

Psychometric validation of a guideline for classifying the medical complexity of children and adolescents with special health care needs

Validación psicométrica de Pauta de Clasificación de Complejidad Médica de niños, niñas y adolescentes 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 Medical Complexity have multiple chronic medical conditions, need specialized health services, and have functional limitations; many of them are dependent on technology, with high use and cost for the health system. Therefore, it is urgent to have an instrument to classify them.

What does this study contribute to what is already known?

This study presents the reliability validation of an instrument for measuring and classifying levels of complexity of CYSHCN patients, carried out by a group of experts, and a proposal for optimizing this instrument. It is possible to establish levels of complexity: Low, Medium, and High allowing a more efficient referral for patient care in the health care network.

Abstract

Children and youth with special health care needs (CYSHCN) present an intensive use of health services resources and demand a high level of coordination between these services, communities, and families. SOCHIPE, along with other experts, generated a Complexity Classification Guideline to allocate resources according to the need of the cases through the Health Care Network. **Objective:** To perform a construct validation of the Complexity Classification Guideline. **Subjects and Method:** With a sample of 488 CYSHCN to whom the Classification Guideline was applied, an instrument reliability analysis was performed, in addition to an exploratory and confirmatory factor analysis. **Results:** The Classification Guideline obtained a standardized Cronbach's Alpha of 0.87; however, the RMSEA, TLI, and CFI model fit statistics were lower than expected. The MI coefficient suggested the elimination of 9 items, from which a summary Guideline of 11 items and three di-

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mensions was generated that presented an RMSEA of 0.60; TLI of 0.970, and CFI of 0.977. **Conclusion:** The study allows us to have a Summarized Complexity Classification Guideline for CYSHNC, with good psychometric properties, quick application, and easy interpretation, for application in the public health network.

Introduction

Children and Youth with Special Health Care Needs (CYSHCN) are “those children and adolescents who present or are at risk of presenting a chronic disease (physical, developmental, behavioral, or emotional one) and who require greater use of health services”¹.

Due to their condition, these patients present particular difficulties for their normal development from birth, unlike a child without it, so they require the possibility of having access to a health team prepared to identify the special needs required, monitoring both the quality of the care provided and the impact of the interventions performed².

One group among all the CYSHCN is made up of those whose health condition is more complex, namely Children with Medical Complexity (CMC), and correspond to those who present a systemic multiorgan compromise due to a chronic health condition for at least 12 months³. They usually require the use of medical technologies that involve a high use of specialized health resources, besides limiting even more their functionality^{4,5}.

The CMC require frequent and prolonged hospital stays (between 10 and 12 a year), requiring a high coordination of care between the family and the health services, as well as between the different levels of care, which greatly increases the expenditure of health resources, representing a third of the total expenditure in child health^{4,6,7}. In addition, the great heterogeneity of needs hinders the comprehensive approach that requires close coordination between health teams throughout the healthcare network. Due to this variability in the epidemiology and etiology of CYSHCN, it is suggested to classify the different levels of complexity of this group⁸.

The CYSHCN Committee of the Chilean Society of Pediatrics (SOCHIPE) considered that the best strategy for grouping children would be based on their “special needs”.

Through a “brainstorming” methodology, a preliminary guideline was elaborated, in which questionnaire items were created (21 in total preliminarily) grouped into the special needs that these items addressed: (1) need for care by specialists, (2) need for special feeding, (3) need for technological assistance, (4) need for stimulation, rehabilitation, and technical aids, and

(5) contextual and psychosocial needs. This guideline has a total score for each child or adolescent, classifying them in High, Medium, or Low complexity.

Considering all the definitions in the literature of CMC, it was verified that each of the aspects of the definition was included in some item of the scale. A first application of the instrument was made to a non-representative sample, with which an expert validation was performed. The validation process and its result is the Medical Complexity Guideline for Children and Adolescents with Special Health Care Needs published in the technical standard for the supervision of children in Primary Health Care⁸.

