CO13-004–EN
Respite/rehabilitation hospital stays for rare neurological diseases and severe disabilities: Reporting on the experience 2003–2011
B. Soudrie
PH MPR responsable du pôle SSR handicaps lourds et maladies rares neurologiques, hôpital Marin-de-Hendaye, Assistance publique–Hôpitaux de Paris (AP–HP), 64701 Hendaye, France

Keywords: Modernization of care; Creation of a network; Improvement of the quality of life of the families involved

The respite/rehabilitation program was launched in 2003 when a new accessible and automated wing was opened with the aim of progressively expanding the capacity to 30 beds by 2010. In 8 years, we have been able to serve approximately 1000 neurological patients. Those patients, who normally live at home, stay with us for an average duration of one month.

They are generally referred to us by centers specializing in rare diseases such as they exist in the Paris area (AP–HP) or in other major cities, and by partner physicians working in the field of physical handicap in places such as Garches or La Pitié.

The stays are designed according to a collaboration charter, which defines the objectives specific to each pathology. In collaboration with the various Patients Associations we have established a questionnaire, which targets each specific disease and its rehabilitation needs. This questionnaire is completed before admission and allows us to greet the patient being fully aware of his/her needs and equipped to meet them.

Our specialty:– Summer stays designed for patients from various backgrounds (students, people in the work force…) who can benefit from our “handiplage” site, a beach specially equipped to offer outdoors activities to individuals with physical disabilities.

We also have a special unit of 8 beds to care for patients with spinal injuries hooked up to a ventilator, once they become stable after surgery. One of the 8 beds is marked for a patient eligible for respite/rehab care.

This department also offers a myology consultation, which is open to both patients staying at the hospital and outsiders.

The hospital is set up to offer accommodations to visiting families and 8 studio apartments are available to relatives who wish to stay near their loved ones. Overall the experience has been extremely successful and the social impact of such a program, which combines support for the caretakers and rehab, should be emphasized.


CO13-005–EN
Self-assessed well-being in a cohort of chronic locked-in syndrome patients
F. Pellas
CHU de Nîmes, Nîmes, France

Keywords: Locked-in syndrome; Quality of life; Survey; Coma; Consciousness; End of life

Objectives: Locked-in syndrome (LIS) consists of anarthria and quadriplegia while consciousness is preserved. Classical vertical eye movements or blinking allow coded communication. Given appropriate medical care, patients can survive for decades. We studied the self-reported quality of life in chronic LIS patients.

Design:– Hundred and sixty-eight LIS members of the French Association for LIS were invited to answer a mail questionnaire on medical history, current status and end-of-life issues. They self-assessed their global subjective well-being with the anamnestic comparative self-assessment (ACSA) scale, whose +5 and −5 anchors were their memories of the best period in their life before LIS and their worst period ever, respectively.

Results:– Ninety-one patients (54%) responded and 26 were excluded because of missing data on quality of life. Forty-seven patients professed happiness (median ACSA +3) and 18 unhappiness (median ACSA −4). Variables associated with unhappiness included anxiety and dissatisfaction with mobility in the community, recreational activities and recovery of speech production. A longer time in LIS was correlated with happiness. Fifty-eight percent declared they did not wish to be resuscitated in case of cardiac arrest and 7% expressed a wish for euthanasia.

Conclusions:– Our data stress the need for extra palliative efforts directed at mobility and recreational activities in LIS and the importance of psychological or drug therapy. Recently affected LIS patients who wish to die should be assured that there is a high chance they will regain a happy meaningful life. End-of-life decisions, including euthanasia, should not be avoided, but a moratorium to allow a steady state to be reached should be proposed.

Further reading


Feasibility study in assessment of socio-economical precariousness patients in physical medicine and rehabilitation wards (PMR): The EPICES score (evaluation of precariousness and health inequalities in health examination centers)

B. Barrois a, P. Ribinik
Centre hospitalier Emmanuel-Rain, Gonesse, France
*Corresponding author.

Keywords: Precariousness indicator; EPICES score; PMR

Background.—The EPICES score has proven its effectiveness in assessing precariousness. A parallel was drawn between precariousness and health risks.

Objective.—Identify and quantify precariousness level by the EPICES score for patients in PMR ward (living-in and day hospital).

Method.—Distribution of the assessment grid to all patients on a given day for self-administration.

Results.—Thirty-eight patients, mean age 54.4 years, in PMR ward on 03/23/11, received the grid. Eleven grids were excluded from the analysis: 5 patients refused to answer, 3 could not fill out the grid because of cognitive impairment, and 3 were unworkable because not properly completed. Fifteen patients of 27 were in a precarious situation (EPICES score > 30); 10 at living-in ward (66%) of which 6 had locomotor disorders and 4 had neurological disease, 5 inday-hospital (41%) of which 4 had locomotor disorders and 1 neurological disease.

Discussion and conclusion.—Fifty-five percent of patients were in a precarious situation, reflecting the local socio-economic reality. CH Gonesse is located in the east of Val Oise, ranked as ZUS (sensitive urban zone).

One finds no link between the precariousness indicator and type of disorders or age. Patients are more precarious in in-living ward in this preliminary analysis and this requires further studies to clarify this result. Is the PMR care organization affected by socio-economical precariousness?

References


EVASEP: Role of caregiver in supporting patients with multiple sclerosis treated with interferon beta 1a over 24 months

C. Donzé a, *, S. Demaillé b, C. Crinquette c, P. Hautecoeur d

a Service de médecine physique et réadaptation fonctionnelle, hôpital Saint-Philibert, rue du Grand-But, groupe hospitalier de l’institut catholique de Lille, 59462 Lomme, France
b Service de médecine physique du groupe hospitalier de l’institut catholique de Lille, Lille, France
c Service de neurologie du groupe hospitalier de l’institut catholique de Lille, Lille, France

* Corresponding author.

Keywords: Multiple sclerosis; Caregivers; Activity of daily living

Introduction.—The role of caregivers in multiple sclerosis (MS) is little studied. Their involvement and influence on therapy should be specified to optimize care.

Objective.—This observational study intends to clarify the role, nature of assistance and assess the level of knowledge of the disease among patients and their caregivers.

Methodology.—Two hundred and sixteen MS patient treated with interferon beta 1a over 24 months were included. The questionnaires were given during neurology consultations and included questions using visual analogue scales (VAS) to quantify answers. Descriptive analysis of all parameters collected and Spearman correlations were proposed. Hundred and fifty-one questionnaires patients and matched caregivers were analyzed.

Results.—Caregivers (mean age: 42.9 years) were men (58.6%) and spouses from 86.6% of them. Seventy-five percent said they were caregivers since diagnosis of MS. The level of patient information was sufficient but not sufficient for caregivers (P < 0.05). The level and nature of support varies with age, disease duration and EDSS (P < 0.005). “Fighting the disease” and “psychological support” are more commonly finding in the first year of MS and “physical assistance” and “care” after 15 years of evolution.

Discussion.—Studies of caregivers in MS generally concerned patients with high level of disability (EDSS > 6.5). In our population EDSS is relatively low (2.2), yet there is help available from the beginning of the disease.