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ORIGINAL ARTICLE

Stratification by complexity of children with complex chronic conditions: a retrospective study☆

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KEYWORDS
Chronic disease;
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Abstract
Introduction: Advances in medical care have increased the survival of children with chronic diseases, resulting in a growing population of patients with paediatric chronic complex conditions (PCCCs). The heterogeneity in the used terminology and identification tools hampers consistent stratification and appropriate planning of health care resources.
Objective: To determine the level of complexity in pediatric patients with chronic conditions using validated tools.
Methods: We conducted a retrospective cross-sectional study in a representative sample of paediatric patients with chronic conditions documented in the administrative records from the Community of Madrid in 2023. We collected data on sociodemographic variables and the main diagnosis according to the ICD-10. A sequential stratification process was applied using the Pediatric Medical Complexity Algorithm (PMCA), followed by the PedCom scale in patients classified as having PCCCs with the PMCA. We analyzed differences in patient categorization between the two tools and the variation in complexity according to the primary diagnosis.
Results: The analysis included a total of 355 patients with a median age of 8.1 years, of who 41.4% were female. According to the PMCA, 66.2% of patients were classified as having PCCCs. In this group, only 49.3% met the criteria for PCCCs using the PedCom scale. There was substantial varition in PedCom scores among patients sharing the same primary diagnosis.

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Conclusions: Complexity in pediatric chronic conditions does not depend solely on the main diagnosis but on multiple clinical and psychosocial factors. The combined use of tools such as the PMCA and the PedCom may improve identification of children with greater complexity and support more tailored health care planning.
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PALABRAS CLAVE
Pediatría;
Enfermedad crónica compleja;
Estratificación;
Servicios sociales

Estratificación de la complejidad en niños con patología crónica y complejidad: estudio retrospectivo

Resumen
Introducción: Los avances en la atención sanitaria han incrementado la supervivencia de niños con enfermedades crónicas, dando lugar a una población creciente de pacientes con patología crónica y complejidad (PCC). La heterogeneidad en la terminología y en las herramientas de identificación dificulta una estratificación homogénea y la adecuada planificación de recursos asistenciales.
Objetivo: Determinar el nivel de complejidad de pacientes pediátricos con patología crónica mediante herramientas validadas.
Material y métodos: Estudio transversal retrospectivo realizado sobre una muestra representativa de pacientes pediátricos con patología crónica incluidos en registros administrativos de la Comunidad de Madrid en 2023. Se recogieron variables sociodemográficas y el diagnóstico principal según la CIE-10. La estratificación se realizó de forma secuencial mediante el Pediatric Medical Complexity Algorithm (PMCA) y la escala PedCom en los pacientes clasificados como PCC por la PMCA.
Resultados: Se analizaron 355 pacientes, con una mediana de edad de 8,1 años; el 41,4% eran mujeres. Según la PMCA, el 66,2% fueron clasificados como PCC. De estos, solo el 49,3% cumplió criterios de PCC según la escala PedCom. Se observó variabilidad en las puntuaciones de la PedCom entre pacientes con el mismo diagnóstico principal.
Conclusiones: La complejidad en la patología crónica pediátrica no depende exclusivamente del diagnóstico principal, sino de factores clínicos y psicosociales. El uso combinado de PMCA y PedCom puede mejorar la identificación de pacientes con mayor complejidad y favorecer una planificación más ajustada de la atención.
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Introduction

Medical and technological advances in recent decades have significantly reduced child mortality, resulting in an increased survival of children with chronic conditions, disabilities, technology dependence, and complex medical conditions.[1]

This epidemiological shift has given rise to a new profile of pediatric patients: children with complex chronic conditions (CCCs). Children with CCCs are a subset of pediatric patients with severe multisystemic diseases, a high treatment burden, recurrent hospitalizations, and a need for continuous, multidisciplinary, and coordinated care, including home care.[2] It is estimated that they amount to less than 3% of the pediatric population in the US and Canada, yet they account for up to 40% of pediatric health care expenditures.[3–5] Prevalence estimates vary depending on the definition of CCC and methodology used. In England, Fraser et al. estimated a prevalence of life-limiting conditions of 66.4 per 10 000 individuals aged 0–19 years of age in 2017, with a predicted increase to 84.2 per 10 000 by 2030.[6]

