Brief report

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Quality of life in families and children with medical complexity

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ABSTRACT

Introduction. Specialized units for children with medical complexity (CMC) aim to improve the quality of life of these patients. The objective of this study is to analyze the characteristics of patients and families evaluated in a recently created CMC specialized unit, as well as factors related to their quality of life.

Population and methods. Analytical cross-sectional study that included CMCs seen in a monographic consultation between 2020 and 2024. Clinical data were collected, and parents completed a questionnaire with questions taken from quality-of-life scales.

Results. We included 60 of the 217 children who were seen. The mean age was 7.18 years. 68.3% were male. 41.7% had cerebral palsy; 38.3% were dependent on technical support.

About the questions, 11/19 related to parents and 1/12 related to patients showed negative answers. Risk factors were non-Spanish origin, behavioral disorders, and sleep disturbances.

Conclusions. Our results showed different perspectives on quality of life between CMCs and their families, identifying origin, behavior, and sleep as risk factors.

Keywords: *chronic disease; biomedical technology; pediatric hospitals; cerebral palsy; quality of life.*

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INTRODUCTION

Improvements in the care of patients with serious illnesses have increased the prevalence of children with chronic conditions.[1,2] Children and adolescents with special healthcare needs (CYSHCN) are at greater risk of developing organic, behavioral, or emotional disorders. They consume more healthcare resources than the general pediatric population.[2] Within this group, children with medical complexity (CMC) are distinguished. These are patients who meet any of the following conditions: (a) severe multisystem disease: presence of two or more complex health conditions that are chronic or expected to be prolonged (greater than 12 months); (b) presence of a complex condition dependent on technical support and/or special care.[3] They require more hospital admissions and specialists, have more extended stays, and higher mortality rates.[4,5] They can account for 80% of children's healthcare costs.[6] Burnout has been reported among their caregivers.[7,8] Specialized CMC units, led by a coordinating pediatrician, aim to improve the quality of life of patients and their families.[9]

The objective of the study is to analyze the characteristics of patients and families evaluated in a recently created specialized CMC unit, as well as factors related to their quality of life.

POPULATION AND METHODS

Study conducted at the Hospital Infantil Universitario Niño Jesús in Madrid (Spain), a tertiary pediatric center. The Chronic and Complex Pathology Unit has been active since September 2020. It is made up of two pediatricians, a nurse, two psychologists, and a social worker. It is structured as a long (50-60 minutes) in-person or telephone pediatric consultation with flexible hours. Physical and psychosocial aspects are reviewed, as well as the needs expressed by the family and appointments with specialists. Other professionals may also be involved. In addition, interconsultations and pre-surgical evaluations are performed, and a telephone and email service are available.

Between September 2020 and August 2024, 217 patients were evaluated (685 total consultations). The criteria for follow-up in our unit were residence in Madrid, previous care in three or more hospital services, and being classified as CMC according to the above definition.[3] Family members were asked to participate in our study during their first consultation and signed an informed consent form (ICF). Those for whom we did not anticipate continued follow-up and those with language difficulties were excluded. The Ethics Committee approved the project.

This was a cross-sectional analytical study that included epidemiological, clinical, and psychosocial data extracted from medical records, along with a questionnaire given to parents and caregivers that included items on health-related quality of life (HRQoL). After a literature review, no HRQoL scale specific to CMC had been validated and translated into Spanish, so we decided to design our questionnaire with questions from already validated scales: PECVEC[10] (adult chronic patients), CHIP[11] and KidScreen[12] (general child population), and CP QOL[13] (infantile cerebral palsy). The questions were selected based on their clinical relevance and practical usefulness for the unit's primary objective: to improve the daily lives of patients, parents, and caregivers. The final survey (supplementary material) included 31 multiple-choice questions divided into the following:

- First block: 19 questions about parents and caregivers.
- Second block: 12 questions about patients and 3 about lost days due to health problems.
- Third section: Open-ended answer.

The answers followed a Likert scale with five options ("Very poor", "Poor", "Fair", "Good", or "Very good") or four ("Not at all", "Poor", "Fair", "Good"). For the analysis, the answers "Very bad", "Bad", and "Fair" were grouped versus "Good" and "Very good", and "None" and "Bad" were grouped versus "Fair" and "Good". According to the statement, they were classified as "positive" or "negative" answers.

