A brief of the HEMOPHILIA and other coagulopathies situation in Colombia

2024

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Cuenta de Alto Costo

Fondo Colombiano de
Enfermedades de Alto Costo

A brief of the hemophilia and other coagulopathies situation in Colombia 2024

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

Annual periodicity

Bogotá, C. D., Colombia, February 2025

Suggested citation: Cuenta de Alto Costo (CAC), Fondo Colombiano de Enfermedades de Alto Costo. A brief of the hemophilia and other coagulopathies situation in Colombia 2024; Bogotá, D. C. 2025.

The full textbook in spanish of the situation of the hemophilia and other coagulopathies situation in Colombia 2024 is available at this link.

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1.

Incident population with hemophilia and other coagulopathies

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1 INFOGRAPHIC SUMMARY

| Chapter at a glance |

Incident population with hemophilia and other coagulopathies

Period: February 1st, 2023 to January 31st, 2024.

There were **341 new cases with any coagulopathy;** 61.58% had VWD, 21.41% hemophilia, 12.02% rare coagulopathies and 4.99% were carriers.

The crude incidence rate of VWD was 4.02 new cases per million. For hemophilia A and B was 1.09 and 0.31, respectively.

65.69% of new cases of coagulopathies were women, and of those, 74.11% had VWD and 8.93% had hemophilia. The median age was 21 years old.

The majority of the hemophilia A and B new cases had mild disease, and 50.00% of VWD cases were type I.

The median age at diagnosis was 20, 16, 21, and 26 years for patients with hemophilia A, B, VWD, and rare coagulopathies, respectively.

Among men, 26.83% of hemophilia A and 8.33% of hemophilia B total cases had the severe form of the disease.

The Central region and the third - payer insurance had the highest standardized incidence rate of coagulopathies.

59.65% of new cases of hemophilia A, 75.00% de hemophilia B and 23.33% of VWD had a family history of the disease.

VWD: von Willebrand disease.

2.

Prevalent population with hemophilia and other coagulopathies

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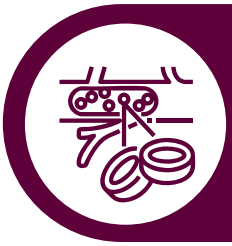
2 INFOGRAPHIC SUMMARY

| Chapter at a glance |

Prevalent population with hemophilia and other coagulopathies

Period: February 1st, 2023 to January 31st, 2024.



In 2024, 6,948 people with any coagulopathy were reported to the national registry, this means an increase of 17.90% compared to 2023.

39.91% of people had VWD, 38.82% hemophilia A, 8.23% hemophilia B, 8.03% other less frequent coagulopathies and 5.01% were carriers.

Out of the total coagulopathies prevalent cases, 53.77% were men and the median age was 29 years old.

49.46% of hemophilia A and 34.44% of hemophilia B cases had severe disease, and 51.03% of VWD cases were type I.

The median age at diagnosis was 2, 3, 17, and 18 years for patients with hemophilia A, B, VWD, and rare coagulopathies, respectively.

65.15% of hemophilia A, 68.18% of hemophilia B, and 31.05% of VWD prevalent cases had a family history of the disease.

The crude prevalence rate of VWD was 5.31 cases per 100,000 people, and the prevalence of hemophilia A and B was 5.17 and 1.10, respectively.

For the first time since the registry began, the crude prevalence of VWD was higher than hemophilia A.

Bogotá, D. C.

and the third - payer insurance

had the highest standardized prevalence rate of coagulopathies.

VWD: von Willebrand disease.

3.

All-cause deaths in population with hemophilia and other coagulopathies

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3 INFOGRAPHIC SUMMARY

| Chapter at a glance |

All-cause deaths in population whit hemophilia and other coagulopathies

Period: February 1st, 2023 to January 31st, 2024.

A total of 25 all - cause deaths were reported

in the population with coagulopathies, representing an increase of 4.17% compared to 2023.

56.00% of the deaths had

hemophilia A and 32.00% had a rare coagulopathy.

Of the total deaths in individuals with coagulopathies, 84.00% were men, and the median age was 53 years old.

