

Epilogue

The ‘*Leitmotiv*’ of this book is a number of ethical questions that arise from the use of sedation at the end-of-life. Among these questions are the following (Table 1):

1. Whether there is an ethically sound difference between palliative sedation (PS) and euthanasia and physician-assisted-suicide;
2. Whether the principle of double effect can be appropriately applied to justify the use of sedation in some cases at the end-of-life.
3. Whether PS might be ethically acceptable in the case of patients that are not imminently dying (agony);
4. Whether decisions to limit medically assisted nutrition and hydration are essentially linked to PS or whether they should be regarded as independent issues;
5. Whether sedation is an adequate response to ‘existential suffering’;
6. Whether sedation could ever be used in the case of patients who are not able to give their informed consent (e.g. patients with cognitive impairment of diverse origins, etc.).

Facing these questions, the need for the identification of the anthropological foundations of the right goals of care at the end-of-life was highlighted and some ethical criteria which facilitate decision-making in health professionals, patients and their families regarding the adequate use of sedation at the end-of-life were identified (Taboada 2006, 2012; Cherny and Radbruch 2009; Hauser and Walsh 2009; National Ethics Committee Veterans Health Administration 2006; Boyle 2004a; Tulskey 2006; Onwuteaka-Philipsen et al. 2003). In each of the chapters of this book, different authors have made important contributions to the analysis of the ethical-anthropological foundations of PS. At the conclusion of this book, it seems adequate to offer a synthesis of the main contributions related to each of these ethical questions. Undoubtedly, the reflections proposed here do not intend to encompass all the complexity and depth of the ethical-anthropological contributions offered in the different chapters of this book. The objective of these closing reflec-

Table 1 Ethically relevant questions related to the use of PS

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1. Are there ethically relevant differences between PS and euthanasia?
 2. Is the application of the principle of double effect necessary for the moral justification of PS?
 3. Is PS ethically appropriate for patients that are not in a stage of imminent death (agony)?
 4. Are decisions to limit medically-assisted nutrition and hydration a necessary condition to indicate PS?
 5. Is sedation an appropriate answer for the management of psycho-spiritual symptoms, including ‘existential suffering’?
 6. Can PS be used in incompetent patients, that is, in the case of patients who are unable to give an informed consent (e.g. due to cognitive impairment of diverse origin)?
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tions is – rather – to motivate a personal reflection and the study of a sensitive topic which still needs some answers.

I shall summarize the main contributions made for each of the six above mentioned questions:

1 Are There Ethically Relevant Differences Between PS and Euthanasia?

A reflection on the ethical-anthropological foundations which guide medical practice suggests that the distinction between appropriate and inappropriate uses of sedation at the end-of-life is clarified when the focus of the ethical discussion is centred on the goals of care at the end-of-life. In this context, it becomes evident that the ethically appropriate use of sedatives must share certain common characteristics with the goals of care of Palliative Medicine in general (Cherny and Portenoy 1994). According to the WHO definition, what characterizes Palliative Medicine is – among others – that it “affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; provides relief from pain and other distressing symptoms” (World Health Organization 1990). We can therefore say that Palliative Medicine’s own objectives specifically exclude the intentional acceleration of death.

Thus, from a clinical and anthropological point of view, to arrive at an ethically appropriate use of sedation at the end-of-life, it is indispensable to clearly formulate the ‘therapeutic objective’ which defines this medical action (Taboada 2012; Cherny and Radbruch 2009; Hauser and Walsh 2009; Cherny 2006; Krakauer 2009; Claessens et al. 2008). According to the *lex artis*, the therapeutic objective of palliative sedation is “to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms” (Claessens et al. 2008, p. 329). This goal of care is completely in agreement with the principles of Palliative Medicine which seek to respect life and the dignity of dying patients, providing them with all the necessary care to alleviate ‘total pain’ during the last stages of life (Cherny and Portenoy 1994; World Health Organization 1990).

