

Nutrition and hydration of patients in a persistent vegetative state

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Abstract. Entering a persistent vegetative state is undoubtedly devastating, as is its temporally unpredictable permanency. However, it is out of the question that the tragic nature of a pathological state such as PVS, however extreme, may in the slightest way alter the dignity of those affected nor their full rights. It is not possible to justify any denial or weakening of the right to care which should be guaranteed as for any other human being. Given the prominent number of people in a persistent vegetative state even in Italy, as well as the ongoing controversy over whether or not nutrition and hydration through a tube or percutaneous enterogastrostomy should be considered medical treatment and/or therapeutic intervention, it seems helpful to reiterate some fundamental bioethical principles.

Key words: Nutrition, Persistent Vegetative State, Bioethics

Introduction

The term persistent vegetative state (PVS) refers to a clinical picture resulting from severe neurological impairment, characterised by an apparent state of vigilance without consciousness, but with open eyes, frequent aphinalalistic chewing movements and motor activity in the limbs limited to retraction reflexes to nociceptive stimuli without finite movements (1). PVS patients sometimes smile for no apparent reason; the eyes and head may rotate towards sounds and moving objects without fixing any gaze. Vocalisation, if present, consists of unintelligible sounds; spasticity, contractures, urinary and faecal incontinence are present. Cardiovascular and respiratory functions are preserved (2), and the patient does not require instrumental support. The gastro-intestinal function is also preserved, although the patient cannot eat by mouth due to severe mastication and swallowing dysfunction (3). While it is true that some terminally ill people can develop an illness in PVS, it is also true that people in

PVS are not always terminally ill, as they can survive for years if properly cared for. Neither is it correct to associate the condition of PVS with coma: the comatose state is devoid of wakefulness, while those in PVS, while offering no clear external signs of consciousness, alternate between phases of sleep and phases of wakefulness (4). The central bioethical problem is the state of dependence on others: those affected need the same things that every human being needs in order to survive (water, food, heating, cleanliness and movement) but are unable to provide for themselves, requiring help, support and care for all their functions, even the most basic.

What needs to be emphasised is that people in PVS generally do not require sophisticated, expensive and difficult-to-access technology (5). What is necessary in order to live is care, not only in the sense of therapy but above all that they have the right to be cared for. To this end, it can be said that people in PVS require care with a high (sometimes remarkably high) degree of human but low technological content.

Indeed, it must not be forgotten that it is neither the extent of the pathology (6) nor the likelihood of recovery from it that justifies care: the need for a weak, sick person to be cared for and possibly undergo medical treatment is reason enough. Moreover, common bioethical intuition points out that the greater a patient's weakness, the greater the ethical and legal duty to take care of them (7). This is incumbent on the healthcare system, family members and every individual who has the capacity and the opportunity to do so. The CNB believes that if the family is willing to care of a patient in PVS at home, then institutions must support them as far as possible in terms of financial and care costs. In order to justify bioethically the basis and limits of the right to care and assistance for those with PVS, it should be borne in mind that basic ordinary sustenance must be guaranteed: this means nutrition and hydration, whether provided by natural or artificial means (8).

Nutrition and hydration are considered acts that are ethically, deontologically and legally required, as they are indispensable in guaranteeing primary physiological conditions for living, ensuring survival, removing symptoms of hunger and thirst and reducing the risk of infection due to nutritional deficiency and immobility. Even when patients in PVS must be provided with nutrition and hydration by others through artificial means, there are reasonable doubts that such activity can be considered 'medical acts' or 'medical treatment' in the sense of other life-support treatment, such as mechanical ventilation. Indeed, water and food do not become medical treatment merely because they are administered artificially. It is rather a procedure that while undoubtedly requiring careful choice and preliminary assessment by a doctor, is manageable and can be supervised even by the patient's family (apart from a minor initial intervention), since hospitalisation is not essential. It is a procedure that following minimal conditions such as cleansing and posture control is well-tolerated and manageable at home by non-expert personnel with appropriate training (9). This is clear from the fact that patients who are not in PVS can be fed using this method without preventing them from living a life of daily contact. Care procedures do not constitute medical acts merely because they are initially implemented and periodically monitored by health-

care professionals. How life-sustaining elements are taken or administered is not relevant from a bioethical point of view.

Providing nutrition and hydration naturally or artificially (the latter with the aid of techniques that substitute natural ways) or feeding and quenching thirst by oneself or through others (in a surrogate manner, without the active participation of the patient) do not constitute differentiating elements, according to a bioethical assessment. The fact that nourishment is provided through a tube or a stomach does not make water or food an artificial preparation (the same can be said of walking, which does not become artificial when the patient has to use a prosthesis) (10). Neither can water and food be considered medical or health therapy simply because a third party provides it. The problem is not how the act is performed for the sick person, nor how he or she is fed or hydrated. Feeding and hydration are indispensable acts for essential life support since they enable an individual to stay alive. Even if it were to be considered medical treatment, judgement on its appropriacy and suitability should depend only on the objective condition of the patient (i.e. on actual clinical needs measured against the risks and benefits) and not on a judgement of others on current and/or future quality of life (11).

The decision not to perform or to discontinue artificial nutrition and hydration is not dictated by the principles governing medical acts (as for other forms of life support). It is generally considered right to discontinue a medical act when it constitutes obstinacy, i.e. persistent technological postponement of death (12) at all costs; a burdensome prolongation of life beyond the limits of what is possible; when disease is severe and incurable; reversibility excluded with certainty (13); imminent death and inauspicious prognosis (14); treatment which is disproportionate, burdensome, costly, ineffective or useless for the improvement of the patient's condition, clinically speaking (15). Artificial nutrition and hydration constitute primary and proportionate forms of ordinary care in the sense that the body gains an objective benefit (moreover, they are practical, not costly, easily accessible and practical, require no sophisticated machinery and are generally well tolerated) (16). The suspension of such practices should not be seen as the dutiful discontinuation

of ineffective treatment but rather as a cruel form of 'abandonment' of the sick person from a human and symbolic point of view (17). It is no coincidence that many request immediate euthanasia as a Coherence Law for PVS patients for whom the decision has been taken to discontinue nutrition and hydration, so as to avoid a procedure which can take up to two weeks. With consequent 'death from hunger and thirst'. On the other hand, there is no doubt about the ethical duty to suspend nutrition (18) if, when death is imminent, the organism can no longer assimilate substances provided. The only objectively recognisable limit to the ethical duty to feed a person in PVS is the organism's inability to assimilate (and therefore jeopardise the act achieving its end, since there is no positive response to the treatment) or a clinically detectable state of intolerance connected with feeding (19).

Reference should also be made to the human value of caring for PVS patients. We can consider it our duty to provide water and food to people who are unable to procure it for themselves (children, the sick and the elderly). This is a sign of a civilisation that is characterised by humanity and solidarity and a recognition of the duty to care for the weakest in the same way (20). We should thus consider it our duty to provide food and liquids to PVS patients, caring for their physical needs and accompanying them emotionally and psychologically in their distinctive condition of vulnerability and fragility (21). This attitude takes on a special human meaning symbolic of social concern for others. We simply cannot reduce the decision to cure or not to cure, to assist or not to assist a patient in PVS to a cold utilitarian logic of balancing costs and interests, deeming benefits in terms of recovery low and costs of care high, calculating the quality of life of others, considering the sick person a family 'burden' as well as a social one (22), limiting our considerations to those of expediency and opportunity rather than a duty and responsibility towards others.

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