We evaluated whether specific clinical or sociodemographic parameters determined more negative answers on HRQoL, analyzing the answers separately by blocks and in general. A comparison of means (± SD) between subgroups was performed using Student's t-test; *p*-values <0.05 were considered significant. Statistical analysis was performed using SPSS Statistics 22.0.

RESULTS

A total of 217 patients were evaluated. Ninety families signed the IC, and 60 completed the questionnaire; 68.3% of the patients were male, with ages ranging from 7.18 ± 4.6 years (range 0-15); 83.3% were Spanish. All had severe multisystem diseases, and 38.3% required technical support; 98.3% had some neurological involvement, and 68.3% had gastrointestinal involvement. The most prevalent pathology was infantile cerebral palsy (41.7%).

Each patient was followed by a median of 7 specialists (range 2-13). Before admission to the unit, each patient had a median of 30 hospital visits (range 0-145). Only 6 had a coordinating pediatrician. Eighty percent required at least one hospital admission (median: 3 admissions per patient, range 0–20); 73.3% were admitted before our follow-up, and 51.7% were admitted after. Each patient attended a mean of 4.72 ± 2.7 consultations in the unit (86.4% in person). *Table 1* compares all patients evaluated in the unit with those included in the study.

The surveys reveal that, in the first block (*Table 2*), 11 questions received mainly negative answers, 7 positive answers, and 1 neutral answer. In the second block (*Table 3*), only one question received negative answers. In the analysis (*Table 4*), there was a statistically significant increase in negative answers in patients of non-Spanish origin and children with behavioral disorders. In the open-ended questions, 30% responded positively to having a coordination consultation.

DISCUSSION

The number of units specializing in CMC is increasing. The Hospital Infantil Universitario Niño Jesús is a leading center in neuropediatrics, among other specialties, and treats a high number of CMC cases. In 2022, our research team published a study on 323 CMCs treated before September 2020.[5] Comparing the 217 patients (*Table 1*) subsequently seen in our clinic with those from a similar unit (Hospital Universitario La Paz, Madrid),[9] our sample had a higher median age (9 years vs. 2 years), greater neurological involvement (97.7% vs. 76.9%), and lower biotechnological dependence (35% vs. 69.5%).

When analyzing the questionnaire answers,

Table 1. Main epidemiological and clinical variables of all patients evaluated in consultation and included in the study

Epidemiological and clinical variables	Total patients evaluated in consultation (n = 217)	Patients included in the study (n = 60)
Age (years)	Mean: 8.76 ± 5.2 Median: 9 Range: 0–18	Mean: 7.18 ± 4.6 Median: 6 Range 0-15
Male/female	139 (64.1%) / 78 (35.9%)	41 (68.3%) / 19 (31.7%)
Spanish origin	166 (76.5%)	50 (83.3%)
Neurological involvement	212 (97.7%)	59 (98.3%)
Most common pathology	CP: 98 (45.2%)	CP: 25 (41.7%)
Dependence on technical support	76 (35%)	22 (36.7%)
N.° of hospital services attended by the patient for follow-up	Mean: 6.73 ± 2.2 Median: 7 Range: 2-13	Mean: 7.19 ± 2.2 Median: 7 Range: 2-13
Presence of a coordinating pediatrician before their first consultation	45 (20.7%)	6 (10%)
Proportion of patients who have required 1 or more hospital admissions	167 (77%)	48 (80%)
N.° of total hospital admissions	Mean: 3.54 ± 4.1 Median: 2 Range: 0-25	Mean: 3.88 ± 4 Median: 3 Range: 0-20
Primary caregiver	Mother: 121 (55.7%) Both parents: 81 (37.3%)	Mother: 33 (55%) Both parents: 26 (43.3%)
Recognition of patient disabiity	120 (55.3%)	42 (70%)
Recipient of assistance under the Dependency Law	89 (41%)	31 (51.7%)
Attendance at therapy sessions	182 (83.9%)	53 (88.3%)
N.° of visits to the Chronic and Complex Pathology Unit	Mean: 3.16 ± 2.8 Median: 2 Range: 1-21	Mean: 4.72 ± 2.7 Median: 4 Range: 1-14

CP: cerebral palsy.

Table 2. Responses to questions regarding the parent/caregiver

QUESTIONS RELATED TO THE FATHER/MOTHER/CAREGIVER

Over the last 7 days. how have you been able to...?