The terminology used to describe children with complex medical conditions is heterogeneous and depends both on the stage of the disease (children with CCCs, with palliative care needs, with life-limiting or life-threatening conditions) and on the level of care complexity (children with special health needs, with medical complexity, or who are technology-dependent). This variability precludes consistent stratification of patients, limits the comparability of studies, and has an impact on clinical practice. Several identification and stratification tools based on diagnoses and clinical and administrative variables exist, the most widely used of which are the Pediatric Complex Chronic Conditions Classification[7] and the and the Pediatric Medical Complexity Algorithm (PMCA),[8] both based on the International Classification of Diseases, 10th Revision (ICD-10). However, newer tools that address clinical, educational, care, and psychosocial needs are also being developed, including the expanded PedCom Scale,[9] which has demonstrated greater validity

Table 1 Summary of the tools used for identification and stratification of children with complex chronic conditions.

Tool	Description	Stratification levels	Target population	Administered by	Validated languages	Accuracy
Adjusted morbidity groups (GMA)	Classification system based on diagnosis, administrative data and health care data to classify population based on morbidity and complexity.	A. No chronic disease B. Low-risk chronic condition C. Moderate-risk chronic condition D. High-risk chronic condition	Adult population	Health care staff	Spanish	Sen: 75% Spe: 86%
Pediatric medical complexity algorithm (PMCA)	Classification system based on ICD-10 diagnoses and administrative data.	Without chronic condition With non-complex chronic condition With complex chronic condition	Pediatric population	Health care staff	English	Sen for CCCs = 86% Spe for CCCs = 87%
Pediatric Complex Chronic Conditions Classification system	Classification system based on ICD-10 diagnoses and administrative data.	No complex chronic condition Complex chronic condition	Pediatric population	Health care staff	English	Sen: 95.1% Spe: 19.1%
PedCom	A numerical classification system based on clinical, educational, care, and psychosocial needs.	No complex chronic condition Complex chronic condition	Pediatric population	Health care staff	English Spanish	Sen: 96% Spe: 97%
Complexity Classification Guideline	A numerical stratification system based on clinical, care, and psychosocial needs.	Low complexity Moderate complexity High complexity	Pediatric population	Health care staff	Spanish	Sen: 85.7% Spe: 79.2%
Expanded PedCom	Numerical stratification system based on clinical, educational, care, and psychosocial needs.	No CCC Low complexity Moderate complexity High complexity Extreme complexity	Pediatric population	Health care staff	English Spanish	Sen: 95% Spe: 99%

Source: Martínez de Aguirre et al.[10]

in the settings where it has been evaluated[10] (Table 1). Implementing stratification strategies is key to planning interventions and allocating resources, taking into account functional, educational, home care, and family needs, in addition to the diagnosis.

Some children with CCCs are eligible for pediatric palliative care, which must be tailored according to the stage of development and the degree of clinical complexity, ranging from a general palliative care approach to intervention by specialized care teams.[11]

Families of children with CCCs face a substantial and prolonged caregiver burden, with a significant physical, emotional, and socioeconomic impact.[12–15] These families require a holistic care approach that safeguards the child's dignity and fosters relationships built on trust, respect, and shared decision-making with the care team.[12,13,16] Caregiving falls primarily on parents, who spend a mean of 3.9 h per week on care coordination and more than 5.1 h providing direct care, which that can increase to 14.4 h in children with greater impairment, such as those with severe cerebral palsy. This caregiver strain extends to personal, social, and professional life: approximately 14.5% of families reduce or forgo employment due to their child's condition, particularly in low-income households or those with young children.[17]

This significant social impact calls for governments and health care systems to implement policies and allocate resources to help families care for their children. In the Community of Madrid, children requiring palliative care have been recognized as a population warranting special protection under Law 4/2023, of March 22, on Rights, Guarantees and Comprehensive Protection of Children and Adolescents of the Community of Madrid.[18] At the national level, Spain also provides disability and long-term care benefits, as well as the Allowance for the Care of Minors with Cancer or Other Serious Illness (CUME, by its Spanish acronym), which allows

one parent to reduce working hours by at least 50%, compensating for the resulting income loss.[19,20]