The majority of people deaths with coagulopathies were affiliated to the third - payer insurance and resided in the Central region.

50.00% of the deaths with hemophilia A had severe disease.

1 case of mild hemophilia A and 1 case of factor XIII deficiency died due to complications associated with the deficiency.

The crude mortality rate from all causes in the population with coagulopathies was 0.48 cases per million.

Bogotá, D. C.

and the third - payer insurance

had the highest standardized mortality rate of coagulopathies.

4.

Treatment in people with hemophilia and von Willebrand disease

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Treatment in people with hemophilia and von Willebrand disease

Period: February 1st, 2023 to January 31st, 2024.

59.31% (n= 1,939)
of the prevalent hemophilia cases were negative for inhibitors.

Among patients with hemophilia without inhibitors on **prophylaxis,**

85.57% (n= 1,115) had severe disease.

- 3.89% (n= 42) of the cases with hemophilia A without inhibitors on prophylaxis received emicizumab in monotherapy or in combination.
- Standard half-life recombinant factors, specific for each type of deficiency, were the most frequently indicated as monotherapy among people without inhibitors on prophylaxis (62.87% in hemophilia A and 50.67% in hemophilia B).
- 17.78% of the cases with hemophilia A without inhibitors on prophylaxis received extended half-life recombinant factor VIII as monotherapy.

- Of the 633 patients with hemophilia without inhibitors on - demand treatment, 40.44% (n= 256) were treated with clotting factor concentrates.
- Of the total cases with high - titer inhibitors (n= 68), 88.24% (n= 60) were on prophylaxis and, of those, 55.00% (n= 33) received emicizumab.
- Among patients with hemophilia and inhibitors on - demand treatment, 43.33% (n= 13) were treated with clotting factor concentrates.
- All cases on ITI (n= 8) had inhibitor follow - up.

Among patients with VWD, **80.92% were on - demand**

treatment (n= 2,244), and 5.28% (n= 120) were on prophylaxis.

ITI: immune tolerance induction.
VWD: von Willebrand disease.

5.

Multidisciplinary management of people with hemophilia

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5 INFOGRAPHIC SUMMARY

| Chapter at a glance |

Multidisciplinary management of people with hemophilia

Period: February 1st, 2023 to January 31st, 2024.

In **88.10%** of hemophilia cases, the hematologist was the specialist leading the medical management.

Hematology

was the specialty involved in the care of most patients, followed by social work and psychology.

The average number of consultations by the hematologist was 2.32 in patients with mild hemophilia and 8.63 in patients with severe disease.

62.31% of patients were evaluated by the multidisciplinary team.

10.98% of the patients were not managed by hematology, orthopedics, dentistry, psychology or social work.

89.97% patients that were not managed by the multidisciplinary team had refused care.

71.43% of the cases on prophylaxis and 66.56% on - demand treatment had at least one encounter with the 5 disciplines.

87.97%
of the cases with
chronic hemophilic arthropathy
had at least one orthopedics consultation during the period.

6.

Bleeding events in people with hemophilia

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Bleeding events in people with hemophilia

Period: February 1st, 2023 to January 31st, 2024.

31.36% (n= 1,025)
of cases with hemophilia had a bleeding event (articular or extra - articular) during the period.

Of the cases with bleeding episodes, 69.37% (n= 711) were on prophylaxis and 29.95% (n= 307) were on - demand treatment.

44.44% (n= 579) of patients with hemophilia without inhibitors on prophylaxis had some bleeding event.

Hemarthrosis

72.50% (n= 2,370)
of individuals with hemophilia had no hemarthrosis during the period.

Traumatic hemarthrosis was the most frequent (66.25%), followed by mixed (18.29%) and spontaneous (15.45%).

75.31% (n= 424) of the people with hemarthrosis had severe hemophilia.

28.88% (n= 473) of the cases on prophylaxis and 6.66% (n= 86) on - demand treatment had hemarthrosis.

Of the total cases with hemophilia with high - titer inhibitors, 35.29% (n= 24) had at least one episode of hemarthrosis during the period.

