



EDITORIAL

The challenge of comprehensive care for patients with cerebral palsy[☆]



El reto de la atención integral al paciente con parálisis cerebral infantil

Dorleta López de Suso Martínez de Aguirre^{a,*}, Ricardo Martino-Alba^b

^a Servicio de Pediatría, Hospital Universitario Puerta de Hierro-Majadahonda, Majadahonda, Madrid, Spain

^b Unidad de Atención Integral Paliativa Pediátrica, Hospital Infantil Universitario Niño Jesús, Madrid, Spain

Cerebral palsy (CP) is the most frequent cause of motor impairment in children. It encompasses a collection of disorders of movement and posture resulting in activity limitation attributed to a nonprogressive injury to the developing brain in the foetal period or the early years of life.

The disorder is frequently associated with multiple comorbidities, such as intellectual disability, sensory disorders, dysphagia, respiratory disorders, pain or epilepsy. The frequency of these comorbidities increases with the level of motor impairment defined by the Gross Motor Function Classification System (GMFCS),¹ in which the greatest severity corresponds to levels IV and V.

Since there are few disease-modifying interventions, treatment should focus on the management of modifiable comorbidities with an interdisciplinary approach. In this regard, the current issue of ANALES DE PEDIATRÍA includes a study on the burden of caregivers of patients with severe CP and its association with different possible comorbidities.²

An adequate nutritional assessment is essential to promote motor activity, maintain the integrity of the skin and preserve immunity. While muscle tone abnormalities, such as spasticity or dystonia, can increase energy expenditure at specific times in these patients, the main cause of malnutrition in patients with CP is insufficient intake of macronutrients or micronutrients. This is due to multiple factors, such as motor impairments that make chewing and swallowing difficult, gastro-oesophageal reflux (GOR) or constipation. Dysphagia, GOR or malnutrition substantially increase the risk of respiratory infection in patients with moderate to severe CP.

Osteoporosis is a common condition in these patients: hypermobility, nutritional deficiencies and osteotoxic drugs such as anticonvulsants, proton pump inhibitors or corticosteroids contribute to increase the risk of fractures. Sometimes, these fractures go undetected and cause pain that is difficult to control.

Pain, resulting from multiple causes (Table 1)³ and frequently underdiagnosed, is a frequent symptom in these patients. More than 90% of children with CP report experiencing recurrent pain in the past year, while only half reported receiving treatment for it.⁴ Pain has a considerable impact on every aspect of daily living, as it can cause anxiety, depression, irritability or sleep disturbances in both patients and caregivers.

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* Corresponding author.

E-mail address: dorleta.lopez@salud.madrid.org
(D. López de Suso Martínez de Aguirre).

Table 1 Common causes of pain in paediatric patients with CP.

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| <i>Surgical</i> | |
| Tenotomy | |
| Fasciotomy | |
| Capsulotomy | |
| Selective dorsal rhizotomy | |
| Spinal fusion | |
| Baclofen pump implantation | |
| Fundoplication | |
| Gastrostomy | |
| <i>Orthopaedic</i> | |
| Hip luxation/dislocation | |
| Displacement of patella | |
| Equines of ankle | |
| Valgus deformities | |
| Radial subluxation | |
| Cartilage degeneration | |
| Kyphosis | |
| Contractures | |
| Degenerative arthritis | |
| <i>Procedures</i> | |
| Intramuscular or subcutaneous injections | |
| Administration of anaesthesia | |
| Blood draws | |
| Placement of nasogastric tube | |
| Dental procedures | |
| Enemas | |
| <i>Neuromuscular</i> | |
| Spasticity | |
| Overuse | |
| Nerve entrapments | |
| Radiculopathies | |
| Myelopathies | |
| Contractures | |
| <i>Gastrointestinal</i> | |
| GOR | |
| Nausea/vomiting following surgery | |
| Gastrostomy change | |
| Chronic abdominal pain | |
| Constipation | |
| <i>Rehabilitation</i> | |
| Stretching | |
| Electrical stimulation | |
| Occupational therapy | |
| Training on use of adaptive devices | |

CP, cerebral palsy; GOR, gastro-oesophageal reflux.
Source: adapted from McKearnan et al.³

The coexistence of different health problems usually involves treatment with a greater number of drugs, which in turn increases the risk of adverse events. The paediatric population, especially when it comes to patients with comorbidities, is at high risk of medication errors due to the use of medication under exceptional circumstances, as the drugs are not usually approved specifically for use in the paediatric population and are sometimes given in doses other than those specified in the label.⁵ This increases the risk of both medication errors and drug interactions with either the

usual medication used by the patient or medication needed for acute conditions, such as antibiotics.

The establishment of specialised care units and the figure of the physician lead are essential to provide adequate care. The care team must include paediatricians with specific training on chronic and complex diseases, knowledgeable of the most frequent comorbidities and with experience in the management of the drugs commonly used in this population. Thus, most of the clinical manifestations in these patients could be managed in a single site, coordinating and integrating care by other specialists. The physician lead is responsible for maintaining a holistic perspective and helps establish priorities in treatment planning.

An integrative approach involves perceiving patients as human beings, taking into account the constellation of attachments, relationships and values in their lives. Delivering quality care with this approach requires inclusion of mental health and social work professionals in the team.

Caregivers of children with CP, especially mothers, spend a significant number of hours in the care of their sick child, either by helping with daily living activities or with the different types of therapy the child requires. This additional investment entails that these mothers can work fewer hours compared to mothers of healthy children, between 65%–80% of full time, which has an impact on their income.⁶

In addition, raising a child with moderate-to-severe CP also carries an emotional burden, as in most cases the child will never become fully independent from the caregivers. However, studies on the subject shows that the main burden for families is not emotional distress but socio-structural constraints that vary depending on the region.⁶ On their part, patients with CP experience psychiatric symptoms characteristic of their disease the frequency of which increases with the severity of intellectual disability. Motor and cognitive impairments cause difficulties in social integration, widening the gap that separates these patients from their peers and exacerbating the associated psychiatric symptoms.

On the other hand, the management of patients with moderate-to-severe CP that reach adulthood is not well defined on account of its usual complexity. Although on reaching the age of majority these patients are legally considered adults, based on their chronic disease, body weight, involvement of different specialists or the care they required they continue to be paediatric patients.

If health care systems aspire to provide patient-centred care, they must be able to push past administrative barriers. Existing programmes for the transition to adult care may not always be appropriate. Due to the increased survival of patients with complex childhood diseases, a greater number are now reaching adulthood. The establishment of specific interdisciplinary units could guarantee a higher quality of care based on individual needs.

Furthermore, CP is responsible for a substantial increase in health care costs and a loss of productivity in both patients and household members. The need to care for the patient takes time away not only from career development, but also from activities related to self-care, leisure or the care of other members of the family. For this reason, there is a growing investment in resources aimed at supporting caregivers, collectively referred to as respite care. Some foundations offer nursing staff that travels to the home to care for chil-

dren with CP for a few hours so the family can spend time on other things. These resources are still being developed for the paediatric population, despite the previous publication of studies demonstrating that the best way to improve quality of life in paediatric patients with severe chronic or terminal disease and their families is to develop a network of family-centred paediatric palliative and hospice care.

In conclusion, patients with moderate-to-severe CP experience heterogeneous manifestations of the disease that require an integrative and interdisciplinary approach coordinated or provided by specific management units. This not only results in a higher quality of care but also supports the efforts of caregivers.

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