In 2022, in light of this situation, the Department of Family, Youth, and Social Affairs of the Community of Madrid, via the Sub-Directorate General for Child Welfare, established a one-time financial assistance program for families caring for a patient aged up to 25 years receiving specialized pediatric palliative care. Although the program was well received, few families applied owing to its eligibility requirements. Thus, in 2023, the criteria were expanded to also include families caring for a patient aged less than 25 years with a CCC, cancer, or other serious illness involving substantial use of health care resources.[21]

The primary objective of the study was to determine the level of complexity among pediatric patients with CCCs who applied for financial assistance through social services, using validated scales that were administered sequentially. The secondary objectives were: (1) to assess the variability in complexity across primary diagnoses in the study sample, and (2) to describe the care and psychosocial needs of patients classified as having CCCs by the PedCom Scale.

Material and methods

Study design

We conducted a cross-sectional retrospective study of the health records of patients included in the files of families that applied for the one-time payment through the program for families caring for a patient aged up to 25 years receiving specialized pediatric palliative care of the Department of Family, Youth, and Social Affairs of the Community of Madrid in 2023.[21]

Study universe

To be eligible for the program, families had to meet the requirement of having a dependent under the age of 25 receiving or meeting the criteria to receive palliative care, with a CCC, with cancer, or other form of severe illness involving high health care resource utilization at the time of the application. This condition had to be certified by a physician through a signed sworn statement attesting that the diagnosed illness persisted as of the date the application was submitted.[21]

In the Community of Madrid, the level of resource utilization is accredited by means of the ''adjusted morbidity group'' (GMA, for its acronym in Spanish) composite indicator, which is based on comorbidity levels derived from records and reports from every day clinical practice. It uses international diagnostic codes from the International Classification of Primary Care (ICPC-1 and ICPC-2) and the International Classification of Diseases (ICD-9 and ICD-10). It includes a list of chronic illnesses used to identify patients with chronic conditions (Table 2).[22] However, this list is based on general medical conditions rather than strictly pediatric ones.

The aid was awarded on a first-come, first-served basis to applicants meeting the requirements, without taking into account the medical complexity of the patients.

Sample selection

In the 2023 application cycle, a total of 4095 families applied for the benefit.

The study analyzed a representative sample selected through simple random sampling. Using the Cochran formula for estimating proportions at a 95% confidence level, we calculated a minimum sample size of 351 patients.

Eligibility criteria

We included children of applicants for the benefit in the 2023 application cycle.[21] We excluded applicants with missing or incomplete data in the database of the Department of Family, Youth, and Social Affairs or the electronic health records system of the Comunidad de Madrid.

Since the deadline for submitting applications was October 1, 2023, the analysis only included records of patients selected up to that date.

Variables and stratification

We collected data on sociodemographic characteristics and the primary diagnosis of the patient based on ICD-10 codes. In addition, we designed a sequential stratification process using two validated tools. The rationale for this process was the suspicion that a significant portion of the sample would not meet the definition of CCC due to the criteria applied to determine eligibility for financial assistance.

First, we used the Pediatric Medical Complexity Algorithm (PMCA),[23] designed to classify children into three groups based on their level of medical complexity (children without chronic disease, children with noncomplex chronic disease, children with complex chronic disease) according to their primary diagnosis (ICD-10) and other clinical and administrative data. It is a tool that can be applied very quickly, with adequate reliability and accuracy, exhibiting a sensitivity and specificity of 86% for the most medically complex category (Appendix B).[8,23]

Subsequently, we administered the PedCom scale in patients who met the criteria for CCC according to the PMCA.[9,24] The PedCom is a numerical scale developed to identify pediatric patients with CCCs. It assesses the clinical, educational, care, and psychosocial needs of these patients, using a cutoff score of 6.5 out of a possible 27 points to classify patients as having a CCC. The scale has a sensitivity of 96% and a specificity of 97% (Appendix 2).[9]

Although the sensitivity of the PMCA is lower than that of the PedCom scale, we chose it as the first step in identifying children with CCCs on account of its ease of use.

