religious motives. In the sixties, Cicely Saunders came under the influence of the civil rights movements, and as a consequence saw the importance of respecting the autonomous decisions of the patients. Thus palliative care began evolving from an ethic of conviction toward a more respectful attitude toward the patients and, therefore, more attentive to the evaluation of personal circumstances and consequences.

In our field there are publications that are clearly orientated toward the ethic of conviction[30]. Frequently, those guided by such ethics express an already classic objection to the ethics of responsibility, accusing the latter of relativism, as a result of not considering deontological principles as absolute or without exceptions. This is a philosophical error, given that relative is the opposite to absolute in metaphysics but not in ethics. In ethics, the opposite of absolute is proportional, and moral absolutism is opposed to moral proportionalism, not relativism. The ethics of conviction is moral absolutism, and the ethics of responsibility is moral proportionalism. The introduction of proportionality always goes hand-in-hand with "prudent" judgement, which overviews formal principles and opens them up to the consequences.

Clinical ethics are a question of practical reasoning with respect to particular patients, specific cases and unique situations. In ethics there are arguably no absolute judgements, because moral judgements are synthetic ones, born of experience, and predicated on sensitive experience. Our decisions are always uncertain, but if we weigh up the circumstances in a reflexive way we shall arrive at what Aristotle terms prudent judgements. A large number of Cicely Saunders' followers are beginning to see it that way, especially among those who apply the usual analysis procedures of bioethics to the world of palliative care. Fiona Rasdall and Robin Downie centre their book on the idea of responsibility[31], and a similar focus can be found in David Roy and Neil MacDonald[32].

4.2. The principle of the double effect

We frequently come across repeated references to this principle, in arguments over the rightness or otherwise of sedation, even in official SECPAL documents[33]. To maintain a minimum level of rigour with regard to the double effect principle, we first have to answer a number of questions: in what context does it come up? what is the double effect? and why do we have recourse to it so much in palliative care?

The doctrine of the double effect or voluntary indirect action has been very important in Catholic moral theology. Its roots stretch back to Thomas Aquinas and his celebrated discussion on the moral justification of killing in self-defence, and has been intensely debated by philosophers and moral theologists, above all in the 16th and 17th centuries. The Church of Rome has applied this doctrine to the resolution of certain ethical problems, and the use of morphine to relieve pain is one of the best known. The act is the administration of morphine, and there are two foreseeable effects: the relieving of pain and depression of the respiratory centre. Is it possible to justify this action? The doctrine states which are the conditions -intention, simultaneity, proportionality- which need to be present to determine the morality of an action when various effects may be derived from it, not all of them good.

There is not one single formulation of the double effect, but many[34]. Here we will spell out one of the more classic formulations, whose elements are as follows:

- The act has to be good, or at least indifferent;
- The good and bad effects have to follow immediately, simultaneous with the act. That is, the good cannot be obtained by means of the bad [simultaneity];
- The effect sought is the good one -to relieve the pain- and the bad one, death, is tolerated; [intentionality];
- There has to be a certain proportion between the desired good effect and the bad [proportionality].

As can be seen, the double effect seeks to state what the relation is between the intentional act and its consequences, to deduce whether these are acceptable. This is what is called an unloading principle, a way of introducing the real conditions and the evaluation of the consequences in an ethic of principles which, despite its absolute character, necessarily has to find a remedy commensurate with the circumstances and consequences under the umbrella of this criterion of proportionality.

The formulation is clear with respect to the first condition: that the act should be good or indifferent. If this were not so, then we should be talking about another issue, that of the relationship between ends and means. Or carrying out a bad act to obtain a good end. Let us look at two examples, that of administration of morphine, and of euthanasia. In the first case we can say that the act is good -relief of pain- and that the good and bad effects, relieving of pain and depression of respiration- are simultaneous. It is obvious that the bad effect is wished involuntarily, and it is here that the importance of intentionality is seen, a point which we shall come back to. In the second example, that of euthanasia, we cannot from the traditional doctrine point-of-view apply the principle of the double effect, since as far as scholarship is concerned there are acts which are "intrinsically " bad, such as killing someone. Thus the first condition is not complied with[35]. That, then, is what the classical formulation states. Another thing is that in the 21st century, and with the distance that ethics have since travelled we should assume, without further ado, that there are intrinsically bad acts. Intrinsically bad, for whom? according to what rubric?

We now come to intentionality which the dictionary of the Spanish Royal Academy, defines as the "determinación de la voluntad en orden a un fin" [determination of the will with respect to an end] in our case the determination with respect to the correct end, which is the relief of pain. The intention makes it possible to differentiate between the desired and the permitted, between -for example- administering a drug for its curative effect and permitting its secondary effects. As clear as that, yet anyone who has found themselves at the bedside of a terminally ill patient knows the difficulty which at times is involved in "dissecting" the many different psychological elements that give shape to our intentions. Timothy Quill, known in the literature for his work on the clinical criteria in medically assisted suicide[36], wrote about the case of Diane. She had been his patient for eight years, and he relates how she began to take control of her life. She had been born into a family of alcoholics and was diagnosed carcinoma of the vagina her youth, had overcome these circumstances only to be faced now with another illness, acute myelomonocytic leukaemia. After a reasonable length of time, she decides, along with her doctor and her family, not to go through another cycle of chemotherapy, rejects palliative care and asks Quill for barbiturates for purposes which they both are aware of[37]. He writes: What were my true intentions in prescribing these barbiturates? to make the pain and suffering go away? make the process of dying easier? help Diane to end her life? offer her the possibility of death in this combined process?[38]. In short, for all that we all might want to relieve the symptoms, we would do well to remember that intentionality can be complex, compulsive, ambiguous and at times contradictory.

Let us apply what we have said here to the issue of sedation. If we speak of terminal sedation or end-of-life sedation, there is not much sense in referring to double effects, since the conflict is not so much between suppressing the symptoms and death, as between suppressing the symptoms and the loss of conciousness[39]. To affirm that end-of-life sedation could cause the death of a patient who is in the process of dying is little short of tautology. In point of fact, survival of patients after onset of sedation is between 2.5 and 3.5 days[40,41]. Notwithstanding, this is a clinical situation in which we have to give reasons for elimination a person's consciousness, and for that reason should only be considered after due application of the usual measures has failed, and one is faced with refractory symptoms that seriously compromise the patient's quality of life.

Sedation does not mean any change in attitude with respect to control of physical or psychological symptoms, which constitutes palliative care's primary objective, but it does mean a change in the means used to achieve this control. Furthermore, ethical correctness requires fulfilment of the conditions derived from the principles of good faith (absence of malice or malpractice) and patient autonomy, conditions which we shall look at below.

In the case of palliative sedation, the type that is effected in a patient with an advanced or terminal illness may involve a different conflict of values. Here the discussion on whether this is or is not active euthanasia makes sense. To analyse this distinction we need to touch on other concepts which we shall discuss in the next section.

4.3. Kill v. allow to die

Palliative sedation, as effected in a patient with advanced or terminal illness, but with remaining life expectancy, is where it can be confused with euthanasia. I will seek to explain that this type of sedation is not exempt from problems, but it is *not* a synonym of euthanasia.

The term euthanasia should be reversed exclusively to designate those acts which are deliberated intended to end the life of patient with terminal or irreversible illness, suffering distress which he or she finds intolerable, at the express and repeated request of the said patient. This definition contains what in law is called triple judgement: of motives - humanitarian or merciful reasons- irreversible nature of the condition, and impaired personal quality of life[42].

Also, in addition, we shall find the elements (see table 2) that characterise precisely what is denoted by the term euthanasia:

a) A specific biological situation, of either terminal or incurable illness, without those two elements necessarily applying at the same time. For example, in a terminal cancer patient we find both, but not so in a quadriplegic patient, whose pathology is irreversible, but with a life expectancy which does not allow categorisation of the patient as terminal;

b) An autonomous person, that is, capable of taking decisions and competent to do so, who feels that their situation is unbearable, according to their own judgement of quality of life, and for that reason makes express, reiterated and constant requests to have their life brought to an end;

c) "Necessary" and "sufficient" action or co-operation of a third party which brings about the death of the patient; this is what is known as causality.

Table 2. Euthanasia: Elements

ELEMENTS WHICH MAKE UP EUTHANASIA
• Terminal or irreversible DISEASE • Subjects SUFFERING serious pain or distress • Reiterated, express and constant REQUESTS • A third person who, moved by pity, carries out an ACTION WHICH LEADS TO DEATH (Active co-operation with acts necessary to bring about the other's death)
TRANSITIVE ACT + CAUSALITY

Anything which does not adhere strictly to this definition will be something else, homicide -in which there is no express request on anyone's part- withdrawal of means of life support, etc., but not euthanasia, and so the term euthanasia should not be applied[43]. Calling something else euthanasia, apart from being incorrect conceptually speaking, clouds the issue and does not bring to bear the rational elements so necessary for the analysis[44,45].

Accordingly, what we are defining here as euthanasia is what is habitually called direct active euthanasia. So why do people talk of so many different kinds of euthanasia? I think the reason is that this word has been used to denote all those situations in which the action or omission of the healthcare professional "appear" to be followed by the death of a patient, and I emphasise the word "appear" because the problem lies precisely in how the causal relations are established. If a patient has amyotrophic lateral sclerosis at an advanced stage requiring a respirator because their muscles are no longer able to move the air, and the professional decides, in conjunction with the patient not to turn on the respirator, this may improperly referred to as "passive" euthanasia. In reality what we have here is the ethical problem of non-application of life-maintenance techniques, rather than of healing measures, in a situation in which medicine can only put off the moment of death. It is, in other words, a clear limiting of the therapeutic effort at the patient's bidding. The latter is a situation concerning which the Spanish Constitutional Tribunal has affirmed the right of the patient to refuse medical treatment. It goes on immediately to say that this constitutes an element of the fundamental right of inviolability of our person: (ART. 15 SC), guaranteeing indemnity for any invasion of our body for which we have not given our consent[46].

It may seem, intuitively, to the healthcare professionals involved that not to turn on the respirator is *the* cause of death, but this is not so, there is not one single cause, there is another cause which is concomitant in time, and irreversible -the ALS at a very advanced stage- which will inexorably bring about the patient's death[47]. In contrast, in the case of a paraplegic without any added pathology, we are met with an irreversible cause (we cannot modify the illness) but in this instance this is not acting concomitantly to precipitate the patient's death in the same way as respiratory failure in ALS. In the patient with sclerosis, my action -turning off the respirator- or my omission -not turning it on- "lets" the patient die, but in the paraplegic, my actions or omissions can lead to the death of the subject -they actually bring about death[1]. So clearly is this so, that the first instance does not constitute a crime under Spanish law, while the second qualifies as the collaboration or "necessary act" specified under article 143.4 of the penal code. The paradigmatic example here is the case of Ramon Sanpedro, whose death was due to the fact that another person put a glass of cyanide within his reach, constituting the "necessary act" to end his life (table 3).

Table 3: Art. 143 of the PC and its consequences

ARTICLE 143	CONSEQUENCES
1. Any person **INCITING ANOTHER TO COMMIT SUICIDE** is liable to between 4 to 8 years' imprisonment. 2. Any person who **CO-OPERATES WITH NECESSARY ACTS in the suicide** of another is liable to between 2 to 5 years' imprisonment. 3. If the co-operation is to the point of actually **EXECUTING** the cause of death, this shall be punishable by between 6 and 10 years imprisonment. 4. Any person **ACTIVELY** causing the death or co-operating with necessary acts in the death of another, * on the other's express **REQUEST,** * in the event that the victim suffers a serious **ILLNESS** which would have led to that person's death, * or produces grievous and continuous **SUFFERING** most difficult to bear shall be punishable by a sentence one or two degrees lesser than those laid down in points 2 and 3 of this article.	• The following will be **PUNISHABLE:** incitement to suicide, simple co-operation and co-operation to the extent of committing the act. • The following are **NOT PUNISHABLE:** omission of medical aid or treatment which is not susceptible to be described as either cause or as active co-operation, provided that this **complies with TWO REQUISITES:** 1. OBJECTIVE: illness 2. SUBJECTIVE: on patient's request • The Penal Code: 1. Excludes so-called "passive and indirect" euthanasia, given that the latter requires active and direct behaviour. 2. Includes as punishable "active" euthanasia but in a very attenuated form. 3. Reduces the punishment for consented homicide compared with the simple homicide of article 138.

This allows us to state at least two things. Firstly, that limitation of the therapeutic effort -the case of the ALS and the respirator- is not euthanasia, although this does not mean it ceases to be a serious moral problem. If it is done when the circumstances do not indicate it, what we have is malpractice. If it is done when there is no call for it, this is also malpractice, being therapeutic aggression (table 4).

Table 4: Limitation of the therapeutic effort

IF IT IS INDICATED (Not malpractice)	IF IT IS THE RESULT OF A CHOICE (Autonomy)
• It is the result of responsible use of the technology • It means either not turning on or withdrawing that which is merely prolonging the death process: CAUSALITY • The traditional terminology -passive euthanasia- is what confuses the issue.	• It appears in two types of clinical situations. Those that are: a) Irreversible and serious b) Acute intermittent episodes in chronic illness. • The evolution of the illness leads to the death of the subject: CAUSALITY • Decisions on patient's QUALITY OF LIFE

Secondly, that in palliative sedation what we have is a similar situation to that of the ALS case, since the cause is not reversible and it acts concomitantly, being none other than the advanced or terminal illness, such that we can categorise the sedation as "allowing to die". However, as we already noted in the case of limiting of the therapeutic effort, the fact that this is not killing does not mean that we are not faced, yet again, with a serious moral problem, that of eliminating the consciousness. This is tantamount to eliminating the psychological capacities needed for subjective knowledge of oneself, of one's awareness of one's thoughts, and the capacity to relate with one's environment.

5. Application

5.1. End-of-life sedation: Gastric carcinoma

This case illustrates the situation of a patient with 1 or 2 days life expectancy. The clinical features furnish enough details for us to be able to state that. However, it can be very difficult to predict the death of the terminally ill, and so it is important to rely on not only clinical experience but also have objective back-up such as laboratory reports[48], or support from second opinions[49].

We were saying that with end-of-life sedation there is no sense in resorting to the double effect, nor is it necessary, since the patient is already dying, and the conflict arises between the relief of symptoms and the eliminating of consciousness. Nonetheless, for the ethical decision to be correct a series of circumstances and conditions need to be taken into account that guarantee both the correct clinical practice and the maximum respect for the autonomy of the individual. The first derive from the principle of non-malpractice (avoidance of malpractice) and oblige one to use all the available resources to detect the complications that wrongly prescribed sedation can lead to[50]. It is necessary to carry out correct clinical procedure, which entails being especially careful not to confuse a symptom which is difficult to control with one that is refractory or intractable to treatment. It may also mean consulting another specialist, since clinical experience shows that in many instances adequate control of symptoms can be achieved when the latter are evaluated by other specialists[51]. This is what the general practitioner did in seeking the palliative care specialist's aid, and what the specialist in turn did before having the patient hospitalised in his unit to be able to use all available resources.

There is another set of conditions, those that enable respect for the patient's right to self-determination, empowering the latter to take his or her own decisions. As a general rule, the explicit consent of the patient is necessary. In these situations, consent cannot be delegated, as is assumed in the protocol for terminal sedation. It is true that at times it will be the self-same mental state of the patient which constitutes the necessary condition for sedation to be initiated, but which will make it impossible for the patient to interpret the information and give explicit permission. However, except in urgent situations or those where the patient is not known personally, the possibility of sedation for such reasons should have been discussed in the communicative process which all therapeutic relations demand, as illustrated in the clinical case in question.