On the other hand, the different moral and legal status attributed to PS and euthanasia in most of contemporary societies is based on the concept of respect for

the ‘inviolability of human life’ (Keown 2012; Finnis 2011; Vivanco 2006). Therefore to judge an action with possible negative consequences – as the eventual hastening of death caused by the use of sedatives at the end-of-life – from an ethical and legal perspective a distinction is usually drawn between the ‘direct intention’ and the ‘oblique intention’ of the acting person, rejecting any action which seeks *directly* to hasten death in a patient (Keown 2012; Finnis 2011; Vivanco 2006). This distinction coincides with the difference between ‘intended effects’ and ‘foreseeable effects’ established by the ethical principle of double effect, a principle whose applicability to the justification of PS has been accurately analyzed in this book.

Thus, in spite of the undeniable importance of respect for ‘autonomy’, both for patients and also for health professionals, respect for autonomy should always be subordinated to the respect we owe to the ‘basic human goods’ of which the first and most important one is life itself (Gómez-Lobo 2006). In fact, life is a necessary condition, albeit not sufficient, for the exercise of autonomy and of all the other basic human goods (Keown 2012; Finnis 2011; Vivanco 2006; Gómez-Lobo 2006).

Consequently, the relevant ethical and legal differences between PS and euthanasia should be sought, basically, at the level of: (a) the ‘therapeutic objective’ (to alleviate severe and refractory symptoms vs. to intentionally cause death); (b) the content of the ‘direct intention’ and of the ‘oblique intention’ of the acting person; and (c) the character ‘intended’ or ‘tolerated’ of the eventual negative effects (application of the principle of double effect). Hence, it can be concluded that it is possible to establish an important and solid distinction between PS and euthanasia, both from the ethical and the legal perspective.

2 Is the Application of the Principle of Double Effect Necessary for the Moral Justification of PS?

The use of medications which alter a patient’s state of consciousness – like sedatives and/or opioids – may give rise to ethical doubts in health care professionals and/or the patients and their relatives (Cherny and Radbruch 2009; Hauser and Walsh 2009; National Ethics Committee Veterans Health Administration 2006; Boyle 2004a; Tulsky 2006; Taboada 2006; Onwuteaka-Philipsen et al. 2003). It is feared that the adverse effects associated with the use of this type of drugs – like hypotension, respiratory depression, impairment in the use of mental properties, etc. - could represent a form of euthanasia (Cherny and Radbruch 2009; Hauser and Walsh 2009; National Ethics Committee Veterans Health Administration 2006; Boyle 2004a; Tulsky 2006; Taboada 2006; Onwuteaka-Philipsen et al. 2003). In fact, in contemporary bioethics some authors have used the expression ‘indirect euthanasia’ to refer to the use of drugs to alleviate pain and other symptoms, when those interventions include the risk of indirectly accelerating death (Tulsky 2006). Even though the use of the term ‘indirect euthanasia’ to indicate these kind of actions seems inadequate from the conceptual point of view, it cannot be ignored that the fear of committing

euthanasia could be one of the reasons that explains the under-utilization of opioids and sedatives, which some authors have reported specially in Latin American countries (Eisenschlas 2007).

With regards to this concern it is worth recalling that when opioids and sedatives are used in a clinically appropriate way, the empirical evidence shows that they do not produce an acceleration of death (Cherny and Radbruch 2009; Claessens et al. 2008; Regnard et al. 2011). Nevertheless, even if in some particular case it could be foreseen that some undesirable effects may occur – including the unintentional acceleration of death – the ethical tradition affirms that the use of these therapies might be morally correct. Indeed, their ethical legitimacy is usually justified through the application of the ethical principle of ‘double effect’ (PDE) (Anscombe 2001; Boyle 1980, 2004b; Cassell and Rich 2010; Jansen 2010; Jansen and Sulmasy 2002; Fohr 1998). According to this principle, an action that has simultaneous and inseparable good and bad effects is morally permitted only if the following conditions are simultaneously fulfilled:

- the action itself must be morally permitted;
- the good effect, which is the object of the agent’s intention, must not be obtained through the bad effect;
- the bad effect, which is foreseeable and inevitable, is not the direct object of the agent’s intention (i.e. the bad effect could be foreseeable, foretold or tolerated, but should not be intended as the purpose of the action);
- there must be a proportion between the good and bad effects (Gómez-Lobo 2006, p. 107–8).

There are authors who add a fifth condition: that there is no other way of achieving the good effect, without having the bad effect (Anscombe 2001; Boyle 1980, 2004b). On the other hand, some ethicists affirm that the above stated conditions could be summarized in two: (1) that the damages (or adverse effects) are not voluntarily intended (but arise as unwanted collateral effects); and (2) that there are sufficiently serious moral reasons to bring about these damages (Anscombe 2001; Boyle 1980, 2004b).