The data collection form used in the study can be found in Appendix B (supplementary material).

Data collection

We started by reviewing the information and documents submitted by families for the application, which were available in the database of the Community of Madrid government administrative services portal. If the required data were

Table 2 List of chronic diseases considered in the Adjusted Morbidity Groups in the Community of Madrid.

Active breast cancer	Active soft tissue sarcoma	Dementia	Leukemia
Active cancer of the ear/larynx	Active stomach cancer	Depression	Multiple sclerosis
Active cervical cancer	Active testicular cancer	Diabetes mellitus	Obesity
Active cervical cancer	Active thyroid cancer	Dyslipidemias	Osteoporosis
Active cervical cancer	Alcohol Use Disorder	Dysrhythmias	Other lymphomas
Active cervical cancer	Anemia	Gastroduodenal ulcer	Parkinson disease
Active CNS cancer	Anxiety	Glaucoma	Retinoblastoma
Active colorectal cancer	Arthritis	Heart failure	Schizophrenia
Active colorectal cancer	Arthrosis	Heart valve disease	Stroke
Active liver cancer	Asthma	Hepatoblastoma	Thyroid disease
Active lung cancer	Attention-deficit/hyperactivity disorder	HIV	Ulcerative colitis
Active pancreatic cancer	Cardiopulmonary disease	Hodgkin lymphoma	Vasculitis
Active prostate cancer	Chronic kidney disease	HTN	
Active renal cancer	Cirrhosis	Intellectual disability	
Active skin cancer	COPD	Active thyroid cancer	

Source: Community of Madrid.[21]
Abbreviations: CNS, central nervous system; COPD, chronic obstructive pulmonary disease; HIV, human immunodeficiency virus; HTN, hypertension.

unavailable, we also reviewed the electronic health records of the patient.

Statistical analysis

The statistical analysis was performed with the software package Stata/IC, version 16.1 software. We summarized categorical data as percentages and quantitative data using the medians and interquartile range.

This study was approved by the Committee on Ethics and Research with Medicinal Products of the Hospital Infantil Universitario Niño Jesús (registration number: R-0064/24).

Results

We analyzed 360 files, of which 5 were excluded due to missing data, resulting in a final sample of 355 patients. The median age was 8.1 years (IQR, 12.2—4.6), and 41.4% of the patients were female.

Table 3 shows the distribution of patients according to their primary diagnosis.

When we applied the stratification tools, 66.2% of the patients (n = 235) were classified as having a CCC according to the PMCA. Of these patients, 49.3% were also classified as having a CCC by the PedCom scale with scores greater than 6.5. Fig. 1 summarizes this stratification process.

We specifically analyzed the PedCom scores for the five most common diagnoses (epilepsy, acute lymphoblastic leukemia, cerebral palsy, and congenital disorders) and found variable value ranges (Table 4).

We also analyzed the clinical and psychosocial characteristics of the sample according to the PedCom (Table 5).

Discussion

This is the first study conducted in Spain that estimates medical complexity in children with chronic conditions in Spain based on data collected by social services.

Table 3 Distribution of patients by primary diagnosis.

Primary diagnosis	Frequency (n)	Percentage (%)
Neurological and/or neuromuscular	161	45.4
Other congenital or genetic disorders	69	19.4
Metabolic	53	14.9
Prematurity / neonatal	22	2.2
Malignant diseases	17	4.8
Hematological / immunological	11	3.1
Respiratory	6	1.6
Gastrointestinal	4	1.1
Renal / urological	3	0.8
Cardiovascular	0	0
Other	0	0

The distribution of the primary diagnoses in the sample indicates that most of these patients have neurologic disorders, followed by congenital diseases or genetic disorders. These findings are similar to those reported in other case series.[25–28]

The results of our study show that, although the financial assistance program was intended for pediatric patients with CCCs, not all recipients met the criteria for CCC according to the applied stratification tools. Specifically, the PMCA scale classified only 6 out of 10 patients as children with CCCs, and of those, only half met the criteria according to the PedCom scale. This discrepancy may be explained by the fact that, while the eligibility criteria established in the application process called for a report from a medical provider attesting to the clinical condition of the patient,[21] the funds were granted strictly according to the order in which applications were received.[21] It should be noted that this study was commissioned by the conducted at the request Department of Family, Youth, and Social Affairs with the aim of using the