To make the consent-giving process viable, the information given to the patient has to be information of guaranteed accuracy, which is comprehensible, and which allows the patient to take a voluntary decision, without pressure or manipulation from the healthcare professionals[52,53]. A standard minimum of information has to cover:

- The level of sedation sought (light, deep) and the type (reversible, irreversible);
- The technical reasons that sanction this type of intervention (for example massive, refractory haemorrhage, progressive dyspnoea, convulsive crises, delirium, and so forth).

Except where the patient is incapable, or not in fit enough condition to interpret the information, or where a situation suddenly presents which requires urgent intervention, we ought not to take decisions of this nature without the patient's explicit authorisation and communication of the fact to family and / or friends that the patient might indicate. The patient's wishes should never be taken for granted without previously ascertaining them. Only in exceptional circumstances can terminal sedation be undertaken without the explicit consent of the patient. Such might include terminal patients who have been wrongly advised, who have with very short life expectancy, and who have symptoms that clearly indicate sedation.

In this clinical case, all the necessary requisites for terminal sedation were met, although admittedly the fact that it was the patient that asked for the sedation made the ethical process much easier. Even then, the professionals concerned acted with considerable constraint, since additionally they strove at all times to adhere to the condition of positive management.

5.2. Palliative sedation for physical causes: Adenocarcinoma of the prostate

The patient had almost never considered the possibility of sedation, and related fairly well to his illness. The rapidity of his deterioration obliged the professionals to consider whether it was right to carry out blood transfusions every five days when it had not proved possible to find the site of the patient's bleeding, and the adenocarcinoma was already so widespread. One difference with the previous case was that the prognosis of survival here was greater.

The worsening of the dyspnoea, increasingly poorly tolerated, led the professional to initiate the dialogue with the patient, arriving at certain conclusions: not to give any more transfusions of blood and to proceed to sedation to control the symptoms. Palliative sedation of the patient in the face of refractory physical symptoms that were proving impossible to control otherwise, generally in very advanced situations, can be analysed from the perspective of the “lesser of two evils”[54]. Clearly the good would be defined as the possibility of maintaining the percent's consciousness lucid while controlling his symptoms, and therefore his quality of life. Given the technical impossibility of achieving this control, it was decided to carry out an action which was “bad” but one that seemed the best under the circumstances. Only an ethic of responsibility is open to the pondering of consequences, enabling the making of exceptions that should be justified individually, case by case[55].

We should also explore the issue using the principle of the double effect, and as we analysed previously, we can characterise the situation as "allowing to die", thus fulfilling the first condition. What is more, the good result (control of the symptom) and the bad one are simultaneous (possible shortening of life?); the only result sought is the good one, and there is clear proportionality between the two effects, a proportionality which can be seen simply by considering the clinical condition and life expectancy of the patient.

5.3. Palliative sedation for psychological reasons: Pulmonary neoplasm

This patient's case is paradigmatic, since here we see a person undergoing immense mental suffering. This suffering is the reason for the patient's continual begging to be sedated, and action which should only be resorted to when all other means that could be used to control the situation have failed[56].

The concept of emotional suffering or psychological distress is complex and difficult to operationalise, as it subsumes cognitive, affective and behavioural aspects[57]. It is characterised by the sensation that the subjects concerned have of threat to the safety of their person, by the feeling of lack of control over the said threat, and by the exhausting of personal and psychosocial resources that would enable them to face this threat. It also subsumes the concept of anxiety, a specific human reaction to the perception of the threat of death, which could undermine a system of moral values that give meaning to a life[58].

When the balance between the perception of threat and the psychological resources available to confront it is tried and found wanting, the spiritual condition of constant suffering or anguish will appear, intimately connected to the feeling of vulnerability[59]. Correct clinical practice obliges us to observe various steps:

1. Detect and evaluate the suffering by means of some non-invasive clinical procedure, one which will be simple, easy, rapidly carried out and which can be carried out repeatedly without loss of reliability[60];
2. Determine whether the anxiety is an escape response to a situation which is viewed with aversion, or alternatively an avoidance response to something as yet unknown which the patient sees is approaching[61];
3. Establish which specific biological or psychosocial symptoms are the ones that the patient perceives as seriously life-threatening;
4. If this is an avoidance response, detect and treat the patient's fears and worries, and attempt realistic cognitive restructuring;

5. Use the therapeutic means available to ease adaptation to the stressful situation; detect and foster the patient's own resources with the objective of reducing or eliminating the sensation of impotence[62].

Given personal fragility of this sort, as explained in the patient's clinical history, there may well be doubts as to the patient's moral autonomy, and while it has to be said that an experience like this does not necessarily lead to loss of autonomy, it certainly is true that one has to take even more care over the relationship with the patient, evaluating their capacities and detecting any pathology which might limit their faculty of decision. It is advisable to:

1. Take time with the patient to go over all the information given to see how much has been understood, as this knowledge will facilitate a more realistic approach to the situation;
2. Explore the patient's ability to decide, the latter depending on certain minimum requisites: the ability to understand the information that has been given during the communicative process and ability to grasp the situation in terms of the illness, its probable development, the treatment options available, and the consequences of any decision;
3. Rule out the existence of any associated psychological pathology that might reduce or eliminate competence (e.g.: sadness in the face of the situation would not rule out competence but depression would do so;

Sedation for psychological reasons involves more ethical complications, amongst other reasons because the refractory nature of a physical symptom is easier to measure and to view objectively than the concept of emotional suffering, which depends in large measure on subjective factors and attitudes to life and the capacity of each individual concerned.

6. Conclusions

In the course of this article we have carried out a careful dissection of the ethical problem of deep irreversible sedation. All the factors reviewed above contribute to the palliative debate being centred on the question of whether irreversible sedation is, or is not, euthanasia. The arguments given here, lead us to affirm that the question of sedation is not the same as the question of euthanasia, but I should like to state once again that this does not mean it is any less serious a moral issue.

Table 5: Progression of measures to combat suffering. Adapted from Barbero and Camell

	Primary objective	**Lesser of the evils**	**Final aim**
1. **Habitual palliative action:** Analgesic ladder + emotional support + reduction of threat + enhancement of resources etc.	Control of pain and other symptoms and situations which worry the patient	**None:** knowledge of opioids a fact that virtually reduces to zero the risk of accelerating death by depression of respiration	Alleviate suffering
2. **Deep permanent sedation** • End-of-life • Palliative	Control of pain and other symptoms and situations which worry the patient	Elimination of consciousness: **CONSCIOUS life** * Shortening of life	End suffering once and for all
3. **Medically assisted suicide and euthanasia** (active, direct and voluntary)	Control of pain and other symptoms and situations which worry the patient	Disappearance of **BIOLOGICAL LIFE**	End suffering once and for all

In table 5, adapted from Barbero and Camell, we see set out what I wish to say. We, as healthcare professionals have been far more preoccupied with the disappearance of biological life (biological death) than with loss of consciousness. This can be seen, for example, in the rapidity and frequency with which decisions on the suppression of consciousness are taken, generally by the anaesthetist, who advises the family of their decision to put the patient "to sleep", so that they can all say goodbye. The palliative context has changed, fortunately, in the manner and form of proceeding to sedation, as well as improving use of medication and doses employed. Only scrupulous use of professional guidelines on the autonomy of the patient can justify this practice, as it should be , as a "lesser evil", assumed from the position of an ethic of the responsibility. And one applied when all other attempted measures have resulted ineffective.

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4. CONTRIBUTION FROM PARTICIPANTS IN THE SEMINAR

The order in which contributions from the different participants appear was exclusively the decision of the moderator, as was the choice of a quotation from the text as a heading for the contribution in question, thought to be particularly relevant within the overall vision of all the comment and opinion received.

The moderator is conscious that such decisions are questionable and indeed risky, but are more the result of intuition than of logic, and might (unintentionally) undermine the message of the commentators in question. I apologise sincerely and ask for indulgence and understanding if this did in fact occur in any instance.

4.1

I find it worrying that, when defending the right to irreversible final sedation, we may do so in such a way that we cause fear of suffering to increase, leading to intolerance of any situation that may seem painful to us. Because in that way we can legitimise socially actions dictated more by a culture of anaesthesia, than one of dignity of living.

Milagros Pérez Oliva

Recurrence to End-of-life sedation should happen only after very careful thought, evaluating very carefully each case on its merits. I agree that we should try to reach consensus on the ideal approach, since this will have meant we have given thought to the problem and the ethical implications of a decision of this importance. But I am concerned that, in order to draw up a typical acceptable protocol of a general nature, we may contribute to consolidating particular concepts concerning the end of life and suffering. It is clear that the main object of sedation is to avoid suffering. But then, who defines what is suffering? And from whose position does one do so? I have had to take the decision to authorise sedation of a very close relative who was in a process of becoming a total vegetable, and at the end, despite having always acted in the interests of his good, I still was not sure if he would really have wanted that. Because one thing is thinking of death or incapacity from the viewpoint of the family, or when the prospect of dying or becoming totally invalid is far off and hazy, and quite another when is certain and close to one’s own life. If I have two months to live, that is all that I have left. And so it may well be that some of the lacks in my life that currently seem unbearable will not seem so bad in that context. Finding myself totally paralysed in a bed in the terminal phase of an illness, perhaps the pain would take on less importance than being able to see my children one more time. I think that evaluation in terms of what is acceptable for one depends on each individual's values and the particular circumstances of that moment.

I am also concerned that defence of the right to End-of-life sedation in order not to suffer we are aiding and abetting in the consolidation of a cultural trend that I see as pernicious: the total negation of pain. I would never defend suffering as an expiation for anything. That's not what I am saying. But pain forms a part of life. The physical and psychological pain we feel when we lose someone we love, for example. One of the situations that would justify End-of-life sedation is the existence of unbearable psychological pain. But apart from the concept of the unbearable, which as I have already mentioned can be very relative, I am concerned that, when defending the right to irreversible final sedation, we may do so in such a way that we cause fear of suffering to increase, leading to intolerance of any situation that may seem painful to us. Because in that way we can legitimise socially actions dictated more by a culture of anaesthesia, than one of dignity of living. To the last breath.

4.2

One of the current problems in Palliative care -and why not admit it- also in society as a whole, is the idea of "zero tolerance" for the experience of suffering.

Javier Barbero

Sedation and suffering

Death, suffering and sedation[1] are linked like three vertices potentially forming a triangle in which the length and strength of the sides depend on a multiplicity of variables.

The relationship between death and suffering is already complex. When a patient is diagnosed cancer, just the cognitive whiff of the real possibility of close and approaching death usually triggers the experience of suffering. Furthermore, the dogged determination to overcome death in a properly diagnosed terminally ill patient - known as therapeutic obstinacy- can also be a source of suffering. In other words, the real threat of death tends to generate suffering, on occasions of the same calibre as that caused by the fruitless struggle to overcome it.

Sedation is a way of ending this suffering. And death. In fact, both one and the other become the worst of enemies. Sedation and death are linked in this way, in a strange brotherhood which has either as its objective or as its consequence the elimination of the experience of suffering.

However -to state the obvious- sedation is not the same as death. In fact, simply mentioning these two words alerts one to the fact that they both have

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[1] By sedation I mean here the medication-induced annulling of the conscience understood as primary, deep and -in its intention- irreversible, for a condition of advanced-terminal disease.

referents with very different symbolic weight, both among professionals in this field, and in the population at large. It is not usual to argue too much about the legitimacy of someone who asks to enter into a "deep and permanent" sleep, and yet on the other hand we usually do question the deliberate request to help end someone's life, however compassionate the motive behind it. In the light of the psychological point of view, therefore, requesting sedation does not seem to be of the same order as requesting death, nor in the strict sense –and I don't have time here to stop and justify this- is there an equivalence from the moral point of view, although this might be solely for the fact that with sedation we end conscious life, but not biological life. And, what is more, in this case death, while expected, is not intended. But yet, however, these two actions, requesting sedation and requesting death, still have much in common. Let us take a closer look.

One of the conditions of human life is consciousness. This polysemic term conscience / consciousness has at least two aspects, one psychological and the other moral - and it is no coincidence that they are interrelated. In terms of the psychological reference of the word, I am alluding to knowledge of self, that is to say, reflexive consciousness (consciousness of self), although I am also referring to consciousness in terms of sensorial input, in terms of being alert. From the moral point of view, human beings are the only animals for whom the fact of belonging to the species leads them to have conscience (consciousness of what is moral), to be able to decide on their moral mission, that of living more or less humanly. In this last sense, in fact, we often hear expressions which talk of the dehumanisation of certain professions, or that such a person is very humane, or even that they have become inhuman. Interestingly enough, in the last case one can say that they have no conscience[2].

Responsibility is a moral concept. One who is responsible is one who responds, who seeks an answer for the reality before them. To be responsible one needs, at the very least, to be connected to reality, to be aware of the reality, to apprehend reality in a conscious way. In sum, conscience-cum-consciousness in its two senses, is an idiosyncratic condition (pathognomonic, some would say) of being truly human, such that its elimination, in principle, will dehumanise and can raise questions about the maintenance of the human condition itself. When this situation of elimination of consciousness presents itself, and is permanent, we have at least the right to question it.

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[2] [Translator's note: in Spanish the same word is used for both conscience and consciousness].

In the end, the question that is raised for all of us is, what to do with the experience of suffering of a human being at the end of life, and whether one can justify the elimination of consciousness as a way of struggling against it.

We could say that suffering presents itself to all human beings, and can be responded to, at basically 3 different levels. It can be:

- An experience operationalisable as a problem to be solved. The strategy here, then, will be one of problem-solving. For instance, when an intensely painful and persistent symptom presents itself and is difficult to control.
- An experience that stems not from one's problems themselves, but from the mystery in which they are inserted, forming part of the human condition, which by definition is limited and unable to deal with all situations. This, for instance, lies behind the question "Why do I have to have cancer, now, aged 37?” The strategy will consist in accompanying this suffering experience; you can't completely eliminate it, but your objective will be to transform it into a bearable experience.
- An experience that cannot be contained or controlled by the usual means (problem-solving and /or accompaniment) and whose intensity and whose pain can only be dealt with by eliminating or extinguishing the consciousness that is undergoing this experience. An example would be the intense and continuing presence of refractory symptoms, or what is known as "existential anguish". Here is where both euthanasia and medically assisted suicide could be fitted in under the heading of lesser evil and last resource.

In my experience, one of the current problems in palliative care -and why not admit it- also in society as a whole, is the idea of "zero tolerance" for the experience of suffering; it is as if we wanted to live in a bubble that had nothing to do with the human condition itself, full as it is of limits and frustrations. Affirming that existing (also) means suffering, does not mean approving of the experience of suffering, nor does it mean promoting resignation as shock tactics to deal with it, thus affirming suffering's moral goodness. It means, quite simply, taking reality as the point of departure, accepting reality to be able to deal with it.

We in healthcare have been trained up in the dialectic of the problem -the solving of problems- but the strategies for accompanying what we cannot solve hardly formed part of our training. Clinical experience tells us that on many occasions, the critically ill (with illness at an advanced stage) ask for our significant presence when facing the questions with no answers or -purely and simply- want to be able to share their questions with no answers without seeing us dodge the issue or flee from their depth and density. Unfortunately, those initiatives that focus their action in subtle but dangerous ways on what has become known as the medicalisation of suffering, tend to do patients a dubious favour. Paradoxically, pursuit of a "Suffering-free Hospital" can become a threat for those that prefer to "live out death", even knowing it will involve undesired suffering.