Nevertheless, some authors question the validity and/or the foundations of the PDE (Veatch 2003; Quill et al. 1997a; Donagan 1988, 1991; Quinn 1989, 1991). Among the main criticisms formulated against this ethical principle are the difficulties of: (1) accepting the existence of causes that could produce effects that are independent from one another; (2) distinguishing between ‘intended’ and ‘foreseeable’ effects and accepting the fact that foreseeable bad effects could be only indirectly tolerated (and are not necessarily included in the intention of the acting person); (3) applying the conditions required by the PDE to certain concrete situations; (4) admitting the existence of absolute moral norms (i.e. norms which do not admit any exception).

A critical analysis of these and other objections to the PDE shows that the PDE has been frequently misunderstood or incorrectly applied, especially in the context of caring for patients at the end-of-life. Indeed, Miranda emphasizes

that the field of application of the PDE is more limited than what is sometimes thought (Miranda 2008).

Therefore, in order to analyse whether the administration of drugs that have the effect of depriving someone of consciousness is an action that could (or should) be justified by the application of the PDE, it is necessary to first establish which is the proper field of application of this principle. We must remember that the PDE is not applicable to all effects that can be called bad/evil. In fact, this ethical principle is only applied to justify those effects that would never be legitimate to intend, not even as means to a good end.

Therefore, when asking if the use of sedatives at the end-of-life belongs to the field of application of the PDE, it is necessary to identify the negative effects whose occurrence requires an ethical justification. It is known that the main negative effects which give rise to ethical questions in relation to sedation are: (1) the deprivation of consciousness at such a significant time in the life of a patient and, (2) the possible acceleration of the patient's death.

The deprivation of consciousness – considered by itself – is not an effect that requires an ethical foundation through the application of the PDE, because it can be provoked intentionally if it were necessary in order to achieve a good end, as is the case in surgical interventions, or in the relief of severe and refractory symptoms of a terminally ill patient. Thus, a deprivation of consciousness does not need to be, in itself, justified by the PDE. The ethical principle that justifies this kind of medical actions is the existence of a proportionally serious reason (principle of therapeutic proportionality or parsimony).

However, when it is possible to foresee that the use of sedatives will produce an acceleration of the patient's death, or that the patient, after being sedated, will not recover consciousness and/or the sedation will impede him/her from carrying out other ethical, legal and/or religious obligations before dying, then the PDE will indeed gain relevance. This is so because, both the death of the patient and the permanent suppression of consciousness that impede the fulfilment of important duties are effects that it would never be legitimate to procure intentionally. However, they might be accepted as collateral effects of actions that are necessary to achieve proportionally important goods, as could be the control of severe symptoms at the end-of-life, which have not responded to other forms of therapy (Miranda 2008). Thus, the ethical justification for the use of sedatives in these cases would indeed require the application of the PDE, because it would draw the distinction between the acceleration of death sought as the aim of the action (euthanasia) or tolerated only as a collateral effect of the use of sedatives.

3 Is PS Ethically Appropriate for Patients That Are Not in a Stage of Imminent Death (Agony)?

Most of the existing clinical guidelines for the use of PS propose to restrict this intervention exclusively to patients in a stage of agony (that is to say, during the last hours or days of life), especially in the case of the so-called 'deep continuous sedation'

(Cherny and Radbruch 2009; Hauser and Walsh 2009; National Ethics Committee Veterans Health Administration 2006; Claessens et al. 2008). For example, the Dutch clinical guidelines establish that: “besides the presence of medical indications, a precondition for the use of continuous sedation is the expectation that death will occur in the reasonably near future, that is, within one or two weeks” (Royal Dutch Medical Association Committee on National Guideline for Palliative Sedation 2009, p. 6). The reasons are eminently pragmatic in character and can be grouped in two categories: (a) that the eventual risk of accelerating death, as an undesirable effect of the use of sedatives, does not have any relevance in the agony stage, neither from the ethical nor the legal point of view; and (b) that the idea of keeping a patient under sedation for longer periods of time (weeks or months) would be counter-intuitive, because it would approximate to a ‘social death.’

However, not all authors agree that the imminence of death should be considered as an indispensable requirement for the ethical and legal justification of sedation at the end-of-life (Keown 2012; Miranda 2008). In fact, from a clinical perspective, there could be situations in which patients who are not in a stage of agony could show severe and refractory symptoms, the management of which would require the use of PS as a last resource (Cherny and Radbruch 2009; Hauser and Walsh 2009; Cherny 2006; Krakauer 2009; Claessens et al. 2008). It is not clear why the use of PS should be proscribed in these situations. In this context, the ethical principle of proportionality in therapies should be enough to justify the recourse to sedation. On the other hand, the distinction between ‘direct’ and ‘oblique’ effects (mentioned before) suggests that – when there is a proportionally serious reason – the use of sedatives can be ethically and legally permitted, even at the risk of accelerating death and/or permanently depriving the patient of consciousness, provided always that these effects are tolerated as collateral effects of legal and necessary actions to bring about a benefit of proportionate importance (application of PDE).

In this context, it may be necessary to mention that ‘proportionality,’ as an ethical foundation for PS, has been criticized for its possible arbitrariness (Cherny and Radbruch 2009). In fact, the degree of ‘severity’ of a symptom tends to be classified according to the subjective assessment that the patient makes of it. On the other hand, the refractoriness of a symptom has also diverse interpretations depending on the experience of clinical personnel, and/or the therapeutic resources available. Thus, a bad application of the ‘proportionality’ criterion could lead to the use of PS in a way that does not comply with the international standards of ‘good clinical practices,’ a risk that could be even higher in economically deprived sectors of society, such as the developing countries (Eisenschlas 2007).

Therefore, when analysing if the imminence of death is a necessary requirement to justify the recourse to PS from the ethical and legal points of view, it is relevant to reflect on the ethical-anthropological implications of the eventual subjectivity of the ‘refractoriness’ and ‘severity’ criteria of the symptoms, as well as the ‘proportionality’ criterion in the therapies, depending on the clinical experience and the socio-economic context in which they are applied. So, even though – in principle – there seem not to be sufficient reasons to restrict the use of palliative sedation to situations

of imminent death, there are prudential arguments that suggest the need to be especially strict in verifying the compliance with clinical and ethical criteria when using PS in a context other than agony.

4 Are Decisions to Limit Medically-Assisted Nutrition and Hydration a Necessary Condition to Indicate PS?

Some authors have proposed that to discontinuing hydration and nutrition would be a 'typical' or 'essential' component of the sedation technique at the end-of-life (Quill and Byock 2000; Quill et al. 1997b; Orentlicher and Caplan 1999; Rietjens et al. 2004; Verkerk et al. 2007). Rietjens, for example, introduces this aspect in the very definition of 'terminal sedation,' which for this author is the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration" (Rietjens et al. 2008, p. 179). Even though this proposition does not have wide acceptance among specialists, it leads to a reflection on its clinical and ethical foundations.

From a clinical perspective, it is expected that a patient who receives PS for the management of severe and refractory symptoms at the end-of-life will lose the capacity to spontaneously hydrate and nourish him/herself. This will occur to a different extent depending on the level of sedation that is required. In those cases in which deep sedation is used, the inevitable clinical and ethical questions arise whether to initiate or maintain artificial hydration or medically-assisted nutrition. During the last decades, the foundations of the prescriptions of artificial hydration and medically-assisted nutrition in terminal patients have been intensively debated (Taboada et al. 2010; Palma et al. 2011). Among the controversial points are not only questions related to the eventual clinical benefits and risks associated with these practices, but also questions regarding the ethical principles and values that are involved. For example, it has been discussed whether artificial hydration in terminal patients can: (a) be a means to alleviate frequent symptoms, like thirst, or to reverse neurological alterations, like delirium; (b) artificially prolong life (or whether its omission could shorten life); (c) provoke unnecessary suffering and risks; etc. It is obvious that these questions have ethical implications because they are directly related to some relevant moral principles and values in the care of terminal patients, like: (1) respect for life and the dignity of the dying; (2) the moral obligation of implementing proportional medical care; (3) respect for the symbolic value attributed to hydration and nutrition, as a manifestation of the duties of care and companionship towards the most vulnerable; (4) the duty not to harm; (5) the obligation to encourage the responsible exercise of patients' freedom (autonomy), especially in the final stages of life; etc (Taboada et al. 2010; Palma et al. 2011).

