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ORIGINAL ARTICLE

Clinical complexity and need for palliative care in non-oncological patients with special health care needs

Complejidad clínica y necesidad de cuidados paliativos en pacientes no oncológicos con necesidades especiales de atención en salud

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What do we know about the subject matter of this study?

Children and adolescents with special health care needs have a high health care burden, especially those with high complexity. They may have a greater need for universal palliative care.

What does this study contribute to what is already known?

There is a strong correlation between clinical complexity and the need for non-cancer palliative care in children and adolescents with special health care needs who are under home hospitalization monitoring. The use of a screening tool (PaPaS scale) made it possible to identify the need for palliative care.

Abstract

Categorizing the complexity of Children and Youth with Special Health Care Needs (CYSHCN) could be useful in guiding their need for pediatric palliative care (PPC). However, there are no studies that have evaluated this association. **Objective:** To evaluate the association between clinical complexity and the requirement for PPC in CYSHCN. **Patients and Method:** Observational, cross-sectional, and descriptive study. Data were collected between 2022 and 2023 at the CYSHCN Home Hospitalization Unit of the *Hospital Clínico San Borja Arriarán*. Non-probabilistic convenience sampling. Patients were categorized according to complexity guidelines for CYSHCN as low, medium, or high; and the “Paediatric Palliative Screening Scale” (PaPaS Scale) was applied to evaluate the need for PPC, categorizing them into: no need for PPC; explain the objectives of PPC to caregivers; prepare the start of PPC, and start the intervention as the central axis of management. **Results:** 70 CYSHCN patients

Keywords:
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were studied, 6 (8.57%) correspond to low complexity, 18 (25.7%) to medium, and 46 (65.7%) to high complexity. Of those studied, 24 (34.2%) did not require intervention, and 46 (65.7%) required PPC with varying degrees of intensity. The association between clinical complexity and the need for PPC had a Pearson correlation coefficient of 0.8225. **Conclusion:** There is a strong correlation between clinical complexity and the need for PPC in CSHCN in follow-up by the CYSHCN Home Hospitalization Unit. All patients in this study who require intensified palliative care are high-complexity CYSHCN.

Introduction

Children and youth with special health care needs (CYSHCN) are individuals who have one or more afflictive health conditions of a physical, behavioral, emotional, and/or developmental nature; these conditions vary in complexity and require continuous care with a comprehensive and multidisciplinary approach[1]. This term was coined in 1998 in the United States[1,2], and in 2008, the Chilean Society of Pediatrics decided to begin using the concept CYSHCN (*NANEAS* in Spanish) as a paradigm shift in dealing with these patients[2]. The CYSHCN population is heterogeneous and can be categorized according to its complexity using a specific instrument[3], based on their needs rather than their diagnoses, classifying them as low, medium, or high complexity.

Besides, palliative care is a field of specialization in health that not only considers "end-of-life care" but also aims to provide preventive actions and interventions for any life-threatening condition from the time of diagnosis, aiming at alleviating the physical, psychological, and spiritual suffering caused by the disease itself, its treatment, or the prospect of death. In this way, efforts are made to improve the quality of life of the patient and their family, with a management plan based on their goals and preferences, enabling them to make informed decisions[4]. Currently, in Chile, Law 21,375 establishes a universal right to access palliative care for all people suffering from terminal or serious illnesses[5].

It can be assumed that the main demand for non-oncological pediatric palliative care will come from the CYSHCN group with higher clinical complexity and life-threatening illnesses, making it necessary to identify who will require it and when a palliative medicine-based approach will be needed.

To recognize the population that requires pediatric palliative care (PPC), the recommendation is to identify anyone with a life-threatening condition and determine the stage of their disease trajectory[6], which will allow for identifying the intensity of PPC needed. The most widely used classification is proposed by the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT). This classification focuses on the diagnosis and expected trajectory and requires professionals familiar with PPC, the clinical course of patients, and their environment. For this reason, it is noteworthy that in 2014, a screening tool was published to define the need for PCC, called the "Paediatric Palliative Screening Scale" (PaPaS)[7], which is an instrument that can be applied by healthcare personnel who are not experts in palliative care.