	Not at all	Poorly	Fairly	Good	Very good	NA	Negative	Positive
Meets job requirements or tasks	1.7%	16.6 %	35%	33.3%	11.7%	1.7%	53.3%	45%
Devoting time to hobbies	33.3%	18.3%	25%	18.3%	3.4%	1.7%	76.6%	21.7%
Sleeping at night	8.3%	21.7%	35%	25%	8.3%	1.7%	65%	33.3%
Enjoy or be happy for something	1.7%	5%	26.6%	50%	15%	1.7%	33.3%	65%
Contact friends or acquaintances	6.7%	20%	26.6%	41.6%	3.4%	1.7%	53.3%	45%
Tell others what is troubling you	10%	10%	46.6%	25%	6.7%	1.7%	66.6%	31.7%
Spend some time with other people	35%	25%	18.3%	11.7%	8.3%	1.7%	78.3%	20%
Fighting for your desires or needs	6.7%	13.3%	45%	26.6%	6.7%	1.7%	65%	33.3%

In the last 7 days, to what extent have you felt...?

	Not at all	Poorly	Fairly	Good	NA	Negative	Positive
Sad and/or depressed	15%	50%	18.3%	15%	1.7%	33.3%	65%
Attentive and focused	6.7%	41.6%	46.6%	1.7%	3.4%	48.3%	48.3%
In good spirits	1.7%	39.9%	45%	10%	3.4%	41.6%	55%
Apathetic/indifferent	30%	41.6%	20%	3.4%	5 %	23.4%	71.6%
Concerned and uneasy	5%	28.3%	43.3%	20%	3.4%	63.3%	33.3%
Active and full of energy	15%	48.3%	28.3%	5%	3.4%	63.3%	33.3%
Calm and/or relaxed	59.9%	3.4%	28.3%	5 %	3.4%	63.3%	33.3%
Tired and/or weak	1.7%	33.3%	45%	16.6%	3.4%	61.6%	35%
Angry and/or irritated	5 %	50%	33.3%	8.3%	3.4%	41.6%	55%
Frightened and/or threatened	41.7%	33.3%	13.3%	8.3%	3.4%	21.6%	75%
Hopeful and/or optimistic	10%	38.3%	35%	13.3%	3.4%	48.3%	48.3%

NA: no answer.

the different perspectives of fathers, mothers, and caregivers on their quality of life and that of their children were striking. Family members reported fatigue, restlessness, and lack of sleep as symptoms of burnout. Similar analyses of caregivers described insomnia,[7] emotional disturbances, gender gaps in caregiving tasks,[14] and burnout with social determinants.[8] In the second part, negative answers were few, although there was a high degree of abstention on some questions. Family members claimed they did not know whether their children might harbor such feelings. Asking the children themselves is difficult, as there are few scales adapted to people with developmental delays. Our group developed a questionnaire for patients, but the sample size was small and limited to adolescents with adequate cognitive levels. One study analyzed the quality of life of children with cerebral palsy; the parents' perspective on their children was worse than that of the patients themselves.[15] The reasons could lie in feelings of overprotection, the children's lack of awareness of their limitations, and/or their adaptation to them from the outset (the disability paradox).

The study of risk factors (*Table 4*) only showed significant differences in patients of non-Spanish origin, behavioral disorders, and sleep disturbances. This poorer perception of HRQoL could be related to problems associated with the migrant population: lower economic status or cultural differences that cause difficulties in accessing the healthcare system. Behavioral and sleep problems are explained by the strain they place on patients and their families and should be considered in the assessment and treatment of these patients from the first visit.

In our opinion, this study is relevant because

Table 3. Answers to questions regarding the child

QUESTIONS RELATED TO THE CHILD

During the last 7 days...

	Very poor	Poor	Fair	Good	Very good	NA	Negative	Positive
How has your child's health been?	5%	5%	43.3%	35%	10%	1.7%	53.3%	45%

During the last 7 days..

	Not at all	Poorly	Fairly	Good	NA	Negative	Positive
Did your child have fun?	3.4%	31.6%	35%	26.6%	3.4%	35%	61.6%
Has your child felt strong?	0%	40%	43.3%	11.7%	5%	40%	55%
Has your child felt healthy?	1.7%	33.3%	45%	15%	5%	35%	60%
Has your child felt happy?	0%	15%	46.7%	33.3%	5%	15%	80%
When your child was ill. did he/she recover quickly?	8.3%	31.7%	40%	11.7%	8.3%	40%	51.7%
How many days has your child been in bed due to health problems?	Mean: 1.73 ± 2.3 days. Median 1; Mode 0; Range 0-7 (n = 55)						
How many days of school has your child missed due to health problems?	Mean: 1.92 ± 2 days. Median 2; Mode 0; Range 0-7 (n = 53)						
How many days of everyday activities or free time has your child lost due to health problems?	Mean: 2.06 ± 2.14 days. Median 2; Mode 0; Range 0-7 (n = 52)						

Regularly, is your child...?