The tendency to utilise sedation much more frequently in palliative care, according to the principle of "zero tolerance" of suffering, could be one indicator more of the increasingly common tendency to create an "anaesthetised society". The doctor sedates, administers drugs that induce the loss of lucid consciousness to ensure that the patient does not perceive the signs and symptoms of their illness, or of situations which can generate great suffering. Politicians sedate, they induce loss of critical consciousness with their information strategies and misleading propaganda so that the public are not aware of the frauds, lies, and corruption that might cause them considerable suffering. Or -in this case -possible change of attitude or, simply, change of voting allegiance.

The social system is in itself ready to foster avoidance and escape behaviours among the public, lowering the threshold of critical consciousness and damping down conscious rebellion against the system. It is no coincidence that disturbing, wounding reality (the decrepit old man, the psychiatric patient, the terminal cancer patient, the AIDS patient, etc.) tend to be shut away out of sight in institutions, instead of trying to integrate them into the normal, habitual community networks. Of course, to temporally salve the collective conscience, we train obedient and submissive voluntary workers, social workers with designer solidarity, ready to do a cosmetics job on all the ugly wrinkles of society. What is involved here, in short, is steady loss of awareness of reality, leading to an equally steady lose critical consciousness of reality.

I would like to close by saying that I ethically accept sedation as an exceptional strategy -that is, not normative and not the first choice - without any problem. Provided, that is, there is specific experience of suffering, and provided sedation is indicated and is the choice - basically -of the patient. As is well known, the exceptional instances, both in clinical medicine and in bioethics, have their associated conditions and I believe that these should be duly observed since the more radical the measure (and elimination of consciousness is radical) the greater the necessity there is to have ethical and technical guarantees. One should not forget that depriving someone irreversibly of their consciousness is still in principle a "bad" action (action with negative results) that accordingly has to be justified and which has to carry the burden of proof.

The experience of suffering becomes an unavoidable moral imperative for the palliative care professional. On occasions, this will mean sedating….

4.3

If, in our hedonist society, professionals and family project our suffering on the ill person, we can be tempted to sedate in a somewhat indiscriminate way. In trying to safeguard what we inaccurately understand as beneficence, we rid the patient of his or her autonomy.

María Nabal

Introduction

The Víctor Grífols i Lucas foundation, organised the "Ethics and End-of-life Sedation " seminar, bringing together multidisciplinary experts in a very enriching forum. The direction taken by the first two talks have enabled us to approach the subject from two different viewpoints.

End-of-life Sedation, and palliative sedation

Notice that the literal translation of the English term "terminal sedation" has led us to talk of "sedación terminal" (the literal translation) in Spanish. This term is confusing: it confuses various different therapeutic process in the last stages of life.

Under the heading of "End-of-life sedation" is included the use of medical drugs to induce more or less profound and irreversible reduction of consciousness with the intention of alleviating physical or mental suffering during the last hours or days of life. This is carried out with the explicit, implicit or delegated consent of the patient.

By "palliative sedation" I understand deep lowering of consciousness with the aim of alleviating refractory suffering, either physical or mental, in a patient affected by an incurable malady, but with weeks or months of life still remaining. This should be carried out with the explicit consent and agreement of the patient.

In both cases, sedation constitutes a useful, effective tool in palliative care. Nonetheless, as in any other treatment, this in itself is neither good nor bad. The goodness or badness of the technique depends on factors like respect of the principles of bioethics, the fact of the technique being really indicated, and the proportionality existing between the process carried out and the cause that motivates it.

The controversy that has arisen on the use of end-of-life sedation has to do with these factors. Apparently there are more questions than answers:

- Autonomy or benefit?
- Autonomy or avoidance of malpractice?
- Benefit or avoidance of malpractice?
- Refractory suffering?

To be able to give a proper answer to these questions it would seem to me essential that the approach to the patient undergoing suffering is done by means of an interdisciplinary team. A well-trained interdisciplinary team can ensure a more all-round or global approach to the person and their problems, and be able to weigh up the different therapeutic options.

Suffering at the end of life

The end of a life produces great suffering. It produces suffering in the patient who is approaching death and who suffers physical and emotional symptoms; it produces suffering in the family who feel helpless to halt the deterioration and the approaching loss; and it produces suffering in the team looking after the dying patient, more trained as they are to cure than to accompany the process of dying.

It is this suffering that motivates the requesting and /or development of measures like sedation, especially in those cases in which one can see that the suffering is severe.

As with any medical problem, extreme suffering should pose questions concerning the cause or causes that produce it and that modulate it, whether in the patient or in the family or in the medical team itself.

Sedation, as I see it, can only be indicated if all other available therapies and other measure have been tried and found ineffective. For that, it would seem essential that when taking the decision to apply palliative sedation one should have:

- a specifically trained team, trained to an advanced level,
- a multidisciplinary approach to the problem with sufficient technical and human resources,
- the informed consent of the patient.

Risks of palliative sedation

As in the case of any medical treatment we may run the risk of abusing (over using) sedation or alternatively under using it.

At the present time we live immersed in a hedonist culture where frustration is not easily tolerated, where what counts is to appear young and beautiful. In this context death is very poorly tolerated. If within this framework or social context we professionals and family members project our suffering on the dying person, we could be tempted to sedate somewhat indiscriminately. In order to confer what we wrongly see as a benefit, we eliminate the patient's autonomy.

On the other hand, the historic Judeo-Christian influence in our culture and its interpretation of suffering as redemptive, could lead to under use of sedation.

Conclusion

Palliative sedation is a complex decision. For that reason, in order to safeguard the rights of patients, relatives and the hospital medical teams, healthcare professionals need to work in collaboration with the hospital ethical committees to develop consensus in this area, allowing us to unify criteria and draw up protocols on the taking of decisions and their recording in patients' records.

4.4

Tolerance of suffering should be at the patient’s choice .

María Casado

Background

When analysing the ethical aspects of sedation at the end of a life, as we are doing in this Seminar, I believe that there are two main points that we should deal with: firstly the patient’s decisions regarding sedation at the end of his own life, and secondly, the medical criteria regarding the most appropriate attitudes on how to approach this final stage of human life from a professional stance, on a general level. As one would logically expect, both aspects are, in practice, intertwined. This is why I believe we should analyse some points that may be implied in the relationship between the patient, his family and the healthcare professionals who are attending to him.

On the first point, the choice of making decisions regarding one’s own health is an example of assuming self-autonomy. To be able to make decisions whilst one is still capable, and to establish provisions in advance of not being able to, should the case unfortunately arise, is one of the most important socio-legal victories in recent years. This will of course include the need to deal with living wills, anticipated directives and the designation of representatives, and even to deal with euthanasia. It is important to highlight the legal recognition that currently exists regarding living wills as documents where an individual demonstrates his wishes in reference to those treatments or types of care to which he does not wish to be submitted, in an irrefutable manner; and where provisions may be made should age or illness cause the incapacity to state or take such decisions. This is how the patient’s will at the end of his life can be determined, and he may also designate a representative or executor as a valid interlocutor. This possibility, accepted in law, plays a role in the decisions of the healthcare professionals, as it provides a clear, dependable point of reference that they can rely upon when taking decisions if the patient is no longer conscious. I believe that the public administration should take on an active role in encouraging individuals to take the initiative in this context.

The end of life places before us proof that curative medicine has its limits, and that there are processes which, although they cannot be cured, do in fact need to be attended to and care be provided. For this reason they should be considered by the system in general, and by the health and social welfare systems in particular, in order to offer a complete care package which advocates and allows for the highest quality of life possible. In the event of terminal illness there should be two alternatives: either home care, or in a specialised institution. Problems can arise from both situations, and these should be carefully analysed in order to minimise difficulties. In the case of home care, the lack of carers should be emphasised – not to mention the emotional connotations involved. A very important point is often left out when dealing with these carers, we ought really to talk of "female carers" in the majority of cases, and this reality is of great significance and plays a great impact on the intellectual and professional lives of women, who not only assume the role of raising their children, but also the care of all types of sick and elderly relatives.

Also, the introduction of ethics committees in smaller institutions, palliative care units and also on a general practice level, not just in large hospitals, should be recommended by the Administration. These other organisations also experience ethical problems, and an interdisciplinary debate on the subject could well prove invaluable to them. The committees would discuss not just specific cases, they would also formulate general protocols to channel the ways of approaching the many problems that exist, according to previously established criteria, after a rational and inter-disciplinary debate. They should also provide training for their members to increase the ethical culture at such centres, improve general awareness in the public as a whole, and provoke a general debate on the subject.

This problem is an extreme one, and in this context we should also bear in mind the problem of euthanasia. Poised as we are on the edge of the new millennium, this debate should be considered from two points of view: as a question of respect and solidarity, and as a true test of the principle of respect for the choice of an individual, a principle on which we should centre not only any moral decisions, but the general life of our society (which at least accepts the definition of 'liberal'). If we really do respect the rights of the individual, we must prove that we do so by accepting the decisions of those who do not agree with us. Accepting and respecting opinions and behaviour of which we approve is very easy. The tolerance test – in the most positive and active sense of the term – is to respect behaviour or actions, the reasoning behind which we are not in agreement with.

This can be clearly seen in the case of euthanasia, as we cannot demand that the rights of others be undermined, nor can we allow “innocent third parties” to get involved. By definition, active voluntary euthanasia (which is the core of the debate at this time) only affects two people: the person who requests it in a lucid, express and repeated manner, and the person who agrees to practice it – who may always refuse or conscientiously object, if we were to make the supposition that such a legal duty existed, which would indeed be a big supposition to make. Why does the euthanasia debate still rage on so violently in society today? I believe that the reason behind it is the huge ideological baggage that the debate carries, and which causes those in favour and against the issue to take refuge in extreme, and in many cases, intolerant attitudes. Amongst the detractors of euthanasia, one often sees a stance which leads to a confrontation of absolute values (this, of course, is not the only area where such attitudes may be found). Whilst amongst the defenders of the right to die, the argument centres on a question of respect. Both sides call upon the defence of human dignity, but, obviously they interpret the meaning of this term in very different ways; we shall probably have the opportunity to go into the subject more deeply over the course of this debate.

As for the position of healthcare professionals regarding end-of-life sedation, it is interesting to highlight the fact that it is their responsibility to put together the corresponding protocols and rules regarding professional behaviour, according to scientifically agreed stages. Recent national and regional legal rulings, that regard good medical practice as a criteria when considering what may or may not be demanded by patients, should be recalled. In order that such best practices not be arbitrary (thereby annulling citizens’ rights regarding health care, rights which we should be protecting), they should be established by the corresponding professionals in the clearest, most objective way possible, according to scientific standards. Thus, all of the healthcare workers involved are responsible for determining appropriate models, which, together with a respect for human rights, will establish the limits to the patients’ scope for decisions according to current regulations.

I should also like to raise here something which seems to me to be of prime importance if we wish to arrive at a consensus, and that is the definition and limitations of the objectives which we wish to reach. We should also be conscious of the fact that the conclusions and compromises that we may arrive at, will, necessarily, be of a provisional nature. Of course, it is more uncomfortable to reach a provisional state and not one of eternal truth, as this demands responsibility for decisions taken freely. And, the way I see it , we should state explicitly that one can agree on correct behaviour, and even if one differs on the whys and wherefores it is possible to construct specific agreements as we go along. That, in my opinion would be an excellent objective for this meeting.

Comments after the debate

In the end-of-life sedation area we should not lose sight of a first principle that should focus our decisions, and that is the avoidance of suffering. This should be made explicit because traditional culture has not been very demanding in requesting analgesics. With the right professional help, we can now state that almost any pain can be kept to a minimum, if not totally eliminated. If this is not always the case in practice, it is due to lack of trained professionals. Which would lead us to a problem of "do no-harm", and of a lack of adequate professional training. Or we should ask ourselves whether the situation exists because there are still some taboos regarding the 'ennobling' power of pain. If it is the patient's choice to endure such suffering, then this, of course, is to be respected. But it should in no circumstances be tolerated if is due to the reticence of the personnel attending to that patient. Tolerance of suffering should be at the patient's choice.

Death is currently a medical process. As with pain, it is not just a physical but also an emotional experience, generally speaking in our society . And it is a subject which is not spoken of in personal terms, it is not taken for granted, and we should point out that death does not always mean that something has failed, but rather it is something natural and inevitable at a certain stage of life: it is the one thing in life which we can be certain of. Death is so certain of her victory that she "gives us" life; what should be avoided is not death, but painful or "early" death, or a life cut short.

It is interesting to highlight, in such an informed social debate, that a general tendency exists for healthcare programmes to adopt the latest technology and research programmes as a priority, and to pay scant attention to long-term care, and especially care for the terminally ill. This observation, always made when for example medical faculties are talking of changing study plans, has led to the questioning of some of the traditional aims of medicine in order to pay special emphasis to the care aspect.

Finally we should highlight that palliative care units are not available to all citizens. Not to make this explicit is dangerous and misleading. There still remains a lot to be done in order that this type of care, which makes the dying process and the final stages of life more dignified, be universally available. And this could be a cause for discrimination as, in practice, it is limited to certain areas, illnesses or patient numbers.

4.5

I believe that one of the most complex dilemmas that are raised in the "last days" phase is related to the evaluation of consent to sedation.

Joan Padrós

There are two factors which have transformed the practices of the medical profession over the last few decades. On the one hand there are the technical and scientific advances that have allowed us to prolong life to previously unsuspected lengths; and on the other hand, the so called "principle of autonomy", which is becoming an integral and inevitable part of healthcare.

As a consequence of both factors, fate is beating a retreat, and the need to take decisions, which lie clearly in the realm of confronting moral dilemmas, are appearing more frequently. At this moment in time, when and how one dies, can in many cases, be the result of choice.

It is difficult for healthcare professionals who have been brought up with the cultural heritage of a medicine based on the supremacy of illness-beating aims, on the sanctity of science, and on the paternal model of relations with our patients, to feel comfortable in a continually changing world, a world where the possibilities and challenges of science and technology are multiplying. And yet at the same time we are aware that limits on the availability of healthcare resources, and a new type of user, fully aware of their rights and therefore more demanding, are both appearing on the horizon.

We know from the data deriving from research projects on the process of dying, published especially in English-language literature, such as the well-known SUPPORT study, that there are many short-comings in the care of terminally ill patients. Deficiencies in the correct control of symptoms, and problems in communications between healthcare professionals and patients are just two demonstrative examples which can be easily extrapolated into the Spanish healthcare system. But there are many more, such as the problems of recognising when an illness has become terminal, the doubts and fears about the withdrawal or non-application of certain treatments, certain cultural and religious barriers, and the inability to communicate with patients and their relatives. Not meeting these needs correctly can lead to a situation where neither the patient nor his family knows that death is near, this in turn can produce a lack of confidence in the medical team, and distress, and to psychological and spiritual needs not being properly addressed, and finally, the subsequent process of grief of family members can be made so much more difficult.

The Palliative Care movement was a quite surprising relief for hospitals. On the one hand a new discipline in symptom management control, unknown until then, was introduced. The intravenous fluids and pharmacological armamentarium that were used on a conditional basis, have gradually disappeared in the "last days" phase. It would be difficult to find healthcare professionals who would question the qualitative advance of this new focus. On the other hand, being able to introduce the subject of death into conversations with patients was a wake-up call to those paternalistic attitudes of many doctors, who until then had considered that the “bearable truth” did not include the verbalisation of imminent death.

One of the aspects of care in Palliative Care units where consensus has been sought, has been that connected to sedation, discussed brilliantly and thoroughly by Dr. Porta and Dr. Couceiro.

