Continuous Sedation until Death: A French way for End-of-life Care

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Abstract

Continuous sedation until death (CSD) is a rapidly developing practice in several countries, appearing as more acceptable than euthanasia/physician-assisted-suicide, since more close to a ‘natural death’. The French parliament is going to adopt soon a law recommending CSD on request of the patient, along with forgoing artificial feeding and hydration. France will have thus a unique international position for end-of-life care.

Yet many ethical problems raised by CSD, in which psycho-social death precedes the biological death, have already been raised in the literature. The legitimacy of CSD, especially if deep and not proportionate, is questioned in case of existential distress. The primacy given to autonomy is questionable for vulnerable patients who deserve mainly a social solidarity. The double effect principle is replaced by a co-intention, putting CSD in a grey zone between palliation and euthanasia.

Background

Continuous sedation until death (CSD) is a rapidly developing practice in several countries, including Belgium and the Netherland where euthanasia/physician-assisted-suicide (E/PAS) is legalized [1]. Surveys in the Netherland tended to show a decrease in the number of voluntary euthanasia, with a simultaneous rise of CSD [2]. The ‘UNBIASED’ study in UK, Belgium and the Netherland following death of adult cancer patients who had received CSD found that Dutch and Belgian physician and nurses often positioned CSD as an alternative to euthanasia, allowing a ‘natural death’ while UK interviewees placed emphasis on the medical management of symptoms [3]. Considering CSD as an equivalence to a natural death was first questioned by Seymour et al. [4] who argued that sedation just mimics it, allowing to consider it as a ‘good death’. For Raus et al. [1] such simulation of a natural death, including a deep sleep, with fading away peacefully, and dying from internal causes without prolonging or shortening life, is fundamentally wrong; CSD is a medically provoked coma, and the frequent associated decision to forego administration of food and fluids may contribute to shorten life. Actually CSD might be felt more acceptable altogether by the carers, the patients and the families, because less rapid than E/PAS, but, on the other side, the longer duration of CSD and uncertainty of time to death might be difficult to tolerate [5].

In France, where palliative care are currently proposed for terminally ill patients, sedation during the end of life is considered as one of the normal modalities to relieve suffering, when refractory to the other modalities of palliative care. However, according to the guidelines of the French Society for Palliative Care (AFSAP), a proper sedation should be provided only when necessary, with drug titration, careful monitoring, and eventual reversibility [6]. These guidelines fit with the recommendations of the European Association for Palliative Care to use CSD only for refractory and unbearable suffering, when the patient’s disease is irreversible and advanced, and without primary intent to hasten death [7]. In addition, sedation is not considered as a recommended treatment for existential distress, which rather deserves psychological support and accompanying [8].

In addition several situations raise specific questions about the clinical and ethical aspects of CSD. The first one is when a CSD is requested by patients who are not in terminal phase of their disease, but are willing to stop treatments necessary to maintain their vital function, for example to withdraw or withhold a respiratory mechanical assistance. This occurs not infrequently in patients with advanced neurological diseases (eg amyotrophic lateral sclerosis (ALS)), or in persistent vegetative or minimally conscious state). Also currently such when decision are made in intensive care units to stop treatments sustaining vital functions. In such situations, ‘palliative’ sedation - in fact CSD-, is simultaneously administered in order to prevent suffering, especially from respiratory distress [9]. Obviously these decisions result in shortening of life, although not considered as E/PAS.

In any case, the decision is mainly based on the patient’s own values and wills. Several modalities have been developed for promoting advance directives, either very general - avoid prolonging life through futile treatments -, or more precise, according to the specific clinical condition (e.g. avoid tracheostomy and respiratory mechanical support in case of worsening of ALS) [10]. Also a designed surrogate might help making a medical decision which could fit with the patient’s
own values. Ethical and judicial problems are raised however when such advance directives are not relevant by the physicians, or when conflicts raise among members of the family, without a clear argument for the advice of the surrogate [11].

The French legal project

Palliative care had been developed in France since the late 80 as the best way to relieve suffering at the end of life, while preventing prolonging survival through futile treatments. Palliative care settings have become a recognized component of appropriate end-of-life care in France, and proper sedation is provided when necessary for unbearable suffering refractory to other treatments. Yet the development of palliative care through specialized units, hospital support teams and home care is still insufficient with an irregular repartition throughout the national territory. A national survey has shown that only 35% of nurses judged the quality of dying and death acceptable for themselves [12]. Principal factors significantly associated with this perception were non availability of a written protocol for end-of-life care, including anticipation of death, informing the family, surrogate designation, adequate control of pain, attendance of family or friends at the time of death, and staff meeting with the family afterwards. Such permanent insufficiency gives arguments to the active movement in favour of legalization of euthanasia, aimed at preventing ‘undignified’ deaths.

During his presidential campaign, François Hollande claimed that ‘every patient in advanced or terminal stage of an incurable disease, with unbearable and refractory physical or psychological suffering, should be allowed to benefit from medical help to terminate his/her own life with dignity’. At first, a presidential decision was to nominate special commissions to open a public debate and prepare the law. Extensive public debate and institutional consultations took place during two years: a commission (commission Sicard) [13] observed that former laws, especially the law adopted in 2005 [14] to respect of patient’s wishes and to prevent futile/intensive treatment, was adapted to the majority of situations but yet largely ignored and unapplied. Then in 2013, the National Consultative Ethical Committee (CCNE) which, in its majority, was against legalizing euthanasia, recommended mandatory advanced directives and CSD when requested by the patient [15].

The French parliament is now going to adopt soon a law which proposes CSD as a regular procedure for end-of-life care. Namely ‘on request of the patient to avoid any suffering and prolonging his/her life uselessly, a treatment aimed at sedation and analgesia provoking a deep and continuous suppression of vigilance until death, while forgoing all treatments aimed at maintaining life’. Such CSD will be undertaken for patients with an incurable disease, a short term life expectancy, and a suffering refractory to treatments, or, alternately, when a patient decides to withdraw or withdraw a vital treatment -including artificial feeding and hydration -. It is also planned that, when a patient is unable to express his/her wishes, a physician will be allowed to stop a futile treatment which could prolong life, and start a CSD. Such decision should be made following consultation of the care team and advice of a second physician.

Priority is given to the patient’s will, including through advance directives which should be mandatorily applied, except if found inappropriate by two physicians. Such advance directives, that the patient can modify or cancel at any time, should have priority over his/her wishes or values expressed by a surrogate.

This proposal of law was adopted on march 17, 2015 by a large majority of the first chamber - Chambre des Députés – and, with no doubt, will be confirmed by the Senate. Thus France will be the first country to adopt CSD as an official method for end-of-life care, an intermediate or a compromise between palliative sedation and E/PAS.

Discussion

The impending French law should be compared to the practices of CSD in several European countries, where it has rapidly developed. In the UNBIASED study a large range of practices and opinions was observed, differences being accounted by several factors [3]: level of suffering and distress, requests of patients and their family, expected time to death, and country - whether euthanasia is legalized or not -. UK respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rare practice of deep sedation. In contrast, most Belgian respondents perceived CSD and euthanasia to be ‘alternatives’ which could be chosen by patients following discussions along with their families. Dutch respondents emphasized the importance of making an official medical decision based on the patient’s wish and confirmation that a refractory symptom was present. Although Dutch clinicians sometimes reported discussing the ‘option’ of CSD with patients, this was usually in situations where euthanasia had been talked about at an earlier point but could not be carried out at the time of the appearance of refractory suffering. Another recent European study based on the opinions of experts has shown that debates over CSD still persist on multiple grounds (conceptual, medical and ethical) and indicates that concerns seem to be focused on specific questions [16]: Is CSD an extreme facet of end-of-life sedation? Is psycho-existential suffering an indication for CSD? Is withdrawing or withholding of artificial nutrition and hydration potentially life-shortening?

The present French project of law for CSD has to be considered from two standpoints.

At first, with regards to its clinical and institutional aspects, there are a number of factors which may vary: the type of drugs administered, their dosages, whether progressive or at high dose from the beginning, the deepness of sedation, its reversibility or not, the level of observed or supposed remaining consciousness of the patient, the length of sedation and uncertain delay until death, and the consequent concerns and emotional burden for the carers and the relatives. The French project of law has made mandatory a ‘collegial consultation’ before making a decision for CSD, but this seems restricted to physicians, without a clear role for the nurses and the family. In addition a major step has been clearly included in this law: artificial feeding and hydration are qualified as ‘treatments’ rather than ‘care’, while patients are
allowed legally to refuse or withdraw any treatment [14]. This raises open questions such as whether CSD with starving and dehydration can cause additional suffering and abbreviate life.

However the main questions raised by this law on CSD are ethical. They have been already repeatedly raised in the literature: namely could CSD correspond to a ‘slow euthanasia’, at least a psychic euthanasia, with a ‘social death’ preceding the biological death, or is it rather close to a natural death following palliative sedation? The perception by medical practitioners, the patients and their relatives that CSD might correspond to a natural death, as compared to euthanasia, which is more rapid and frequently felt as violent and unethical, probably explain the recent increase of its use.

That sedation is a major tool to abrogate suffering is certainly true, at least for unbearable suffering and distress, especially when proportionate to their level, and adequate symptom relief is key to the experience of a ‘good death’. However ethical questions have been raised about the legitimacy of such pharmacological sedation in case of an existential suffering, related to hopelessness, loss of autonomy and of meaning of life, and it has been argued that the adequate approach to relieve such existential suffering consists mainly in moral support and accompanying, rather than technology and drugs [8]. But some other authors denied any validity to distinction between physical or existential of distress sources, which deserve altogether CSD when refractory to other measures [17].

On the other hand palliative care, including palliative proportionate sedation, is repeatedly questioned in term of its efficacy, with a constant albeit minor rate of failure to relieve physical or psychological suffering and distress, and is even sometimes accused to prolong unwanted lives, a kind of medical practice which might be not less futile and disproportionate than futile intensive care. In any case, from an ethical point of view, prolonging life per se, even through good palliative care, should not be regarded as an absolute goal, especially if it is not the main wish of the patient.

Also one should consider the priority given, like for voluntary E/PAS, to patient’s autonomy. Respecting and preserving patient’s autonomy can be regarded as one of the major principles of biomedical ethics [18]. Practically this relates to the possibility for the patients to determine and elicit their preferences for the last part of their life: when, where, with whom, how completing last wills etc. Saying goodbye was considered as an important theme for the bereaved relatives of patients died after CSD [5]. Despite differences between countries, highlighting the influence of cultural norms and expectations, this should be taken into account for the time and place of starting and pursuing a CSD, in order to preserve the possibility to say goodbye and to accompany the dying patient. More generally, one might consider, following Hans Jonas, that the ‘contemplative right to his/her own death’ is an essential part of human dignity, the problem lying in the domain of being rather than action [19]. This legitimate right might be an argument for starting a CSD at a time determined with the patient, preventing from the permanent risk of an involuntary CSD, namely without information and agreement of the patient and his/her family. On the other side, possible pressures from the patients and/or their relatives might influence the medical decision [20]. These possible difficulties raised by the decision to start a CSD are normally avoided by a comprehensive collaboration between the carers, the patient and the relatives, in order to determine the best measures to adopt for the end-of-life care. Completing advance directives by advance care planning appears a positive step towards a shared decision [21]. In any case accompanying patients during their last part of life is essential to legitimate an eventual CSD, giving an important emphasis to the interpersonal relationship and psychosocial support rather to individual autonomy per se. This is especially relevant for patients particularly vulnerable in relation to their advanced age, comorbidity, psychiatric illness, social isolation, for whom autonomy might appear as a burden, eventually a social pressure, rather than a broadening of their human rights.

Another ethical aspect of sedation is related to the intention, especially the intention of the physician who decides to perform a CSD. In palliative care, a medical decision to start a sedation is based on the double effect principle, the intention being to relieve, while the risk of shortening life is accepted both by the carer, the patient and the family as a possible but not intentional consequence. While the application of this principle is frequently uneasy in such clinical situations, it seems that CSD makes even more difficult to distinguish between the priority objective and the foreseeable and eventually wished consequence, resulting in a kind of ‘co-intention’ [22]. According to some authors, the decision to withdraw or withhold artificial nutrition and hydration during CSD is potentially life-shortening, thus crossing the line of intentions between alleviating suffering and hastening death, and bringing CSD one step closer to a slow euthanasia [16,23]. This lack of clarity of intentions in CSD could result in a grey area between the two practices. In addition the text of the law voted by the French parliament includes that sedation is aimed at ‘preventing from prolonging a useless life’ (understand useless viewed as such by the patient). This wording expresses a normative value, put on a more or less useful life, that is ethnically questionable: while one can understand that for many patients in such conditions, prolonging their life is useless, the inclusion of the word ‘useless’ in the law includes an objective meaning, that could appear as a social constraint.

A final consideration is related to the role and possible consequences of a law to determine the proper way to approach end-of-life care. The legal recommendations might appear as mainly administrative, reducing decisions to binary choices. This is already present by making mandatory the advance directives and designation of a surrogate, thus ignoring the emotional and existential burden for people approaching their own death, and for the relative thus designated [11]. But the main ethical question is related to the places and institutions where a CSD will be put into practice and the carers in charge of it. This is not a problem for the palliative care teams, whose carers are competent to appreciate the suffering of their patients, and propose or accept a requested palliative sedation, eventually until death, providing a good titration, monitoring, and accompanying. But one can fear that in many other institutions without the capacity of palliative
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References