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Patients in a permanent vegetative state or minimally conscious state in the Maine-et-Loire county of France: A cross-sectional, descriptive study

Situation des patients en état végétatif chronique et en état paucirelationnel en Maine-et-Loire. Enquête transversale

V. Saoût a,*, M.-P. Ombredane b, J.-M. Mouillie c, C. Marteau d, J.-F. Mathé e, I. Richard a

^a Service de médecine physique et de réadaptation, CRRRF-CHU d'Angers, rue des Capucins, BP 40329, 49103 Angers cedex 02, France

^b Service de soins de longue durée, CRRRF-CHU d'Angers, rue des Capucins, BP 40329, 49103 Angers cedex 02, France

^c Département de sciences humaines, faculté de médecine, rue Haute-de-Reculée, 49103 Angers cedex 02, France

^d Service de soins de suite et soins de longue durée, CHU d'Angers, 43, rue des Claveries, 49124 St-Barthélémy-d'Anjou, France

^e Service de médecine physique et réadaptation neurologique, hôpital Saint-Jacques, CHU de Nantes, 85, rue St-Jacques, 44093 Nantes cedex 1, France

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Abstract

Purposes. — To determine how many patients in a permanent vegetative state or a minimally conscious state are living in healthcare institutions in the Maine-et-Loire county of western France. To evaluate patient management, physical complications, problems encountered by nursing staff and the patient care teams' wishes.

Patients and methods. — We performed a cross-sectional, descriptive study in physical medicine and rehabilitation departments, nursing homes, geriatric units and local hospitals. All patients and their medical records were examined by the same investigator. A questionnaire for carers was used to evaluate nursing tasks and a second questionnaire for head nurses served to assess staff needs and the patient care teams' wishes.

Results. — Thirteen patients were identified. Four were in a permanent vegetative state and nine were in a minimally conscious state. Ten patients were cared for in geriatric units, one in a physical medicine and rehabilitation department and two in local hospitals. All patients displayed limited joint angle ranges. All the patient care teams reported practical difficulties and ethical issues.

Discussion. — Our survey highlighted the variety of care scenarios for patients in a permanent vegetative state or a minimally conscious state. It revealed practical difficulties and, above all, ethical questions. The present work could serve as a basis for implementation of a recently issued French government circular on defining specific wards for these patients.

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Keywords: Permanent vegetative state; Minimally conscious state; Nursing; Ethics

Résumé

Objectifs. – Évaluer le nombre de patients en état végétatif et paucirelationnel chroniques vivant en institution dans le département de Maine-et-Loire. Évaluer les complications somatiques rencontrées, la charge en soins, les difficultés relevées par les soignants et les souhaits des équipes. Patients et méthodes. – Étude descriptive transversale des structures de médecine physique et de réadaptation (MPR), de soins de suite, de long séjour et des hôpitaux locaux. Tous les dossiers cliniques ont été analysés et tous les patients examinés par le même observateur. Un questionnaire dédié aux soignants a permis l'évaluation de la charge en soin et un autre questionnaire à réponses ouvertes pour le cadre infirmier a évalué les besoins en personnel et les souhaits des équipes.

Résultats. – Treize patients ont été recensés. Quatre sont en état végétatif chronique. Neuf sont en état paucirelationnel. Dix patients se trouvent en unité de soin de longue durée, un en MPR et deux en hôpital local. Tous ont des limitations importantes d'amplitudes articulaires. Toutes les équipes font état de difficultés pratiques quotidiennes et de questionnements d'ordre éthique.

E-mail address: vsaout8@gmail.com (V. Saoût).

^{*} Corresponding author.

Discussion-conclusion. – Ce travail montre que les situations de prise en charge sont variées. Il met en évidence les difficultés matérielles mais surtout les questionnements éthiques actuellement rencontrés. Il fournit une base de travail pour l'application au cours du SROSS de la circulaire sur la prise en charge de ces patients.

