The background of the slide features a complex network of blue lines and dots, resembling a molecular or digital structure. A large, glowing blue teardrop shape is positioned on the left side, containing a smaller, solid purple teardrop shape. The overall color scheme is dark blue with bright blue and purple highlights.

## CHARACTERISTICS AND SELF-REPORTED OUTCOMES OF CHILDREN AND ADULTS WITH SEVERE HEMOPHILIA A FROM COLOMBIA

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# CHARACTERISTICS AND SELF-REPORTED OUTCOMES OF CHILDREN AND ADULTS WITH SEVERE HEMOPHILIA A FROM COLOMBIA



## Introduction

Patient-reported **outcomes** are **useful** to **optimize** care of **patients** with hemophilia



Little is known of the **differences** between **adult and children reported outcomes**

## Methods



A **cross-sectional study** conducted in the context of a **Hemophilia Educational Bootcamp** was held on Nov 29<sup>th</sup> to Dec 1<sup>st</sup>, 2019 in Medellin, Colombia



The bootcamp **organized** by the **hemophilia patient organization** “*Liga Antioqueña de Hemofilia*” responsible for **contacting and inviting patients** with Hemophilia A (PwHA), **independently of their treatment**.

## Objective

*To provide a patient-centered framework to collect information on:*

**HEALTH BELIEFS**

**TREATMENT EXPERIENCE**

**HEALTH-RELATED  
QUALITY OF LIFE (HRQoL)**

**Focus group  
& interviews**

**PROBE**

(EuroQol five-dimension EQ-5D-5L)

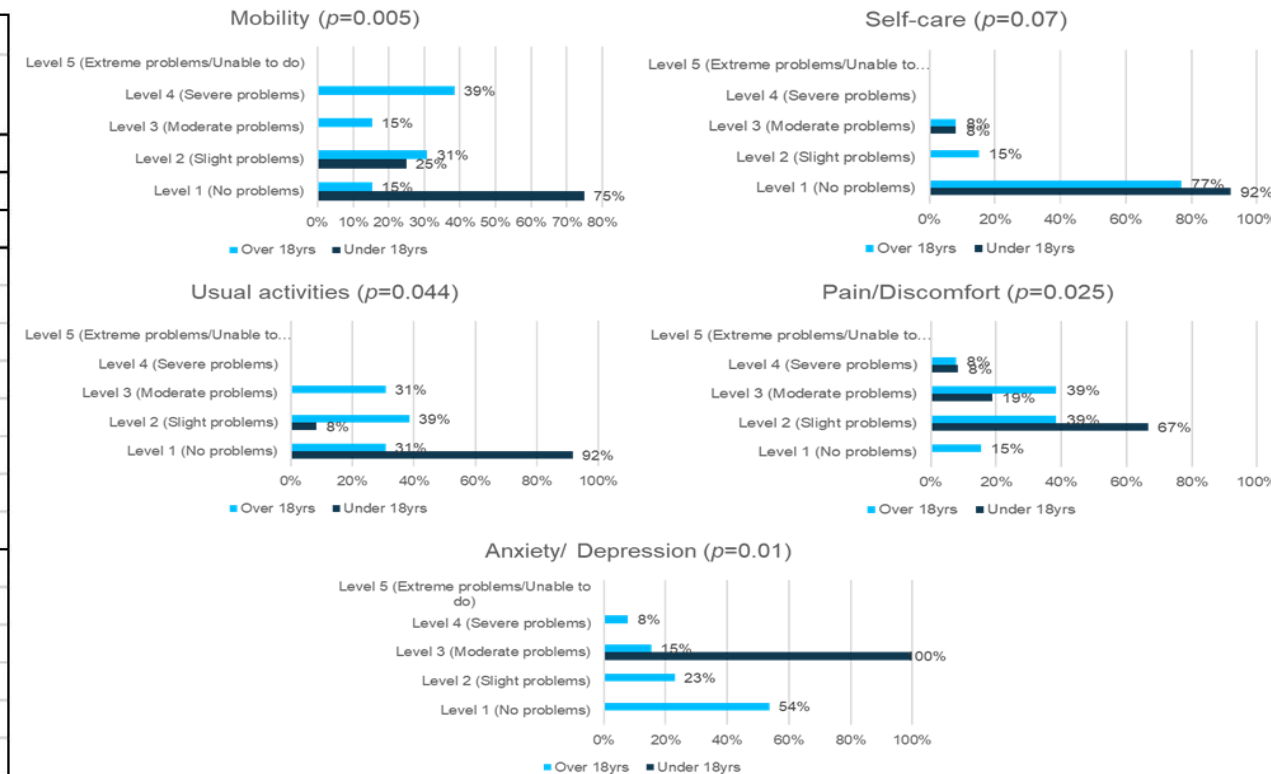
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## Results



- Overall, 24 of 25 were severe PwHA and 15 (60%) **live in** urban areas
- Thirteen patients (52%) were aged  $\geq 18$  years (mean age 32.4 years), 12 (48%) were  $\leq 17$  years-old (mean age 13.4 years)
- Self-reported overall **HRQoL**, measured by EQ-5D VAS, was lower in adults than children (mean (SD): 75.5 (15.5) vs 90.4 (8.6), respectively)

Characteristic		Under 18yrs	Over 18yrs
		n(%) N=12	n(%) N=13
Acute pain in the past 12mo		7 (58.3)	13 (100)
Chronic pain in the past 12mo		2 (16.7)	8 (61.5)
Difficulty with ADLs		2 (16.7)	10 (76.9)
Bleeds in the past 12 months	0 bleeds	5 (41.7)	2 (15.4)
	1 bleed	2 (16.7)	0
	2-3 bleeds	5 (41.7)	4 (30.8)
	4-7 bleeds	0	6 (46.2)
	8-10 bleeds	0	0
	11-15 bleeds	0	1 (7.7)
	16-30 bleeds	0	0
	More than 30 bleeds	0	0
Treatment frequency	Daily	0	0
	Every other day	0	0
	3 times per week	8 (66.6)	10 (76.9)
	2 times per week	4 (33.3)	0
	Once per week	0	2 (15.4)
	Other (Not described)	0	1 (7.7)



**Table 1.** PROBE comparison among age groups of under and over 18 years-old

**Figure 1.** EQ-5D comparison among age groups of under and over 18 years-old



# CHARACTERISTICS AND SELF-REPORTED OUTCOMES OF CHILDREN AND ADULTS WITH SEVERE HEMOPHILIA A FROM COLOMBIA



## Conclusions

- Adults with severe Hemophilia A in Colombia report worse outcomes and a greater impact on their QoL compared to children, except for the emotional disorders' domain.
- Additional strategies must be implemented to ensure an early intervention with appropriate prophylaxis treatment regimen across all ages.