The objective of this study is to present the results of a construct validation of the CYSHCN SOCHIPE Committee and other experts' Complexity Classification Guideline. The study was conducted with children and adolescents with special health care needs, users of the public health network in Chile.

Subjects and Method

Study of construct validation of the Complexity Classification Guideline to identify the care needs of children and adolescents with special care needs. The original Complexity Classification Guideline was submitted only to an expert validation. In this work, we began with a reliability analysis of this original instrument and a construct validation and then presented a proposal for an optimized Guideline, with its respective reliability analysis.

The study was carried out using a cross-sectional observational design. The sample consisted of 488 children and adolescent users of the CYSHCN program belonging to the public health network. The ages of the children ranged from 2 months to 17 years and 2 months. For instrument validation studies, a sample size calculated in relation to a minimum number of cases per item of the instrument to be validated is required, considering generally a minimum of five cases per item⁹. If the criterion for calculating the sample size of this study presented a ratio of five cases per item, considering that the Complexity Classification Guideline has 21 items, a minimum of 105 subjects would be required. Given the above, the size presented far exceeded the required sample size and is considered a good

size for instrument validation studies¹⁰. In this sense, it is expected that the sample will allow analyzing the psychometric properties of the instrument rather than providing descriptive or analytical information on the CYSHCN population.

The validated Complexity Classification Guideline originally had 21 items grouped into five variables or dimensions, each of which has its respective rating levels. Table 1 describes the variables, their descriptors, and rating levels.

For the validation of the Complexity Classification Guideline, descriptive analyses such as summary measures and calculation of interquartile range per item were performed. For the reliability analysis of the instrument, standardized Cronbach's alpha and Guttman split-half tests were calculated, in addition to correlation analysis between items based on Pearson's coefficient. The standardized Cronbach's alpha was reported since the items of the instrument have different levels of valuation. The psychometric analysis was performed using classical measurement theory¹¹.

The construct validation was performed by exploratory and confirmatory factor analysis. First, the Kaiser-Meyer-Olkin test for sampling adequacy was used to assess whether the proportion of variance observed in the study variables was explained by underlying factors. A value of this statistic higher than 0.8 allows a satisfactory answer to the previous question¹⁰. In order

to determine the degree of relationship between the variables, Bartlett's test of sphericity was used, where a value lower than 0.05 allows the conclusion that a factor analysis is useful to perform with the sample¹⁰.

In the confirmatory factor analysis, the Root Mean Square Error of Approximation (RMSEA)^a, Tucker-Lewis Index (TLI)^b, and Comparative Fit Index (CFI)^c model fit statistics were used, in addition to the Modification Index (MI)^d. A model was considered to have a good fit if it presented an RMSEA lower than 0.05, and a TLI and CFI equal to or higher than 0.9.

After the construct validation of the original 21-item Guideline through confirmatory factor analysis, the Modification Index (MI) was applied in order to generate an optimized Guideline that maintained the items that summarize a greater amount of information. The optimized version was evaluated by reliability analysis and confirmatory factor analysis with the RMSEA, TLI, and CFI tests. The cut-off points to distinguish levels of complexity of the screening instru-

^aBasically, it measures the amount of error that exists between two sets of data.

^bCompares the fit per degree of freedom of the proposed and null model.

^cStatistic to evaluate the model fit.

^dThis is an estimate of the amount by which the chi-square would be reduced if a single parameter constraint were removed from the model.