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Mots clés: État végétatif chronique ; État paucirelationnel ; Unités dédiées ; Charge en soins ; Éthique

1. English version

1.1. Introduction

A vegetative state, "wakefulness without awareness" [18,19], is observed in patients having emerged from coma. It is defined as "the presence of sleep—wake cycles, with either complete or partial preservation of hypothalamus and brainstem autonomic functions" and no evidence of awareness of the self and the environment [27,28]. Although this state is usually transient, it can become permanent in a small proportion of patients. The term "permanent vegetative state" (PVS) is used when the condition persists 12 months after traumatic brain injury or 3 months after brain damage from other causes.

A minimally conscious state (MCS) is characterized by "inconsistent but clearly discernible behavioural evidence of consciousness" [13]. This state may also be transient or permanent. The patient is considered to have left the MCS if he/she displays functional, interactive communication and/or displays the functional use of two different objects [13].

In France, the overall prevalence of PVS/MCS has been estimated at about 25 per million inhabitants [7]. Specific medical care is necessary [13,14,20,27–29,37,41]. Patients are totally dependent and require between four and a half to seven hours of care per day [7]. In France, PVS/MCS patients are cared for in small, dedicated units (as proposed in a recent government circular). These regulations were issued in response to the absence of any "organized response for these totally dependent persons" and should prompt the standardization of care nationwide [7].

The Maine-et-Loire county in western France lacks this type of dedicated facility. Anecdotal evidence suggested that most PVS/MCS patients were housed in geriatric units. We decided to perform a cross-sectional, descriptive study in order to determine how many PVS/MCS patients were being cared for in healthcare institutions in Maine-et-Loire and to assess patient management, physical complications, problems encountered by patient care teams and the decision-making process.

1.2. Patients and methods

1.2.1. Population

We performed a cross-sectional, descriptive study. All physical medicine and rehabilitation (PMR) departments, nursing homes, geriatric units and local hospitals were approached via a mail contact with either the administrative director or the medical staff. All over, 18 PVS/MCS patients housed in institutions in Maine-et-Loire were included in the study.

1.2.2. Evaluation

All patients and their medical records were examined by the same investigator. Individual data were collected on the following parameters: gender, age, PVS or MCS, the date of the brain injury, the aetiology, the care protocol and the patient's personal, professional and legal status. Medical difficulties were listed. Medical records were screened for written advance directives or instructions on the care to be provided in the event of worsened health status. An interview with a member of the care team served to evaluate the existence of non-written advance directives.

The Wessex Head Injury Matrix (WHIM) was used to evaluate wakefulness and the patient's neurological and orthopaedic statuses were analysed.

A questionnaire for carers aimed at estimating the daily nursing load and routine for each patient (nursing, physiotherapy, participation in activities and the state of involvement of the patients' relatives).

A second questionnaire for head nurses was used to gather data on the staffing ratio, problems encountered by the carers, the care team's wishes, staff meetings, dialogue with the patients' families and the presence or absence of dedicated accommodation for the latter.

1.3. Results

1.3.1. Population

Thirteen patients were identified (eight men and five women). The mean age at the time of the survey was 48 [range: 29 to 77]. Nine of the patients were married and 11 had children. Eight patients were in work at the time of brain injury. There were four PVS patients and nine MCS patients.

Seven patients had sustained traumatic brain injury, five patients had experienced anoxic brain injury and one patient had undergone a stroke.

The mean time since brain injury was 7 years [6 months—15 years].

Ten patients were housed in geriatric units (in six different institutions), one in a PMR unit and two in local hospitals.

All patients had been initially admitted to an intensive care unit (ICU), for an average of 1.4 months [0.5–4 months]. Six patients had then been admitted to a PMR department (for an average period of 7.2 months [0.5–19 months]) and two had been readmitted to a PRM department for further assessment.

1.3.2. Clinical findings

The highest-ranked WHIM behaviours ranged from 3 to 43. The PVS patients scored 3 or 4. The MCS patients scored between 7 and 43: three had a score of 26 (frowns, grimaces,

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