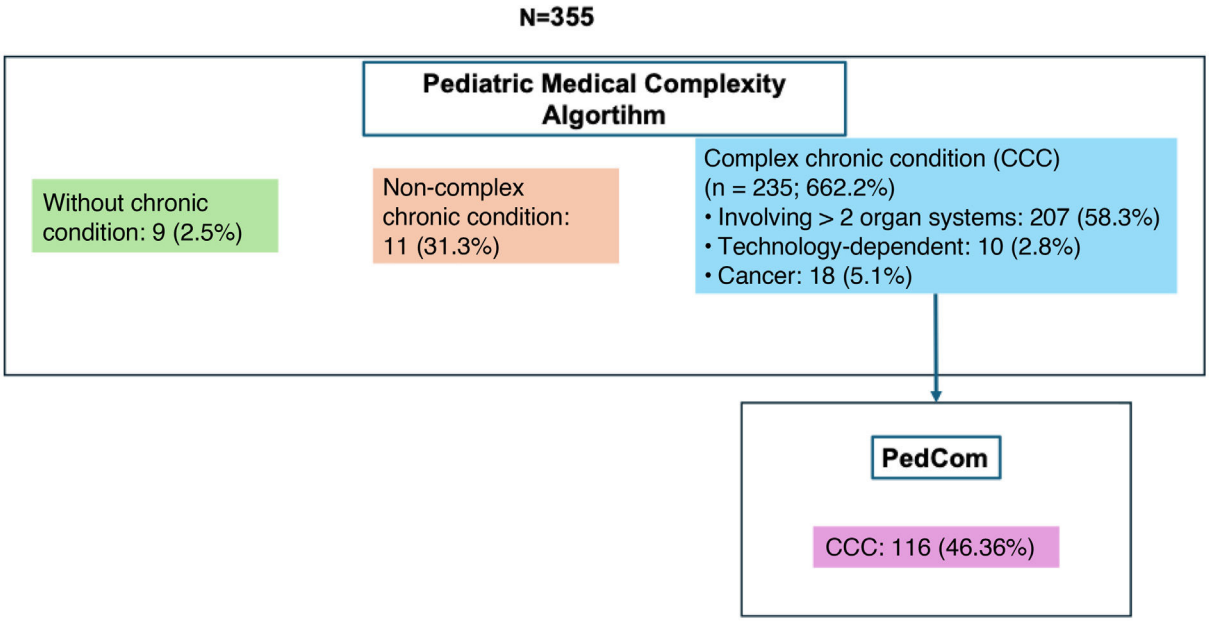

Figure 1 Stratification of the study sample.

Table 4 Association between the primary diagnosis and the PedCom scale score.

Primary diagnosis	Minimum score	Median score	Maximum score
Acute lymphoblastic leukemia	2	6	11
Cerebral palsy	4	7	20
Congenital disorder	3	5.5	19
Epilepsy	3	7	19

Sources: Godoy-Molina,[9] Godoy-Molina et al.[24]

results to optimize the clinical selection criteria for future application cycles or similar benefit programs.

Our findings highlight the variability in the results obtained with the various tools currently available for the purpose, as well as the need to standardize the terminology and tools used for assessing medical complexity and to improve care and support strategies.

There are many reasons for this variability. One of them may concern the criteria used by each tool to define complexity. In this regard, the PMCA identifies this population through a definition based on the primary diagnosis (ICD-10). It is very easy to use, allowing quick identification of patients with CCCs.[8,23]

In contrast, the PedCom scale identifies patients with CCCs based on a set of multidimensional items that assess the medical and psychosocial complexity of patients with excellent sensitivity and specificity. On the other hand, due to the number of items in the scale, more time is required for its administration.[9,24]

The analysis of the variation in PedCom scores among patients with the same primary diagnosis highlight the significance of these differences. The results show that the criteria that determine whether a pediatric patient has a CCC are more closely related to clinical and psychosocial factors associated with the underlying condition than to the diagnosis in itself.