	Not at all	Poorly	Fairly	Good	NA	Negative	Positive
Annoyed by hospital visits	25%	53.3%	13.3%	3.4%	5%	16.7%	78.3%
Upset when absent from school for health reasons	38.3%	38.3%	8.3%	6.8%	8.3%	15.1%	76.6%
Annoyed by being assisted by other people	33.3%	41.7%	13.3%	5%	6.7%	18.3%	75%
Concerned about who will take care of him/her	55%	11.6%	6.7%	1.7%	25%	8.4%	66.6%
Concerned about having a chronic illness	55%	11.6%	5%	3.4%	25%	8.4%	66.6%
How much pain does your child feel?	25%	36.7%	21.7%	5%	11.6%	26.7%	61.7%

NA: no answer.

it offers novel insights into burnout, risk factors, and the diverse perspectives of caregivers and patients. However, the use of an unvalidated instrument is a clear limiting factor. It is our group's objective to continue with this validation.

CONCLUSIONS

The results of our survey revealed differing perspectives on the quality of life between parents, caregivers, and their children. Family members expressed fatigue, restlessness, and insomnia, which contrasts with a positive view of patients. The main risk factors observed were non-Spanish origin, behavioral disorders, and sleep disturbances.

The well-being of family members is essential because it directly affects that of children with medical complexity. ■

The supplementary material provided with this article is presented as submitted by the authors. It is available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2026/10676_CB_GomezGarrido_Anexo.pdf

REFERENCES

1. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics.* 2011;127(3):529-38.
2. Flores J, Carrillo D, Karzulovic L, Cerda J, Araya G, Matus MS, et al. Niños y adolescentes con necesidades especiales de atención en salud: prevalencia hospitalaria y riesgos asociados. *Rev Med Chil.* 2012;140(4):458-65.
3. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC Pediatr.* 2014;14:199.
4. Simon TD, Berry JG, Feudtner C, Stone BL, Sheng X, Bratton SL, et al. Children with complex chronic conditions

Table 4. Relationship between epidemiological and clinical variables and the mean number of negative answers per patient to the survey questions

Variables		Percentage of patients with mostly negative answers					
		Questions about parents (19)	p-value	Questions about children (12)	p-value	Total questions (31)	p-value
Gender	Male (68.3 %)	9.71 ± 6.0	0.71	3.10 ± 2.9	0.75	12.81 ± 7.5	0.86
	Female (31.7%)	10.30 ± 2.1		2.85 ± 2.7		13.15 ± 6.9	
Spanish origin	Yes (83.3%)	9.45 ± 5.5	0.18	2.57 ± 2.4	**<0.01***	12.02 ± 6.7	**0.03***
	No (16.7%)	12.0 ± 6.08		5.09 ± 3.5		17.09 ± 8.7	
Main diagnosis	CP (41.7 %)	9.04 ± 5.8	0.31	3.46 ± 2.9	0.29	9.70 ± 5.9	0.70
	Otro (58.3%)	10.53 ± 5.5		2.69 ± 2.6		10.27 ± 5.1	
Epilepsy	Yes (50%)	9.61 ± 6.1	0.69	2.58 ± 2.8	0.23	12.19 ± 7.5	0.43
	No (50%)	10.19 ± 5.2		3.45 ± 2.8		13.65 ± 7.1	
Spasticity	Yes (43.6%)	8.12 ± 5.6	0.18	2.94 ± 3.5	0.68	11.06 ± 8.6	0.38
	No (56.4%)	10.74 ± 5.8		2.89 ± 2.8		13.63 ± 7.4	
Wandering without assistance	Yes (41.7%)	10.44 ± 5.7	0.54	2.60 ± 2.7	0.34	13.04 ± 7.4	0.92
	No (58.3%)	9.54 ± 5.7		3.30 ± 2.9		12.84 ± 7.2	
Normal verbal language	Yes (28.3%)	8.12 ± 5.6	0.13	2.94 ± 3.5	0.90	11.06 ± 8.6	0.22
	No (71.7%)	10.58 ± 5.6		3.04 ± 2.5		13.62 ± 6.7	
Sleep problems	Yes (46.7%)	11.52 ± 5.4	**0.03***	3.10 ± 2.6	0.82	14.62 ± 7.5	0.08
	No (53.3%)	8.48 ± 5.6		2.94 ± 3.1		11.42 ± 6.9	
Behavioral disorders	Yes (29%)	12.78 ± 5.6	**0.01***	4.06 ± 2.8	0.06	16.83 ± 6.3	**<0.01***
	No (71%)	8.73 ± 5.3		2.59 ± 2.7		11.32 ± 7.1	
Depending on technical support	Yes (36.7%)	10.20 ± 5.1	0.70	3.64 ± 2.8	0.20	13.91 ± 6.7	0.43
	No (63.3%)	9.70 ± 5.9		2.68 ± 2.8		12.3 ± 7.6	
Presence of a coordinating pediatrician	Yes (10%)	9.33 ± 4.9	0.80	3.00 ± 2.2	0.99	12.33 ± 6.2	0.84
	No (90%)	9.96 ± 5.7		3.02 ± 2.8		12.98 ± 7.4	
Has required one or more hospital admissions	Yes (80%)	10.51 ± 5.5	0.10	3.33 ± 2.9	0.09	13.84 ± 7.2	0.05
	No (20%)	7.62 ± 5.6		1.85 ± 1.8		9.46 ± 6.7	
Total		9.90 ± 5.6		3.02 ± 2.8		12.92 ± 7.3	