The majority of palliative care specialists coincide in stating that invasive forms of medically assisted nutrition are not part of the usual care required by patients

who have lost the ability to feed themselves spontaneously in the final stages of life (Cherny and Radbruch 2009; Taboada et al. 2010; Palma et al. 2011). However, there seems to be also a certain agreement among specialists on the need to provide a minimum degree of artificial hydration to those patients whose estimated time of survival is greater than one or two weeks, because otherwise their normal loss of liquid could cause death by dehydration (Cherny and Radbruch 2009; Jansen and Sulmasy 2002; Cassell and Rich 2010; Jansen 2010). This suggests that – in principle – there should be a moral obligation to assure a minimum of hydration to those patients who require to be sedated and whose estimated life expectancy is more than one or two weeks. If this were not carried out, those cases in which an early death occurs as a consequence of dehydration and not as a consequence of the natural evolution of the disease could correspond to acts of euthanasia by omission.

Therefore, the European Association for Palliative Care (EAPC) proposes that prescriptions of PS and indications regarding artificial hydration and medically-assisted nutrition should be considered as independent decisions, because they correspond – in fact – to separate clinical problems and, are – therefore – based on different clinical and ethical criteria (Cherny and Radbruch 2009).

5 Is Sedation an Appropriate Answer for the Management of Psycho-Spiritual Symptoms, Including ‘Existential Suffering’?

Some of the existing clinical guidelines suggest the use of PS both for the management of physical symptoms as well as psycho-spiritual symptoms, including the so called ‘existential suffering.’ The latter has been defined as “the feeling that one’s own existence is empty or meaningless” (Royal Dutch Medical Association Committee on National Guideline for Palliative Sedation 2009, p. 6). This subjective perception of the ‘meaninglessness’ of one’s own existence, particularly when death is expected to occur within a few days or weeks, may cause intense anxiety or unbearable suffering to dying patients. Under these circumstances, a patient could request sedation as a means to no longer feel this insupportable anxiety. Among the ethical principles that have been called upon to justify sedation in these cases is the respect due to the autonomous decisions of patients (Cherny and Radbruch 2009; Bolmsjo 2000; Roy 1990; Breitbart et al. 1998, 2000; Morita et al. 2000; Cherny 1998; Rousseau 2001).

As should be expected, at present there is no consensus among specialists on the medical and ethical justification for the indication of PS in these cases. In fact, the management of psycho-spiritual symptoms and ‘existential suffering’ through sedation is one of the most controversial indications of this clinical practice. Some palliative care specialists ask themselves if the aims of medicine should include the alleviation of all forms of human suffering. The majority seems to agree that the

relief of psycho-spiritual suffering goes beyond the limits of medicine (Cherny and Radbruch 2009; Jansen and Sulmasy 2002; Cassell and Rich 2010; Jansen 2010; Bolmsjo 2000; Breitbart et al. 1998, 2000; Morita et al. 2000; Cherny 1998; Rousseau 2001). We know that human suffering – in its different forms – is an integral part of human existence and it could never be completely eliminated by medicine (Cherny and Radbruch 2009; Jansen and Sulmasy 2002; Cassell and Rich 2010; Jansen 2010).

Thus, some authors sustain that the management of these kinds of situations requires special considerations, which go beyond the strict respect for autonomy (Cherny and Radbruch 2009; Keown 2012; McCall Smith 1997; O’Neill 2002). The reasons adduced for that are fundamentally the following:

- The nature of these symptoms makes it very difficult to establish criteria to determine their true ‘refractoriness;’
- The severity of the distress caused by these symptoms could be very dynamic and idiosyncratic and the appearance of adaptation mechanisms is frequent;
- The normal interventions for the relief of this kind of symptoms (e.g. psychotherapy, spiritual accompaniment, alternatives therapies, etc.) usually are very cost-effective.
- The presence of these symptoms does not necessarily indicate progress towards psychological deterioration.

