Rehabilitation of 190 non-ambulatory children with cerebral palsy in structures of care or in liberal sector

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Aims: To describe the rehabilitation of non-ambulatory children with cerebral palsy, in the community or in medico-social structures.

Methodology: Data reported are extracted from a national cohort, following during 10 years 385 children with cerebral palsy, aged 4 to 10 years, Gross Motor Function Classification System 4 and 5. We analysed data from the first 190 patients (6y10mo (SD 2.0), 111 boys) in medico-social structures and in the community.

Results: In medico-social structures, duration of paramedical care is significantly more important than when rehabilitation is performed in the community (structure: median = 4.25 h/week; community: median = 2.00 h/week) (p < 0.0001). More than four different types of care per week are given in medico-social structures, versus two in the community. In the investigator’s opinion, rehabilitation in medico-social structures is adapted to the needs in 71.65%, as opposed to 18.75% in the community (p < 0.001). Children level V have less time of rehabilitation than the others (p = 0.0424).

Discussion: Rehabilitation of children with cerebral palsy who are not able to walk, with an objective to improve quality of life, is better adapted in medico-social structures than in the community.

Further reading
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Multiple disabilities taken care in specialized hospitals

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Keywords: Profound and multiple disabilities; Handicap; Death

Objectives: This retrospective study concerns aetiologies, associated comorbidities, places and causes of death of a population of children and adults with polyhandicap (PLH) taken care in specialized hospitals. The followed patients were all medical heavy patients PLH (tetra paresis, IQ < 20, Functional Independence Measure < 20, GMPCS IV and V).

Patients and methods: In a population of 133 adults and children with polyhandicap died between 2006 and 2012, we collected the following data: aetiology, duration of hospitalization, sex, age, place and cause of death and the following comorbidities: chronic respiratory failure, pulmonary infections (upper or equal to 4 a year), urinary infections (1 or several a year), epilepsy, severe scoliosis (superior to 50 degrees), chronic digestive disorders, behaviour disorders.

Results: Sex ratio: 84 males/49 women, 70 children/63 adults. Main aetiologies were: perinatal anoxia (26), encephalopathy of unknown aetiology (19), epileptic encephalopathy (15), lysosomal disease (16), malformations of the central nervous system (six), genetic (six), newborn child infection (five), polymalformative syndrome (three). Progressive encephalopathies represented 27% of aetiologies. The average duration of hospital stay was 10 years (1 month–43 years), the average age of death was of 21 years (3–52), death occurred in 60% of cases in specialized hospital, in 31% of cases in intensive care unit, in 6% of cases at home and for 3% of cases in nursing homes. The causes of death were in decreasing order: pulmonary infections (63.2%), sudden death (18%), epileptic seizures (6.8%) and unknown causes (12%). 79.7% suffered from chronic respiratory failure and 72.2% presented episodes of iterative pulmonary infections, 21.8% presented chronic urinary infections, 60.2% were carriers of important scoliosis, 66.9% had drug resistant epilepsy, 78.9% presented digestive disorders and 6.8% of patients presented behaviour disorders.

Discussion: The main comorbidity and the main cause of death of patients with polyhandicap was respiratory failure. 66.9% of the patients presented epilepsy. Patients presented numerous others comorbidities with justify acts of prevention. The average duration of hospitalisation were very long and mostly in specialized hospital.

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