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Fieldwork and Research Note

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Living without Existing: The Permanent Vegetative State

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Abstract

The situation of persons in a permanent vegetative state, characterized as a state of wakefulness without awareness, raises ethical issues concerning the meaning of a life extended by artificial nutrition and hydration. Incarnating paradoxes which question the boundaries between life and existence, these patients lead us to consider new categories of Being: how do we talk about a 'non-existent human being'?

Keywords: Permanent Vegetative State, medical ethics, Artificial Nutrition and Hydration, decision making, mind/body problem, philosophy

要旨

覚醒状態にありながらも意識を持つことができないという特徴をもつ持続的植物状態に陥った人間の状態は、人工的水分栄養補給によって延命することの倫理的な問題を提起する。生きる事と存在する事の境界線を問い直す矛盾を突きつけることで、植物状態の患者は我々に新しい生命の分類について示唆する。「存在しない人間」をどう議論すればよいのだろうか。

キーワード：持続的植物状態、医学的倫理、人工的水分栄養補給、意思決定、心身問題、哲学

Father of a female patient in PVS: “I talked with doctors as well as priests. Ok, there is a body. But where is my daughter? The medical profession can’t give me an answer and the church even less, there is a blank, there is a hole...”

Researcher (EC): “... there is some uncertainty...”

Father of a female patient in PVS: “Yes that’s it... Is she alive? Is she dead? We can’t mourn her because she’s still here... And the church can’t help. And neither can the doctors. It’s up to us to handle this, no matter the consequences.”

(Extract of an interview)

1. Definition of Permanent Vegetative State (PVS) and ethical issues.

With the progress made in intensive care and resuscitation techniques, the chance of survival after brain injury has increased considerably in recent years. Unfortunately, recovery is often imperfect and though patients are sometimes in a waking state it is not possible to ascertain exactly if a residual consciousness is present or not. This is particularly the case for patients in a vegetative state.

A vegetative state follows a period of coma and is characterized by a state of “wakefulness without awareness” (Multi-Society Task Force on PVS, 1994). Contrary to a patient in a coma, a patient in a vegetative state retains a sleep-wake cycle (episodes of spontaneously opening the eyes). The term vegetative means that autonomous functions are retained; i.e. cardiovascular regulation, thermoregulation and respiratory functions are stable (Schnakers 2008). A ‘permanent’ vegetative state (PVS) is diagnosed when the vegetative state persists beyond three to six months in the case of a medical etiology (e.g. anoxia) and beyond twelve to eighteen months for a traumatic etiology. The chances of recovery become minimal past these time-frames (Multi-Society Task Force on PVS, 1994, cited by Vanhaudenhuyse et al. 2007). Persons in a permanent vegetative state generally have no associated pathologies, are not particularly medicalized and they are not in end-of-life phase. They therefore receive artificial nutrition and hydration, often with a gastrostomy tube. Thus, in these patients, survival is often correlated with artificial nutrition and hydration, and nursing care. These patients can live in PVS for many years, five or six on average.

By definition, there is no manifestation of consciousness in PVS unlike in other minimally conscious states. In patients in PVS, manifestations of motor function, auditory and visual functions are restricted to reflex responses; emotional responses are not adapted to the context (Thonnard et al. 2011). Still, it remains difficult to distinguish a reflex behavior from a voluntary behavior. Indeed, in some cases, behaviors such as laughing, crying or

grimacing, are manifest but for no apparent reason, or again the production of inadequate words can be observed. However, this is considered compatible with a PVS diagnosis as none of these behaviors are voluntary or the result of an intention directed towards a specific purpose; they are not a sign of consciousness but rather of a reflex activity.

Care-givers and families may feel confused by the paradoxical situation of a patient in a vegetative state “who has been rescued from death to live deprived of what appears to be the main resource of human existence: the ability to communicate with others” (Graftieaux 2009: 93). So, many families and medical staff then question the meaning of a life thus extended.

