Psychometric Properties of the Quality of Life Questionnaire in Pediatric Patients with Hemophilia Mexico (QoLHMEX)

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Abstract

The present study describes the psychometric properties of the Quality of Life Questionnaire in Pediatric Patients with Hemophilia Mexico (QoLHMex). To prepare the instrument were taken into consideration the main actors of the disease (patients, parents, physicians) who expressed valuable opinions throughout the process of correction. The questionnaire is composed of 63 reagents with different subscripts for a total of 162 items, with dichotomous response and has 13 dimensions: Concentration, Self-Esteem, Family Support, Level of Activity, Disease Awareness, Risk, Physical Complaints, Feelings about Disease, Social Area, Area Emotional, Future, Truancy, and Joint Problems. 3 parallel forms were developed as form A (children 4 to 7 years), form B (8 to 16 years) and form P (parents). Participated in the validation study 89 men with a mean of 8.6 years (SD = 1.96), 76% with hemophilia A and 24% hemophilia B. 27% with mild hemophilia, 52% moderate and 21% severe. The results indicate that the QoLHMex has high internal consistency (α = 0.95), a low significant correlation with the instrument EuroQoL served as gold standard (r = 0.238, p <0.01), and 11 of its 13 dimensions greater internal consistency at α = 0.60. There was a significant correlation between the answers given in the instrument for parents and children (r = 0.76, p <0.01). Therefore, the instrument revealed significant differences in some dimensions regarding patient's clotting activity, which reveals high sensitivity to indicators of morbidity. It is important to have a valid instrument for mexican population that gives reliable indicators for use in the planning and structuring of comprehensive care and treatment.
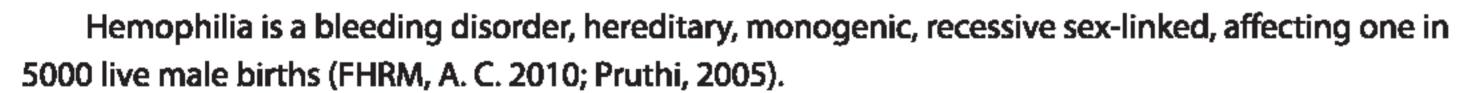
Introduction

The research carried out into the psychology of children's health is also dedicated to creating valid and reliable instruments to measure objectively the factors that come together and affect different pediatric patients with acute and chronic illnesses, and how these influence the welfare of children and / or adolescent (Osorio, 2004).

A disease subject of interest in this branch of psychology, is undoubtedly due to hemophilia, chronic illness such as this requires care, treatment, information and special support.

Hemophilia is a bleeding disorder, hereditary, monogenic, recessive sex-linked, affecting one in 5000 live male births (FHRM, A. C. 2010; Pruthi, 2005).

In recent decades, research and advances in knowledge and comprehensive treatment of hemophilia, have allowed the quality of life of people with hemophilia to rise significantly, which has changed the classical notion of hemophilia as a chronic disabling (Remor, 2005).

Despite these advances, there are few studies to reliably assess the quality of life of these patients, (Aznar, Magallón, Querol, Gorina, Tusell 2000; Solovieva, 2001).
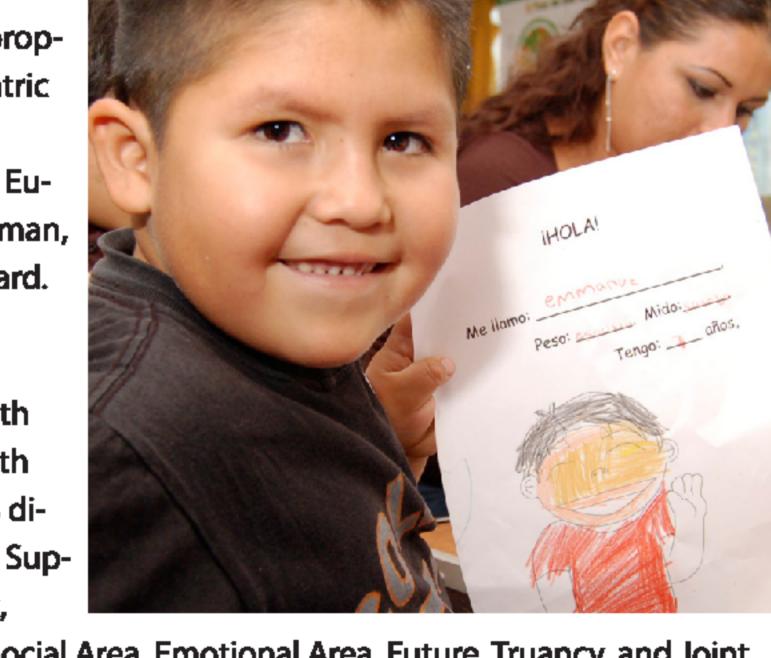
Objective

Describe and present the psychometric properties of Quality of Life Questionnaire in Pediatric Patients with Hemophilia Mexico (QoLHMex), comparing levels of criterion validity with the EuroQoL (Spanish version of Badia, Rosset, Herdman, 1999) instrument that served as a Gold Standard.

