Available online at
SciVerse ScienceDirect
www.sciencedirect.com

Elsevier Masson France
EM|consulte
www.em-consulte.com

Annals of Physical and Rehabilitation Medicine 56 (2013) 253–267

ANNALS OF PHYSICAL AND REHABILITATION MEDICINE

Original article / Article original

A survey of medical and paramedical involvement in children with cerebral palsy in Britanny: Preliminary results

Enquête sur la quantité de soins délivrés aux enfants paralysés cérébraux en Bretagne : résultats préliminaires

E. Sacaze[a,d], R. Garlantezec[b,j], O. Rémy-néris[a,f,i,k], S. Peudenier[c], H. Rauscent[e], H. le Tallec[g], V. Bernier-Francois[g], D. Pichancourt[h], S. Brochard[a,*,f,i,k]

et le Groupe de Recherche sur la paralysie cérébrale en Bretagne

[a] *Service de médecine physique et de réadaptation, CHU Morvan, 5, avenue Foch, 29609 Brest cedex, France*
[b] *École des hautes études en santé publique, 35043 Rennes cedex, France*
[c] *Service de pédiatrie, CHU Morvan, 5, avenue Foch, 29609 Brest cedex, France*
[d] *Centre d'aide médicosocial précoce, centre hospitalier de Cornouailles, 29107 Quimper cedex, France*
[e] *Service de rééducation fonctionnelle pour enfant, CHU de Rennes, 2, rue Henri-le-Guilloux, 35033 Rennes cedex 09, France*
[f] *Centre de rééducation fonctionnelle pour enfant, 27, rue Mathieu-Donnart, 29200 Brest, France*
[g] *Centre mutualiste de rééducation et de réadaptation fonctionnelles de Kerpape, BP 79, 56276 Ploemeur cedex, France*
[h] *Centre de rééducation et de réadaptation fonctionnelles Trestel, 22660 Trevou Treguinec, France*
[i] *Inserm 1101, laboratoire de traitement de l'information médicale, CHU Morvan, 29609 Brest cedex, France*
[j] *Inserm U1085, 35043 Rennes cedex, France*
[k] *Université de Bretagne Occidentale, 22, avenue Camille- Desmoulins, 29238 Brest cedex 3, France*

Received 14 February 2012; accepted 24 November 2012

Abstract

Aim. – To describe the amount of medical and paramedical involvement in a sample of Breton children with cerebral palsy as a function of the Gross Motor Function Classification System (GMFCS).

Materials and methods. – This is a transversal descriptive study. All children with cerebral palsy in Brittany were eligible. Parents who accepted to participate were asked to fill in a questionnaire regarding medical and paramedical involvement with their child.

Results. – One hundred and thirty-three parents participated. 40.6% of the children were level I on the GMFCS, 20.3% II, 12.03% III, 13.53% IV and 13.53% were level V. Thirty-nine percent of the children took at least one medication (of which 43% were antiepileptic drugs). 33.1% of the children had received at least one injection of botulinum toxin within the year. Forty-four percent used a mobility aid. Eighty-five percent of the children had at least one orthotic device, most often a night ankle-foot orthosis. The median number of rehabilitation sessions per week was 3.85 [0.5–11.5]. The frequency and type of sessions were mostly related to the GMFCS level.

Conclusion. – This study reports high levels of medical and paramedical involvement. Studies must attempt to define optimal practice.

Keywords: Cerebral palsy; Treatments; Medication; Devices; Care; Rehabilitation

Résumé

Objectif. – Décrire les fréquences des soins médicaux et paramédicaux d'un échantillon d'enfants paralysés cérébraux bretons en fonction de la Gross Motor Function Classification System (GMFCS).

Matériel et méthode. – Il s'agissait d'une étude transversale descriptive. Tous les enfants paralysés cérébraux résidant en Bretagne étaient éligibles. Les parents acceptant de participer répondaient à un autoquestionnaire contenant des informations sur les soins médicaux et paramédicaux de leur enfant.

---

* Corresponding author.
E-mail address: sylvain.brochard@chu-brest.fr, sb20814@gmail.com (S. Brochard).