Our objective was to determine the association between the clinical complexity of CYSHCN patients and their need for palliative care in a home hospitalization unit.

Patients and Method

Observational, cross-sectional, descriptive study with non-probabilistic convenience sampling, which invited to participate all patients aged between 1 and 18 years who were under the care of the CYSHCN Home Hospitalization Unit of the *Hospital Clínico San Borja Arriarán* (HCSBA) in Santiago, Chile, during 2022 and 2023. The PaPaS scale is designed and validated for use in this age range[7,8].

Patients were included if they had informed consent signed by their guardians, and assent was requested from those patients older than 7 years with the cognitive capacity to sign the document. Exclusion criteria were defined as refusal by the caregiver or the patient to participate in the study, and those who did not understand Spanish.

The primary variables are CYSHCN clinical complexity and need for palliative care, while the secondary variables correspond to patient and caregiver demographic data, educational level, nationality, and household income level.

Income level is expressed in Chilean pesos and its equivalent in US dollars, considering that the minimum wage in Chile at the time of the research protocol's development was CLP 400,000 (USD 422) and that the average wage in Chile in 2021 was CLP 681,000 (USD 719). For this reason, income level was classified into three categories: < $400,000 (less than $422), $400,000 to $700,000 ($422 to $738), and > $700,000 (more than \$738) (Table 1).

The clinical complexity of CYSHCN and the need for PPC with its intensity of intervention were evaluated. The former was evaluated using the complexity guidelines published in the Technical Guidance for the Comprehensive Management of CYSHCN 2022 by the Chilean Ministry of Health[3]. This classification (supplementary material 1, available online) evaluates three main dimensions: need for complex care, need for respiratory support, and need for technical aids. Each item receives a specific score, and the total sum allows the level of complexity of the patients to be defined as low (≤ 8 points), medium (9-15 points), and high (≥ 16 points).

The PaPaS scale was published by Bergstraesser et al. in 2013[7] and validated in 2014 for use in children aged from one year to 18 years[8]. It has five domains (Figure 1), which assign a score. The total score determines the requirement for PPC, the intensity, and the timing of intervention. The instrument was translated into Spanish with the author's permission (supplementary material 2, available online), and the maximum score is 35 points. The score ranges to define the intensity of PPC are as follows: < 10 points, there is no PPC requirement; ≥ 10 points, the concept should be introduced and the objectives of PPC explained to caregivers, explaining the benefits they could have on quality of life in the future; ≥ 15 points, the start of PPC should be prepared by referring to related teams and managing mild and initial symptoms; and ≥ 25 points, the intervention should be initiated as the central axis of continuous management, with personnel trained to treat complex and/or refractory symptoms.

To perform the descriptive analysis of the quantitative variables, the mean and standard deviation or median and interquartile range were used, according to the distribution, and for the descriptive analysis of the qualitative variables, n and percentages were used.

The association between clinical complexity and the need for palliative care was evaluated using Pearson's correlation coefficient. The data were analyzed using Stata 16 software. A $p < 0.05$ was considered statistically significant.

As this was an exploratory study and no similar work existed, the sample was obtained for convenience, including all patients between 1 and 18 years of age under home hospitalization. To confirm the validity of the sample size, a t-test was performed with reference to a previous study by Song et al.[9], with a power of 80%, an α of 5%, and an average difference of 2 points (on the PaPaS scale), resulting in 53 patients.

This study was approved by the Scientific Ethics Committee of the Central Metropolitan Health Service (identification number 149) and the Research Committee of the HCSBA, with informed consent and assent in relevant cases.

