A brief of the

hemophilia

and other coagulopathies

situation in Colombia 2025

2025

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A brief of the hemophilia and other coagulopathies situation in Colombia 2025

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Fondo Colombiano de Enfermedades de Alto Costo
Cuenta de Alto Costo (CAC)

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The full textbook in spanish of the situation of the hemophilia and other coagulopathies situation in Colombia 2025 is available at this link.

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Incident population with hemophilia and other coagulopathies

INFOGRAPHIC summary

Chapter at a glance

Incident population with hemophilia and other coagulopathies

February 1st, 2024 to January 31st, 2025

1

389 new cases of **coagulopathies** were reported, representing an increase of 14.08% compared to the previous period.

Of the total of incident cases, **59.38%** corresponded **to VDW,** 21.08% to hemophilia A, 5.40% to hemophilia B, 3.34% to carriers, and 10.80% to other less frequent coagulopathies.

The SIR of **hemophilia** was **2.15 cases** per million inhabitants, while that of VWD was 4.67 cases per million inhabitants.

Bogotá, D. C. and the Central region recorded the highest number of incident coagulopathy cases, as well as the highest SIR.

The median age of incident cases was 18 years (IQR: 11 – 35), and 66.32% were women.

More than 70% of hemophilia A and B cases corresponded to mild forms of the disease. Regarding VWD, 48.92% were type I and 19.91% had no classification.

The median age at diagnosis was lower in people with hemophilia A (13 years) and hemophilia B (16 years), and higher in carriers (29 years) and those with other coagulopathies (26 years). For VWD, the median was 17 years.

Among incident women with hemophilia A, 97.37% had the mild form of the disease, while in **hemophilia B this percentage was 88.89%.**

VWD: Von Willebrand disease.
SIR: Standardized incidence rate.
IQR: Interquartile range.

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Prevalent population with hemophilia and other coagulopathies

INFOGRAPHIC summary

Chapter at a glance

Prevalent population with hemophilia and other coagulopathies

February 1st, 2024 to January 31st, 2025

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During the analyzed period,

7,683 prevalent cases

of coagulopathies were reported, representing a 10.58% increase compared to the previous period.

42.35% of

people had VWD

37.04% hemophilia A, 7.81% hemophilia B, 7.98% other coagulopathies, and 4.82% were carriers.

The crude prevalence of coagulopathies was **14.58** cases per 100,000 inhabitants, showing a

9.54% increase

compared to the previous period.

57.79% of prevalent cases were men, and the median age was 29 years (IQR: 18 – 44).

The median age at diagnosis was 2 years for hemophilia A, 4 years for hemophilia B, 25 years for carriers, 18 years for VWD, and 19 years for other coagulopathies.

In hemophilia A, 96.78% of women had the mild form, while 56.63% of men were diagnosed with the severe form. In hemophilia B, 97.33% of women had the mild form, and 38.67% of men had the severe form.

Bogotá, D. C. and the Central region recorded the highest crude and standardized prevalence rates of coagulopathies.

VWD: Von Willebrand disease.
IQR: Interquartile range.

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All-cause deaths in population with hemophilia and other coagulopathies

INFOGRAPHIC summary

Chapter at a glance

All-cause deaths in population whit hemophilia and other coagulopathies

February 1st, 2024 to January 31st, 2025

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A total of **28** **all-cause deaths** were reported among individuals with coagulopathies.

Of these **64.29%** (n= 18) had hemophilia A, 14.29% (n= 4) had VWD, and 21.42% (n= 6) were distributed among hemophilia B, carriers, and **other coagulopathies.**

75% (n= 21) of the deceased **were men** and the median age was 39 years (IQR: 24 – 68).

Main causes of death were external causes (29.63%), followed by other causes (22.22%), cardiovascular disease (11.11%), and cancer (11.11%). Only one case (3.70%) was attributed directly to the coagulopathy, and in 22.22% the cause of death was not recorded.

The crude mortality was 0.38 per million for hemophilia and 0.53 per million for all coagulopathies combined, representing increases of 30.87% and 10.70% compared with 2024.

The Pacific region recorded the highest SMR.

VWD: Von Willebrand disease.
SMR: Standardized mortality rate.
IQR: Interquartile range.

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Treatment in people with hemophilia and von Willebrand disease

INFOGRAPHIC summary

Chapter at a glance

Treatment in people with hemophilia and von Willebrand disease

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February 1st, 2024 to January 31st, 2025

53.13% (n= 1,831) of prevalent hemophilia cases had negative **inhibitors titers.**

Among individuals with hemophilia without inhibitors on **prophylaxis,** 86.83% (n= 1,121) had severe disease.

6.09% (n= 66) of hemophilia A cases without inhibitors on prophylaxis received **emicizumab.**

Standard half-life recombinant factors specific to the deficiency were most frequently indicated among people without inhibitors on prophylaxis (55.77% in hemophilia A; 50.48% in hemophilia B).

26.59% of hemophilia A cases without inhibitors on prophylaxis received extended half-life recombinant factor VIII.

Among high-titer inhibitor cases (n= 61), 93.44% (n= 57) were on prophylaxis; of these, 70.18% (n= 40) received emicizumab.

Among the 535 individuals without inhibitors on-demand treatment, 36.26% (n= 194) used clotting factor concentrates.

Among individuals with inhibitors on-demand treatment, 33.33% (n= 6) used clotting factor concentrates.

All cases on ITI (n= 6) had inhibitor monitoring during the period.

75.95% (n= 2,472) of individuals with VWD were on-demand treatment and 4.09% (n= 133) **were on prophylaxis.**

ITI: Immune tolerance induction.
VWD: Von Willebrand disease.

