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News

Nutrition and hydration of patients in vegetative state: a statement of the Italian National Committee for Bioethics

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Without Abstract

The vegetative state (VS), an undesired consequence of the great advancements that have occurred in intensive care medicine and in long-term artificial nutrition and hydration (ANH), was first described by Jennet and Plum in 1972 [1]. Patients in a VS are unaware of themselves and their environment. The condition is defined as permanent when there is no prospect of any change in this state by any means, usually 1year after brain trauma or 3–6months after brain anoxia. A clinical problem regarding the reliability of the definition of irreversible unawareness exists [2]. Yet, the return to clinically evident awareness is extremely rare and difficult to substantiate [3].

Long-term survival (even years) of patients in VS is possible thanks to continuous support of basic care. This poses great bioethical problems regarding the duty of care towards such patients [3, 4]. A large agreement exists regarding the possibility of limiting medical care once the irreversibility of VS has been reasonably established. Yet, the nature of ANH is still discussed: if ANH is considered just medical treatment, it should be forgone when the burdens outweigh the advantages.

In some countries, the possibility of forgoing ANH in patients in permanent VS has been granted. In the USA, ANH can be forgone, respecting the principle of autonomy, i.e., when there is “clear and convincing evidence” that this is the patient's wish [5, 6]; in case they have no previous wishes (as in newborns) the decision is supported by the best interest standard. In the UK, the decision is made respecting the patient's dignity and best interests [7].

At least two facts recently rekindled the discussion about the whole issue. The first was the papal address on life-sustaining treatments and the vegetative state [8]. In it, John Paul II stated that “The sick person in a vegetative state ... still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.). (...) The administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and

proportionate, and, as such, morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering."

A second relevant fact was the closing of the case of Theresa Marie (Terri) Schiavo, which lasted for about 15years, cost nearly a decade of litigation and went as far as to involve nearly 20 judges and, finally, the US Congress and President George W. Bush [5, 6, 9, 10]. Most important, it raised deep public interest and much discussion regarding the value of ANH, the morality of forgoing ANH in patients in permanent VS and who and how should eventually make such decisions. On January 2006, a Google search gave 5,930,000 results for "Terri Schiavo." A Medline search permitted retrieving more than 40 papers, published in scientific peer-reviewed journals, which contain the name Terri Schiavo in the title.

On September 30, 2005, the Italian National Committee for Bioethics (INCB) published a document on nutrition and hydration of patients in VS [11]. It consists of nine paragraphs, the first three being an introduction (paragraph 1), a clinical description of VS and a presentation of the relevant moral problems (paragraphs 2–3). In particular, it states that, "The central bioethical problem is the state of dependence on others (…). People in VS need a care with very high human content, but low technological content".

In paragraph 4 the concept is declared that, "Nutrition and hydration should be considered proper acts on ethical grounds (and on deontological and legal grounds, as well), as they are indispensable to guaranteeing the basic physiologic conditions for survival (…); the fact that nourishment is delivered through a tube or a stoma does not make water and food an artificial preparation (as walking does not become artificial when the patient needs an artificial limb)".

The possibility that ANH could lead to a sort of "therapeutic obstinacy" is excluded in paragraph 5, which states, "As long as the organism gains an objective benefit, artificial nutrition and hydration are forms of basic and proportional ordinary care". The document goes on to say that forgoing of ANH is ethically proper only when, in the imminence of death, the organism is unable to assimilate any substance (paragraph 6). Paragraph 7 stresses the particular human value of caring for patients in VS. The INCB continues that an advance directive document by which a patient refuses to be artificially hydrated and fed in case he falls into a VS can be granted only when ANH can be considered a form of disproportionate treatment (as in paragraph 6). Normally, such directive cannot be granted, as it would constitute euthanasia by omission, which is ethically and legally forbidden (paragraph 8).

The INCB document concludes (paragraph 9) that human life is not a disposable good; that any distinction between worthwhile or un-worthwhile living is arbitrary; that ANH of patients in VS should normally be considered as basic vital subsistence; and that forgoing of ANH can be ethically and legally proper when they lead to real therapeutic obstinacy, while it is improper when done on the basis of other people's perceptions of the patient's quality of life.

More than 20 members of the INCB signed this document. A 5-paragraph dissenting opinion follows, in which 13 dissenting members hold that ANH should be considered medical treatments (paragraph 1); that the care of patients in VS should be guided by the patient's own reasonably reconstructed valuation of his/her conditions (paragraph 2); that the forgoing of ANH should not be considered active euthanasia (paragraph 3); that every treatment should be forgone on the patient's own reliable request, both actual and advanced (paragraph 4). At the end, the dissenting members questioned the validity of the entire document, stressing that, in some situations, honouring patients' previous request to forgo any treatment is an extreme tribute to their dignity (paragraph 5).

The division of the INCB is probably the consequence of the moral valuation of the dissociation between biology and biography that typically occurs in VS. This dissociation is quite new in the history of humanity, and we have not yet elaborated clear and shared moral categories for its appraisal. The core problem is: what is the value of biology (a quite intact, well-functioning organism) once the biography (the possibility of consciousness, feelings, memories and relationships) is reasonably lost forever? Surely, the biology is very important,

as the indispensable prerequisite for biography. But is the biology something more than a mere "mechanical" support for biography? Does biology reach a (at least minimum) level of bioethical dignity? Those who support this view usually refer to the sanctity of life and claim to back a "culture of life" [4, 6]. On the other hand, those who object to such a view refer to the quality of life, meaning that biology alone might not be sufficient to a meaningful human life [4].

The signatory members of the INCB document believe that ANH actions are proper in order to "guarantee the basic physiologic conditions for survival", even against the patient's previously stated will. In this way, they assume a great value for biology, which should be considered real life and, therefore, according to Italian law, out of the patient's control. They also believe that forgoing artificial nutrition and hydration can be considered a form of euthanasia. This is also the opinion of other authors [7, 12]. Interestingly, the same view about AHN was expressed by the Irish Medical Council in 1995, when it stated that ANH is among "the basic needs of human beings" [13].

On the contrary, the dissenting members of the INCB believe that a patient can be allowed to renounce his/her biology if he/she does not consider biology a value per se and when biology cannot help to support a biography which is already irreversibly lost. The substance of this view had been previously expressed in Italy by a working group of the Italian Society of Neurology [14] and by an ad hoc Commission of the Italian Ministry of Health [15]. The discussion is bound to continue.

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