In recent years, the debate has focused on two points: first, the level of treatment to adopt when a complication threatening a patient’s life arises; and second, the decision to withdraw artificial nutrition and hydration, made possible by the French legislation on “rights of patients and end-of-life” of April 22nd, 2005.

The status of artificial nutrition and hydration (ANH) for PVS patients has always been ambivalent: for some it is a care that may not be stopped and for others it is a treatment that artificially keeps the patient alive. Subsequent to the French legislation on “rights of patients and end-of-life”, the concept of “unreasonable treatment” has been discussed regarding the role of nutrition for people in PVS: should nutrition be regarded as a care or as a treatment that can be stopped? (Aubry 2008).

2. Disconcerting boundaries between life and death.

My PhD Thesis in philosophy at the University of Franche-Comté, France, concerns the question of the state of being of a person in PVS and the ethical issues with regards the meaning, from the care-givers and families point of view, of keeping such a person alive through artificial feeding. In this framework, a cross cultural comparison between France and Japan can be pertinent and fruitful.

The considerations mentioned above refer to issues of boundaries and more specifically to the boundary between life and death. The situation of persons in PVS puts us in an uncomfortable position as it confronts us with the meaning of life, the limits of medical progress and the definition of death.

Indeed, in such situations, the boundary between life and death loses all limits; life is akin to death while death retains the appearance of life. The ordinary boundary between being alive and being dead deprived of its evident nature is, incarnate in the body of the patient, a disconcerting paradox. Indeed, death seems here already lived, but yet elusive. A person in PVS is not, strictly speaking, in an end-of-life situation yet everything seems as though that person is ‘beyond’ the end of life, of their own life. Paradoxically present to their own absence, a person in PVS seems, in an impossible way, to embody his or her own death. How should such people be regarded? What to think of their state of being? How should such people be cared for when they are both already dead or as dead and yet alive and present?

As if between two worlds, a person in PVS is, in the words of both care-givers and families, “neither dead nor alive”. We could take this expression and rephrase it as: people in PVS are both living and dead, or rather, both present and absent.

3. A ‘person’ who does not ‘exist’: a philosophical paradox

Such formulation, however, needs to be further clarified because from a biological point of view there is no doubt that these people are alive. Furthermore, from a biological point of view, people cannot be both dead and alive. It is from the plane of human existence (not only of life) which makes humans human, that this question arises. In these situations, defined by a waking state without consciousness, life becomes basic survival and can no longer be perceived as existence. What is the state of being of a person whose life no longer has the characteristics of human existence?

My research then, focuses on the problem of state of being of a ‘person who does not exist’. What is living without existing? What does to be ‘present’ mean for a human being if he does not ‘exist’? How can this presence be qualified? Is it possible to talk of a ‘non-existent human’? What does a person become when he or she exists only by virtue of the investment of others to create the conditions for existence?

My research is based on a national clinical study conducted by the University Hospital of Besançon, France, in the framework of which I conducted 137 semi-structured interviews in twenty-three specialized care units in France and on the situation of thirty-two patients. 103 Care-givers and thirty-four family members were questioned in semi-structured interviews based on a photo-elicitation method. The analysis of interviews was then carried out by thematic analysis to identify categories and then

concepts. The analysis grid focuses on the question of representations of state of being of a person in PVS through the responses of families and care-givers.

As this work leads to issues of boundary between life and death, definition and evaluation of consciousness, as well as considerations of the mind/body problem and symbolism of the act of feeding, it is now interesting to compare French and Japanese conceptions regarding these issues. Indeed, as far as we have been able to ascertain, there are many points of difference regarding the situation of people in PVS in Japan. As an example, the definition of PVS in Japan makes no difference between PVS and other states of altered consciousness. This means, especially for the families, that a person in PVS is not perceived as unconscious but only as being incapable of having communication and relationship. This difference in diagnosis affects how families handle the prognosis. Indeed, such families can have more (false?) hope for a future recovery.

Therefore, we believe we can hypothesize that these issues would be further clarified by an interdisciplinary and international comparison, which in turn would provide further ethical reflection on cultural difference and a deeper understanding of the situation of persons in PVS in its entire complexity.

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