The definitions proposed in 2002 by SECPAL (Sociedad Española de Cuidados Paliativos), both for “Palliative Sedation” as well as “Terminal Sedation”, include both aspects of prescription, as well as matters related to patients’ autonomy, specifically those aspects related to the patient’s “explicit, implicit or delegated consent”.

In her presentation, Dr Couceiro referred to the intentions of professional healthcare workers to relieve patients’ symptoms, which can on occasions be “complex, compulsive, and at times contradictory”. This goes without saying, but we should also state that the patient, his family or representative can themselves suffer from the same problems.

I believe that one of the most complex dilemmas that arise during the "last days" phase is related to the evaluation of consent to sedation. The ambiguities and contradictions of patients' wishes have been demonstrated in the few studies that have taken place, and in the experience of healthcare workers of these situations.

The relief of physical and/or psychological pain, should wherever, possible stem from previous dialogue with the patient. Questions regarding the patient's main worries, his fears and values, and his attitude towards death, should be explored in advance. The equivalent of such anticipated directives would thus be reflected much more fairly in any subsequent decisions that needed to be taken.

Even so there are exceptional situations which go beyond the limits of consensus encompassed by the definitions. On some occasions the needs of a compassionate society are sometimes put to the test when consent is not available, for whatever reason. And there will most certainly be other exceptional occasions when there is a moral desire for early death in the absence of conditions allowing a proper existence, when there is no quality of life, and the patient can no longer be helped. Of course the frontiers are no longer precisely defined in such cases, but such decisions also belong to the area of clinical ethics.

4.6

The people who most often ask for sedation are those closest to the patient.

Eduardo Irache

End of life sedation and General Hospitals.

Death comes to us all. In a high percentage of cases it comes at the end of a process which we call illness, which has been treated by a medical team or by one particular doctor. The person or persons who have dealt with the illness, should be the ones who helps the patient to die a good death. In order to do this, the doctor or medical team should possess minimal but clear ideas on how do help the patient to die with dignity. This should be done in the same way as a doctor might treat hypertension, diabetes, anaemia or might listen to the concerns involved in an emotional problem. If these syndromes become complicated, the doctor will refer to the corresponding specialist. In the same way, if the process of a terminal illness looks as if it will be of a long evolution or to have clinical, social or family complications, the Palliative Care unit should be consulted, or the case should be passed over.

Over the course of this seminar we have discussed the great step forward that has been made in the creation of the speciality of Palliative Care and of Palliative Care teams in the improvement of clinical practice in terminal *processes*. We have also discussed how the great majority of these terminal illnesses end in either healthcare institutions or at home. These places should therefore be up to the task, maybe not in complicated cases, but certainly during normal final phases, the end of life phase and pre-terminal phase, and, especially, in the very final moments. If they are not able to cope, they run the risk of spoiling the hard work that has taken place during the course of the illness, and the corresponding trust built up by the patient in his *doctor or medical team* which have derived from good doctor-patient relations.

We believe that healthcare workers are still a long way away from having the minimal acceptable training in facing this task from all of its clinical-biological, psychological and social standpoints. The training we have received (not including nurses) exclusively to cure, and not in the provision of care, might justify this tendency. With the objective of finding out the current state of the question of dying, and in particular the question of sedation, which, it goes without saying, is not the only means of securing a dignified death, we carried out an opinion poll, details of which follow.

Nursing and end-of-life sedation

The Nursing body are the healthcare providers which accompany the patient's stay in a General Hospital in the closest, most continuous and consistent way. We chose to sound out nurses' opinions regarding "Sedation for the terminal patient or end-of-life sedation". We explored the personal opinions on the subject of the nurse her/himself and her/his experience regarding how it was dealt with in practice by: colleagues, patients and their families, and doctors. We also asked for details regarding the potential influence that nurses had decided to try to exert in such cases. The study and its results cannot claim to be statistically conclusive, however they represent opinions which might serve as a point of reflection or as stimulus to the debate. The design and the work of the poll was carried out with the active participation of ***María Rosa Pujadas*** and ***Rosa Batet,*** both nurses and members of the Ethical Care Committee of the Sacred Heart Hospital of Barcelona (Hospital del Sagrat Cor).

Fifty completed questionnaires were collected which had been distributed between the various admittance wards and between different shifts in a random manner. The ICU was not included as the nature of this ward is very different from other wards.

Results of the "Sedation in terminal patients" questionnaire.

Number of completed questionnaires: 50

1. **94%** of those questioned believed that sedation of terminal patients should take place if there is severe suffering. One respondent replied that it should not. Two answered "it depends".
2. **64%** of respondents replied that they often saw terminal patients with a high degree of pain that were not sedated, whom they believed should have been sedated.

   34% of respondents replied that they had not. One respondent did not provide an answer.
3. In their experience those most likely to request terminal sedation were:

   55% (33): family members.
   30% (18): the nurse.
   10% (6): the doctor.
   5% (3): the patient.

   (10 respondents chose more than one option, figures in brackets show the actual number of responses)
4. **52%** of respondents had come across doctors who repeatedly resisted sedation.

   48% of respondents had not.

5.- **20%** of respondents had come across nurses who repeatedly resisted sedation.

   80% of respondents had not.

6. **74%** of respondents had tried to influence others, sometimes doctors, in the need for terminal sedation

   26% of respondents had not.
7. Of those that had tried to play an influence:

12 (36%) respondents stated that doctors usually changed their minds after such intervention.

22 (64%) respondents stated they did not. There were two respondents who added a note saying, “Sometimes”, and one who added, “Depends”.

8. If they are informed, how do families normally react?

   57% (30): Satisfactorily.

   7% (4): They appeared to be against it.

   34% (18): Ambiguous, difficult to tell.

   (Two respondents chose two options, the actual number of replies is shown in brackets)

Conclusions

The fact that many nurses who took part in the survey were in favour of end-of-life sedation and that they believe that there are patients that should be receiving it who are not, stands out.

They say that it is mainly family members who request sedation, and that once it has been performed they generally react satisfactorily, with a lower percentage acting in an ambiguous manner.

They discovered that almost half of the doctors and a minority of nurses were against sedation.

A majority of nurses had tried to influence the doctor regarding sedation, and a third of these believed that their intervention did have some effect.

Comments

As we had previously imagined, the survey suggests more than it concludes. It leads us to believe that those closest to the patients are those that most frequently request sedation. This may be due to an identification with the suffering, and emotional overtones. One might also be led to think that proposing sedation is not the same thing as actually administering it when we compare the notable differences between doctors, nurses and family members.

The patient’s apparent lack of “say in the matter” is surprising. This may be due to him not wishing to exercise his rights, having asked another person to speak for him, or to the fact that he is not aware that such rights exist and that nobody has advised him or reminded him of them.

Human rights, their application in bioethics and, in this particular case in palliative care, place before us the challenge of continuing to research and debate this speciality, as well as attempting to encourage training and motivation in the subject throughout the whole healthcare sector in order to achieve improved end-of-life care.

4.7

In general, patients are expressing a desire to control pain and anxiety, more than the desire to die. Personal preferences in these situations change according to the changing circumstances and stages of life.

Manel Salamero

I should like those here present to consider three aspects of this debate: the role of doctors and other health care professionals, the theoretical definition or demarcation between different clinical scenarios, and the social perception of these distinctions.

Firstly, I believe that when faced with a problem involving such emotional involvement we should avoid placing all of the ethical weight of the act of relieving suffering in death on the shoulders of the professionals. We should remember that in Switzerland, assisted suicide (which I shall talk of in more detail later) has been decriminalised and does not require the involvement of a doctor. In discussion forums such as this one where the majority of us are healthcare professionals, in order to avoid giving too much importance to the professional perspective, it is important to separate the discussion on the ethics of sedation and related actions, from the healthcare professionals' role.

But, I also believe that just in the way that we should respectfully heed each specific patient's requests, we should also consider the scruples of each particular doctor. The difficulties, both theoretical and practical, of the rule of double effect have already been discussed. But it might prove useful, in spite of such difficulties, to achieve a balance of sorts - something which is always difficult when differing convictions and sensibilities in human relationships are so powerfully opposed. As Sulmasy and Pellegrino[1] said, "According to the rule of double effect, [however, the appropriate and compassionate use of morphine] is morally permissible even for those who are morally opposed to euthanasia and assisted suicide. This rule allows physicians opposed to euthanasia and assisted suicide to treat pain adequately in these situations with a clear conscience." However, in a society such as ours with sufficient resources, and tolerant attitudes in the face of diversity, different alternatives which preserve both patients' choice of treatment and the way they live, and the clear conscience of the healthcare professionals attending to them, should be promoted.

Secondly, I should like to link the scenarios according to the clinical criteria differentiated by Dr Porta, with the distinction between principle-based ethics and the consequence-based ethics described by Dr Couceiro. In the first presentation the different types of sedation available were demarcated with very clear concepts, reference being made also to euthanasia. In relation to the ethical problems which the issue raises, I believe that we must add a third element, assisted suicide. Deep and irreversible sedation, assisted suicide and euthanasia can be theoretically defined as distinct entities, but in practice such differentiation is not so clear; it is easy to imagine several borderline situations where ascription to one category or another, is at the end of the day, a question of convention.

And in relation to the third aspect, social perception of the differences, I should like to add that the distinction between the different scenarios made by doctors is not the same as that made by the general public, as a recent study by Morita[2] showed. According to the study, the general public place continuous deep sedation nearer to assisted suicide and euthanasia, than to mild or intermittent deep sedation. The doctors tended to take the opposite view. For the individual most concerned in how his own death, or that of his nearest and dearest, will take place, the loss of consciousness is of more significance than to the professional who is attending to the death of the patient. This perception from outside the medical profession adds to the questioning of the distinctions between the three scenarios within the context of the ethical discussion.

The differentiation between sedation, assisted suicide and euthanasia, is in principle, very relevant for an ethics code based on principles, but not so relevant when viewed from a perspective of *consequence-based* ethics. If one presupposes the patient's consent and the avoidance of pressure on vulnerable individuals, the three scenarios have, as a fundamental consequence, the voluntary interruption of the existential and/or biological life of whoever requests it. For consequence-based ethics the level of participation of the subject in the final act necessary to end existential or biological life is irrelevant, as is a distinction between those two types of life. In my opinion, from a principle- based ethic standpoint, the questioning of either of these situations leads to a questioning of just one principle: the right of the individual to dispose of his own life. In this context, an excessive reliance on the theoretical limits can lead to a confusion between ethical debate with the margin for action that legal guidelines allow in each socio-historic context.

As the European Association for Palliative Care[3] stated in a recent document, " the requests for euthanasia and assisted suicide often change with the provision of global palliative care" (p 99). This declaration is of significant importance, as in general, patients are expressing a desire to control pain and anxiety, more than the desire to die. Personal preferences in these situations change according to the changing circumstances and stages of life. A very important aspect of the work of a doctor is to gauge these preferences through dialogue with the patient.

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4.8

In difficult decision-making situations, the phenomenon of " the loneliness of the professional" can appear. Defined as a complex situation where the professional must make decisions which he does not feel able to make for various reasons: family or patient pressure, the time factor, inefficient treatment strategy.

Jordi Trelis

If we understand the concept of life to be the state of activity of rational beings, and therefore death as the end of such a state, any issue or action regarding this aspect should imply a level of knowledge regarding what life and death consists of for those involved.

Our society denies death, it is lived mainly as a failure. Adaptation mechanisms related to age (well, he was old, death was to be expected), to incurable illnesses (he did not respond to the treatment), to suffering (it was no kind of life…) to loneliness (he had nobody to look after him) and the many other examples that could all be used to illustrate this point, all stem from this negation.

The reality is that death in itself generates a feeling of powerlessness, but when faced with difficult or desperate situations, we provide it with a role where we feel we can use it as an ally. This is the point from where opinions, thoughts, debates, laws, etc. all emerge.

If we ask if somebody is ready to die, the most probable reply is that the majority of us are not (it is a question of priorities), but the weakest amongst us are, perhaps, ready. By weak, I mean people of an advanced age, people with chronic illnesses, people without family, people with emotional disturbances, etc. In these circumstances (some of them reactive), death may provide a solution to the problems generated by life. The processes of life and death should be in harmony, and any factor which tips the balance will lead to an imbalance with its consequent manifestations. Such manifestations will be different for each individual, according to the way he is, the way he thinks, or the way he relates with others, etc.

The problem is amplified when healthcare professionals have to take a stance on a matter where powerlessness, fear and insecurity play a major role in the decision-making process, with the patient, family members, and quite often the professional himself being adversely affected. It is like adding confusion to the existing confusion already surrounding the subject. This is why any measures that might be employed, to reduce these feelings of powerlessness, fear and insecurity, would be welcomed. From undergraduate to postgraduate training, from care protocols to ethics committees, from publications to debates.

The concepts of terminal sedation and palliative sedation have been appropriately defined by the speakers; the next step is to put the theory into everyday practice. Sedation should be considered not as a means but as a tool, and each situation or case should be considered individually. We should be aware that in specific circumstances we, the professionals, will have to take the initiative, with the patient's consent or with a family member's consent when the patient cannot decide.

In difficult decision-making situations, the phenomenon of " the loneliness of the professional" can appear. Defined as a complex situation where the professional must make decisions which he does not feel able to make for various reasons: family or patient pressure, the time factor, inefficient treatment strategy. In these circumstances it is advisable to talk with other professionals (doctors, nurses, etc.) and to use teamwork as a means to attain the desired goal. Otherwise, it is very probable that such decisions will be so subjectively skewed as to induce even more stress in the doctor .

Consequences of this phenomenon may include cold-blooded treatment, lack of follow-up, euthanasia, break down of the doctor-patient-family relationship, lies, and irrational decision-making.

The professional dealing either directly or indirectly with the end of life should adopt the same type of model as is applied in other medical disciplines such as intensive care, heart surgery or transplants. We should evaluate the criteria for entering a programme, reach a consensus on the different strategies available to resolve a problem, apply the established protocols, identify difficult situations and the means of preventing them from arising, advise on and be aware of patient-family opinions, and conduct a detailed evaluation of the evolution of the process.

The development of palliative care and ethics committees in hospitals have thus provoked a new debate in a medical sector which has been extremely dedicated to curing, but, to a lot lesser extent, to pain relief. The end result should be a heightened awareness of the subject.

4.9

We must consider the fact that the intense suffering produced by refractory symptoms affect not only the patient, but his family and the way they handle the subsequent grief process, and the healthcare workers that attend to him as well.

Joaquín T. Limonero

I should firstly like to congratulate the Víctor Grífols i Lucas foundation, the organisers, and the other speakers, and also thank them for allowing me to take part in such an enlightening and quality debate on ethics and end-of-life sedation.

I should now like to go over some of the points made today for further reflection and detailed debate.

Clarification of the concepts

In a situation of terminal illness, it would be more sensible to speak of feeling well/ill rather than quality of life, as some publications have already stated, due to the different implications of these terms. Also, existential anguish or psychological distress is often referred to. These concepts can also generate confusion. I believe we should talk of ***intense continued suffering*** in a patient with a very short life expectancy (hours or days), this term should encompass the personal history of the patient, and his attitude towards life, as well as a very high level of anxiety. This intense suffering, with a high level of anxiety that cannot be reduced or alleviated (also sometimes referred to as refractory suffering), should be one of the criteria used for the application of end-of-life sedation, and even in cases where a patient has a longer life expectancy, for example two or three weeks when the treatment that has been given or might be given has not or would not reduce or alleviate such suffering, if and when the explicit consent of the patient has been granted. We must consider the fact that intense refractory suffering affects not only the patient, but also his family, and the way they handle the subsequent grief process, and also the healthcare workers that are attending to him.

