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EDITORIAL

Medium to long-term follow-up of premature children and their families in Spain☆

Seguimiento a medio-largo plazo de los niños prematuros y sus familias en nuestro país

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In recent decades, there have been significant advances in the fields of obstetrics and neonatology.[1] Newborns receive exquisite care in neonatal units thanks to improvements in staff training and the introduction of cutting-edge medical equipment. This has made possible a significant increase in the survival of very preterm newborns. On the other hand, this increase has been associated with a significant decrease in the prevalence of severe neurologic impairment compared to the past, especially when it comes to cerebral palsy (which at present occurs in only 5% of children born before 32 weeks' gestation), intellectual disability, sensorineural hearing loss and blindness secondary to retinopathy of prematurity. However, other medium- and long-term neurodevelopmental problems (of lesser severity but higher prevalence than the ones just mentioned) have become the focus of interest of health care and education professionals as well as families themselves. At present, vision problems, hearing loss of varying severity, neuropsychological and learning disorders, autism spectrum disorder, attention-deficit hyperactivity disorder and behaviour and conduct disorders are significantly more prevalent in this population compared to the general population, and may be present in up to 50% of children born very preterm.[2,3]

In Spain, the follow-up conducted after discharge from the neonatal unit of preterm infants could be improved in several ways. Despite efforts made in recent years, including the design and implementation by the Sociedad Española de Neonatología (Spanish Society of Neonatology, SENeo) a national protocol for the follow-up of preterm infants,[4,5] the quality of the care given to families after discharge is far from guaranteed.

This is due, on one hand, to disparities in the services provided in terms of the varying duration and quality of the care offered by follow-up programmes in different health care facilities and geographical regions. Follow-up units continue to lack appropriate staff, including specialists in neonatology and other professions necessary in multidisciplinary care teams: rehabilitation specialists, physical therapists, speech therapists, occupational therapists, psychologists, etc. (professionals whose work should start while the

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newborn is still in hospital). Furthermore, only a minority of the neonatologists involved in follow-up programmes have specific training in neurodevelopment and the problems derived from prematurity. On the other hand, the resources available to follow-up programmes to address the needs of these children and their families are insufficient.

On the other hand, the channels for communication and coordination between the different actors involved in care delivery to these families, especially in early childhood education centres, hospital-based follow-up units, primary care and the education system, are poorly developed at the moment.

Lastly, there are no data on the health care and education needs of this population in Spain beyond the age of 2 years. One of the greatest limitations we face is that we do not know the current situation of the school-aged subset of this population. Few studies have been conducted in Spain to analyse these aspects, and nearly all had very small samples.

All of the above hinders the development of follow-up programmes as well as the early detection and rehabilitation of abnormalities that developed through childhood and adolescence.[6]

In this regard, the articles published by Bachiller-Carnicero et al.[7] and Alcántara-Canabal et al.[8] in the current issue of ANALES DE PEDIATRÍA contribute information on the real-world situation of children born preterm in Spain in the past decade. The study by Bachiller-Carnicero et al., conducted in 214 children aged 6 years who were born with a weight of less than 1500 g or before 32 weeks' gestation confirmed that, as observed in neighbouring countries, these children are more vulnerable to psychosocial and mood disorders and experience greater difficulty in their relationships with peers. Alcántara-Canabal et al. broached a subject that is relatively unknown in Spain: the impact on families of children born preterm; the study found that it is not preterm birth itself but the presence of developmental abnormalities resulting from prematurity that determines the level of stress and overburden in caregivers.

In light of the obvious need to improve the quality of the care received by these families after discharge from hospital, which was highlighted by a recent article based on data from a nationwide survey to assess follow-up services in Spain,[9] we suggest some of the strategies that could be pursued to this end:

- Specific education and training for neonatologists in charge of the follow-up of these patients. Specific training on this subject should be part of the educational and training curriculum of the medical specialty of neonatology.
- Allocation to this population of a greater number of providers in different specialties, including neonatologists, neuropsychiatrists, clinical psychologists and social workers.
- Extension of follow-up programmes beyond early childhood, at least through age 6–7 years. Restricting follow-up to the first 2 years of life neglects potential future needs of these children and their families.
- Optimisation of nationwide follow-up registers, including data on long-term morbidity. It is essential for us to know the actual prevalence of the different disorders and their severity in Spain to be able to offer efficient and high-quality care.
- Creation of specialised and multidisciplinary follow-up units for the comprehensive management of these families and for their subsequent referral to the most appropriate rehabilitation and early intervention services based on their specific needs.
- Development of adequate communication channels to promote coordination between the health care providers that manage these patients at the outpatient and inpatient levels.

We are aware that the goals we intend to pursue are ambitious, but we believe that children who are born preterm today in Spain not only deserve the best perinatal care that we can offer, but also all the care and interventions that may promote their healthy development and wellbeing. Only then can we guarantee the adequate integration of these children in the family, the education system and society.[10]

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