All these reasons tend to support the need for an integral and periodical clinical assessment of terminal patients with psycho-spiritual symptoms and reinforce also the need for a multi-professional team-work which includes psychiatrists, psychologists, chaplains, therapists, ethicists, etc. Such a team could explore the multifactorial causes that are often hidden behind intense psycho-spiritual symptoms. Similarly, the intrinsic dynamism and the idiosyncrasy of the answers demonstrate the need to give enough time to the different therapeutic strategies implemented, without the premature recourse to the wiping out of consciousness.

Thus, the validity of ‘existential suffering’ as a criterion to prescribe PS is undermined by the ambiguity of its definition, as well as by the practical difficulties that the assessment of this symptom and the determination of its refractoriness entail. In fact, a review of the literature shows that this term has been used in a way that includes virtually all types of psychological symptoms. On the other hand, the proposition of limiting its use to symptoms related to the *distress* caused by one’s mortality itself has not helped to improve its specificity, because practically all the preoccupations at the end-of-life are strongly coloured by the context of mortality.

Accordingly, it seems suitable to consider ‘existential suffering’ not only as a symptom emerging from ‘inside’ the patient, but also as coming from the exterior: from the patient’s ‘social context’. From this consideration a very concrete therapeutic proposition is derived, namely, to mobilize all the patient’s family and other significant people and all the members of the medical team who could have an important role in the relief and prevention of ‘existential suffering’ at the end-of-life. In fact, the occurrence of unbearable existential anguish at the end-of-life could be secondary to a failure to implement the appropriate interventions during the early

stages of the development of the disease. Indeed, several useful therapeutic tools have been described for the management of this type of symptoms, coming from psychiatry, psychology and spiritual support. They have demonstrated clinical success in the alleviation of psycho-spiritual symptoms, including ‘existential suffering.’ In fact, these interventions help to prevent or deal with existential suffering and foster the psychological and spiritual growth of patients at the end-of-life, enabling them to face that moment in peace.

Notwithstanding the foregoing, a thorough analysis has to be made as to whether, in exceptional and well qualified cases, the need for the recourse to an intermittent sedation could be established, with the objective of offering ‘respite’ periods to over-distressed patients, thus gaining time so that the psychological processes of bereavement and the adaptation mechanisms can come into play. In other words, the possibility of using PS for the alleviation of psycho-spiritual symptoms at the end-of-life cannot be totally excluded. But the need to use it in this setting could reflect a lack of the timely application of other support tools that are available today.

This has important ethical-anthropological implications, because inducing a permanent loss of consciousness at such a crucial life moment could represent a form of ‘social euthanasia’, especially if the clinical criteria of severity and the lack of response to other types of interventions has not been duly verified. Consequently, the eventual ethical justification of PS for the alleviation of ‘existential suffering’ at the end-of-life is conditioned to a clarification of the definition of the symptom and of the criteria for refractoriness and intolerability. It would be desirable to have an early referral to specialists in mental health or spiritual accompaniment, so that an adequate assessment and a timely management of ‘existential anguish’ can be done, avoiding the use of sedation.

6 Can PS Be Used in Incompetent Patients, that is, in the Case of Patients Who Are Unable to Give an Informed Consent (e.g. due to Cognitive Impairment of Diverse Origin)?

The respect for the right of competent and informed patients to actively participate in medical decision-making is an ethical principle that is widely accepted today (autonomy). In fact, among the ethical criteria that are frequently invoked to justify the recourse to PS is that its prescription responds to an express request from the patient and/or that there is an informed consent signed by the patient or a valid surrogate (Veatch 2003; Finnis 2009; Keown and Gormally 1999).

That is why some clinical guidelines propose that an ‘ethical requirement’ for the prescription of PS is to obtain a valid informed consent and do not permit its use in those cases in which the patient is not able to give the due consent and/or does not have someone that could represent him/her in decision-making (Royal Dutch Medical Association Committee on National Guideline for Palliative Sedation 2009). Besides safeguarding the principle of autonomy, another reason underlying

this requirement is the possible misuse of sedation in the case of incompetent patients, that is to say, in the case of patients with cognitive impairment of diverse origin, for example when they show socially inadequate behaviour and/or their conduct could be disturbing to others. The potential risk of abusing the recourse to sedation in such cases could be exacerbated in those health centres with shortage of staff, as often happens in the most exposed socio-economic sectors in Latin-American countries (Eisenschlas 2007).