End-of-life sedation should be applied when the patient manifests continued refractory suffering (through either bio-medical or psychological symptoms), and when the explicit consent of the patient, or a family member (when the patient's consent is not available) has been obtained. However, the other available psychological and/or pharmacological treatments that are available before applying palliative sedation at the end of life or close to the end of life should be adequately considered; we should undertake a full evaluation of the suffering or of its probable causes, and not "confuse" the complaints or demands of the patient which may be a result of his circumstances, rather than refractory symptoms.

Other important issues related to refractory symptoms also stem from this point: How can we measure a patient's suffering or its intensity in a reliable and repeatable manner? What characteristics should such evaluative instruments fulfil? Might they be applied to a patient who has difficulty in communicating? There are not many instruments, such as symptom severity over time or the Edmonton Assessment System, available for such evaluations at present. We believe that this aspect should be studied in more detail, as the evaluation of suffering might be an indicator of the quality of palliative care given to this type of patient. As you might have realised, what seem to have come out of these deliberations are new questions, rather than solutions to the problems.

How might difficult situations at the end of the life of a patient, that might "complicate" the application of sedation and make the patient more

uncomfortable, be prevented?

Some of the potential difficult or complex situations that may occur in the circumstances of terminal illness, may, in part, be reduced or even avoided if adequate ***planning*** is provided for in the ***therapeutic relationship*** which is established by the patient, family and healthcare team 'triad'. That is to say, comprehensive and easily-assimilated information should be provided through frank and honest communications, so that the patient/family can understand the situation they are facing, and prepare themselves for potential future changes or events in such a way that they can make decisions regarding sedation or other treatments available in the most autonomous way possible. It is therefore ***necessary to plan,*** to have previously raised the possibility of sedation in the communication process that all treatment necessarily involves.

We should not forget that ***information*** is the means by which uncertainty and suffering can be reduced, but only when it is sensitively provided to the family as it needs it. This process of communication, as I have already mentioned, should start at the very beginning of the treatment, not just as a means of providing treatment for current problems, but also to play a ***preventative role*** in reducing the impact of potential future problems. In order to achieve this objective, continued and personalised treatment of the patient should take place, and he should be directly asked ***what it is that is causing his suffering or pain,*** i.e. what are the particular things that are worrying him or are most important to him, and that might cause him further suffering. With this preventative anticipation, we can detect and prepare for potential situations that may cause suffering, either by boosting the resources available to the patient and his family, or by lessening the impact that such situations may cause when they inevitably arise.

If we bear in mind the points just raised, the proposal of possible sedation of the patient as a means of ending refractory suffering should be raised within the climate of dialogue that has just been described. ***Consent to sedation*** should, obviously be ***explicit,*** and it should be the patient himself who consents to its application. However, once sedation has been offered as a possible method of palliative treatment for untreatable or refractory suffering, the attending physician should continue to emphasise that sedation is provided within established treatment guidelines in order to ascertain that the patient has fully understood the objectives of such treatment, or to ensure that he has not changed his mind as his illness has evolved. One should also bear in mind that a continuous evaluation of the patient along the final stages of life should be carried out in order to ensure that palliative care is provided which meets his priorities or needs.

As for the family, unnecessary suffering or a more difficult subsequent grief process can be avoided if one applies the same principles we apply to the patient, i.e. ***anticipation, prevention and education.*** Thus, we should ***involve the family*** from the outset in the patient's care and in the decisions regarding treatment to which the illness may lead. By providing clear information on the situation, on the probable evolution of the illness, of the treatments that may be given to make the patient as comfortable as possible, and on the role that the family itself can play in the care of the patient, we can facilitate active participation in the patient's care. This will provide a sense of control over the situation, lessen the feelings of uselessness or powerlessness, and facilitate frank and open communications with the patient, and above all we are preparing or ***enabling*** the family to anticipate future events.

Also, if we explain to the family, in the same way as we explain to the patient, the possibility of giving ***palliative*** or ***end-of-life sedation*** when there are refractory symptoms which cause great suffering and that cannot be otherwise controlled, we can avoid the sense of subsequent guilt which might appear, and we can also avoid more complicated grief processes. However, it is essential that it be explained very clearly to the family that ***sedation is not the same thing as euthanasia.*** It should be pointed out to them that when a patient is at the end of his life, the main priority is no longer to save his life, but to make him as comfortable as possible and to reduce any suffering. That the aim of the sedation is to relieve the patient's suffering by decreasing his consciousness, and that death, when it comes about, is not an undesired effect of the sedation but that, with or without such sedation, the patient would die in a few hours or days.

Problems or questions still pending with relation to end-of-life sedation

Despite the fact that we have dealt with critical aspects of end-of-life sedation over the course of today's debate, I believe that there are still some matters pending that we should go into in more detail in order to clarify them. They include:

- **A clarification of the difference between end-of-life sedation and euthanasia for society in general.** The feelings of guilt in a family member who believes that they are "killing" or "asking" for a sick patient "to be killed" could thus be avoided, as could family pressures on a healthcare team to end the life of a patient when the illness covers a prolonged period but there is no suffering or discomfort in the patient.

- **The creation of tools to measure the presence and intensity of suffering.** This is one of the points that I think should be a priority in this sphere, for two main reasons. The first is due to the fact that end-of-life sedation is applied in the existence of refractory suffering (what suffering? how much? for how long?); and the second is related to the main aims of palliative care which consist of avoiding or reducing suffering and providing the most comfort possible to the patient and his family.
- **The improvement of the procedures of informed consent.** Such consent should be explicit, in the majority of cases. It should be the patient himself who decides on treatment alternatives in an autonomous manner, and in a few special cases, due to the seriousness or speed of events, in an implied manner or through a spokesperson.
- **An analysis of the time period elapsing between applying end-of-life sedation and actual death.** In this way we might be able to discover whether dying patients who have received end-of-life sedation live as long as, or less than, those patients in similar conditions who have not had such sedation. The ethical question of not applying sedation to a dying patient in pain could be resolved in some cases if the control group (non-sedated patients) were made up of those patients who had declined or did not want sedation, or if a delegated family member had refused such treatment. The results of such a comparison would be extremely useful in clinical practice.

4.10

An important aspect which must be debated in the analysis of these situations is the confusion that sometimes arises between the anguish and the requests of the patient, and the anguish and demands of family members ("above all, don't let him suffer"), or even the emotional instability of the healthcare workers involved.

Màrius Foz

In the two excellent presentations of today, what has been made very clear is the need to clearly differentiate between *palliative sedation*, probably definitive, of a patient in an advanced stage of illness, or of one who is terminally ill but not dying who may still have a few days or weeks left to live, and *end-of life palliative sedation* or *real terminal sedation.* Although the latter is not exempt from ethical problems, *palliative sedation* throws up more important and complex issues.

There are two central aspects of the ethical analysis of this type of sedation. The first is centred on the true refractory nature of the symptoms (pain, dyspnoea, deliriousness, anguish, etc). This is a crucial point that should always be analysed in detail by experts in palliative care, before we consider the possibility of *palliative sedation.* The other central aspect is the explicit consent of the patient, which only in very rare cases may be implicit or delegated to another. An important point to bear in mind when considering such situations is the confusion that sometimes arises between the anguish and the requests of the patient, with the anguish and demands of family members ("above all, don't let him suffer"), or even the emotional instability of the healthcare workers involved. I experienced difficult situations in an Internal Medicine ward at the end of the 80s, where terminal situations with some AIDS patients were particularly dramatic, and where the collective anguish (of the family and healthcare workers) may have led to an abuse or incorrect use of lytic cocktails.

Dr Bayés, today's chair, recalled at the beginning of the seminar the concept defended by David Callahan, that the mission of a doctor is not just to try to cure his patients, but also to care for them and alleviate their pain when their illnesses are irreversible and terminal, and to help them to die peacefully.

Although there is no doubt that significant advances have been made in Spain over the last twenty years, especially after the introduction of palliative care units in many hospitals over the 1984-1992 period, there is equally no doubt that there still remains much to do in the cultural change of direction propounded by Callahan. I should like to make two comments related to this matter. The first is related to budgetary limits and resource management, and the second is related to the danger of excessive specialisation and lack of training in this area.

I experienced the severe difficulties that arose in attempting to recruit professionals in patient care and relief (psycho-oncologists, AIDS unit psychologists) for hospital staff, directly and indirectly, over many years when working in the Internal Medicine department of the Germans Trias i Pujol University Hospital. Budgetary limits and the need to optimise resources were arguments that were difficult to refute and which almost always led to the recruitment of professionals specialising in diagnosing and “curing” patients. Fortunately, last year our hospital secured a Palliative Care Unit, but according to a comment made to me today by Dr Trelis, the current chances of extending this unit are nil, because of the same problems of budgetary limits and other “priorities”. It is very unlikely that such a situation will change in the future, which is why the best hopes for a change in culture should revolve around improved training in healthcare professionals, especially amongst general practitioners, in the way indicated by Callahan. One danger that should be avoided is that palliative care becomes just another speciality, where a doctor who was no longer interested in treating an incurable patient could just pass him over to the corresponding “specialist”. This obviously cannot, and should not, be the answer – all healthcare professionals should have a more complete vision of patient care during all the phases of an illness, with the assistance of professionals in palliative care provided under very special circumstances. This concept obviously demands improved training in this area. In the majority of Medical syllabuses, this type of training is clearly insufficient and should be improved without waiting for such deficiencies to be made up either by optional courses or postgraduate training. I believe that a good time to improve doctors’ training is during the residence period. In Barcelona’s Hospital Clínico they have introduced such a training initiative and it has received a high level of acceptance by the residents. This is one path we should follow in order to advance that change in culture which we are all demanding.

4.11

Without appropriate training, the responses of professionals may be influenced by fear, and all of the defensive positions that accompany such an attitude, this may lead us to incorrectly diagnose a refractory symptom having been influenced by our own fears and as a result of the scant training we might have received in overcoming such fears.

Mª Pilar Barreto

I should like first of all to emphasise the importance of debates like this one where we have listened to two excellent presentations, and the thoughts of a significant number of professionals involved and implicated in one way or another in promoting the dignity of human life during its final phase.

I think that the metaphor of the statue is particularly pertinent in this case - it is often invoked to show the variety of different points of view that are available of the same object, depending on one's position, and which, when all of the angles and view points are considered together, produces an even more beautiful image.

Although there are many different topics of great interest which have made up the debate over the course of today's seminar, I should like to focus my comments on one particular aspect – the meaning of psychological refractory symptoms.

My concurrence with Dr Couceiro, on the need for analysis from the stance of ethical responsibility, using Weber's extremely graphic and lucid expression of 'responsible conviction', goes without saying. She went on to discuss how for an ethical judgement to be sound, the circumstances and conditions which guarantee both correct clinical practice, as well as the maximum respect of the autonomy of the individual, should also be considered. I should like to add my opinion on this matter.

I am in absolutely no doubt that in the same way as physical symptoms, psychological symptoms can be truly of a refractory nature. To refute this fact would be to accept the omnipotence of the professionals and of the mental health disciplines, the reality, and of course my intentions, are far from this. Furthermore I believe that the advance of knowledge can only be achieved from a position of humility, we need to be aware of our own vulnerability and limitations when faced with such enormous professional difficulties. Only when we recognise these limits can we act honestly and responsibly. However, some questions might arise when we begin to consider psychological refractory symptoms, and I should like to raise them here because I believe they may be useful in helping improve our interdisciplinary behaviour as doctors. Good clinical practice and taking ethical decisions, as my good friend and colleague Javier Barbero pointed out, demands that exceptions be made, and the application of sedation is obviously an exceptional measure[1].

A) The first point I should like to refer to is the ***existence of "pure" psychological symptoms*** which, in these circumstances are of vital importance when the decline of the body is so marked, and when the problems produced by the illness can be confused with psychological alterations, basically of an emotional nature. The big question of doctors and researchers is whether we are seeing some kind of emotional disturbance, such as depression, or whether the majority of symptoms (asthenia, sleep problems, eating disorders, etc.) are a result of the progression of the illness, or if we are faced with a problem such as "demoralisation" or a problem of a different nature, such as for example spiritual needs[2]. A positive starting point would perhaps be to look at all of the symptoms and study how they interact with each other.

B) The difficulty in defining the nature of the symptoms does detract from the importance of the need to control them effectively, and this is why the second point I should like to emphasise is ***the importance of true teamwork.*** Without employing teamwork we cannot be certain of having tried all of the resources that the various disciplines, and people that represent such disciplines, can bring to the most appropriate control of such symptoms. The experience in our field reflects how, in the vast majority of cases, the appearance of the psychologist is only deemed necessary when the emotional disturbance exhibited by the patient is very severe or when he does not respond to other types of treatment[3].

If we delve deeper into this point, there are serious difficulties as well as great advantages to teamwork. It may be very useful to reflect upon the way we actually carry out our profession. I should like therefore to ask some questions which may assist us in this task:

– Is my attitude one of co-operation or competition with the colleagues in my field or in other fields? I.e. am I working towards common goals, or do my own personal goals take prevalence?
– Am I really convinced of the multi-faceted nature of the human being, and of the need for intervention on a 'whole person' level?

- Would I be prepared to fight for the goals which are implied when talking of efficient teamwork? n.b. the following should at least be considered:
    1. Sharing loads, releasing tensions and obtaining the proposed treatment objectives.
    2. Planning work
    3. Creating a good group climate which facilitates task orientation. Establishing a relationship of trust, avoiding improvisation, and broaching conflicts (regarding organisation, communication, roles etc).
    4. Developing methodologies for decision taking based on deliberation, negotiation and consensus.
    5. Defining the functions of each group member and thereby clarifying common and specific functions.
    6. Facilitating the active participation of team members.
    7. Identifying the needs of those who make up the team.
    8. Developing group cohesion for the common good.
    9. Developing flexible, creative and good-humoured strategies.

Finally, an inner examination would be very useful in acknowledging our own personal resources and any shortfalls in our training, in order to be able to harness those aspects that are truly useful, and to acquire those which we are lacking so that we may improve the way we exercise our profession. I should like here to emphasise the importance of assertive communication (specifically to make or reinforce constructive criticism), the ability of controlling one's personal emotions, and a knowledge of the key elements for working well in a team.

C) The ***need for training*** of healthcare workers in order to give adequate emotional support to patients and their families relates, of course, to all of this. We have always defended[4] the fact that it is a duty of all the professionals in a team to communicate properly with each other, and to provide emotional support to patients and families. All professional healthcare workers have the ethical obligation of knowing how to provide a minimum of emotional support, however as situations can become very complex, improved preparation for meeting the needs that may arise is also necessary. In the final stage of life, because the emotional impact throughout the dying process is very intense and because of the transcendence of the period that the patient and his family are going through, a solid grounding and training in counselling and an attitude of availability are required. We should also acknowledge that greater complexity demands a higher level of specialisation. Excellency in the emotional support provided, is without doubt, the responsibility and main aim of the professionals who have chosen this option. Without training, the professional's response is often dominated by fear, and defensive stances are also obviously involved, such as us talking of refractory symptoms when these have been diagnosed more from a position of our own fears and the scant training we have received to face them, than from the nature of the symptoms themselves.

D) Finally, I would not like to finish without giving ***special mention to the family.*** As has been raised many times over the course of this seminar, the most accessible spokesperson is often a family member because of the patient's enormous vulnerability, sometimes expressed, for example, in the great difficulties in communication. I should like to warn of the danger of taking them for mere amateurs or available caregivers. We would have a much better chance of obtaining their co-operation if we could listen to and understand their personal and family- related difficulties. If the emotional upset of family members is intense and is not attended to, this may prevent a clear understanding of the patient's situation and the appropriate recognition on how best to act at a later stage. Furthermore, any defensive responses might betray, as with healthcare professionals, an expression of their own fears.

To summarise, I have attempted to emphasise the complexity of labelling a psychological symptom as a refractory one - the multiple causes of such symptoms, the necessity of team work when attending to such cases, the importance of training in order to provide adequate emotional support, and the ability to decide when a symptom will not go into remission, and to be able to justify such reasoning, and finally, the absolute need to see members of the patient's family not just as a basic source of support to the patient, but also as individuals who are suffering in their own right, and whose needs also need to be attended.

Only when we have considered all of these factors, can we accept that we have used all of the resources available before turning to sedation, as Bioethics so wisely directs.

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4.12

We should highlight the need to look at the whole patient and to work as a team in order to truly provide comfort. Control of just the physical symptoms, deriving either from the illness or its treatment, is not enough.

Núria Gorchs

Shaping the values of Society

I should like first of all to agree with Milagros Pérez Oliva's statement that between all of us and using discussions such as this one, we can help to shape the values of Society. This is why we should correct any mistakes and clarify the difference between terms which are often employed by the man or woman in the street indiscriminately or quite incorrectly, for example, *request for euthanasia* and *assisted suicide,* or *comfort* and *well being.* Such terms are often "prostituted" in our society, and these are concepts which also pertain to the psychological, philosophical and existential realms.

"Listening to the heartbeat of the emotions "

And with reference to Dr Porta's magnificent presentation where sedation, in a clinical situation presenting refractory symptoms, or with the aim of reducing distress or suffering, is considered appropriate. Other reasons for applying sedation have been defined as "extreme anxiety", "existential crisis" "extreme suffering" etc.

In 1989, Dame Cecily Saunders defined the concept of "TOTAL PAIN" to identify the various sources of suffering: of a somatic nature, or of a psychological, social or spiritual nature, i.e. without physical pain. This alerted us to the need to treat the whole patient, and to work as a team to truly provide comfort, where the control of the physical symptoms derived from the illness or treatment is not enough. Pharmacological prescriptions and specific resources for palliative care and training etc have advanced greatly since that time. But even still and when facing difficult situations, who will listen to the heartbeat of the emotions? who has taught us how to do this? the bioethicists, nurses, social workers, psychologists, priests etc. And how should we act in the face of despair, or the values of others?

There are words and existential aspects that go beyond medical and psychiatric terminology (despair, loss of meaning, dignity and demoralisation), if we refer to the work of William Breitbart, a psychiatrist in the Memorial Sloan-Kettering Cancer Center in New York[1], who is carrying out research on psychotherapeutic treatment in palliative care centred on the construction of meaning. The final conclusions have not yet been reached, however it would appear that although depression, anxiety, fear, hopelessness and despair are distressing experiences, they can be foreseen. This would help a lot in the systemisation and standardisation of this type of treatment. And, on the other hand, in clinical practice, there is still much to be done to improve our definition of dignity, an area where many factors come into play, and where many aspects of the experience of illness are also involved[2].

Quality of life threshold: Individualism and change over time

Realities and expectations are perceptions which are unique to each patient, and which can change continually within that same patient over time. I have seen circumstances over the course of my career which could easily be catalogued as situations of intense suffering (weakness and extreme cachexia, communicating in code etc) which, however, were perceived calmly and reasonably. It is difficult, when one is experiencing normal health and activity levels, to predict or imagine how you might live in certain situations, or the capacity of the human being to adapt to different situations of risk, danger and stress is truly incredible. And we, as professionals, should be very conscious of these distinct realities and expectations, and pay them their due respect, regardless of the field we are in (AIDS, oncology, geriatrics, neurology etc)

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I should also like to acknowledge all of those professionals and individuals linked to the end of life process who, often, just with their simple presence and experience, can help us to learn new habits and unlearn old, less helpful attitudes.

4.13

Demands for euthanasia and physician- assisted suicide, when examined in their true contexts, do not obey so much the need to affirm the right to dispose of one's own life, as much as the need to find the least bad solution to an extreme situation.

Francesca Puigpelat

Palliative sedation can be seen as a widely accepted way of "helping someone to die". In contrast to this, there are other models of helping someone to die which are much more widely debated, such as physician assisted suicide and active euthanasia- often confused with terminal sedation.

What all of these situations have in common, despite their conceptual differences, is as Dr Couceiro pointed out, that their ultimate aim is to definitively end suffering.

Understanding terminal sedation, physician assisted suicide and active euthanasia as different ways of "helping someone to die" allows us to give a more satisfactory answer when we are trying to justify and regulate such conduct. Why? Because only from a "helping someone to die" perspective can we view the death of the patient in these cases as it really is: the result of a ***mutual agreement*** between the various parties, the patient, family members, if there are any, and the healthcare workers, an agreement that is based above all on notions of responsibility and care, rather than on rights and fairness.

Demands for euthanasia and physician-assisted suicide, when examined in their true contexts, do not obey so much the need to affirm the right to dispose of one's own life as much as the need to find the least bad solution to an extreme situation. This is why the patient requests the help of a third party to put an end to a state that they consider unbearable. This request for assistance cannot be sufficiently explained if we are to use only talk of rights and their corresponding duties. In such cases it is not a question of exercising rights and duties, as much as understanding that death is always a painful and difficult test, one which can only be overcome humanely if the patient knows that he can count on the help and commitment of all those around him.

This participation of third parties, which I consider desirable, is not well represented in the arguments given in favour of active euthanasia and physician-assisted suicide. Such situations call, above all, on the right of disposing one's own life and on free will. The existence of a right normally implies the duty or obligation of another person to satisfy the claims of the individual with the right. In this case, if we consider that the patient has the right to die, we must then maintain that the medical profession has the duty or obligation of providing such a death when the patient cannot undertake it alone through the act of suicide, or when to undertake it alone would be particularly painful or inhumane.

To attach such an obligation to the medical profession does not seem to me to be the best solution. It is a very different thing to allowing doctors to help patients to die when they request such help. Allowing somebody to help a patient to die is not the same thing at all as making it their duty to provide such assistance. Third parties would be forced not to interfere in the behaviour of doctors that offered such help.

This is the stance of the Spanish Constitutional Tribunal.

In its ruling STC 120/1990 the Tribunal ruled that the right to decide about one's own life was a manifestation of free will, but not a fundamental right. It is not a fundamental right because free will is legally covered by article 1.1 of the Spanish Constitution, and does not appear in the section of the Constitution that covers fundamental rights. Although it is not a fundamental right, it might be argued that the State cannot legitimately forbid suicide. But if it may not forbid suicide, can it forbid third parties from becoming involved? If we deem the aim of the prohibition of third party intervention to be the avoidance of potential abuse, we might consider such a prohibition as being neither arbitrary nor disproportionate. If we conceive the ability to dispose of one's own life as a right, it would be even more conceivable that the State might punish the intervention of any third parties in the suicide of a competent individual.

Greater acceptance of terminal sedation is due to the fact that we do not conceive of it so much as exercising the right to die, as appropriate treatment at the heart of a doctor-patient relationship, when one might appeal for compassion and care in helping someone to die. Physician assisted suicide and active euthanasia should be approached in the same way. If living a good life requires the affection and solidarity of others, a good death, in today's highly 'medicalised' or medicated and secular society, also demands the affection and solidarity of healthcare professionals. This commitment may not be legally forced upon us, but it should be legally permitted for those amongst us who wish to assume such a position.

From the speakers' presentations today it may clearly be understood that although terminal sedation is an accepted and acceptable practice, abuses may occur; this is why the need to establish protocols, guaranteeing the correct application of such treatment, and equality and safety measures, are being fought for. Abuses are also possible in the provision of physician assisted suicide and active euthanasia, and this is why they should also be submitted to strict controls. Legislative intervention in such matters would be especially useful, not with the aim of prohibiting it, but in order to see such actions channelled correctly. Dutch law, regarding the termination of life at one's own request and assisted suicide, in force since April 1st, 2002, where the doctor-patient relationship is given particular emphasis, might serve as a point of reference for us when undertaking legal reform in Spain in accordance with the new value conceptions which are ever more widely shared by wide sectors of the public. This legislation should not in any way act as a substitute for palliative care. The Dutch experience could also prove very useful to us in this regard. Many patients who have their request for euthanasia denied them choose to die by not taking any food or liquid. This is a painful process where patients should also be able to depend upon the co-operation of doctors. Palliative care could provide such co-operation.

4.14

We should teach what sedation actually means, to Society in general, and explain the problems we are facing

Eduardo Clavé

Types of end-of-life sedation. Definition and concept of "terminal sedation". Should we alter the expression "terminal sedation"? Definition and concept of "palliative sedation".

As Loewy[1] stated, sedation consists of keeping a dying patient in an anaesthetised state. Other treatment is stopped and the patient is administered sufficient medication as to leave him in an unconscious state. Sedation is undertaken with the full understanding that no other active treatment will be given, and that patients will die as quickly as possible of the illness which they are suffering. With profound and irreversible sedation, the patient's death is not only foreseen, it is, in fact, what it is all about. It can however be masked by language which talks of the intention of alleviating pain and suffering.

The use of the word “sedation”, with the aim of naming a treatment which is applied under various circumstances – despite the fact that it is qualified by an adjective which attempts to frame it within a more appropriate context – carries the risk of confusion. This makes research into when treatment should be applied and how to undertake control procedures more difficult.

If we look at SECPAL’s definition of “terminal sedation” – where terminal sedation is defined as palliative sedation used in the end-of-life stage – it would seems that this type of sedation (as shown in the example demonstrated in case **“1”** by Dr Couceiro) would not present serious ethical problems, and would be easily understood and accepted by the vast majority of the population. My doubts arise regarding *“psychological suffering”* alone, which can be deduced by the definition, as it would be difficult to identify end-of –life phases where physical symptoms were not present .

Regarding “palliative sedation”, reference is made to alleviating one or more refractory symptoms (not when suffering the final death throes). But it is not clear whether physical, psychological or both types of symptoms are being referred to. As for the alleviation of physical symptoms, there seems to be no argument against it, after the judicious use of the available medical and psychological resources, and the request for a second opinion from another professional expert in symptom control has been sought. As Dr Couceiro discussed in case **“2”,** the use of sedation can be argued from a “lesser evil” perspective, or even from the principle of “double effect”.

There does however appear to be more difficulties in using sedation for psychological reasons – *existential suffering/ extreme anxiety*– as hospitals do not have any easy way of making objective judgements here.

I would firstly try to use the term “sedation” only when referring to “deep, irreversible sedation”. Secondly, I would differentiate between end-of life sedation and palliative sedation. In the end-of-life stage I would withdraw the term “sedation”, and I would include it as standard treatment in controlling symptoms of this stage, using a different name such as for example, *“sedative treatment at the end-of-life phase”* (or another term that was capable of expressing something similar and eliminated the word “sedation”). I would use a similar wording, *“sedative treatment of physical refractory symptoms”* for what those documents under discussion today might call “palliative sedation” for physical refractory symptoms.

I would thus reserve the word "sedation" for that form of treatment which comprised most difficulties in justifying, i.e. sedation for psychological reasons. The reasons behind such changes are:

- That the sedative treatment at the end-of-life phase or for the control of refractory symptoms might be considered "good practice", and may therefore be included in the Principle of No Harm. This does not preclude seeking the consent of the patient to any sedative treatment, and his being informed of such a possibility throughout his illness.
- That sedation for psychological reasons, apart from the difficulties in measuring, is linked more to the principle of Autonomy and requires explicit consent as well as a series of other prerequisites, as demonstrated by Dr Couceiro in the steps which should be taken in order to ensure correct practice is followed. We should also be aware that the patient may remain quite some time (weeks or months) with this type of sedation.
- In this way we could include the first type in an ethics based on the principle of minima, and the second type in an ethics based on the principle of maxima.

Criteria and conditions that should be considered when applying sedation. Definition and concept of "extreme anguish". The importance of evaluating the intensity and irreversibility of psychological discomfort that might lead to palliative sedation. Can some or most cases of uncontrolled end-of-life anxiety be prevented? How? When? Where? By whom?

What I have called, "*sedative treatment at the end-of-life phase or of physical refractory symptoms*", should be included in a protocol of best practice. It should be a treatment alternative that the patient (and society) should be aware of, so that he may decide to accept or reject such treatment from a position of autonomy.

As for what I call "*sedation*", meaning the use of sedating medication to eliminate the patient's consciousness in an irreversible form, which I would reserve for psychologically motivated treatment, I should like to make some observations:

- The end of a person's life is the end of ***"his life"*** and he is undergoing ***"his own death".*** Even bearing in mind the prudence of medical staff who would wish to be absolutely certain in cases where their evaluation of psychological anguish leads them to deduce the need to administer deep and irreversible sedation, we ought to eradicate the "need" of the doctor to control the process of death. That is to say we should avoid the type of *disguised "paternalism"* which, using the excuse of the difficulty of measuring or evaluating the psychological suffering of a patient, might decide that the patient should not be sedated.

- Whether or not to tolerate the end-of-life suffering – with appropriate palliative treatment- corresponds to the patient himself. We can thus, guided by prudence and by our own medical knowledge, agree upon various treatments- including temporary sedative treatment, psychological and emotional support, availability etc – whilst we are waiting for "results" over a "period", which must also be agreed with the patient, and which will allow us to arrive at the Treatment Limitation agreement, or to agree upon (deep and irreversible) **sedation.**

As for preventing such situations - this would derive from an appropriate doctor-patient relationship. The cultivation of such a relationship would have its foundations in the ***technical knowledge*** and ***the care ethic.*** I consider both of these elements to be fundamental to Palliative Care, and they were discussed magnificently by Javier Barbero and Francesc Torralba.

Are there clinical guidelines or a recommended protocol for sedation? Should one exist? Role of patient, family members, doctor, other healthcare workers, and team. When facing major refractory symptoms, how might one determine a "reasonable" waiting period before proceeding to the sedation of a patient ?

All protocols should make reference to the ***patient's wishes.***

As for *"sedative treatment at the end-of-life phase or of physical refractory symptoms"*, this should also be included as a treatment alternative in the guidelines or protocols of best clinical practice. The possibility of such treatment should always be made known to the patient, in order that during the process of communication between doctor and patient he might either accept or reject such treatment.

Furthermore, such treatment should also be available as an alternative treatment for psychological suffering. The protocol should also state the need to revise the points proposed in Dr Couceiro's text, and should attempt to avoid the risk of *"wanting to control the death process"* on the doctor's part, this should correspond solely to the patient. Consent, should, of course be explicit.

The "reasonable" period should be determined by the patient – an appropriate degree of communication between doctor and patient would facilitate an agreement on a "reasonable period".

Family members – but only with the patient's consent- may participate (in our society it is right that they should) in the process of communication and reflection necessary for taking such decisions. If we take the position that the doctor must always side with the patient, in the event of any conflict between the patient and his family, the doctor must always defend the patient's position and explain, in a convincing manner, why the patient's decisions are to be respected.

Difficulties in applying informed consent. How might they be resolved? In what type of circumstances might the possibility of sedation abuse be more likely to occur? Explicit, implicit and delegated consent. Sedation at the patient's request. Under what circumstances might sedation be considered as psychological euthanasia?

Informed Consent should be explicit in those cases of sedation for psychological motives. In other cases it should be considered as a best practice alternative, to which the patient may or may not give his consent, as with any other treatment.

The risk of abuse exists in all situations where the doctor-patient relationship is governed by a paternalistic viewpoint. It is often caused by the deficiency in communication technique resources which prevents an explanation to the patient of the various alternatives open to him.