Description

The instrument consists of 63 reagents with different subscripts, for a total of 162 items, with two response options (Yes and No) and has 13 dimensions: Concentration, Self-Esteem, Family Support, Level of Activity, Disease Awareness, Risk, Physical Complaints, Feelings about Disease, Social Area, Emotional Area, Future, Truancy, and Joint Problems. Test 3 parallel forms were developed as A (for children 4 to 7 y. o.), the form B (patients 8 to 16 y. o.) and the form P (for parents) developed to corroborate the answers given by patients.

All three forms have same variables considered, writing is according to the age of the respondent.

Table 1. QoLHMex questionnaire scores by dimensions, specified levels of quality of life: low, medium and high.

Results

The data indicate that the instrument is highly reliable because it was obtained α = 0.95. Moreover, the reliability analysis performed EuroQoL instrument, who served as Gold Standard, was found to be α = 0.66, which can be considered an acceptable reliability (Kerlinger and Lee, 2002).

To determine validity of the instrument we calculated the correlation between the EuroQoL and QoLHMex and which was equal to r = 0.238 (p <0.05), moderately low significant correlation was found between two instruments, although the correlation is low QoLHMex instrument can be considered as valid and reliable test in determining the quality of life of pediatric patients with hemophilia.

In regard to the reliability of each of the dimensions of QoLHMex found that 11 of them internal consistency is higher than α = 0.60 and only 2 have a low consistency (risks and truancy) (See Table 2 .)

Based on the analysis of correlations between the subscales of the instrument, it appears that many of them are significant, the highest correlations found are level of activity and joint problems (r = 0.884), followed by level activity and disease awarness (r = 0.794) also found a strong correlation between level of activity and concentration (r = 0.783) as well as a strong correlation between joint problems and future (r = 0.781). It is very interesting that the largest number of high correlations were found about future dimension and joint problems dimension. In Table 3, we can observe all of the resulting correlations.

Comparison between groups

There were no significant differences between ages and types of hemophilia. However, Tukey's honest significance test revealed significant differences between A, B and P forms of QoLHMex regarding the severity of hemophilia. We can observe there are significant differences between the level of activity and the clinical grade (mild, moderate and severe) were also significant differences in the dimensions of truancy and joint problems, in mild and severe grades.

Conclusions

In Latin America specialized psychological literature published so far could confirm the absence of specific tools, valid and reliable for assessing the quality of life in children with hemophilia, a view shared by authors such as Remor (2005) and Osorio (2006) .

To prepare the instrument followed specific criteria set by experts as essential for an instrument to be representative and useful, that is, they took into account the protagonists of the disease (patients, parents, doctors, psychologists and social workers) (Remor, 2005) who expressed valuable opinions throughout the process and correction of the instrument.

The relevance of developing a specific instrument, reliable and valid for assessing the quality of life of patients with hemophilia, lies mainly in three points: 1) having an instrument developed within and for mexican population with validity accurately measure levels of quality of life, 2) have a measure of the specific dimensions that need to be addressed, developed or enabled to maintain and / or increase the quality of life and 3) is the starting point for planning and structuring of comprehensive care and treatment of these patients.

Finally, the psychometric properties that make QoLHMex, a suitable instrument to measure quality of life in pediatric patients with hemophilia are its high internal consistency, the correlation with an instrument known in the literature as the EuroQoL, the levels of consistency inside each of their dimensions and significant correlations between each of them, the ability and sensitivity to detect differences between the various levels of quality of life (low, medium and high) and above all, the sensitivity to indicators of morbidity.

Table 2. Internal consistency and number of items of each of the dimensions of QoLHMex.

Dimensions	Items	Cronbach's alpha
I. Concentration	7	0.82
II. Self-Esteem	12	0.71
III. Family Support	18	0.84
IV. Level of Activity	15	0.94
V. Disease Awarness	8	0.81
VI. Risk	6	0.28
VII. Physical Complaints	34	0.72
VIII. Feelings about Disease	9	0.60
IX. Social Area	11	0.62
X. Emotional Area	12	0.76
XI. Future	4	0.90
XII. Truancy	6	0.40
XIII. Joint Problems	20	0.90

Methods

Participants

89 boys with hemophilia, with a mean of 8.6 years old (DS = 1.96, range = 4-13 y. o.), 76.4% hemophilia A, 23.6% hemophilia B. 27% mild severity, 51.7% moderate and 21.3% severe.

Environment

The instruments were applied in an approved Psychology Service of a Public Hospital of Mexico City with the informed consent of parents and patients, during the period January 2009 to January 2010.

Dimensions	Quality of Life		
	Low	Medium	High
I. Concentration	7-9	10-12	13-14
II. Self-Steem	12-15	16-20	21-24
III. Family Support	18-23	24-30	31-36
IV. Level of Activity	15-19	20-25	26-30
V. Disease Awarness	8-10	11-13	14-16
VI. Risk	6-7	8-10	11-12
VII. Physcal Complaints	34-45	46-57	58-68
VIII. Feelings about disease	9-11	12-15	16-18
IX. Social Area	11-14	15-18	19-22
X. Emotional Area	12-15	16-20	21-24
XI. Future	4-5	6-7	8
XII. Truancy	6-7	8-10	11-12
XIII. Joint Problems	20-26	27-33	34-40
Total	162-215	216-270	271-324