Table 1. Description of the population of Children and Adolescents with Special Health Care Needs and their caregivers

Sample Description (n = 70*)	
Age (Years)	
Range	1 to 17
Average (DS)	5.8 (4.76)
Sex	
Female (%)	31 (44.3%)
Male (%)	39 (55.7%)
Number of siblings	
Range	0 a 6
Average (DS)	1 (1.2)
0 siblings (%)	29 (41.4%)
≥ 1 siblings (%)	41 (58.6%)
Primary Caregiver	
Mother (%)	61 (87.1%)
Parent (%)	3 (4.3%)
Other (%)	6 (8.6%)
Caregiver Age (Years)	
Range	20 a 51
Average (DS)	36 (7.7)
Nationality of the Caregiver	
Chilean (%)	38 (56.7%)
Foreign (%)	29 (43.3%)
Caregiver Education Level	
Basic Education (%)	5 (7.5%)
Secondary Education (%)	29 (43.3%)
Higher Education (%)	33 (49.2%)
Income Level (in dollars)	
Range	\$137 a \$4746
Average (USA\$)	\$740 (\$645)
< \$422 (%)	19 (28.4%)
\$422 - \$738 (%)	24 (35.8%)
> \$738 (%)	24 (35.8%)

*For the categories: Age of caregiver, Nationality of caregiver, Educational level of caregiver and Income level, n=67 was used, since 3 institutionalized patients did not have an exclusive primary caregiver.

Results

All patients who met the inclusion criteria agreed to participate in the study. Table 1 shows their demographic characteristics. The patients included were between 1 and 17 years of age; 44.3% of them were female and 55.7% male.

Direct care at home was mainly provided by Chilean women who were related to the patients, mostly their mothers (61/70, 87.1%), in two cases, maternal

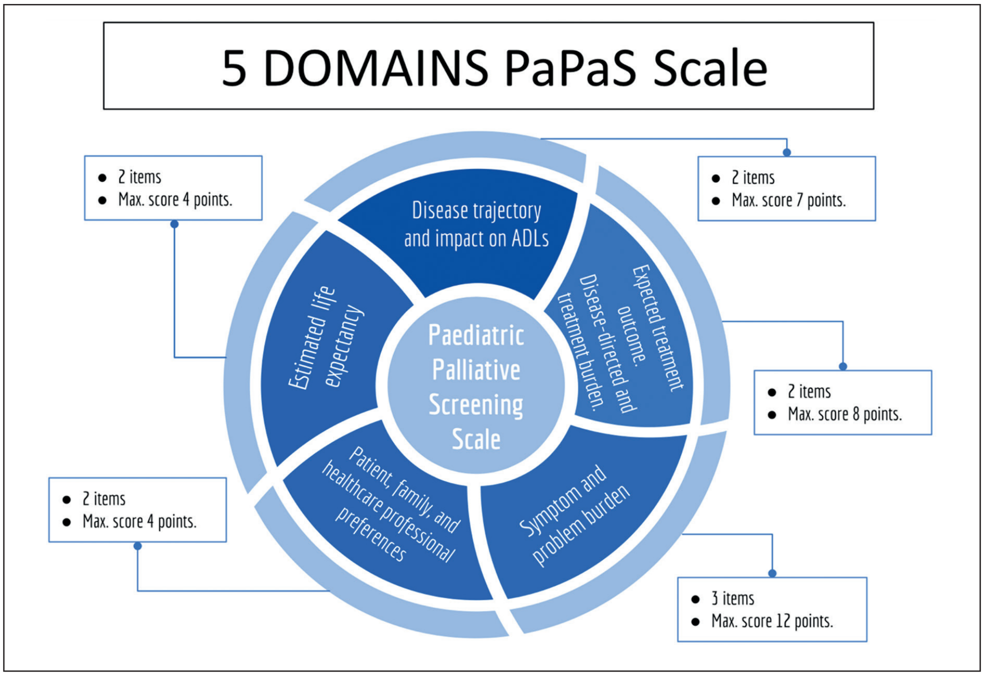

Figure 1. PaPaS Scale (Paediatric Palliative Screening Scale) domains and scores.

aunts, in one case, their grandmother, and in three institutionalized patients by formal caregivers. The average age of caregivers was 36 years (± 7.7 SD). 51 out of 67 caregivers (76%) had completed secondary education. 33 caregivers reported having pursued higher education (technical or university), but only 20 out of 67 (29.8%) managed to complete their studies. Three caregivers (4.4%) did not complete primary education.