Delegated consent may come through his representative via previous directives (oral or advanced directives) when a patient is no longer competent to take such decisions.

Before applying irreversible sedation, how should the "psychological grief" of family members be handled?

The family should be informed at the same time as the patient. Family members' grief should not be any different just because we are dealing with sedation. The alleviation in suffering that sedation provides is a strong consolation. The doctor's duty is to provide arguments that distinguish between sedation and euthanasia. It might be helpful in this respect, to make people aware of the concept of deep, irreversible sedation, i.e. both healthcare professionals and the general public (perhaps first waiting until such time as a high level of consensus is reached amongst healthcare workers before exposing the public to such argument).

Pending problems

- The need to make society aware of the meaning of sedation, and to explain the problems we are faced with.
- Resolve the problem of the confidentiality of the end-of-life, as the dying process is an intimate period which should not be invaded by a whole team of healthcare workers with different values and beliefs, and differing levels of maturity and sensitivity.
- Resolve the difficulties that sedation, as an alternative treatment which might involve the "slow" death of patient, might cause in hospital wards or at home, such as: the controls which must be given to the patient (type and how often), the acceptance of the various health workers involved (nurses on different shifts, doctors on cover etc) whose participation in the sedation decision has either been minimal or has not taken place at all, control of family anxiety caused by doubts over the procedure or of the "slowness" of the end: the medication – temporary wakefulness – or its side effects such as paradoxical agitation.

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4.15

Waiting, just waiting, is undoubtedly one of the most difficult situations a human being can find himself in (…) Waiting, and what is more, waiting for our own death throes which in turn herald our own death, seems to me to be something awful, inhumane, a great mistake born of ignorance in a culture which is always in a hurry to get a result, even if the result is the end. But it should not be a question of waiting to die, but of living life intensely, even in its final stages.

Clara Gomis

What are we silencing when we sedate a terminally ill patient?

Waiting, just waiting, is undoubtedly one of the most difficult situations for a human being to bear. Humans have arrived where we are in today's cosmos through our capacity to transform, create, and give meaning to our environment as well as to our own lives. Waiting, and what is more, waiting for our own death throes which in turn herald our own death, seems to me to be something awful, inhumane, a great mistake born of ignorance in a culture which is always in a hurry to get a result, even if the result is the end. But it should not be a question of waiting to die, but of living life intensely, even in its final stages.

Ever since Cecily Saunders began building the road towards palliative care in the 60s, healthcare systems and individuals have been becoming increasingly aware that there is still much to be done in the final stages of life. Almost at the same time, Elisabeth Kübler-Ross was working on identifying the stages of the grieving process to increase our understanding of what happens when somebody dies, and what might be expected. And these days, the opportunity to actively face the facts is even more possible when we have authors such as Worden talking not of "stages of grief" but of "tasks" to be undertaken.

Death is certainly a process, and a process which has the particular effect of accelerating the evolution of an individual, and making it possible, in a few days, to overcome personal issues which we had avoided achieving (such as asking for forgiveness), or to fall into situations which we had achieved avoiding over decades (such as desperation). Everything about us evolves over our final stage: our hopes, fears, values, attachments, tasks and emotions. Something which was of the utmost importance to us three years ago, was different three months ago, and even today might have changed from yesterday. This is why facing death alone is a difficult task, as is watching a dying person face it and not knowing what to do or what to say; and the capsizing might make us lay anchor even before we feel we have reached port.

Helping someone to die is, above all, in the palliation of the patient's physical pain because so much pain is capable of nullifying the individual. The current pharmacological painkilling possibilities, and more specifically, the possibility of adjusting the type and level of sedation of each patient, has been an incalculable achievement of medical science. An achievement which in turn throws up ethical questions to which the medical community is ever more sensitive, and which it wishes to respond to in a conscientious manner, that is to say, reflectively and studying each case according to its own particular circumstances, not according to a few basic principles which have been dictated to us.

But helping someone to die also means helping them to die well, which means, amongst other things, helping them to die at peace with themselves, with others, and with life itself: to die when the moment has arrived, when we close the circle, when we arrive at the port, or when, we have at least been able to take some measures which allow us to leave feeling satisfied. Innumerable circumstances make such a dignified death difficult, if not impossible: anguish and suffering over the end of our own life, because we fear being separated from those we love, because of the grudges we might bear or the hate we may feel, because of the bitterness at having become a burden to others, the humiliation of no longer being able to control almost anything, because of what we have done or left undone, because of what others may still continue to do, because of fear of the beyond or of a vacuum, because of the "who will look after you?", or the "what will become of you all?", and all of this lived often alone or in silence. I believe that suffering, tied into our life as it is, should be undone, not cut off. But that requires a lot of help, help of various types.

Firstly we should silence the physical pain as far as possible, and doctors – in open dialogue with the patient- will decide on the if, the how and the when of sedation. However, emotional suffering or pain, needs to be expressed before it can be undone, resolved or transformed. Suffering is not, nor should it ever be, considered as an end to itself, but it is a part of the progress of man, which often lives through difficulty, contradiction or meaninglessness, and must be forced to face such things in order to be able to advance. Psychological and spiritual suffering is probably the symptom that can be cured, wants to be cured and must be cured. But very few people can achieve this alone. And this is where my thoughts and my question on today's debate on *"Ethics and end-of-life sedation"* lie: What is it *that we are not doing,* within the healthcare system, when we sedate a dying being? Or to put it another way: are we certain that his suffering is refractory?

We sedate to alleviate or quieten pain and suffering when the illness is at an advanced stage and the symptoms which cause the distress are refractory, i.e. can no longer be controlled by any other way than affecting the consciousness of the patient. We sedate, of course, with the patient's consent, or when this is not possible, his family's. But, what have we been able to offer (support, direction, careful listening, attendance, care, company) before we decide that the suffering that that person is undergoing is indeed refractory, that is, that there is nothing else that can be done, that we have reached rock bottom?

Waiting, just waiting is abominable. Waiting for our own death or the death of another (friend, relation or patient). We do not have the proper words for it (terminal illness, death throes), because culturally and socially we have an absolutely passive and factual concept of death as an indisputable fact involving total extinction. But death, when it is not a sudden death, is a task that human beings can often undertake and consciously direct. The dying person is indeed undertaking a difficult process, one of the most difficult that he has ever had to face, the opposite in many senses of the one he has been undertaking ever since he was born. Now it is time to let go, to say goodbye. We should support him, help him to die whilst attending to his physical, psychological and spiritual needs as they appear; give him time and space (intimacy); without fear and up close; with the appropriate means, with training and with tact.

4.16

A true ethos of palliative care can only be developed if we consider it on two levels. On the first level, any moral judgements made should be imperative and categorical, abstract and universal. However, on the second level, judgements should always be concrete, particular and specific

Juan Manuel Núñez Olarte

The relevance of cultural considerations to sedation in Palliative Care

Might the ethics of palliative care be culturally dependent? This question has recently been addresses by Professor Diego Gracia. In his analysis of our moral experience, he pointed out the differences between the "what should be, but is not yet" level, and another level "defines our duty here and now, what we should be doing". On the first level, the moral judgements that are made are imperative and categorical, abstract and universal. However, on the second level the judgements are always concrete, particular and specific. The two levels never coincide: the first one is universal and the second one is specific, the first one is free of cultural conditioning, and the second is culturally dependent. The thesis defended by Prof. Gracia is as far away from "moral fundamentalism" as it is from "cultural relativism". A true ethos of palliative care can only be developed if we consider both "levels". The *prima facie* categorical imperatives of the first level should be balanced by empirically conditioned imperatives which may be defined through a process of deliberation. This should in no way allow itself to denominated "cultural relativism" because it takes cultural aspects into account, although, it might perhaps be called "prudentialism" or "deliberationist". His opinion is that the only reasonable stance is one of "relative absolutism", a stance which aspires to an ideal world, but recognises at the same time the exceptions that prove the moral rules of an imperfect world[1].

The presentations on palliative care, undertaken by Professor Couceiro and Doctor Porta, which we have been debating today, call for an integrated vision, but in my opinion, they both respond rather to the prerequisites of the two levels of ethics as described by Professor Gracia. One of the best elements of this debate has been the positioning and juxtapositioning of both excellent texts and authors.

Hence, this debate is a true reflection of the need to attain that ideal balance between the two levels of ethics already mentioned. In fact, our legislators also attempted to attain such a balance when they established the law Ley 41/2002, a basic regulatory law regarding patient autonomy, and the rights and duties regarding clinical information and documentation[2]. This text establishes the basic principles of the dignity of the human individual, respect for autonomy and will, and a respect for privacy. Furthermore it establishes the patient's right to have access to all available information regarding his health. However, the same legal text specifies the right of the individual to have any wishes respected regarding the desire not to be informed, as well as the option of the doctor to limit such information if he deems it necessary for treatment purposes. It also considers the possibility of access to such information by those individuals close to the patient, if he allows it either expressly or tacitly.

I should like briefly to highlight some cultural considerations, which, in my opinion, are basic, if we are not to fall into that sort of "moral fundamentalism" which our lawmakers have so assiduously attempted to avoid. The existence of a cultural specificity in the practice of palliative care is an undeniable fact, and it has been shown to affect numerous areas, such as:

- Death rituals
- Grieving patterns
- Family systems and relative roles
- Emotional expression
- Dietary requirements and the use of alternative medicines
- Beliefs regarding the origin of illnesses
- Definition of terminal illness
- Traditions of "agony" or death throes, versus "the final 48 hours of life"
- The tradition of hospices versus the traditional lack of hospices
- The prescription of opiates and psychotropic drugs
- Communication of the truth, and revelation of the diagnosis and prognosis to the patient in an advanced stage of illness[3].

In the analysis of our attitudes toward sedation in palliative care, some authors have considered it important to go more deeply into the persistence of specifically Spanish cultural models in the dying process[4]. The "Spanish death", as initially described by art historian specialists, is a daily, clinical reality for the specialists in palliative care in Spain. The concept of "agony", meaning that period where the senses are confused, and which comes immediately before death, has not been modified since it was first defined in the *Ars Moriendi* treatises of the 16th century. In the traditional, Spanish "good death", the dying person's lucidity is neither expected nor desired.

This brief historic review would not make much sense if it were not accompanied by data which support our thesis on the persistence of such cultural models. This is why it is extremely important to recall the comparative cultural studies on sedation on palliative care that our unit has been carrying out. These studies have been the only multicultural comparisons carried out to date. In the first study, our unit contributed with 100 consecutive patients to a multi-centre study, with similar units in Canada, South Africa and Israel[5].

Varying differences were found amongst the centres that participated, and these were the subject of subsequent discussion. The most surprising difference, from the non-Spanish participants' point of view, was the need for sedation for psychological/existential suffering in our centre.

As a consequence of this, a second study was designed whose only aim was to test the hypothesis that there were significant differences in the importance that patients and family members attached to lucidity, and information regarding the diagnosis, between a palliative care unit in Edmonton (Canada), and a corresponding one in Madrid (Spain). This work has also been recently published and can be summarised as follows. The population under study was made up of patients submitted to a first consultation with one of two Palliative care teams located in acute care wards in Madrid (M) and Edmonton (E). All consecutive patients with a diagnosis of terminal illness, over the age of 18, who presented with a normal Mini-Mental State examination, were included. The patients had to be capable of communicating clearly in English (E) and Spanish (M). A standardised translation was used to structure identically phrased questions in both centres that would allow patients and family members to give (Yes/No) answers to four respective questions. These questions broached the following subjects: lucid thinking; drowsiness/ confusion induced by painkilling/ antiemetic medication; drowsiness/ confusion induced by anti-anxiety /anti-depressant medication; awareness of the diagnosis.

The results evaluated 100 patients from each centre. Significant differences were found in sex (M - females 39%; E – females 60%; $p<0.05$); type of primary cancer ($p<0.05$); education levels and occupation (lowest in M; $p<0.05$). Patients and family members in E were in agreement in their opinions almost 100% of the time, however agreement in M varied between 42 and 67% of the time. These results would suggest the existence of significant differences between patients and their families in E and M, regarding the importance given to full lucidity, and to an awareness of the diagnosis. The absence of agreement between patients and family members in M is a significant factor which could potentially complicate communication between patients and families. Medical management in E and M might be influenced by the importance attributed to cognitive alteration by both patients and their families in both centres.

I should like to end with the editorial comment that accompanied the publication of our last study. It stated that it is on the basis of universal values, and not on the basis of relativism, that the moral debate on life and bioethics should and must continue. However, cultural diversity and pluralism are enriching because of their insistence on difference and not homogeneity, and because of the fact that they put people and places into context. Cultural diversity empowers us, both at the patient's bedside as well as during bioethical debate[7].

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4.17

A lot of the problems raised by terminal sedation derive from us not being able to view some principles of ethics with a critical and responsible eye, because they have been transmitted to us as both absolute and irrevocable.

Victoria Camps

The ethical perspective

The world of palliatives has been viewed from an ethos of conviction, i.e. from an ethical paradigm that considers that moral judgements and acts consist of the deductive application of some general principles. Azucena Couceiro, following Max Weber, proposed an "ethos of responsible conviction" to counter this model: principles, but principles faced with the consequences, making individuals responsible for the results derived from the application of their convictions or principles. I think it is important to begin with such a consideration, because a lot of the problems raised by terminal sedation derive from us not being able to view some principles of ethics with a critical and responsible eye, because they have been transmitted to us as both absolute and irrevocable.

What are these principles? In the case under discussion, there is basically just one: the value or right to life, from where we seem to derive that causing death is not legitimate, even when it is imminent. Given that terminal sedation usually generates an irreversible loss of consciousness, sedation cannot be seen as a lessening of suffering, but quite simply as the provocation of death.

It is true that the consideration of principles as absolute, and not open to interpretation, is being increasingly modified in an age like ours which tends to take shelter in relativism. If this were not so, the matter we are discussing today would not be subject to such debate, nor would terminal sedation be considered as a thing that is not only ethically acceptable, but also often imperative from an ethical stance. It is increasingly this way because we have added another duty to the duty of protecting life: the duty to palliate suffering. Attempting to lessen suffering is an obligation, a duty, it humanises clinical practice.

Furthermore, given that palliative care at the end of life actually accelerates death, to maintain both the principle of protecting life and that of palliating suffering, forces us to consider not only these principles, but also the consequences of our actions. If palliating suffering contributes to ending a patient's life, or if attempting to keep a patient alive produces more suffering, which option is the most responsible one? The ethos of responsibility is always much more uncomfortable than such rigidly interpreted absolute principles. This latter stance does give clear answers, whilst a perspective of responsibility forces us to adapt our response to each specific situation.

Zero tolerance to suffering?

The change of ethical perspective, towards an ethos of responsibility, or towards an ethos of flexible principles in the face of diverse circumstances, implies a transformation of moral values. We know that values are a social artefact that depends upon cultural ideologies and conceptions that are not static, but are trying to adapt to other changes, such as that provoked by technology. It has been biotechnological innovation, amongst other things, which has made the relief of suffering into a real possibility, one that lies increasingly within everybody's reach.

Furthermore, an individual's autonomy is the most prized value in today's society. The right to free will has, over time, become the primary human right, and it is perhaps the most basic right, as all other rights are just forms of the right to free will. What is the right to protect our health, other than the right to continue to live and opt for diverse life styles? But also amongst the possibilities of choice open to individuals, is that of opting not to suffer, or even to accelerate the death process. A living will only serves to *confirm* the right of the individual to determine up until what point he is disposed to put up with the physical or psychological suffering that inevitably accompanies death.

