



## ORIGINAL ARTICLE

# Children's medically complex diseases unit. A model required in all our hospitals<sup>☆</sup>

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### KEYWORDS

Disabled child;  
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### Abstract

**Introduction:** The increase in survival of children with severe diseases has led to the rise of children with chronic diseases, sometimes with lifelong disabilities. In 2008, a unit for the specific care of medically complex children (MCC) was created in Hospital La Paz.

**Objectives:** To describe the work and care activities of this Unit.

**Patients and methods:** An analysis was performed on all discharge reports of the Unit between January 2014 and July 2016.

**Results:** The MCC Unit has 6 beds and a daily outpatient clinic. A total of 1.027 patients have been treated since the creation of the unit, with 243 from 2014. The median age was 24.2 months (IQ: 10.21–84.25). The large majority (92.59%) have multiple diseases, the most frequent chronic conditions observed were neurological (76.95%), gastrointestinal (63.78%), and respiratory diseases (61.72%). More than two-thirds (69.54%) of MCC are dependent on technology, 53.49% on respiratory support, and 35.80% on nutritional support. Hospital admission rates have increased annually. There have been 403 admissions since 2014, of which 8.93% were re-admissions within 30 days of hospital discharge. The median stay during 2014–2016 was 6 days (IQ: 3–14). The occupancy rate has been above 100% for this period. Currently, 210 patients remain on follow-up (86.42%), and 11 children (4.53%) were discharged to their referral hospitals. The mortality rate is 9.05% (22 deaths). The main condition of these 22 patients was neurological (9 patients). Infectious diseases were the leading cause of death.

**Conclusion:** MCC should be treated in specialised units in tertiary or high-level hospitals.

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**PALABRAS CLAVE**

Discapacidad infantil;  
Enfermedad crónica;  
Tecnología  
biomédica;  
Hospital;  
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**Unidad de niños con patología crónica compleja. Un modelo necesario en nuestros hospitales****Resumen**

**Introducción:** El incremento de la supervivencia de niños con enfermedades graves ha supuesto el aumento de niños con patología crónica altamente compleja, en ocasiones con discapacidades de por vida. En el año 2008 se creó una unidad para la atención específica de los niños con patología crónica compleja (NPCC) en el Hospital La Paz.

**Objetivos:** Describir el funcionamiento y la actividad asistencial de esta unidad.

**Pacientes y métodos:** Se analizaron todos los informes de alta de la unidad entre enero de 2014 y julio de 2016.

**Resultados:** La unidad dispone de consulta y 6 camas de hospitalización. Se han atendido 1.027 pacientes, 243 desde 2014. La mediana de edad fue de 24,2 meses (IC: 10,21-84,25). Un 92,59% presentaron pluripatología, siendo las condiciones crónicas más frecuentemente observadas las neurológicas (76,95%), gastrointestinales (63,78%) y respiratorias (61,72%). Un 69,54% de los NPCC fueron dependientes de tecnología, el 53,49% de soporte respiratorio y el 35,80% nutricional. El número de ingresos ha aumentado anualmente, hasta 403 desde 2014, con un 8,93% de reingresos. La mediana de la estancia fue de 6 días (IC: 3-14). La tasa de ocupación fue superior al 100% en este período. En la actualidad se mantienen en seguimiento 210 pacientes (86,42%), 11 niños han sido dados de alta a sus hospitales de referencia y 22 han fallecido (9,05%). De estos 22 pacientes, la principal condición fue neurológica, y la principal causa desencadenante del fallecimiento fue infecciosa.

**Conclusión:** La unidad de NPCC ha incrementado su actividad en estos años, poniendo de manifiesto la necesidad de crear estas unidades en los hospitales terciarios.

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**Introduction**

In the last half century, improvements in paediatric care have succeeded in reducing childhood mortality and increasing survival in children with severe diseases.<sup>1</sup> This has resulted in an increase in the number of children with chronic disease, at time with lifelong disabilities, who are more medically fragile and complex.<sup>2,3</sup> This increase in chronic patients demands a shift in the approach to the development of paediatric treatment plans, which should aim to deliver comprehensive, multidisciplinary and coordinated care. The care of chronic patients is the main task of health care systems in the developed world.<sup>2-4</sup>

Children with special health care needs (SHCNs) are those presenting with, or at higher risk of, a chronic physical, developmental, behavioural or emotional condition that consequently require health and related services of a type or amount beyond that required by the general paediatric population.<sup>5</sup> Within this group there is a smaller subset, that of medically complex children (MCC), or children with complex chronic conditions (CCCs). The best definition of a child with a CCC is that of a patient with a health condition that would normally be expected to last at least 12 months (unless the patient dies) with involvement of different organ systems or involvement of a single system that is sufficiently severe to require specialised paediatric care and probably periods of hospitalisation in a tertiary care centre.<sup>6</sup> Although in countries like the United States SHCNs amount to only 13–18% of the total of children that use the health care system, some studies report that they generate more

than 80% of the total health care costs in the paediatric population.<sup>7</sup> This substantial proportion of the total costs is mainly due to these children requiring a greater number of hospitalizations, more frequent admission to intensive care units (ICUs), longer lengths of stay, more technological support, and more specialised services involving multiple specialty clinicians.<sup>5,8-14</sup>

There is evidence that this subset is at higher risk than the rest of the paediatric population of potentially preventable hospital admissions and/or events, and also at higher risk of being subject to medical errors.<sup>6,8,15-17</sup> Many hospitalizations could be avoided by improving care in this group of patients.<sup>5,8</sup> In recent years, programmes for the care of patients with chronic complex conditions have been developed, mainly in the United States, to address their needs and improve their management, providing coordinated care.<sup>8</sup> There is evidence that the creation of specific units for the care of MCC significantly decreases overall health care costs in this group of children with high use of health care resources.<sup>10,18</sup>

At present, the Spanish health care system does not have specific care pathways for MCC, which hinders delivery of continued, coordinated and holistic care in this population. In 2008, a unit for the management of complex conditions was created in the Hospital de la Paz, the first of its kind in the country. Our purpose was to describe the operations and health care delivery in this unit, which we consider a model that is both feasible and necessary in other tertiary hospitals and regions of Spain.

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