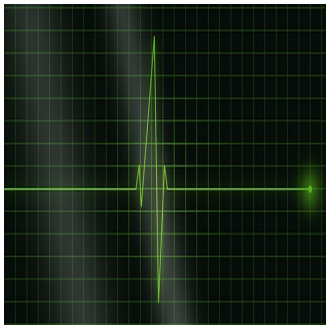
What Can Doctors Ethically Do To Ease Suffering Of The Dying?



The death of a loved one is often an ordeal and a tragedy for those who witness it, as death is not merely the end of a life, but also the end of an existence, the loss of a unique individual who is special and irreplaceable. Ethical unease arises as the dying patient falls prey to death throes and to the manifestations of ebbing life and the physician can only stand by and watch. From this point on, medicine can put an end to suffering by the use of neuromuscular blockade, but in so doing life ceases at the same time.

The ethical problem then becomes the shift from the original ethical concern, ie, the dying patient, to the patient's loved ones. Is such a rupture due to a difference in nature or a difference in degree, given that the dying patient remains a person and not a thing as long as the body continues to lead its own life, expressed through movement and sound?

In this review the Ethics Commission of the Société de Réanimation de Langue Française (SRLF Ethics Commission) submit ethical reflections on end-of-life signs and symptoms in the intensive care setting, and on the use of neuromuscular blockade in this context, with presentations on the subject by two philosophers and members of the SRLF Ethics Commission, Ms. Lise Haddad and Prof. Dominique Folscheid.

Review

Part 1: The Point of View of the SRLF Ethics Commission

For many people, whether or not death has meaning depends more on the sense, or lack of it, accorded to life, in accordance with their religious, spiritual or philosophical views. The perception of death differs according, for example, to whether life is held to have no meaning unless it is lived with full possession of all physical and mental faculties, or rather that it is part of a greater whole that includes, for example, an afterlife, which gives transcendent meaning to the hardships of the life that is coming to an end. It is the tension between the natural side of death and what death contributes to the meaning of life that is today at the heart of debates in France on the end of life.

In the struggle for life, it is medicine's task to preserve the conditions of a life sufficiently viable to give rise to a veritable existence, and not to seek to avoid death indifferent to the conditions of the existence that ensues. It was in this spirit that the SRLF made its recommendations of 2002 on the withholding and withdrawal of treatment in intensive care. These recommendations were updated in 2009 and were fundamental in the drawing up of Leonetti's law on the rights of patients and the end of life (No. 2005ñ370 of 22 April 2005).

Particular Case of End-of-Life Signs and Symptoms in the ICU

Perkins and Resnick, in an article published eleven years ago, clearly posed the question of the use of neuromuscular blockade to end the most extreme end-of-life signs, the gasps of agonal respiration, which are a source of intolerable distress for loved ones. In earlier publications, the authors firmly condemned the use of muscle relaxants (devoid of sedative or analgesic effect) initiated just before withdrawal of mechanical ventilation with the sole aim of suppressing impending terminal signs, so as to give the appearance of a calm and serene patient. They deemed this practice ethically indefensible and likened it to a form of euthanasia. The authors reaffirmed their opposition to intention to cause death.

Among the many arguments advanced by Perkins and Resnick, two are particularly worth looking into since they lie at the heart of the dilemma facing caregivers. The first relates to what a patient may or may not feel in the gasping phase of the dying process, while the second concerns the obligation felt by caregivers to alleviate the distress experienced by the patient's loved ones for whom the suffering perceived in the gasping respiration becomes intolerable.

Is the Patient Suffering During Agonal Respiration?

Gasping respiration is the last phase in the dying process. It is irreversible and always followed by death. Before this, consciousness may fluctuate and the patient may or may not alternate between phases of coma, confusion, or agitation. Scientifically, everything suggests that gasping patients do not feel pain or respiratory discomfort since clinically there is no objective evidence of residual consciousness. Some authors consider that all medications, including sedatives and analgesics, are useless and disproportionate at this stage of the dying process. Only muscle relaxants can suppress gasping respirations.

It is clear that at this stage of the dying process, medication offers nothing and should give way to support not only of the dying patient, but also of the patient's loved ones.

Gasps in the Terminal Phase as Witnessed by Loved Ones and Caregivers

This moment of the death process is always hard for loved ones, but also for caregivers. It starkly confronts everyone with the realities of finiteness and death. The occurrence of gasping, however, should not raise doubts in the clinician's mind. An imperative for all caregivers seeking to make the unbearable more tolerable is to explain, describe, and inform so as to shed light on this demise and to inscribe it in the

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natural process of life. In this context, the perception by loved ones of the feelings of caregivers regarding gasps, of a perceptible awkwardness of personnel ill at ease or on the contrary more "supportive" and able to speak of what is happening as a troubling but natural phenomenon, would also contribute to a greater acceptance (or not) of these end-of-life signs.

Ethical Questioning

Ethical tensions arise from the fact that the physician cannot alleviate the dying patient's gasping respiration, except by relieving it and at the same time curtailing the life he is witnessing. The ethical problem raised is that of a shift in ethical aim, which initially targeted the patient and now focuses on loved ones. What to do when loved ones beg for something to be done to end the signs that they find unbearable and which they often think must be intolerable for the person from whom they emanate?