When applying the complexity guidelines of the Technical Guidance for the Comprehensive Management of CYSHCN 2022, 8.6% corresponded to low-complexity CYSHCN, 25.7% to medium-complexity CYSHCN, and 65.7% to high-complexity CYSHCN.

Table 2 shows the number of patients according to complexity category and PPC requirement according to the PaPaS scale. It was found that 34.3% of CYSHCN did not require a palliative approach, 20% needed an introduction to the concept of palliative care, 34.3% required preparation for the initiation of palliative care, and only 11.4% of patients in follow-up required an intensive palliative approach.

Figure 2 shows the distribution of CYSHCN patients according to their level of complexity and the need for palliative care differentiated by category when applying the PaPaS scale.

Figure 3 shows the association between clinical complexity and the need for palliative care according to Pearson's correlation coefficient (0.8225). No patients with low clinical complexity require palliative care according to the PaPaS scale (category 1), and all patients who require intensive palliative care (category 4) are of high clinical complexity.

Discussion

The main finding of our research confirms the existence of a strong correlation between clinical complexity and the need for non-oncological palliative care in CYSHCN patients treated in a home hospitalization setting.

Internationally, it is estimated that the demand for palliative care corresponds to between 10 and 120 per 10,000 children[10]. In 2000, the American Academy of Pediatrics supported a comprehensive approach to palliative care[11], and in 2014, the 67th World Health Assembly declared it a health priority[12], considering the importance of including the pediatric population as recipients of palliative care, emphasizing integration at all levels of care and calling for consideration of primary care, to promote equity in early access[12], through the creation of public policies with funding and the formulation of training programs, including palliative care as an integral component of curricula, especially in medicine and nursing[4,12]. All health professionals who care for children should have the basic knowledge, attitudes, and skills to provide timely care and referral in this area.

Despite this declaration of fundamental rights, there are no official reports in Chile on the actual demand for non-oncological palliative care, as is also the

Table 2. Number of Children and Adolescents with Special Health Care Needs by category of complexity and palliative care requirement.

	Number of patients according to complexity category and palliative care requirement			
	Low complexity	Medium complexity	High complexity	Total
Does not require palliative care	6	13	5	24
Explain Palliative Care Benefits	0	3	11	14
Preparing for Palliative Care Initiation	0	2	22	24
Initiation of palliative care as a central axis	0	0	8	8
Total	6	18	46	70

case in other Latin American countries. However, it seems plausible that this demand is mainly focused on the CYSHCN pediatric population with life-threatening conditions and clinical complexity, corresponding to less than 1% of the total child and adolescent population with technological dependencies to live and a high impact on the family, who have been identified as those with more than one-third of health care costs, at risk of readmission (80% within 30 days of discharge), and higher mortality[13].

The findings of our study corroborate this assumption of a greater need for universal palliative care in the more complex CYSHCN population. This finding confirms the need to apply screening instruments such as the PaPaS scale in CYSHCN, as suggested in the technical guidance for CYSHCN 2022 (MINSAL), in order to timely assess the need and intensity of palliative care that each patient requires in repeated evaluations according to the clinical turning points they present.

It is important to note that the PaPaS scale should be applied by a professional or team familiar with the patient's history, disease trajectory, and diagnoses, without necessarily having expertise in advanced palliative care management.

