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ORIGINAL ARTICLE

Psychometric properties of the Spanish version of the Pediatric Quality of Life Inventory Family Impact Module (PedsQL FIM)

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KEYWORDS
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Abstract
Introduction: This study analysed the psychometric properties of the Spanish version of the Pediatric Quality of Life Questionnaire Family Impact Module (PedsQL FIM) in the Argentinian population.
Patients and Methods: The sample included 232 caregivers, of who 108 were parents of children with chronic diseases (mean, 9.54; standard deviation [SD], 4.43) and 124 parents of children in the general population (mean, 12.37; SD, 4.6).
Results: We assessed the validity of the instrument with the known-groups method, finding significant differences between the case and control groups in the overall and subscale scores ($P < .01$). We also assessed test validity by means of exploratory factor analysis, which yielded an 8-factor model that explained 74.03% of the variance. We assessed reliability with the Cronbach alpha and found a high internal consistency ($\alpha = 0.95$).
Conclusion: The PedsQL module proved to be a valid and reliable tool to assess the impact of a chronic paediatric condition on caregiver quality of life and family functioning.

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PALABRAS CLAVE
Familiar;
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Propiedades psicométricas de la versión en castellano del Cuestionario Calidad de Vida Pediátrica Módulo de Impacto Familiar (PedsQL FIM)

Resumen
Introducción: Este trabajo analiza las propiedades psicométricas de la versión en castellano del Cuestionario de Calidad de Vida Pediátrica Módulo de Impacto Familiar (PedsQL FIM) en población argentina.
Pacientes y Métodos: Se obtuvo una muestra de 232 cuidadores, 108 de niños con enfermedades crónicas (M = 9,54, DE = 4,43) y 124 de niños de población general (M = 12,37, DE = 4,6).
Resultados: La validez del instrumento se estudió a través del método de grupos contrastados, encontrando diferencias significativas en la escala total y subdimensiones de la escala ($p < 0,01$). A su vez, se realizó un análisis factorial exploratorio en el que se encontró un modelo de 8 factores explicando el 74,02% de la varianza total. La confiabilidad fue estudiada a través del Coeficiente Alfa de Cronbach y se encontró un valor alto de consistencia interna $\alpha = 0,95$.
Conclusiones: El instrumento PedsQL demostró ser una herramienta válida y confiable para estudiar el impacto que tiene una condición pediátrica crónica a nivel de la calidad de vida del cuidador y del funcionamiento familiar.

Introduction

Chronic diseases have an impact that extends beyond the patient, affecting the entire household. In the case of paediatric chronic diseases, there is a transformation of the roles within the family, so that one member assumes the unofficial role of non-professional caregiver of the ill child. This caregiver role implies the reallocation of responsibilities within the family, shifts in supportive relationships and a reorganization of family dynamics. The parents handle care activities, support the child during hospitalizations and medical appointments and make decisions regarding treatment options.[1]

Due to the importance of caregivers in the care of children with chronic diseases, many studies have focused on assessing caregiver quality of life (QoL). The evidence shows that QoL decreases in parents caring for an ill child.[1,2] Parents of children with chronic diseases report symptoms of anxiety, depression, stress and being overwhelmed.[3–5]

The Pediatric Quality of Life Inventory Family Impact Module (PedsQL-FIM) is one of the most widely used instruments for assessing the impact of chronic disease on families. It is used to assess health-related QoL in children aged 2–18 years. From this instrument, different modules have been developed to assess specific diseases or other factors related to the disease. Some of these modules have been validated for use in the Argentinean population.[6,7] The PedsQL-FIM is the module that evaluates the impact of a medical condition in a child or adolescent at the family level. It explores the impact on the QoL of the primary caregiver in the family and on family functioning.[8]

The PedsQL-FIM has been adapted for different populations. The original version of the instrument was validated in San Diego in a sample of 23 families of children with chronic health conditions who either resided in a long-term care convalescent hospital or resided at home with their families. This initial study found a good internal consistency (Cronbach α, 0.82 and 0.97). The construct validity was assessed with the known-groups method and found that the instrument could differentiate parents of institutionalised children versus parents of children residing at home.[8]

We also identified 11 studies that assessed the reliability and validity of this instrument in different countries and populations. Overall, an adequate reliability was found in every population in which it was assessed, with Cronbach α values greater than 0.70 reported in all the reviewed studies.[9–20]