Table 1. Variables of the original screening instrument

Item	Variable	Descriptor	Code	Valuation levels
1	Specialist	Number of compromised systems	e1	1-3-4
2		Need for palliative care	e2	0-2-4-6
3		Need for polypharmacy (excludes vitamins and homeopathy)	e3	0-1-3-4
4		Alternative via of drug administration	e4	0-1-2-3-4
5		Drug complexity	e5	0-1-3-4
6	Feeding	Nutritional condition	a6	0-1-3
7		Special feeding needs	a7	0-1-2-3
8		Special feeding via	a8	0-1-6-8
9	Technological assistance	Need for alternative feeding via	t9	0-1-2-3
10		Use of oxygen therapy	t10	0-4
11		Aspiration requirement	t11	0-1-3
12		Need for ventilation	t12	0-3-4
13		Cardiovascular Technological Assistance	t13	0-2
14	Stimulation,	Need for early stimulation or rehabilitation due to delayed psychomotor development	at14	0-2-4
15	Rehabilitation and technical aids.	Need for technical aids for autonomy, social participation and inclusion	at15	0-1-2-3-4
16		Need for technical aids for care and hygiene	at16	0-1-2-3
17		Need for orthopedic technical aids	at17	0-1-2
18	Psychosocial context and social vulnerability	Caregiver mental health need	c18	0-2-3-4
19		Need for a trained caregiver at home	c19	0-2-3-4
20		Access to transportation services	c20	0-1-2-3-4
21		Need for adequate housing	c21	0-2-3-4

ment in the optimized version were calculated using the ROC curve.

The analyses were performed with R v. 4.0.0 software, especially the Lavaan package.

Results

According to the distribution of the sample by level of care, 54% corresponded to the primary care level. As for the distribution by region of the sample, 54.5% corresponded to the Metropolitan Region, 18.2% to the O'Higgins Region, 12.5% to the Valparaíso Region, 7.8% to the Maule Region, 4.1% to the Biobío Region, 2.5% to the Coquimbo Region, and 0.2% to the Araucanía and Antofagasta Regions. The rest of the country's regions did not present any cases in the sample.

Table 2 presents the relative frequencies for each score of the 21 items of the original guideline, as well as the interquartile range of the distribution (IQR). In general, the frequencies are concentrated in the low scores of the items, where a higher score means greater complexity of the individual on the item. Regarding item e1 (Number of systems involved), for example, 35.1% of the sample scored one point and 56.3% scored 3, considered a medium level. According to the IQR, there were several items with high homogeneity in the responses, specifically items e2, t10, t11, t12, t13, c20, and c21. Besides, the items with the greatest dispersion in their distributions are highlighted in color (IQR over 1) corresponding to the items e3, e4, a7, at14, and at15. According to this first analysis, the items that discriminate in the complexity of the cases were the use of alternative route of drug administration, complexity of drugs, need for special feeding, need for early stimulation or rehabilitation due to delayed psychomotor development, and need for technical aids for autonomy, social participation, and inclusion.

The original guideline with 21 items presented a Cronbach's Alpha of 0.88, a standardized Cronbach's Alpha of 0.87, and 0.9 in the Guttman split-half test. According to the reliability analysis, there were 4 items to be eliminated in order to improve the Alpha value (a6, t9, t13, and c20), while the Alpha resulting from the elimination of any of the 4 items was 0.89. The items just identified presented at the same time the lowest correlation coefficient with the rest of the items of the original guideline (0.252, 0.058, 0.058, and 0.152, respectively), therefore, eliminating them increased the average correlations between the items and the general instrument. Table 3 shows that items a6, t9, t13, and c20 present the lowest item-instrument correlations (0.252; 0.058; 0.058; 0.152, respectively).

Table 3 presents the linear correlation between the item and the corrected total score, with the respective Cronbach's Alpha if the item is eliminated. According to this table, considering an overall Cronbach's Alpha of 0.88, when item a6 is eliminated, Cronbach's Alpha is 0.89, and the same occurs with the elimination of items t9, t13, and c20.

Regarding the construct validation of the original guideline, the Kaiser-Meyer-Olkin test and the sphericity test were performed to evaluate the level of adequacy of the sample for an exploratory and confirmatory factor analysis. In the Kaiser-Meyer-Olkin test, the value obtained was 0.9, while in Bartlett's test of sphericity, the value obtained was 0.000. These values show that a significant proportion of the variance of the study items is explained by at least one underlying factor.