However, recent publications have demonstrated good agreement among different actors involved in the

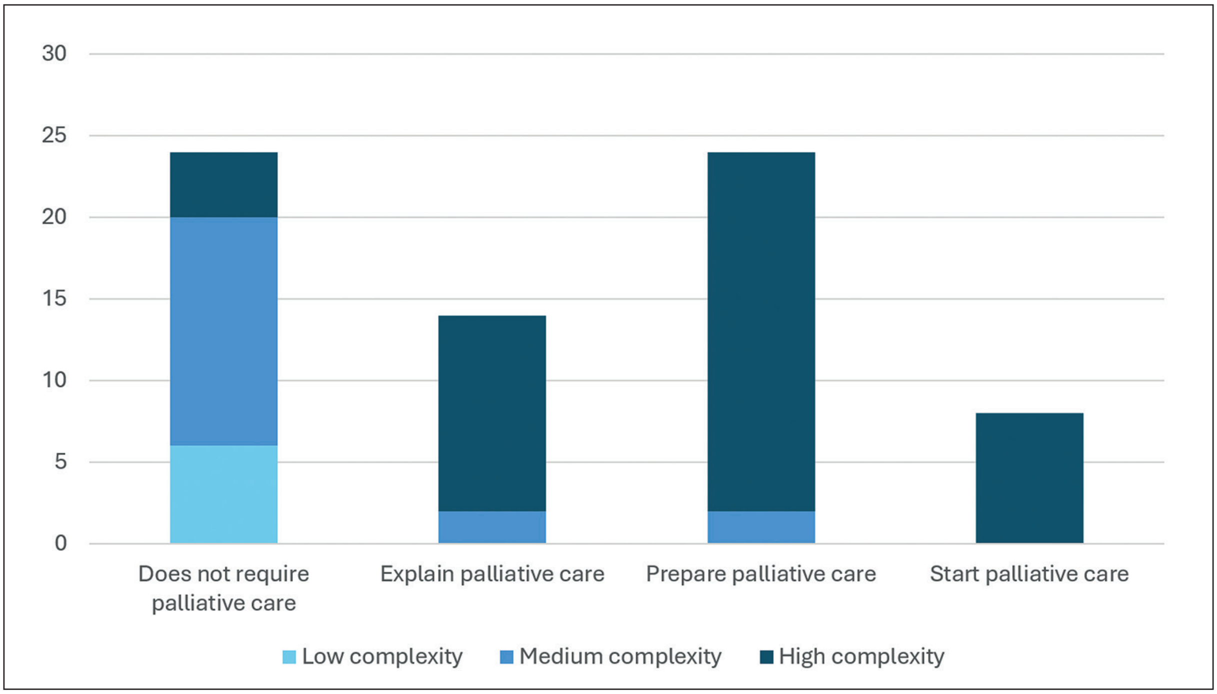

Figure 2. Distribution of Children and Adolescents with Special Health Care Needs (CYSHCN) according to their level of complexity and the need for palliative care differentiated according to category.