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Multidisciplinary management of people with hemophilia

INFOGRAPHIC summary

Chapter at a glance

Multidisciplinary management of people with hemophilia

February 1st, 2024 to January 31st, 2025

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In **86.74%** of hemophilia cases, the hematologist was the specialist **leading the medical management.**

Hematology had the highest service **coverage followed** by social work and psychology.

The average number of **hematology** consultations was 8.37 (SD ± 3.84) in individuals with severe hemophilia and 4.43 (SD ± 3.93) in **moderate hemophilia.**

61.98% of individuals with hemophilia were assessed by a multidisciplinary team.

12.60% of individuals did not access any services from the multidisciplinary team (hematology, orthopedics, dentistry, psychology and social work).

Among those not receiving multidisciplinary care, 73.50% had abandoned treatment.

61.35% of individuals on-demand treatment and 77.67% on prophylaxis were seen at least once by the **five disciplines.**

SD: Standard deviation.

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Bleeding events in people with hemophilia

INFOGRAPHIC summary

Chapter at a glance

Bleeding events in people with hemophilia

February 1st, 2024 to January 31st, 2025

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29.69%

(n= 1,023) of individuals with hemophilia had at least one **bleeding episode.**

Of these, **67.35%**

(n= 689) were on prophylaxis and 31.67% (n= 324) on-demand treatment.

40.82%

(n= 527) of hemophilia cases without inhibitors on prophylaxis had at least one **bleeding episode.**

Hemarthrosis

71.71% (n= 2,471) of individuals with hemophilia had no hemarthrosis.

Traumatic hemarthrosis was the most frequent (74.11%), followed by spontaneous (14.64%) and mixed (11.25%).

76.43% (n= 428) of the people with hemarthrosis had severe hemophilia.

27.91% (n= 470) of individuals on prophylaxis and 6.54% (n= 87) on-demand treatment had hemarthrosis.

Extra-articular bleeding

22.43% (n= 704) of people with hemophilia had extra-articular bleeding.

54.55% (n= 384) of the people with extra-articular bleeding had severe hemophilia.

The median frequency of extra-articular bleeding was 1 annual episode (IQR: 0 – 1) of traumatic origin and 0 (IQR: 0 – 1) of spontaneous origin.

0.29% (n= 10) of individuals with hemophilia had central nervous system bleeding.

24.63%

(n= 318) of hemophilia cases without inhibitors on prophylaxis had **extra-articular bleeding.**

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Complications in people with hemophilia

INFOGRAPHIC summary

Chapter at a glance

Complications in people with hemophilia

February 1st, 2024 to January 31st, 2025

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Inhibitors

Inhibitors were **measured** in **58.38% (n= 2,012)** of individuals with hemophilia.

Among individuals with **mild and moderate hemophilia, 1.07% (n= 20)** had inhibitors; among severe hemophilia cases, 10.12% (n= 161) tested positive.

Chronic hemophilic arthropathy

37.00% (n= 1,275) of individuals with hemophilia had chronic hemophilic arthropathy.

66.00% (n= 1,050) of severe hemophilia cases had arthropathy.

67.87% (n= 1,143) of cases on prophylaxis and 6.99% (n= 93) on-demand treatment had arthropathy.

Other complications

1.92% (n= 66) of people with hemophilia had a history of HCV infection.

Pseudotumors occurred in 0.41% (n= 14) of hemophilia cases, 0.23% (n= 8) had fractures, and one case of hemophilia B had anaphylaxis.

1.10% (n= 38) of people with hemophilia reported disability; of those, 68.42% (n= 26) had hemophilia A and 84.21% (n= 32) **had severe disease.**

HCV: Hepatitis C virus.

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Risk management indicators in people with hemophilia

INFOGRAPHIC summary

Chapter at a glance

Risk management indicators in people with hemophilia

February 1st, 2024 to January 31st, 2025

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Bleeding rates among individuals on

prophylaxis

decreased in 2025, regardless of inhibitor status.

67.89%

of individuals with

hemophilia

on prophylaxis had chronic hemophilic arthropathy.

99.45%

of individuals under 18 with severe hemophilia without inhibitors and 93.13% of adults with severe hemophilia received

prophylaxis.

62.50% of people with hemophilia were managed by a multidisciplinary team, 0.95% higher than in 2024.

The average number of hematology and dentistry appointments in individuals with severe hemophilia was 8.45 and 2.93, respectively.

17.45% of people with hemophilia self-infused independently at home, while 39.98% did so with nursing assistance.

3.36% of individuals with hemophilia A and 1.44% with hemophilia B had high-titer inhibitors.

Loss to follow-up

met the target (< 10%),

but was 9.83%.

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Characterization of women with hemophilia

INFOGRAPHIC summary

Chapter at a glance

Characterization of women with hemophilia

February 1st, 2024 to January 31st, 2025

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A total of **479 women** with hemophilia were reported, of those 84.34% with hemophilia A.

The median age was **34 years** (IQR: 24 – 47), 64.09% were affiliated to the third-payer insurance, and 27.56% lived in the Central region.

The median age at **diagnosis** was lower in women with hemophilia B (19 years) than in those with hemophilia A (25 years).

3.13% (n= 15) of women with hemophilia had moderate or severe hemophilia.

1.04% (n= 5) of women with hemophilia had hemarthrosis and 11.27% (n= 54) had extra-articular bleeding.

0.42% (n= 2) of women with hemophilia had inhibitors.

0.84% (n= 4) of the women with hemophilia had chronic arthropathy.

The median number of hematology consultations was 2 for women with mild or moderate hemophilia (IQR: 0 – 3) and 6 for those with severe hemophilia (IQR: 0 – 12).

The proportion of women manged by the multidisciplinary team was 47.39% (n= 227).

IQR: Interquartile range.

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