

# EXPLORING PATIENTS' PERCEPTION IN HEMOPHILIA A: KNOWLEDGE AND BURDEN OF DISEASE, A CROSS-SECTIONAL STUDY IN COLOMBIA

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**Conflict of interests:** J. Satizabal, X. Salazar, D. Benavides and R. Gamarra are employees of IPSOS Napoleon Franco S.A., and the outcomes research consultancy was commissioned by Bayer to conduct the qualitative analysis of this study. L. Torres, O. Peñuela, M.R. Forero, M. Rivera, D. Vizcaya and J.S. Franco are employees of Bayer. All authors have no further conflicts to disclose.

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## Introduction



Hemophilia A patients' perception and experience of their medical journey might have an impact on treatment adherence, quality of life (QoL) and clinical outcomes.

Collecting and Interpreting **patient-reported outcomes questionnaire (PROs)** in Hemophilia A supports understanding **patient's perspectives and optimizing their healthcare.**

In **Colombia**, this information is not available.

## 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 was organized by the **hemophilia patient organization** "*Liga Antioqueña de Hemofilia*" responsible for **contacting and inviting patients with Hemophilia A, independently of their treatment.**



**Objective** – To describe the knowledge, perception and burden of disease from the patient's perspective.



**Focus group & semi-structured interviews** were performed focused on health beliefs about hemophilia A, challenges with treatment, characteristics of an ideal treatment and interactions with healthcare system.





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## Results

A total of 25 moderate or severe hemophilia A patients (age range 10-59 years) were interviewed and participated in the focus group.

Most patients had adequate knowledge of hemophilia, recognized early signs of bleeding (hemarthrosis) and the route of care. However, **they felt overprotected by their caregivers and want to be able to make their own decisions.**

Patients reported **limitations for some activities and difficulty in relation to employment** given the time required to take care of their disease.

An overall generational effect of treatment was identified with **novel FVIII treatments, offering improved tolerability and QoL.**

Their ideal treatment should **decrease bleeding events and infusion frequency, improving QoL** by reducing their dependency to perform other activities.

The main access barrier reported was **the long period of time waiting for medicine approval and dispatch, and difficulty in receiving medical multidisciplinary accompaniment.**

Category	Variable	Description	Example
Knowledge of the disease and experience	Psycho-social sphere	Feelings	"As we have lived by the norm, with overprotection, sometimes we simply want to be free, and seeking that freedom, we exceed ourselves in certain activities, sometimes we also bleed, because we do not put the factor on time"
Living with hemophilia	ADLs	Limitations	"It costs me a lot to get off the bike, that is, I almost have to stay in the same position for a while, because since I have had my knees flexed all the time, stretching them costs me a lot due to my arthropathy"
Knowledge of the disease and experience	Treatment	Generational comparison among treatments Personal experience with the treatment	"I would have liked to be born in this era where prophylactic treatment prevents joint bleeding and its complications"  "Well, it takes 40 minutes. Imagine for one to commute an hour and a half, while they do the procedure and then, another hour and a half back"
Barriers for the treatment	Administrative	Authorizations Legal procedures	"I put a legal procedure, I put a complaint in the insurer, before the Secretary of Health, and in other health departments, specifying that, and the other places also because it is that they have sent me many therapies, and they have not wanted to approve them"
Ideal Treatment	Application	Frequency  Results	"If I decreased 1 infusion, I had more time to do my activities"  "The ideal medicine would be the one that does not make me bleed spontaneously, and that allows me to demand more of myself in my daily activities, as an almost normal person, despite the consequences, but to be able to demand more of myself, to be able to walk."

Table 1 Summary of the main insights obtained from semi-structured interviews

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## Conclusions

- Although prophylaxis has marked a generational change with overall benefit in terms of QoL, hemophilia patients have relevant unmet needs.
- **Less frequent treatment dosing, more independence in daily life activities and a holistic and convenient medical accompaniment** were the top priorities identified in this study for patients with Hemophilia A.