As for the original Complexity Classification Guideline, it is important to note that it has 21 items grouped into 5 dimensions: Specialist, Feeding, Technological assistance, Stimulation/rehabilitation and technical aids, and Social context and social vulnerability. Figure 1 is a sedimentation graph with the eigenvalues of 21 initial dimensions of the exploratory factor analysis, suggesting a factorial solution of four factors that exceed an eigenvalue of 1. This solution would explain 45% of the observed variance, while a 3-factor solution would explain 42%. That is, if the eigenvalue of the dimensions is considered, 4 dimensions should be maintained, although a solution with 3 dimensions optimizes the time of application of the instrument and improves interpretability, losing only 3% of the variance explained.

The structure of 5 dimensions and 21 items of the original guideline, with 33 parameters to be estimated and 87 degrees of freedom, was tested by confirmatory factor analysis, obtaining an RMSEA of 0.127, a TLI of 0.810, and a CFI of 0.843. However, by reducing the dimensions to 3 and grouping the items in these dimensions (Figure 2), we obtained an instrument with only 11 items, 23 estimation parameters, and 41 degrees of freedom. This summarized version was evaluated by confirmatory factor analysis and obtained an RMSEA of 0.060, a TLI of 0.970, and a CFI of 0.977. This decision was confirmed by the MI coefficient, which suggested eliminating items e2, a6, a8, t9, t13, at14, c18, c19, c20, and c21 in order to improve the goodness of fit of the tested model.

Figure 2 presents a schematic of the confirmatory factor analysis of the optimized guideline version, with the factor loadings of each item in its respective dimension. The three dimensions of the summarized version were called Need for Complex Care, Need for Respiratory Support, and Need for Technical Aids. The first dimension consisted of 5 items and the se-

Table 2. Descriptive statistics of items from the Complexity Classification Guideline

		%							RIQ
Item		0	1	2	3	4	6	8	
e1	Number of compromised systems		35.1		56.3	8.6			1
e2	Need for palliative care.	80.1		4.9		14.4	0.6		0
e3	Need for polypharmacy (excludes vitamins and homeopathy)	41.7	24		18.5	15.8			2
e4	Alternative via of drug administration	41.7	32	24.8	1	0.4			2
e5	Drug complexity	41.9	37		15.8	5.3			1
a6	Nutritional condition	57.7	23.2		19.1				1
a7	Special feeding needs	68.4	6.6	23	2.1		0.6	0.6	1.5
a8	Special feeding via	73.1	25.7						1
t9	Need for alternative feeding via	94.7	3.1	1.6	0.6				0
t10	Use of oxygen therapy	91.6				8.4			0
t11	Aspiration requirement	88.1			7.2	4.7			0
t12	Need for ventilation	95.5	0.2		2.1	2.3			0
t13	Cardiovascular Technological Assistance	98.2		1.8					0
at14	Need for early stimulation or rehabilitation due to delayed psychomotor development	33.1		14.4		52.6			2
at15	Need for technical aids for autonomy. social participation and inclusion	61.2	13.3	14.2	6.4	4.9			2
at16	Need for technical aids for care and hygiene	70.4	13.6	11.5	4.5				1
at17	Need for orthopedic technical aids	64.5	31	4.5					1
c18	Caregiver mental health need	68.6		23	7	1.4			1
c19	Need for a trained caregiver at home	62		32.9	3.5	1.6			1
c20	Access to transportation services	86.7	12.3	0.6	0.2	0.2			0
c21	Need for adequate housing	93.4		6		0.6			0

Table 3. Item-instrument correlation and Cronbach's Alpha corrected total score upon item removal

Item	Correlation Item-test	Cronbach's Alpha
e1	0.69	0.87
e2	0.65	0.88
e3	0.84	0.87
e4	0.83	0.87
e5	0.68	0.87
a6	0.25	0.87
a7	0.61	0.89
a8	0.47	0.88
t9	0.06	0.88
t10	0.47	0.89
t11	0.58	0.88
t12	0.37	0.88
t13	0.06	0.89
at14	0.69	0.88
at15	0.80	0.87
at16	0.72	0.87
at17	0.75	0.88
c18	0.46	0.88
c19	0.70	0.87
c20	0.15	0.89
c21	0.21	0.88

cond and third dimensions consisted of 3 items. In the Need for Complex Care dimension, items e3 and e4 presented the highest factor loadings (2.06 and 1.13, respectively); in Need for Respiratory Support, the highest factor loading was presented by item t11, while in the Need for Technical Aids dimension was item a15. In this summarized version, items from the Social Context dimension were not included, and the Need for Complex Care dimension was the one with the greatest explanatory weight, that is, the dimension with the greatest capacity to discriminate between levels of complexity.

For this optimized version, a standardized Cronbach's Alpha of 0.89 and a value of 0.92 in the Guttman split-half test were obtained. For the optimized proposal, the cut-off scores were calculated using the ROC curve, with the classification made by the Original Complexity Guideline as the gold standard. The cut-off point to distinguish high complexity from medium and low complexity was 16 (15.5 approximate), with a specificity of 85.7% and a sensitivity of 79.2% for this cut-off point, and 88.9% of the area under the curve. To distinguish medium complexity from low complexity, the cut-off point was estimated to be between 9 and 15 points.

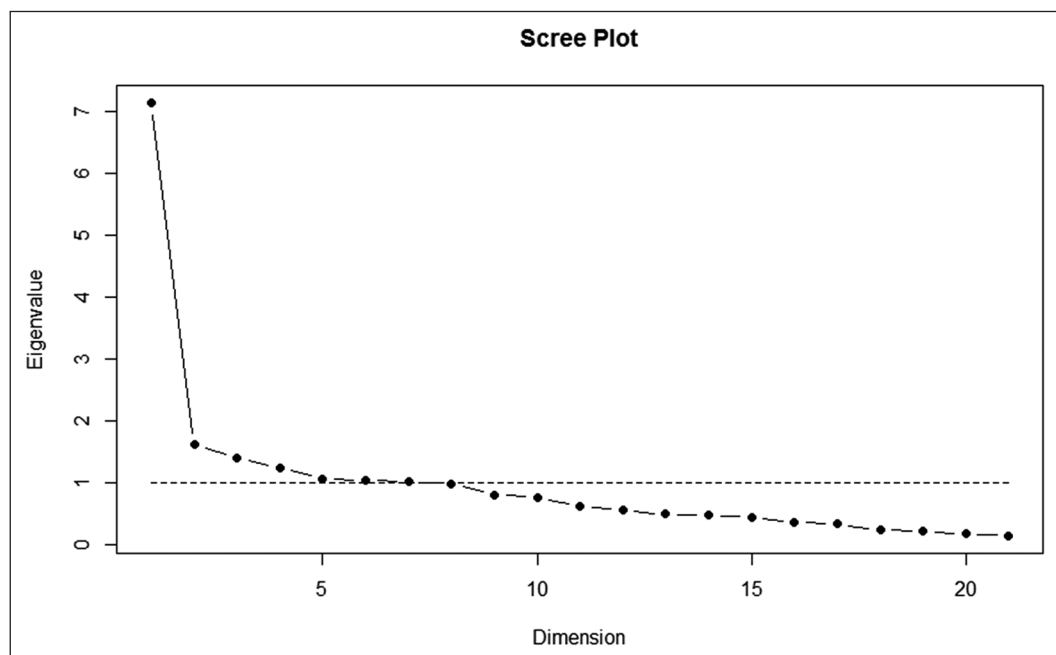


Figure 1. Scree plot with dimensions from an exploratory factor analysis of the Complexity Classification Guideline

Discussion

The CYSHCN Committee of the SOCHIFE together with other experts generated a screening instrument to identify levels of complexity of children and youth with special health care needs (CYSHCN) who are treated in the public health network, called the Complexity Classification Guideline (Supplementary material: Complexity Evaluation Guideline in CYS-HCN).