The question now however, is raised even more forcefully; do technical advances also represent moral, humane advances? In other words, coming back to the theme of today's seminar: is the systematic and often indiscriminate use of palliative care when dealing with refractory symptoms really representative of best practice or a form of charity in every case? Does easier access to the relief of pain and suffering not contribute to trying to avoid something that is an essential part of the human condition?

End-of –life sedation and palliative sedation for psychological reasons have been differentiated during the course of this seminar. They are not the same thing at all. Both demand, as an indispensable prerequisite, the patient's consent (if it is possible). But even so, and bearing in mind that we can inform the patient and ask for his consent in many different ways, should we not also be thinking of other ways of palliating anxiety other than resorting to sedation, especially if this sedation is irreversible?

It is impossible to expect formulae from bioethics which will resolve difficult cases for us. We should also avoid the extremes which lead us to adopt rigid postures, which are basically fundamentalist. A medicalised society tends to confuse pain and suffering and to ask for a remedy for everything. Suffering – as has been said several times over the seminar – forms part of the human condition. Avoiding it at all costs would end up depriving us of dimensions that form part of what is so essentially human. Awareness of our own death, and finding oneself on the threshold of death is an experience that only human beings can experience. As Heidegger said, man is a "being towards death".

Does loss of consciousness dehumanise death?

Sedation does not always mean the permanent abolition of consciousness. Josep Porta referred in his presentation to the various situations which call for sedation, differentiating them from the sedation when a patient is close to death. "End-of-life palliative sedation" should not raise any ethical problems, as death is imminent. However, any assistance in dying, and sedation without doubt provides such assistance, requires the express desire of the patient as a precondition, a precondition which is not always available in such circumstances. Living wills have been able to cover such a shortfall. Further, employing such wills correctly, and writing and revising them, should lead to more frequent communication with the doctor. As Marc Broggi says, knowing a patient is fundamental to making the appropriate decisions in each case.

But beyond knowing the patient's wishes, the application of measures which might still be delayed is still a cause of concern and doubt. Would the patient really want to "leave this world?". Would he not prefer to live life consciously and make the most of each minute even if it means suffering, precisely because he has not got much time left? One never knows whether the decision made calms the hospital or the family members more than the patient himself.

Taking such a decision on behalf of another person who is in no condition to make it himself should never be done lightly. But there are ways of broaching these problems which go beyond the dilemmas that such problems raise: palliative care versus the protection of life. The debate over the ethical legitimacy of end-of-life sedation should indeed be undertaken, to supply the argument for those who find themselves in the face of an always-difficult decision. But it should also contribute to society's awareness that facing death, either one's own or that of a loved one, is an experience that all of us must eventually face. It is no bad thing to instruct the general public about the possibilities of sedation, on the options of sedation available to them, about the need to know the desires of our nearest and dearest, and to demand that medical bodies also broach such matters. There are, most certainly, ways of educating people to face death.

4.18

Our experience having treated 74 patients is not valid when treating the 75th. One must uncover the "world" of this latest patient

Marc-Antoni Broggi

I should like to thank the Víctor Grífols and Lucas Foundation for the opportunity to debate upon this subject; I should also like to thank Ramón Bayés for having organised it in such a well-designed and attractive manner; and I should like to thank the keynote speakers, Azucena Couceiro and Josep Porta, for their rigorous presentations.

I agree with Azucena that, regarding informed consent, it is one thing to discuss a situation of imminent death, and quite another to extend such a discussion to a situation of terminal illness, or if one does not wish to use such a term, to a situation of an individual with a fatal short or medium term illness with a definite prognosis of progressive deterioration. In the first case we understand that tacit consent, perhaps previously noted down and delegated might often be enough to warrant sedation, if one knows a patient well, and he is agitated and not very receptive to reasoning. I believe that this is not enough in the second case when faced with a lucid patient; I believe that it is essential to obtain express, informed consent to sedate a patient who is not yet in the very final stages of life, consent which carries with it all of the preconditions of an autonomous decision: a clear lack of any attempt to influence the patient, adequate information regarding the alternatives and consequences (both pluses and minuses) of each of the alternatives, and above all, the full capacity to understand the decisions he is making. It is important that professionals understand that they cannot assume the right to decide when a patient must die or be switched off. They can, of course, decide when they should stop fighting death, but, in principle, they should not go any further than that by themselves. There may also be previously established pacts, which may be considered to fall within a very personal or interpersonal area, what Timothy Quill calls the "dark areas" of each relationship, and which should thus be respected from the outside if they are true to the unequivocal desires of the patient.

In reply to Victoria Camps' question, I would reply that I do defend "zero tolerance" of suffering (although I also agree with Javier Barbero when he states that absolute zero would be Utopia), but that is our ultimate aim. We must fight against unwanted suffering, against that which is not desired for the patient, against that other evil which is an unawareness of one's surroundings.

However, we must be certain that our own interpretation of what the patient wants does not lead us into unilateral action; an extremely grave action indeed, if it is definitive. I believe we should alert doctors to the possibility of "interpretation" (with due respect to Freud). It might be inevitable that we make our own interpretations of what the patient is saying, but such interpretations should always be made with the "double check" test. If a patient tells us he "is tired", he may actually be asking for sedation, but we should make sure. Interpretation will assist us in asking ourselves what it is the patient desires: but later, with due caution, we should ask him himself what it is he wants. And our experience having treated 74 patients is not valid when treating the 75th. One must uncover the "world" of this latest patient. I believe that is very in tune with what Milagros Pérez Oliva was saying about not presupposing the good of the patient, because there is always the possibility of our interpretation not being valid, and validation in these cases is extremely difficult. Do not interpret - check. We should guard against our own values.

And here I think it is appropriate to talk of the models of relationships with patients described by the Emmanuels, of which all of you are no doubt aware. I believe that we should make use of the relationship models which they expound, but with some provisos which I should like to resume here. In the situation that we are dealing with, the alternative to the paternalist model cannot be what they call "informative", it would be purely contractual (this is why I call it just that, "contractual": I advise somebody of the situation well, and I await their decision): although this kind of relationship might be enough in many cases of more or less medical routine, where it would be considered normal behaviour. But in order to know how to help a patient to die, we must know how to go up to a higher model. I know that making such a statement here, to experts in palliative care and to psychologists, might seem blindingly obvious; you are already aware of this, indeed you will already be acting in such a way. But it is not so obvious in everyday practice, which is normally based upon a very cold, contractual situation where a patient is dying, unless the higher model employed is the one which the Emmanuels call "interpretative". Here I should like, once again, to add my previous warning, although I do agree with the Emmanuels when they explain that this is about basing such a relationship on the patient's personal values. I would (and do) call this model "personalised", because I want to emphasise that the interpretation of the 'good' that the other person expects, or of the values that he holds, is not enough, I need to be sure of them. This type of relationship would indeed be something to aim for. Although, in order to be able to provide the optimum or excellent assistance, it would be better if we could reach the highest model, the one the Emmanuels call "deliberative": I call it "friendly" (although it is not perhaps a true friendship) because I believe that it comprises parameters of horizontality which make one think of an intimate relationship, with solidarity on the one hand, and confidentiality on the other, and mutual trust in the middle. Deliberation of values would exist in both models, but in this "friendly" model, it is not just about discovering and seeing the values which must be respected, but of handling them and prioritising them, working with them in open deliberation. Both models demand working on a similar discovery of personal values, but the curiosity and the implication of the doctor is very different in each model. The first model might prove sufficiently empathetic or understanding, but the second model is more sympathetic or compassionate. However, this does not always happen as we might wish, and sometimes an intense relationship is not always possible because of a lack of time, or of personal affinity etc. But the doctor should be openly disposed to such a possibility, despite its emotional cost.

The most important thing about this work of dialogue, always inescapable, is that it is based upon the possibility that the patient's real values might not yet have shown themselves. And I believe that in difficult circumstances, such a situation is not unknown (I believe this is what Milagros Perez Oliva experienced in the case that she described). Therefore we should always: 1. try to corroborate the values expressed by the patient, if they are really saying what they mean to say 2. check and help him to check whether any other values or wishes still lie buried or badly expressed, or if they might change, and 3. help the patient to prioritise which of his values must be mostly strongly fought for.

And it is in this process of work that I believe it necessary to warn of the danger of interpreting, and I insist on the need, 'just in case', of finding the opportunity to prove it true or false. Of course, if there has been a process of previous dialogue with the patient, these things are always easier, and are almost already done for us. But they can be difficult, especially when the patient finds himself having to re-think too many things in his scale of values, in his defences, and he has his work cut out. As the poet, Jorge Manrique said "… and when coming from deceit/ when we wish to turn around/ there is no space". But we should help the patient to turn around if he needs to. Sometimes comprehension, not necessarily reasoned but glimpsed, an instant, an insight, is enough.

On the other hand, as Jordi Trelis said, we should avoid increasing any suffering. And here I should like to state a personal concern, which regards the handling of hope. I agree with Comte-Sponville that hope is a poor counsellor, and trying too hard to give hope, sometimes results in not helping the patient at all. It is difficult not to fall into this temptation when one sees another suffering. I am concerned that my hope should not give false comfort and that I might, in fact, be increasing future suffering if I am making it more difficult for a patient to "turn the corner" in accepting a situation. Giving hope is not the same thing as trying to increase a patient's self esteem, putting time and life into context, explicitly re-evaluating a person's achievements, his relationships and friendships. This, in fact, is an argument to let the doctor "get involved" with a patient that needs him. But I am not sure that this it is right to say, as it does in some guidelines, that we must give hope. I fear that this is badly expressed. I do not believe that we should give hope as a matter of routine, but only after reflection. It is possible that some lytic cocktails and sedations have been imposed as a consequence of building up false hopes which later need to be knocked back down, something that neither family members or doctors are then capable of doing.

Also, I am convinced that Manuel Núñez' statistics on cultural differences do reflect the reality. I do not myself have any numerical proof (or evidence?), but I am not at all surprised, because his statistics coincide with something I have always intuited (something that seemed obvious to me). It has been said that perhaps we ought to decide which culture deals with this matter better, the Canadian one that prefers lucidity, or the Latin one that prefers disconnection. I believe the most important thing to consider is the fact that we are dealing with human beings. The fact that we know that a patient shares one "culture" or another, can help us to “interpret” what they want, or how they want it, but I must once again emphasise my previous warning: this inference is dangerous if we do not check it with the individual that we are trying to help. We should not be trying to teach people to die well, but to die in their own manner, if we are able to, and we know how. If we do not start from this objective, if we decide that one way of dying is better than another, we might perhaps take up once again that paternalist way, telling people how best to use their autonomy, in this case on how to die… I believe that the differences of interest to us here, are the personal ones, of individuals, which will not be related, although some might indeed appear to be similar to others.

In fact, they are extremely different! For some, lucidity is synonymous with a dignified death, and sedation in these cases should be employed with great prudence. For others, unconsciousness is synonymous with happiness, and in these cases such sedation is much to be desired. I believe that dignity and happiness(the dignity and happiness that each of us imagines or hopes for) in the process of dying, are already extremely connected to previous symbolisations and to a certain aesthetic(that of “life as a work of art”). For one person, for everybody else to know he is dying, and not him, would be to ridicule him. Whilst for the next, watching himself die would be too painful: he prefers not to know in order not to be aware of it. One person might prefer to make the most of those last moments. But for the next, for his grandchildren to see him in agitation is awful and he would prefer sedation to prevent such a scenario. These are just some of the things our patients say to us. Why do we not listen to them if we can help?

Once again I find myself in agreement with Manuel Núñez, in that accelerating or shortening the end of life process, if the family is suffering and if the patient is already very disconnected from his surroundings, does not in principle seem to me to be wrong, provided it does not require clearly disproportionate measures. In principle, under such circumstances, the suffering of the family should take centre stage, and it should always be attended to, provided it does not involve any abuse or betrayal of any pacts made with the patient. However, before we begin, we must deliberate on each case, as Azucena Couceiro demonstrated. Anticipated Directives documents can assist a lot in respecting the will of patients, even when faced with the impatience of family members. People expect that much of us.

5. A brief summary by the moderator

The contents offered to the readers of this publication – the two presentations, and the additional comments made by other participants - possess, I think, a conceptual and informative wealth capable of provoking reflection, on an individual or interdisciplinary basis, regarding the matter of sedation. Such contents may also be of use as the foundation material for a doctorate course, or the starting point for new expert seminars attempting to go deeper into some of the points raised, which, after today's debate, might still need to be further clarified.

As a person who has had the double opportunity to be both present throughout the seminar, and to have been able to read all of the additional comments made by other participants in detail, I should like to be able to provide a brief summary of the matters we have been dealing with here today.

The first observation is that we need to accept that we live in a world of suffering (Barbero). However, the fact that we find ourselves in the heart of a hedonistic society that will not tolerate, and indeed must avoid pain (Nabal) makes it easier for family members and healthcare workers to impose the suppression of a patient's pain as an almost universal value (Barbero, Camps, Pérez Oliva). However, the elimination or palliation of suffering throughout the long dying process should not always necessarily be the main objective of any medical intervention (Pérez Oliva). Such a decision should always be made by the person that is suffering (Casado, Clavé, Padrós). The situations of approaching death should be raised in such a way that the influence of family members, (Foz, Irache, Porta), although of value, can only determine sedation treatment in truly exceptional cases (Broggi, Couceiro).

For this reason, as far as possible, we should be able to: a) foresee with sufficient time, the most difficult and conflictive situations; i.e. those which may later give rise to the appearance of psychological refractory symptoms (Clavé, Couceiro, Porta); and b) be able to alleviate suffering as far as possible, whenever the patient requires it (Broggi).

It seems that, currently, the ideal instrument to detect such situations is that of communication (Couceiro, Porta), carried out in an empathetic atmosphere (Puigpelat, Salamero), between a patient and a health worker of his choice, throughout the dying process. However, in tandem to this, we should consider the importance of undertaking empirical research to provide us with reliable, valid and sensitive instruments (Limonero) which allow us, as far as possible, to detect and evaluate: a) the symptoms or situations which may later lead to refractory symptoms, or symptoms that are difficult to manage (Porta): b) refractory symptoms, especially those of a psychological nature (Couceiro, Gomis); c) up until what point an individual finds himself at peace throughout his individualised and constantly changing (Gomis, Salamero) dying process.

Healthcare workers find themselves at a crossroads, where ethical principles and cultural influences (Camps, Núñez Olarte) meet up with the unique and personal life story of the patient (Broggi), our own fears (Barreto, Trelis), and limitations in our time and training (Barreto). Maybe this is why doctors often feel unsure (Camps) and would like to place the emphasis on the need to make sedation treatments a matter for protocol, without at any time forgetting about the need to provide individualised attention for each patient (Broggi, Pérez Oliva, Salamero).

I believe that this seminar has contributed in some way, albeit modestly, to the construction of a necessary psycho-social consensus (Gorchs, Pérez Oliva), which is still a long way from being complete. It is necessary, indeed urgent, to make society aware of the meaning of sedation, and to explain the problems that we are facing (Clavé).

In trying to interpret the overall feelings of the participants in today's debate, I feel that the practice of sedation comprises the following two primordial ingredients: a respect for the autonomy and dignity of the individual, and the promotion of excellency amongst healthcare workers caring for patients near to the end of life.

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7. Other monographs published by the foundation

9. Ethics and sedation at the end of life
8. El uso racional de los medicamentos. Aspectos éticos (The rational use of medication: ethical aspects)
7. La gestión de los errores médicos (The management of medical errors)
6. Ética de la comunicación médica (Ethics of medical communication)
5. Problemas prácticos del consentimiento informado (Practical problems of informed consent)
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