1877-0657/$ – see front matter
http://dx.doi.org/10.1016/j.rehab.2012.11.003

Résultats. – Cent trente-trois parents ont participé. 40,6 % des enfants étaient stade I de la GMFCS, 20,3 % II, 12,03 % III et 13,53 % IV et 13,53 % V. Trente-neuf pour cent des enfants prenaient au moins un médicament (dont 43 % des antiépileptiques). 33,1 % des enfants avaient reçu au moins une injection de toxine dans l'année. Quarante-quatre pour cent des enfants bénéficiaient d'une aide technique au déplacement. Quatre-vingt-cinq pour cent des enfants bénéficiaient d'au moins un appareillage orthotique, principalement une orthèse mollet-plante nocturne. Le nombre médian des prises en charge paramédicales par semaine était de 3,85 [0,5–11,5]. La fréquence et le type de soin étaient le plus souvent associés au niveau de GMFCS.

Conclusion. – Cette étude rapporte des fréquences de soins élevées. Les recherches aidant à la définition de pratiques optimales doivent se poursuivre.

Mots clés : Paralysie cérébrale ; Traitements ; Médicaments ; Appareillages ; Soins ; Rééducation

1. English version

1.1. Introduction

The term Cerebral Palsy (CP) includes a group of permanent disorders of motor and postural development following cerebral lesions which occurred in the developing brain before the age of 2 years [9]. It is the most frequent cause of motor disability in children. The prevalence, which has been stable for the past 30 years, is 2 for 1000 live births [3]. The impairments, clinical symptoms and functional limitations which occur are very heterogeneous because of the diversity of the lesions and the fact that they occur at very young age. The Gross Motor Function Classification System (GMFCS) is commonly used to provide a description of the type of CP based on the child's global level of motor function. The GMFCS consists of five levels of abilities with level I representing is the highest level of ability and level V the lowest [17]. The scale has been shown to be reliable, valid and clinically relevant for the classification and prediction of motor function in children aged 2 to 18 years old [18,21].

The medical and paramedical management of children with CP very much depends on the degree of cerebral lesions and their functional repercussions. The management strategy includes drug treatments (general or local treatment of spasticity, epilepsy, etc.), mobility aids (sticks, walking frames, wheelchairs, etc.), postural aids (ankle-foot orthoses, corsets, adapted seating, etc.) and rehabilitation (physiotherapy, occupational therapy, speech therapy, vision rehabilitation, etc.). Other paramedical staff such as special educators and psychologists are often involved with the children and their families within or out with specialized establishments. Medical follow-up is multidisciplinary and can include a physiatrist, a neuropediatrician, pediatrician, and general practitioner.

Many epidemiological studies based on registers of children with CP have been carried out, providing descriptions of the impairments and the possibility to observe changes in their prevalence within the population [3,11]. However, there are few studies regarding the therapeutic management of these children. Most studies which have evaluated treatment have evaluated a single treatment within the whole management strategy. Over the past 20 years, these studies have completely changed the management of children with CP because the effectiveness of new treatments such as intramuscular botulinum toxin injections has been demonstrated [4,5] as well as the effectiveness of new rehabilitation techniques such as constraint induced therapy [22]. New drug treatments combined with rehabilitation have probably increased the amount of treatment received by the child, possibly burdening his or her daily routine. To our knowledge, no studies have been carried out to describe and quantify the total medical and paramedical involvement in the care of children with CP.

In order to fill this gap, an observational study on 'the medico-social management of Breton children and adults with CP' was set up in February 2010 in Brittany, France. The main aim of this first phase report is to describe the frequencies of medical and paramedical involvement in a sample of Breton children with CP according to the GMFCS classification.

1.2. Materials and methods

1.2.1. Type of study

Transversal descriptive study based on a self-report questionnaire.

1.2.2. Sample

Between February 2010 and June 2011, 450 questionnaires and prepaid envelopes were sent to 40 physicians with case load of children with CP in the four departments of Brittany (neuropediatricians, physiatrists, pediatric surgeons, doctors from the Medico-Education Institute, Institute of Motor Education, Center of early medico-social assistance, Education Department and Specialized home care). The doctors in this network distributed the questionnaire to the parents. Phone call and email reminders were regularly sent to the physicians during this period.

1.2.3. The questionnaire

The aim of the questionnaire was to define current medical management of children with CP by capturing a specific instant of their treatment. The questions asked to the parents concerned medical and paramedical involvement at the time that the questionnaire was filled in: oral medication (the prescription was copied on to the questionnaire), botulinum toxin injections (within the last 6 to 12 months) and the site(s) of the limb(s) injected, baclofen pumps, mobility and postural aids, medical input and rehabilitation (frequency). The questionnaire was based on the recommendations of McColl et al. [12] and met the following criteria: