



# QUALITY OF LIFE PERCEIVED BY PEDIATRIC HEMOPHILIA PATIENTS AND THEIR PARENTS IN MEXICO

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## ABSTRACT

Quality of life as an object of study for psychology and behavioral sciences is a core component of human well-being, related to aspects such as health and the functionality of interpersonal and social interaction abilities with family, school, work and the community. The concept *quality of life* related to health was introduced to the sanitary sphere under the view that the patients' well-being is an important aspect to be considered both in treatment and in the whole health-illness process. 1) To analyse and describe the perception of quality of life levels associated to the hemophilia patient's health and their parents. 2) To show the size of the effect between the average quality of life for hemophilia patients and for patients with other chronic diseases. **Materials and methods.** 180 patients and their parents who attend hospitals in Mexico City participated in the project. A questionnaire was elaborated to obtain sociodemographic data, and the Pediatric Quality of Life questionnaire was also applied (PedsQL™ 4.0). An Analysis of Variance (ANOVA) was carried out. For the second objective, there was a complementary analysis that contrasted averages using the *Cohen's d*, which calculated the maximum and minimum size of the effect. **Results.** The participant's perception indicates that 67% of children and 58% of parents feel at high risk. The index of the size of the effect evidences that there are differences in the score averages of the hemophilia patients and the chronic disease patients. **Conclusions.** The participants perceive themselves at high risk (parents and children); plus their quality of life is below that of the patients with other chronic diseases, which is why it is necessary to implement institutional programs that can guarantee an integral treatment that changes their perception.

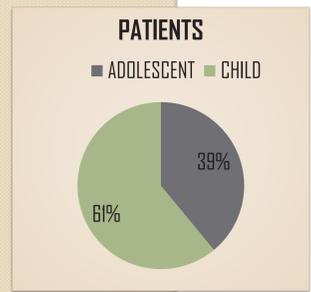
## METHOD

**Sampling Frame**  
Participants: 180 men with hemophilia A or B of different clinical degrees (mild, moderate and severe) between eight and 18 years (M = 11.91, SD = 3.37), registered in the census of FHRM A.C. residents in Mexico City and the State of Mexico, and their parents.

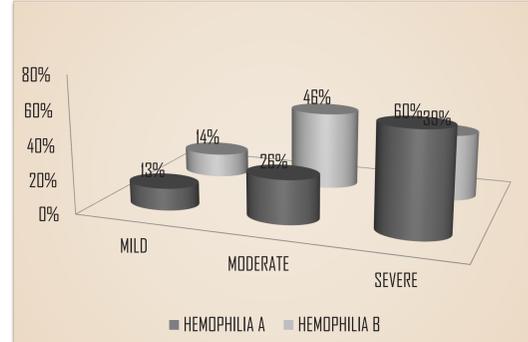
**Measures**  
A questionnaire for sociodemographic data of the PCH and their progenitors.  
Pediatric Life Quality Inventory, (PedsQL™ 4.0): 8-12 and 13 - 18); Pediatric Life Quality Inventory (PedsQL™ 4.0 - Parent 8-12 and 13-18)  
The 23 items PedsQL™ 4.0 encompass 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning ( 5 items) (Varni, 2003; Villarruel y Lucio, 2010).The research protocol was reviewed and approved by the Bioethics Committee of Multidisciplinary School for Higher Studies Iztacala UNAM

## RESULTS

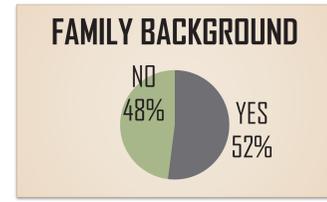
**Graphic 1.** Percentage of children (8-12 years) and teenagers (13-18 years) involved in the study and their perception of quality of life related to health



**Graphic 2.** Severity



**Graphic 3.** Family Background



**Graphic 4.** Percentage levels of quality of life related to health according to the perception of patients and their parents.



Regarding the classification of levels of quality of life according to the self-report of children, 55% are at high risk, meanwhile reported by parents the percentage increases to 60%. Meanwhile reported by parents the percentage increases to 60%. These data show that more than half of the PCH have poor quality of life and are at high risk of having serious affectations and this is perceived by children and parents (graphic 4).

**Table 2.** Pearson Correlation Coefficients between PedsQL 4, for Patients Self-Report and Parent Proxy-Report

Scale	r	p
Total Score	.40	.00
Physical Health	.42	.00
Psychosocial Health	.39	.00
Emotional Functioning	.30	.00
Social Functioning	.27	.00
School Functioning	.41	.00

There are moderate correlations in the 6 areas, being in the Physical Health where there is greater agreement. As rates are low, between what the patient and caregiver says, the Student t test was applied to verify if there were differences, finding that there were statistically significant differences in the Social Functioning (table 2 and 3).

**Table 3.** t Student Coefficients between PedsQL 4, for Patients Self-Report and Parent Proxy-Report

Scale	t	gl	P value
Total Score	1.92	179	.06
Physical Health	2.17	179	.06
Psychosocial Health	1.61	179	.11
Emotional Functioning	1.14	179	.25
Social Functioning	3.09	179	.00
School Functioning	-.54	179	.59

**Table 1.** Scale descriptives for the PEDSQLTM 4 Child Self-Report and parent Proxy Report: Hemophilic Sample and Chronic Sample

Scale	Hemophilic Sample			Chronic Sample			t score	p	d	IC 95%
	N	Mean	SD	N	Mean	SD				
<b>Child Self Report</b>										
Total Score	180	67.05	15.61	574	74.16	15.38	-5.39	.00	-0.45	-0.62 -0.28
Physical Health	180	70.22	18.18	574	79.47	17.07	-6.24	.00	-0.52	-0.69 -0.35
Psychosocial Health	180	66	16.24	573	71.32	17.13	-3.67	.00	-0.31	-0.48 -0.14
Emotional Functioning	180	67.72	18.98	573	69.32	21.36	-0.90	.45	-0.07	-0.24 0.10
Social Functioning	180	70.69	19.53	572	76.36	21.57	-3.14	.01	-0.27	-0.44 -0.10
School Functioning	180	59.58	21.98	568	68.27	19.05	-5.13	.00	-0.42	-0.59 -0.25
<b>Parent proxy-report</b>										
Total Score	180	64.54	16.39	831	73.14	16.46	-6.35	.00	-0.52	-0.68 -0.36
Physical Health	180	66.77	21.24	830	76.99	20.2	-6.09	.00	-0.49	-0.65 -0.33
Psychosocial Health	180	63.80	16.90	830	71.04	17.32	-5.10	.00	-0.42	-0.58 -0.26
Emotional Functioning	180	65.83	18.69	829	71.08	19.75	-3.26	.01	-0.27	-0.43 -0.11
Social Functioning	180	65.02	21.05	824	75.06	21.75	-5.64	.00	-0.47	-0.63 -0.31
School Functioning	180	60.55	22.55	756	65.58	20.75	-2.87	.01	-0.23	-0.39 -0.07

### Perception of quality of life related to health.

As we can see in the table 1, the highest average in the patients self-report was the area of social functioning, followed by physical area and on the reports from parents it was the physical area followed by emotional. The lowest scores were in the school area for both (See table).

### Comparison of averages between the PWH and chronic patients.

It was considered important to compare the scores obtained for this sample with the theoretical values proposed by the author (Varni, et al., 2003), in this way they were compared from the student's t mean scores of both samples, finding significant differences in favor of patients with chronic diseases, in all areas of the instrument, except emotional functioning in the reporting of children (See table ).

### Effect size of D of Cohen

To analyze the effect size was applied the D of Cohen which as one can see in Table 1. Have negative values, this indicates that average levels related quality of life (HRQDL) reported by patients with hemophilia and their parents are lower than those reported by the sample where the instrument was validated. It can also be noted that these effects are moderate. These values indicate that the average for example in the Physical Helth 69.85% exceeds the average of the PCH. Regarding the scores of parent reports show that the average total score of parents of patients with chronic disease exceed approximately 69.85% to the average of the parents of PCH (table 1).

## CONCLUSIONS

- It is important to give account to the perception of patients and their parents about the levels of quality of life in order to know first hand how they live and how they real the difficulties they face.
- The results show as perceived by patients and their caregivers most are at high risk and there are significant differences between this category and risk levels and good quality of life.
- The results indicate as perceived by patients and their caregivers most of them are at high risk and there are also significant differences between this category and risk levels and good quality of life.
- The supplementary analysis contrasts the average ( D of Cohen) showed that the values were negative which means that the scores of PCH are below the scores of chronic patients, ie have less physical, social and school functioning.
- In the same way, the scores of parents in the sample were below the scores of parents of patients with chronic diseases, significantly.
- It is necessary to design intervention programs and catch the attention of all those involved in the treatment of these patients- politicians, authorities, doctors, psychologists- about the importance of receiving adequate medical treatment and how it will provide a better quality of life to which patients are entitled.

## REFERENCES

Varni, J.W., Burwinkle, T.M., Seid, M. y Skarr, D. (2003). The PedsQL™ 4.0 as a Pediatric Population Health Measure: Feasibility, Reliability and Validity. *Ambulatory Pediatrics*, 3(6), 329-341.  
Villarruel, M. y Lucio, M. (2010). Propiedades psicométricas del Inventario de Calidad de Vida Pediátrico, Versión 4.0, en adolescentes Mexicanos. *Psicología y Salud*, 20 (1), 5 - 12.

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