However, it cannot be ignored that there are some patients with cognitive impairment of different origin – who, by definition, are incompetent – who could experience severe and refractory symptoms at the end-of-life, as any other patient. Moreover, with this kind of patients it is not infrequent to have difficulties to find a valid legal representative, especially in low socio-economical settings (Eisenschlas 2007). The fact that in these situations it is not possible to obtain a valid informed consent should not necessarily imply that the recourse to sedation should be totally excluded for these patients, as they may need this therapeutic tool as any other patient with severe, refractory symptoms. Hence, the danger of abusing sedation in incompetent patient should not become an argument to discriminate them by not allowing them the access to a therapeutic tool that might be clinically justified.

Although incompetent patients correspond, by definition, to a vulnerable group, in which the exercise of autonomy must be usually subrogated (Finnis 2009; Keown and Gormally 1999), for an adequate decision-taking in relation to the use of sedation at the end-of-life it is not enough to identify a legally valid representative. We must also make sure that the decision is really oriented to the ‘best interest’ of the individual patient. In this context, it is important to point out that autonomy must be subordinated to the principle of inviolability of human life and that the concept of ‘best interest’ (welfare) has always a double component, ‘objective’ and ‘subjective’ (Keown 2012; Vivanco 2006).

Consequently, the ethical criterion that requires the informed consent of the patient (or a legally valid representative) in order to prescribe PS at the end-of-life needs to be refined. Without ignoring the importance of the respect due to the responsible exercise of freedom (principle of autonomy), a complement to this important ethical principle could be proposed in the light of other ethical-anthropological criteria, that are perhaps equally relevant, such as the ‘best interest’, solidarity and justice, especially with the most vulnerable. A complement of this kind would help to do justice to the different clinical scenarios described above.

To conclude these reflections, we want to stress that the variety of ethical and anthropological questions that arise at present from the recourse to sedation at the end-of-life bear witness to the need to identify criteria which could guide health professionals, patients and their relatives in clinical decision-making. Despite the fact that PS is considered today as a helpful therapeutic tool for the management of severe and refractory symptoms at the end-of-life, the possible adverse effects and eventual risks associated with the use of sedatives demands a prudent and well founded use of this tool, especially in the case of terminal patients.

Among the values and ethical principles that guide an adequate use of PS, the following can be mentioned (Table 2): (1) The inviolability of human life; (2) The

Table 2 Some ethical principles/values relevant to the use of sedation at the-end-of-life

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1. Inviolability of human life
 2. Respect for the dignity of the dying
 3. Therapeutic principle and proportionality in care
 4. Principle of double effect
 5. Respect for the responsible exercise of freedom (autonomy)
 6. Justice and solidarity
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respect due to the dignity of the dying; (3) The therapeutic principle and the proportionality in care; (4) The principle of double effect; (5) The respect for the responsible exercise of freedom (autonomy); (6) Solidarity and justice.

Dying people correspond – undoubtedly- to one of the most vulnerable groups of people in our society (Taboada 2006, 2012; Cherny and Radbruch 2009; Hauser and Walsh 2009; National Ethics Committee Veterans Health Administration 2006; Boyle 2004a; Tulsy 2006; Onwuteaka-Philipsen et al. 2003). Consequently, their life and dignity deserve our special respect and attention. If we accept the premise that an individual’s *moral quality* is expressed – in an eminent manner – by the way in which that individual cares for the most vulnerable in society, we could assume that future generations could judge the *moral quality* of contemporary societies by the way in which we treat the most vulnerable groups, among which are certainly the dying. It is precisely here where our respect for human life and dignity, as well as the meaning we attribute to the value of belonging to the human family is put to the test.

Palliative Medicine understands the ‘right to die with dignity’ as the right of each person to receive competent, holistic and compassionate assistance at the end-of-life. This form of accompaniment to the ‘good death’ implies a number of *ethical requirements* for health professionals and for society in general. These requirements take the shape of a duty to provide medical assistance of technical and humane quality, which encompasses all dimensions of the person, that is to say, the moral obligation to alleviate not only physical symptoms, but also the different sources of psychological, spiritual and social suffering that usually accompany the dying process: the so called ‘total pain.’ Hence, the access to palliative medicine of excellence – both technical and humane – should be considered as a right derived from the most fundamental human rights.

Santiago, Chile

Paulina Taboada

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