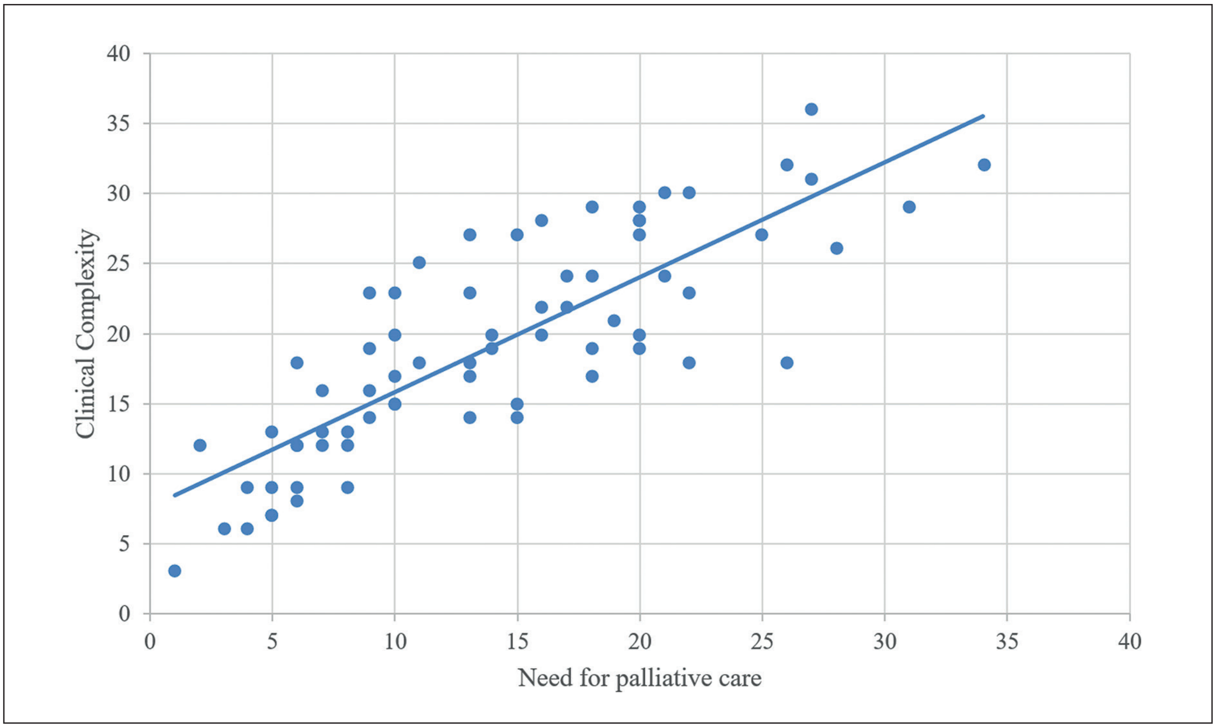

Figure 3. Association between the clinical complexity of Children and Adolescents with Special Health Care Needs and the need for palliative care. Clinical complexity was expressed according to the score obtained in the complexity guideline for the comprehensive management of CYSHCN of Technical Orientation 2022 and the need for palliative care according to the score in the PaPaS Scale.

clinical management of patients. Song et al. demonstrated that the PaPaS scale was a reliable tool for primary care physicians (PHC) who are not familiar with palliative care. Good agreement (kappa = 0.546) was observed for PaPaS scores applied by PHC teams and palliative care specialists. When comparing PHC teams and specialists, the application of the PaPaS scale by PHC teams showed a sensitivity of 83.7% and specificity of 100%[9]. Chong et al. concluded that patients who continued to receive palliative care after 1 year had significantly higher scores (median 19.23 points) compared to those who were discharged within a year (median 7.86 points), with a sensitivity of 82.54% and specificity of 100% for the PaPaS scale compared to standard clinical assessment[14].

It should be noted that in our study, no patients with low clinical complexity required palliative care according to the PaPaS scale (category 1), and that although not all high-complexity CYSHCN patients will require palliative care, all patients who required intensive palliative care (category 4) correspond to the high-complexity group. High-complexity CYSHCN patients who do not require palliative care are children with technological dependencies and a need for permanent care, but whose disease trajectory is toward recovery and rehabilitation rather than functional deterioration or a life-threatening condition.

For this reason, clinical teams should actively seek to identify the need for palliative care and interventions within their population of highly complex CYSHCN.

Among the limitations of our study, we can highlight that the instrument was translated into Spanish in a free version, without linguistic validation. However, as it was applied by healthcare personnel who are familiar with the scale and not as a questionnaire for caregivers, this does not seem to be a real problem. In recent years, the PaPaS scale has been disseminated and used in Spanish-speaking countries, such as Chile, where it was suggested as a screening method in the Technical Guidance for the Comprehensive Management of CYSHCN 2022[3]. It is also known in Colombia, where it is recommended in the palliative care journal published in 2023 by the Colombian Palliative Care Association[15]. Regarding the domains it includes, it should be noted that there are items where interpretation could be subjective, such as the one that assesses the "psychological distress of the child," which could be assigned a different score by different members of the healthcare team. For this reason, it should be emphasized that this is a screening tool and that it is important for PHC teams and other levels of care to be able to identify this group of patients, their prognosis, and/or the turning point of the pathology or pathologies they are experiencing, with the final decision on intervention based on clinical criteria and the support of teams with experience in palliative care[16,17].

Conclusions

There is a strong correlation between clinical complexity and the need for universal non-cancer palliative care in CYSHCN under home hospitalization monitoring.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Financial Disclosure

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