Therefore, while diagnosis-based identification tools are useful for initial screening, other tools that take relevant variables into in addition to the diagnosis should be used for stratification.[10] At the individual level, these tools can be useful for monitoring the level of complexity of specific patients over time, but they can also be used to identify and stratify the complexity of large cohorts of patients by incorporating variables beyond the primary diagnosis.

This study has several limitations inherent to its design. First, it is a retrospective study based on the review of existing files and health records, so some relevant variables may not have been adequately documented, which could affect the accuracy of the classification obtained through the applied scales.

On the other hand, there are several potential sources of selection bias. First, the sample was selected using simple random sampling without stratification, so it is possible that certain social groups or diagnostic categories were under- or overrepresented. At the same time, the analysis may have underestimated the complexity of CCCs in the region, as it included data for families that applied for assistance in the 2023 application cycle. However, a similar financial assistance program was open for applications in 2022, in this case limited to patients receiving pediatric palliative care. Applicants who received financial assis-

Table 5 Characteristics and needs assessed by the PedCom scale.

Variable	Frequency (n)	Percentage
Specialist care		
Four or more specialties	128	54.7
Medication		
Polypharmacy (> 5 drugs)	53	22.5
Medication administered in hospital/immunosuppressants	27	11.4
Nutrition		
Enteral feeding with the possibility intermittent feeding	28	11.9
Respiratory care		
Continuous vital signs monitoring at home	14	5.9
Aspiration of secretions	3	1.2
Supplemental oxygen at home	9	3.8
NIV (with disconnections)	13	5.5
NIV (without disconnections)	1	0.4
Tracheostomy	5	2.1
IMV (with disconnections)	1	0.4
IMV (without disconnections)	1	0.4
Psychomotor development and functional limitations		
Mild impairment	90	39.2
Moderate impairment	53	22.5
Severe impairment	29	12.3
Specific therapies		
Early intervention / occupational therapy / motor physical therapy	166	70.6
Respiratory physical therapy	25	10.6
Speech therapy	42	17.8
Mental health services	8	3.4
Educational needs		
Ordinary school without adaptation/support	86	36.5
Ordinary school with curricular adaptation/support	78	33.1
Special education school	65	27.6
Inability to attend school	6	2.5
Life expectancy		
Life expectancy < 12 months	8	3.5

Sources: Godoy-Molina.[9] Godoy-Molina et al.[24]
Abbreviations: IMV, invasive mechanical ventilation; NIV, noninvasive ventilation.

tance through that program were automatically excluded from the 2023 application process. Therefore, it is reasonable to assume that patients with more complex conditions would have been left out of the sample because they had applied for financial assistance in the previous application cycle.

The application process called for, among other requirements, submitting a signed statement by a clinician attesting to the diagnosis of a medically complex chronic condition, cancer, or other severe illness associated with high resource utilization and still present at the time of the application.[21] The need to submit this documentation, combined with the difficulties associated with the administrative process involved in applying, whether in person or online, may have limited access to disadvantaged families or families with language barriers, leading to underrepresentation in the sample.

Given the voluntary nature of the application process, we cannot rule out the possibility of selection bias, as some families may not have requested financial assistance because they were unaware that it was available.

There is also a risk of classification bias stemming from the sequential use of two tools, starting with the PMCA, which is less sensitive, because it is easier to administer as a screening tool compared to the PedCom, which requires more time because it has more items.

One of the main strengths of this study is that it is the first study in Spain to analyze the clinical characteristics of children with CCCs from the perspective of social services. In addition, the results underscore the importance of using stratification tools adapted to this population that take into account both clinical and psychosocial aspects, beyond the primary diagnosis, as is the case of the PedCom scale.[9,24]

Conclusions

The sequential stratification of children with CCCs using the PMCA8,23 and PedCom9,24 scales can help ensure that financial, social, and family support resources are allocated equitably to those who need them most, guaranteeing priority access to public resources to improve the quality of life for patients and their caregivers.

In the field of pediatrics, complexity does not depend solely on the primary diagnosis but on multiple clinical and psychosocial factors, which highlights the need of combined approaches to enable appropriate stratification and care planning.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.anpedi.2026.504239.

Declaration of competing interest

The authors have no conflicts of interest to declare.

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