The validity of the PedsQL-FIM has been assessed chiefly through 3 methods. On one hand, construct validity was assessed by the known-groups method, the approach used originally by the authors of the instrument,[8] evincing significant differences in PedsQL-FIM scores between parents of children in the general population and parents of children with chronic conditions, such as neurodevelopmental disorders,[11] asthma or cardiac diseases,[12] chronic gastrointestinal disorders[15] and cancer.[19] Other studies assessed the convergent/divergent validity of the instrument, studying its correlation with parameters such as the satisfaction with the care received,[10] symptoms of autism,[11] adult QoL[15] and paediatric QoL, pain catastrophizing, functional impairment and emotional and behavioural problems.[16] Last of all, a third group of studies used factor analysis, supporting the current 8-factor structure in every study[12,13,15,17] except the one conducted in Malaysia.[14] Two of the studies identified in the literature review only reported reliability results and did not assess the validity of the instrument.[9,20]

While the family impact module has been translated and validated for use in different countries, the nearest adaptation in the Latin American population is the Brazilian version. With the aim of obtaining an instrument that would enable the assessment of the impact of chronic conditions at the family level, we set out to assess the psychome-

tric properties, reliability and validity of the PedsQL-FIM Spanish version, developed by the authors of this article, and thereafter evaluated by 6 raters from Spain and Argentina (Universidad de Deusto, Bilbao, Spain and Universidad Católica Argentina, Buenos Aires, Argentina).

Sample and methods

Participants

The sample included 232 parents of children and adolescents aged 2–18 years with and without chronic diseases or conditions. Of this total, 108 were parents of children with chronic conditions (case group), and 124 parents of healthy children (control group). The chronic conditions that respondents reported on included genetic, neuromuscular and developmental disorders. Table 1 presents the characteristics of the parents and children that completed the instrument.

Instrument

The PedsQL-FIM[8] was designed to assess the impact of paediatric diseases on the family. This module was developed as a parent-report questionnaire. It consists of 36 items that assess the impact on the family through 8 main factors: physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (4 items), communication (3 items), worry (5 items), daily activities (3 items) and family relationships (5 items). The answers are given on a 5-point Likert scale (0 = it is never a problem, 4 = it is almost always a problem) and are reversed scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that a greater score indicates better functioning. In addition to the overall family impact and subdimension scores, the instrument yields 2 summary scores: the caregiver health-related quality of life summary, which includes the physical, emotional, social and cognitive functioning dimensions, and the family summary, which includes daily activities and family relationships. In the original study, the instrument exhibited adequate reliability ($\alpha = 0.82-0.97$) and construct validity.

In this instance, we did not need to adapt the language of the original instrument. The research team of the Mapi Research Institute had already developed a Spanish version of the PedsQL-FIM for Argentina.[21] The authors of this version had themselves suggested an evaluation of its psychometric properties.

The authors of the Spanish version[8] gave their permission for us to publish the wording of the items in this article, featured in Table 2 (Spanish version), which presents the results of the factor analysis. However, it is still necessary to seek authorization from the authors to apply this instrument.

We collected the data by recruiting a non-probability sample. We obtained part of the sample from previous studies[22,23] that sought to describe the QoL of children with neuromuscular diseases or disabilities and their families. Caregivers of children with chronic conditions were recruited through patient associations in Argentina, which disseminated the questionnaire to their members. The control group of caregivers of healthy children was recruited through chain-referral sampling using an online version of the questionnaire. Both groups were recruited at the same time. Data were anonymised and pooled, and the study adhered to the principles of research involving human subjects of the Declaration of Helsinki.[24] we safeguarded the confidentiality of personal data, performing all statistical tests excluding the names of participants. We provided participants with an electronic mail address and a telephone number they could use to request any additional information or clarification as needed.

Statistical analysis

We conducted the statistical analyses with the software IBM SPSS Statistics, version 25 for Windows. To assess the psychometric properties of the instrument in the Argentinean population, we decided to use the same approach as the authors of the original instrument[8] with the addition of factor analysis. To this end, we performed the Kaiser-Meyer-Olkin (KMO) and Bartlett tests to verify that the data were appropriate for factor analysis.[25] Then we explored the components of the instrument using factor analysis with varimax rotation. We extracted factors with a factor loading greater than 0.40.[26]

Secondly, to strengthen the evidence on construct validity, we used the known-groups methods. We hypothesised that parents of children or adolescents with chronic diseases would report poorer quality of life compared to parents of children and adolescents in the general population. To determine whether the variables under study followed a normal distribution, we used the Kolmogorov-Smirnov test. Since the obtained p value was greater than 0.05, we applied the pertinent parametric statistics. To assess differences between means, we used the Student t test (significance: $p < .05$). We also calculated the effect size to assess the magnitude of these differences, establishing effect size categories of small (0.20) intermediate (0.50) and large (0.80). The analysis was performed with the statistical software G*Power.[27]

Then, we assessed the internal consistency of the instrument by calculating the Cronbach α. We considered internal consistency excellent if the value was greater than 0.90, good if it was greater than 0.80 and acceptable if it was greater than 0.70. Lastly, we used descriptive statistics (mean $\pm$ standard deviation) to summarise the scores for the total instrument and its dimensions.