Extra - articular bleeding

22.27% (n= 728) of individuals with hemophilia experienced some type of extra - articular bleeding during the period.

56.04% (n= 408) of the people with extra - articular bleeding had severe form of the disease.

The median frequency of extra - articular bleeding was 1 annual episode (IQR: 1 – 2) of traumatic origin and 0 (IQR: 0 – 1) of spontaneous origin.

0.46% (n= 15) of individuals with hemophilia had central nervous system bleeding.

28.78% (n= 375) of the people with hemophilia without inhibitors
on prophylaxis had some extra - articular bleeding.

7.

Complications in people with hemophilia

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Complications in people with hemophilia

Period: February 1st, 2023 to January 31st, 2024.

Inhibitors

Among all people with hemophilia, inhibitors were measured in

65.09% (n= 2,128),

2.08% (n= 68) had high - titer inhibitors and 3.70% (n= 121) had low - titer inhibitors.

Among individuals with mild and moderate hemophilia, 1.67% (n= 29) tested positive for inhibitors, while 10.45% (n= 160) of those with severe hemophilia had inhibitors.

Chronic hemophilic arthropathy

37.14% (n= 1,214)

of individuals with hemophilia had chronic hemophilic arthropathy.

65.06% (n= 996) of people with severe hemophilia had arthropathy.

66.54% (n= 1,090) of cases on prophylaxis and 7.51% (n= 97) on - demand treatment had arthropathy.

Other complications

2.72% (n= 89) of people with hemophilia reported a history of HCV infection.

Pseudotumors occurred in 0.28% (n= 9) of hemophilia cases, 0.06% (n= 2) had a fracture, and 1 case of hemophilia B suffered anaphylaxis.

1.44% (n= 47) of people with hemophilia

reported some disability; of those, 70.21% (n= 33) had hemophilia A and 88.85% (n= 38) had the severe form of the disease.

HCV: hepatitis C virus.

8.

Risk management indicators

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Risk management indicators

Period: February 1st, 2023 to January 31st, 2024.

Compared to 2023, among people with

high - titer inhibitors on prophylaxis,

joint bleeding rates from any mechanism increased by 25.56%, while spontaneous bleeding rates increased by 12.50%.

Among people without inhibitors on prophylaxis, overall bleeding rates increased by

7.55% for all types

and 13.79% for spontaneous bleeding, compared to 2023.

66.54% of people with hemophilia on prophylaxis had chronic hemophilic arthropathy.

97.17% of individuals under 18 years of age with severe hemophilia without inhibitors and 91.19% of adults with severe hemophilia were on prophylactic treatment.

61.91% of people with hemophilia were managed by an interdisciplinary team.

The average number of hematology and dentistry appointments was 8.61 and 3.13, respectively, for people with severe hemophilia.

17.16% of people self-infused independently at home, while 37.17% received nursing assistance.

Loss to follow - up met the target (< 10%), but compared to 2023, it doubled, reaching 9.85%.

3.48% of people with hemophilia A

and 1.96% of people with hemophilia B had high - titer inhibitors during the period.

9.

Characterization of **women with hemophilia**

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Characterization of women with hemophilia

Period: February 1st, 2023 to January 31st, 2024.

In 2024, 417 women with hemophilia were reported

to the national registry, of those 84.41% had hemophilia A.

The median age was

34 years old

(IQR: 24 - 46).

The majority of women were enrolled on the third - payer insurance and lived in the Central region.

The median age at diagnosis of women with hemophilia B (17 years old) was lower than women with hemophilia A (25 years old).

3.12% (n= 13) of women with hemophilia had the moderate or severe form of disease.

1.20% (n= 5) of women with hemophilia had hemarthrosis and 6.71% (n= 28) had some extra - articular bleeding event.

1.68% (n= 7) of women with hemophilia had inhibitors.

Of the all women, 0.72% (n= 3) had chronic hemophilic arthropathy.

The median number of consultations by hematology was 2 for women with mild or moderate hemophilia (IQR: 0 – 3) and 8 for those with severe hemophilia (IQR: 1 – 13).

The proportion of

women managed

by the multidisciplinary team was 48.20% (n= 201).

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