Special ways of managing with neurodegenerative disease at home as seen by a mobile team of the Aquitaine serious disability network, HLA33

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Introduction.– Patients suffering from major neurodegenerative diseases living at home require multidisciplinary management and an adapted environment. By its expertise, a network can provide means and tools, and facilitate progress and implementation of care. It provides the necessary coordination between the professionals concerned.

Objective.– To present the problems most often met with by these professionals and the means used by the HLA33 network.

Method.– Starting from an example, a retrospective analysis of the medical records of patients suffering from neurodegenerative diseases due to parkinsonian syndrome or hereditary disease, compared with the entire group of patients followed by the network.

Results.– In 2010, the neurodegenerative diseases previously mentioned represent the third cause of disability of the patients in our network. From October 2004 to May 2011, out of 67 persons followed for these diseases (that is 10% of the patients in our network), there were 37 women and 30 men, on the average older than the general population of our network (55 years old).

Most of them were referred by a physician (neurologist, specialist in physical medicine or general practitioner). The patients were rarely referred directly after hospital discharge (16%) and most often lived in the Bordeaux area (73%). The members of the staff were always called upon: the psychologist most often to assist the healthcare professional or the family caregiver, the occupational therapists for technical assistance and adaptation of home (renewed request as the disease progressed), the social worker for the needs concerning the human aids and financing. On average, work with these patients was longer than it was for the overall group in our files (18 months).

Seven patients died while they were followed by our network.

Discussion and conclusion.– Taking into account the complexity of the situation and the progressive nature of neuromotor and psychobehavioural disorders, this intervention network is an asset aiming to improve care, organise referral, facilitate coordination, offer educational and occupational training possibilities with the goal of improving the quality of life in the home environment.

Keywords: Hospital discharge; Dependence; Indicators; Coordinated care

Objective.– To evaluate, based on existing recommendations, the criteria of a satisfactory organization when discharging to home a patient who remains dependent. It also aims at establishing simple and measurable indicators of the coordination between hospital and ambulatory care.

Patients and method.– All the general practitioners of Maine et Loire (French administrative district) received a questionnaire asking them to rank the three main criteria (from the most to the least important) out of a choice of 14 [1,2,3] and offering them the possibility to add commentaries. We analyzed for each item the average, the standard deviation and median and highlighted the most important ones through an analysis of the relative frequency distribution.