Results

Construct validity assessment

We used 2 methods to assess construct validity. First, we conducted a factor analysis of the instrument. In this analysis, we took into account the 108 cases of parents of children with chronic conditions. The result of the Bartlett sphericity test (χ^2 [630] = 3014.78; $p < .001$) was statistically significant, indicating an adequate correlation between the items. The KMO value was 0.86, which indicated the data was suitable for factor analysis. The principal component analysis with varimax rotation yielded a model with 8 factors that explained 74.02% of the total variance. Table 2 presents the item distribution and factor loading of these factors.

Table 1 Distribution of the sample based on sociodemographic characteristics.

Sociodemographic variables	Case group		Control group	
	n = 108		n = 132	
Caregiver				
Age, mean ± SD	42.43 ± 7.13		45.28 ± 7.63	
Sex, n, %				
Male	7	8.30%	22	17.70%
Female	99	91.70%	102	82.30%
Educational attainment of respondent, n, %				
Elementary or unfinished secondary level	8	7.40%	2	1.60%
Finished secondary level	23	21.30%	16	12.90%
Started or finished tertiary level	25	23.10%	35	28.30%
Started or finished university	50	46.30%	70	56.40%
No answer	2	1.90%	1	0.80%
Relationship to child, n, %				
Father	11	10.20%	22	17.70%
Mother	89	82.40%	102	82.30%
Other	8	7.40%	–	–
Place of residence, n, %				
City of Buenos Aires	13	12%	27	21.80%
Province of Buenos Aires	69	63.90%	94	75.80%
Elsewhere in Argentina	26	24.10%	3	2.40%
Child				
Age, mean ± SD	9.54 ± 4.43		12.37 ± 4.6	
Sex, n, %				
Male	68	63%	64	51.60%
Female	39	36.10%	60	48.40%
Education, n, %				
Not in school	7	7.50%	2	1.60%
Early childhood education centre	15	14.90%	16	12.90%
Special education primary school	13	12%		
Primary school	45	41.70%	29	23.40%
Secondary school	26	24.10%	76	61.30%
Diagnosis, n, %				
Duchenne muscular dystrophy	25	23.10%	–	–
Down syndrome	27	25%	–	–
Autism spectrum disorder	13	12%	–	–
X-linked hypophosphatemia	12	11.10%	–	–
Other neuromuscular disease	11	10.20%	–	–
Cystic fibrosis	9	8.30%	–	–
Other chronic disease	11	10.20%	–	–

Diverging from the composition of the original instrument, the items *''I worry about how others will react to my child's condition''* and *''I worry about how my child's illness is affecting other family members''* got loaded under the communication factor as opposed to the worry factor. The factor solution was orthogonal, although we found that some variables were represented in more than one factor, in which case we chose to group them in the factor in which they had the highest loading *(''I feel helpless or hopeless'', ''It is hard to find time for social activities'')*.

On the other hand, replicating the original PedsQL-FIM study, we applied the known-groups method. We analysed differences in the scores between the group of parents of children with chronic diseases and the group of parents of healthy children. We found significant differences in the total score (t [230] = −10.15; p = .00). Table 3 presents the mean, standard deviation, effect size statistics and the results of the Student t test for each dimension and subdimension of the PedsQL-FIM. The effect size was large for every dimension and subdimension with the exception of the family relationships and cognitive functioning, which had an intermediate effect.

Assessment of reliability

To assess the reliability of the instrument, we analysed its internal consistency by calculating the Cronbach α. We calculated values for the total sample and for each group for the total score and the dimension scores. We found excellent levels of internal consistency in the parameters under study, with an α of 0.97 for the total score in the total

Table 2 Distribution of items in factors.

	Physical functioning	Emotional functioning	Social functioning	Cognitive functioning	Communication	Worry	Daily activities	Family relationships
1. I feel tired during the day	0.53							
2. I feel tired when I wake up in the morning	0.742							
3. I feel too tired to do the things I like to do	0.644							
4. I get headaches	0.762							
5. I feel physically weak	0.811							
6. I feel sick to my stomach	0.668							
7. I feel anxious		0.672						
8. I feel sad		0.712						
9. I feel angry		0.739						
10. I feel frustrated		0.713						
11. I feel helpless or hopeless		0.541						
12. I feel isolated from others			0.601					
13. I have trouble getting support from others			0.699					
14. It is hard to find time for social activities			0.682					
15. I do not have enough energy for social activities			0.641					
16. It is hard for me to keep my attention on things				0.792				
17. It is hard for me to remember what people tell me				0.79				
18. It is hard for me to remember what I just heard				0.867				
19. It is hard for me to think quickly				0.8				
20. I have trouble remembering what I was just thinking				0.865				
21. I feel that others do not understand my family's situation					0.509			
22. it is hard for me to talk about my child's health with others					0.68			

Table 2 (*Continued*)

	Physical functioning	Emotional functioning	Social functioning	Cognitive functioning	Communication	Worry	Daily activities	Family relationships
23. It is hard for me to tell doctors and nurses how I feel					0.715			
24. I worry about whether or not my child's medical treatments are working						0.808		
25. I worry about the side effects of my child's medications/medical treatments						0.708		
26. I worry about how others will react to my child's condition					0.775			
27. I worry about how my child's illness is affecting other family members					0.451			
28. I worry about my child's future						0.572		
29. Family activities taking more time and effort							0.527	
30. Difficulty finding time to finish household tasks							0.861	
31. Feeling too tired to finish household tasks							0.774	
32. Lack of communication between family members								0.756
33. Conflicts between family members								0.817
34. Difficulty making decisions together as a family								0.761
35. Difficulty solving family problems together								0.775
36. Stress or tension between family members								0.759

Table 3 Differences in total score, dimension and subdimension scores.

FIM scores	Case group			Control group			Student *t* test		Effect size
	Mean	SD	n	Mean	SD	n	*t* (df)	*p*	*d*
Total	59.96	21.17	108	86.31	18.38	124	−10.15 (230)	.00	1.11
Caregiver HRQoL summary	62.16	23.43	108	86.75	18.15	124	−10.55 (230)	.00	1.01
Family summary	61.46	25.71	108	84.53	21.55	124	−7.43 (230)	.00	0.88
Physical functioning	59.65	28.59	108	85.15	20.52	124	−7.70 (191.12)	.00	0.92
Emotional functioning	59.49	27.45	108	86.33	20.01	124	−8.40 (192.99)	.00	0.98
Social functioning	61.28	30.17	108	88.51	19.91	124	−7.98 (180.95)	.00	0.95
Cognitive functioning	55.93	23.98	108	70.60	16.61	124	−5.34 (186.75)	.00	0.67
Communication	66.06	26.2	108	90.84	17.62	124	−8.32 (183.87)	.00	0.98
Worry	31.09	26.21	108	80.51	29.99	124	−13.26 (230)	.00	1.32
Daily activities	51.08	31.60	108	81.65	26.35	124	−7.94 (209.15)	.00	0.94
Family relationships	67.69	29.07	108	86.25	21.42	124	−5.47 (194.32)	.00	0.69

sample, an α of 0.95 for the case group and of 0.97 for the control group. In addition, we verified that the α coefficient did not improve in any case by eliminating any of the elements. Table 4 presents the Cronbach α coefficients for each dimension and study group. All dimensions exhibited good internal consistency with coefficients greater than 0.70, with the exception of the worry subdimension in the case group.

Mean and standard deviation of PedsQL-FIM scores

We calculated these statistics for the total module, dimension and subdimension scores in the total sample, the case group and the control group. The highest scores corresponded to the communication dimension in the total sample (mean = 82.08; SD = 23.99) and in the case and control groups. The lowest scores corresponded to the cognitive functioning score in the total sample (mean = 63.77; SD = 21.66) and the control group (mean = 70.6; SD = 16.61), and to the worry dimension in the case group (mean = 31.09; SD = 26.21). The mean total score in the overall sample was 74.04 (SD = 23.69), compared to 59.96 in the case group (SD = 21.17) and 86.31 in the control group (SD = 18.31). Table 5 presents the scores for every dimension.

Discussion

The management of children with chronic conditions must take into account the impact of these conditions at the family level. Our study contributes information about the psychometric properties of the PedsQL Family Impact Module, which can be used to assess the impact of a condition on the QoL of the caregiver and on family functioning.

Our study adds to previous works that have evaluated the psychometric properties in other countries: the United States, Malaysia, Jordan, Ethiopia, Brazil, China, Turkey and Croatia.[9–20] It is also the first to assess the reliability and validity of the Spanish version of the PedsQL-FIM.

Our study applied the methodology of the original study of the PedsQL-FIM[8] and went one step further with the performance of exploratory factor analysis. This analysis confirmed the 8-factor model proposed by the authors of the original instrument[8] and by previous studies that have analysed its factor composition.[12–14] To date, only one study has not found an 8-factor model, but a 6-factor composition.[15] The difference we found in this study compared to the original instrument is that 2 items in the Spanish version, previously allocated to the worry subdimension, were reallocated to the communication subdimension because their loadings were higher in the latter. Isa et al.[14] also reported issues with some of the items int eh worry subdimension, and opted to remove 2 items from this scale.

On the other hand, the module was able to discriminate between parents of children with chronic conditions and parents of healthy children, both in the total score and in the dimension scores. This results were consistent with those reported in the previous literature, which has demonstrated not only that the PedsQL-FIM can differentiate between families with chronically ill versus healthy children,[15] but also differentiate between parents with chronically ill children depending on the severity of the disease.[11,12,19] Both of these results indicate that this instrument is valid.

In terms of reliability, the PedsQL-FIM has exhibited an excellent internal consistency in the Argentinean population, with values that were similar to those found for the original instrument (α = 0.97; α = 0.96; α = 0.90). Only the α of the worry subdimension was under, although near, 0.70. This was also the case of the communication subdimension in the validation of the Brazilian and Turkish versions of the instrument.[13,19]

The scores obtained in every dimension showed that the QoL of both the main caregiver and the family were both significantly lower in the reports of parents of children or adolescents with chronic conditions, especially in relation to worry and daily activities. This finding was related to the changes in family dynamics that result from receiving a diagnosis and the subsequent burden added to the caregiver, which may be overwhelming.[1,5]

We ought to mention some of the limitations of the study. First, the age group that predominated in both groups was school-age children, with children in the control group being a little older. In the future, it may be convenient to select samples that are more homogeneous in their sociodemographic characteristics, in addition to recruiting parents of preschool-age children or adolescents to be able to com-

Table 4 Cronbach alpha coefficients for the dimensions of the PedsQL Family Impact Module.

Dimension	Total sample	Case group	Control group
Total	0.97	0.95	0.98
Caregiver HRQoL summary	0.96	0.94	0.96
Family summary	0.93	0.89	0.94
Physical functioning	0.91	0.89	0.90
Emotional functioning	0.92	0.88	0.92
Social functioning	0.88	0.84	0.87
Cognitive functioning	0.94	0.94	0.94
Communication	0.86	0.79	0.89
Worry	0.89	0.69	0.89
Daily activities	0.89	0.85	0.89
Family relationships	0.94	0.93	0.95

Table 5 Descriptive analysis of the PedsQL-FIM dimensions in the Argentinean population.

FIM scores	Total sample		Case group			Control group			
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Total	74.04	23.69	232	59.96	21.17	108	86.31	18.38	124
Caregiver HRQoL summary	75.3	24.1	232	62.16	23.43	108	86.75	18.15	124
Family summary	73.79	26.20	232	61.46	25.71	108	84.53	21.55	124
Physical functioning	73.28	27.67	232	59.65	28.59	108	85.15	20.52	124
Emotional functioning	73.84	27.25	232	59.49	27.45	108	86.33	20.01	124
Social functioning	75.84	28.60	232	61.28	30.17	108	88.51	19.91	124
Cognitive functioning	63.77	21.61	232	55.93	23.98	108	70.60	16.61	124
Communication	79.31	25.23	232	66.06	26.2	108	90.84	17.62	124
Worry	57.50	37.51	232	31.09	26.21	108	80.51	29.99	124
Daily activities	67.42	32.65	232	51.08	31.60	108	81.65	26.35	124
Family relationships	77.61	26.87	232	67.69	29.07	108	86.25	21.42	124

pare the different age groups. Furthermore, our study did not take into account the severity of the chronic conditions in the sample. A second study could compare groups of parents of children with disease of different severity, as has been done by other authors,[12,19] to ascertain whether the Spanish version of the PedsQL can detect differences based on disease severity. Also, while the KMO test showed that the data were suitable for factor analysis, the case group is not ideal for it given the number of items in the instrument. We would suggest performance of exploratory and confirmatory factor analysis in a larger sample. Lastly, it would also be useful for future studies to assess the test-retest reliability of the instrument by analysing the changes in the scores.

Our study makes a relevant methodological contribution. We present evidence on the reliability and validity of the PedsQL-FIM applied to the Argentinean population, although the translation to Spanish of the items would allow using this version in other countries, such as Spain. The availability of this module will allow a family-based approach to the management of paediatric chronic diseases, taking into account the key role of parents in care delivery as they support their children with chronic conditions.

Conflicts of interest

The authors have no conflicts of interest to declare.

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