**Statistically significant:* $p < 0.05$.

CP: cerebral palsy.

in inpatient hospital settings in the United States. *Pediatrics.* 2010;126(4):647-55.

5. Gómez Garrido PG, Suárez-Bustamante Huélamo M, Villalobos Pinto E, Retuerta Oliva A, López de Suso Martínez de Aguirre D, Jiménez García R. Atención hospitalaria de pacientes con patología crónica. *Andes Pediátr.* 2022;93(5):640-7.
6. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and costs of health care use of children with medical complexity. *Pediatrics.* 2012;130(6):e1463-70.
7. da Cruz DALM, Pimenta CA de M, Kurita GP, de Oliveira AC. Caregivers of Patients with Chronic Pain: Responses to Care. *Int J Nurs Terminol Classif.* 2004;15(1):5-14.
8. Ahmadi B, Sabery M, Adib-Hajbaghery M. Burnout in the Primary Caregivers of Children with Chronic Conditions and its Related Factors. *J Client-Centered Nurs Care.* 2021;7(2):139-48.
9. Climent Alcalá FJ, García Fernández de Vilalta M, Escosa García L, Rodríguez Alonso A, Albajara Velasco LA. Unidad de niños con patología crónica compleja. Un modelo necesario en nuestros hospitales. *An Pediatr.* 2018;88(1):12-8.
10. Fernández-López JA, Hernández-Mejía R, Siegrist J. El perfil de calidad de vida para enfermos crónicos (PECVEC): un método para evaluar bienestar y funcionalismo en la práctica clínica. *Aten Primaria.* 2013;28(10):680-9.
11. Rajmil L, Berra S, Estrada MD, Serra-Sutton V, Rodríguez M, Borrell C, et al. Versión española del perfil de salud infantil, cuestionario para padres y madres: Child Health and Illness Profile-Child Edition Parent Report Form (CHIP-CE/PRF). *Gac Sanit.* 2004;18(4):305-11.
12. Aymerich M, Berra S, Guillamón I, Herdman M, Alonso J, Ravens-Sieberer U, et al. Desarrollo de la versión en español del KIDSCREEN, un cuestionario de calidad de vida para la población infantil y adolescente. *Gac Sanit.* 2005;19(2):93-102.
13. Badia M, Orgaz MB, Riquelme I, Gómez-Iruretagoyena J. Domains of the Cerebral Palsy Quality of Life Questionnaire (CP QOL) for Children and Adolescents: Spanish Adaptation and Psychometric Properties. *J Dev Phys Disabil.* 2021;33:331-49.
14. Ballesteros de Valderrama BP, Novoa Gómez MM, Muñoz L, Suárez F, Zarante I. Calidad de vida en familias con niños menores de dos años afectados por malformaciones congénitas perspectiva del cuidador principal. *Univ Psychol.* 2006;5(3):457-74.
15. Aza A, Riquelme I, Gómez Vela M, Badia M. Proxy- and self-report evaluation of quality of life in cerebral palsy: Using Spanish version of CPQOL for Children and adolescents. *Res Dev Disabil.* 2024;154:104844.