Laudable though it may be to seek to comfort those who live through the tragic experience of the death of a loved one, is not the use of muscle relaxants in the terminal phase also a way to spare us from thinking about dying and especially its clinical implications?

As there are no simple and unequivocal answers to these questions, the SRLF thought it would be interesting to ask two thinkers who are members of the SRLF Ethics Commission, Ms Haddad and Prof. Folscheid, to share their thoughts on terminal signs and symptoms, and in particular the use of muscle relaxants.

Part 2: The Point of View of Ms Lise Haddad

Between life and death, the dying person seems doomed to complete solitude, and at the same time experiences his death in an absolutely singular way. In him is embodied the unique figure of death, his death. He denies the abstract and hence reassuring character of human finiteness. The circumstances of death form the last manifestation of individuality. The determined form of a person is dimmed and undone, pointing to imminent oblivion. "The truth is not death, only its foreshadowing" explains Bataille. And Didi-Huberman, a contemporary French philosopher and specialist in aesthetics, who quotes Bataille, explains that the violence is not in death, "which would lead to the annihilation of violence itself". It is not death that is the most dreadful, but "only its symptom".

If it is possible to draw a parallel between the aesthetic, that is the field of reflection on art, and the potential treatment of the death struggle, it is because the person we seek to treat with muscle relaxants is no longer the patient assumed to lack all feeling, or at any rate to be incapable of showing it, but the witness, in other words the spectator.

This transition of the patient, who is entering death, raises questions in the minds of those who witness this demise. What are we treating? Do we imagine we are answering the patient's wishes by acting on the form of his body at this ultimate moment? Are we replacing him by his loved ones who will preserve and care for his memory since they now become the sole interlocutors?

From the moment when the patient is no longer thought of for himself, but rather as an object of representation, the landmarks of aesthetic theory are of help in our attempt to interpret this intolerance of the sight of the death struggle. More than the patient's relation to his own death is now the meaning that this demise assumes for those who become its witnesses.

But how far can we protect others from the terrible impact of the death of a loved one? What authorises an act that no longer has any therapeutic purpose, nor even is intended to improve the patient's comfort? As it is effected by physicians at a moment they deem opportune, medical action intended solely to give form to a body in death is an aesthetic preoccupation with scientific methods in a person who is still living when the muscle relaxants are administered. In a sense, by way of concern for tactfulness, the purpose is to mask the truth of what is happening: the end of life of an individual, with no benefit for the dying person.

Neuromuscular block at the end of life seems then to raise several questions: that of the switch from concern for the patient to concern for his family and friends, and in this shift that of the instrumentalisation of the patient as an object gazed upon; that of the legitimacy of physicians acting upon the patient solely to soothe the feelings of the patient's family and friends. The physicians' interest is then concentrated on what is seen of the patient's body, by a shift from the symbolic to the real: they attempt to anticipate and soothe the pain of grief by masking the beginnings of the loved one's demise.

Part 3: The Point of View of Prof. Dominique Folscheid

The words are already suggestive. The patient is no longer dying but is engaged in the death struggle, the agony. Agony means a violent struggle or combat, the struggle that precedes death, from the Greek word agonia. The dying person then is a fighter. However, in the case of gasping, is there still someone, a person, who is struggling?

Here insight is to be found in Leibniz's belief that a simple substance can only vanish through annihilation, a composed substance only by decomposition. This offers an intellectual framework for modern scientific descriptions according to which we die, so to speak, in parts, organ by organ, the stem cells surviving well after death. Respiratory gasps can then be considered as forms of powerless revolt, the desperate struggle of certain parts of the body at a subordinate level-archaic reflexes.

Once the normal means of calming the violence have been exhausted, one can obviously let things run their course and wait. But the situation can be intolerable for loved ones, caregivers, the physician himself. Morally unbearable to see a human being reduced to a subjectless reflex system, to witness the vain revolt of organs against the body, nature rising against herself without for all that inventing a way, albeit diminished, to continue to live. In this situation, loved ones, caregivers, physician become "protagonists" in the strict sense, thrust forward and called upon to provide an answer, if possible.

Is it then ethical to try to humanise this death? We are not speaking of euthanasia, which consists in hastening the death of a living person. Nor are we speaking of rendering life artificial in order to delay an inevitable death. We are already in the orbit of death, and what we can still do there can be understood as a means of combatting death's own waywardness and restoring its naturalness, which is the very definition of medical action. Except that here we do the reverse of what we would do ordinarily, which is to preserve life.

Perhaps one day it will be proved that a patient in this state is already dead. Since the invention of brain death, everything seems possible. If this were to happen, muscle relaxants would pose no problem. Medicine would be nothing more than embalming the patient, but would nonetheless fulfil its role towards others.

Conclusions

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The SRLF Ethics Commission hopes to enrich the thoughts of everyone on a subject that without any doubt calls for other contributions, the aim here not being to provide ready-made solutions, or even orders, but to empower everyone to think in all conscience.

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