This instrument was validated for internal consistency by experts and has a structure of 5 dimensions and 21 items. The original guideline presented good psychometric properties according to Cronbach's Alpha coefficient and Guttman's split-half test. In the first analysis, 4 items of the original guideline showed poor performance (a6, t9, t13, and c20). These items refer to the assessment of nutritional status, the need for alternative feeding routes, cardiovascular technological assistance, and access to transportation services.

After confirmatory factor analysis, the original version showed a goodness of fit lower than expected ($RMSEA < 0.05$; TLI and $CFI \geq 0.9$). From the application of the MI coefficient, 9 items were identified to be eliminated, while the exploratory factor analysis suggested the creation of a summarized version of the original instrument, with 3 dimensions and 11 items.

This version, known as the Summary guideline, presented better goodness of fit in its respective confirmatory factor analysis, in addition to improving in terms of application time and interpretability of

the results. The optimization of screening guidelines responds to a relevant need for health services since it allows more time to perform the intervention and other administrative tasks. In this case, the work of optimizing the original guideline allows professionals to focus on identifying those issues that are more complex for children and adolescents with Special Health Care Needs.

The dimensions of the instrument in a summarized version are "Need for Complex Care", "Need for Respiratory Support", and "Need for Technical Aids". The first dimension groups mainly items referring to pharmacology, the second dimension groups items

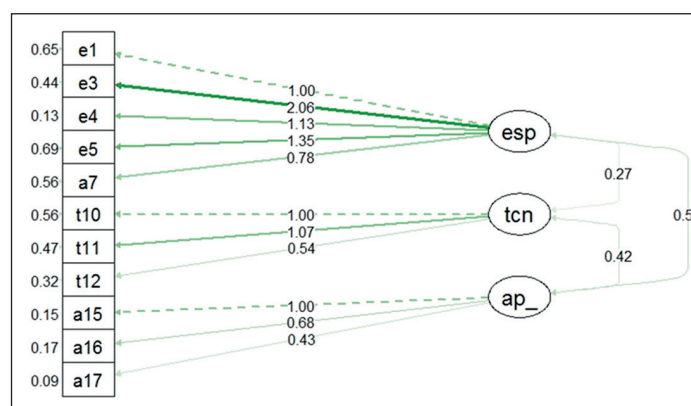


Figure 2. Confirmatory factor analysis scheme version Summary guideline; esp = Need for complex care; tcn = Respiratory support needed; ap_ = Need for technical aids

referring to support to maintain respiratory function, and the technical aids dimension groups items related to autonomy requirements, participation, basic care, and orthopedics for the maintenance of a functional capacity that enables integration and complete social participation. These three items seem to mark the complexity of CYSHCN and also refer to the resources demanded by this population in the healthcare network. As a result of the above, it is necessary to train health teams in the identification of these issues, especially in primary care. A reliable guideline that reflects the complexity of the CYSHCN as High, Medium, and Low, allows according to this, to define in which place of the Assistance Network they will be better cared for, thus, if it has Low complexity they will be treated in the primary level of care, if it is of Medium complexity in the secondary level, and if it is of high complexity in the tertiary level (9).

It is important to note that the optimized version of the instrument with its respective cut-off points to differentiate levels of complexity is open to future improvements. In order to permanently improve the proposed instrument, clinical practice is of utmost relevance.

One limitation of the study is that no sociodemographic data were collected at the time of applying the Complexity Classification Guideline, which translates into the lack of a table with summarized information on the characteristics of the study population.

Conclusions

Based on this study, a screening instrument with construct validation is available to distinguish levels of complexity of CYSHCN for the Health Care Network. This instrument, which consists of 11 items and 3 dimensions, allows the CYSHCN to be referred to the level of care of the Health Care Network that is most

competent in their care according to the current complexity condition reflected by the guideline applied by the health team, based on three types of general needs: "Need for Complex Care", "Need for Respiratory Support", and "Need for Technical Aids". These types of needs must be added to the particular needs of each child according to the analysis of the treating health team.

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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