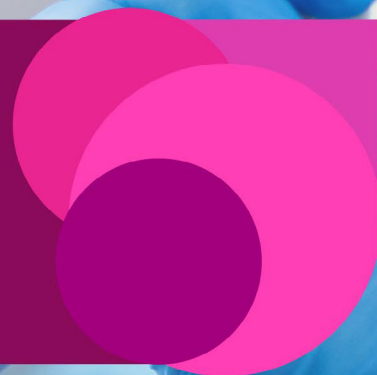


A BRIEF OF
HEMOPHILIA
SITUATION IN COLOMBIA 2021



A BRIEF OF HEMOPHILIA SITUATION IN COLOMBIA 2021.

Situation of hemophilia in Colombia 2021

CUENTA DE ALTO COSTO

Fondo Colombiano de Enfermedades de Alto Costo



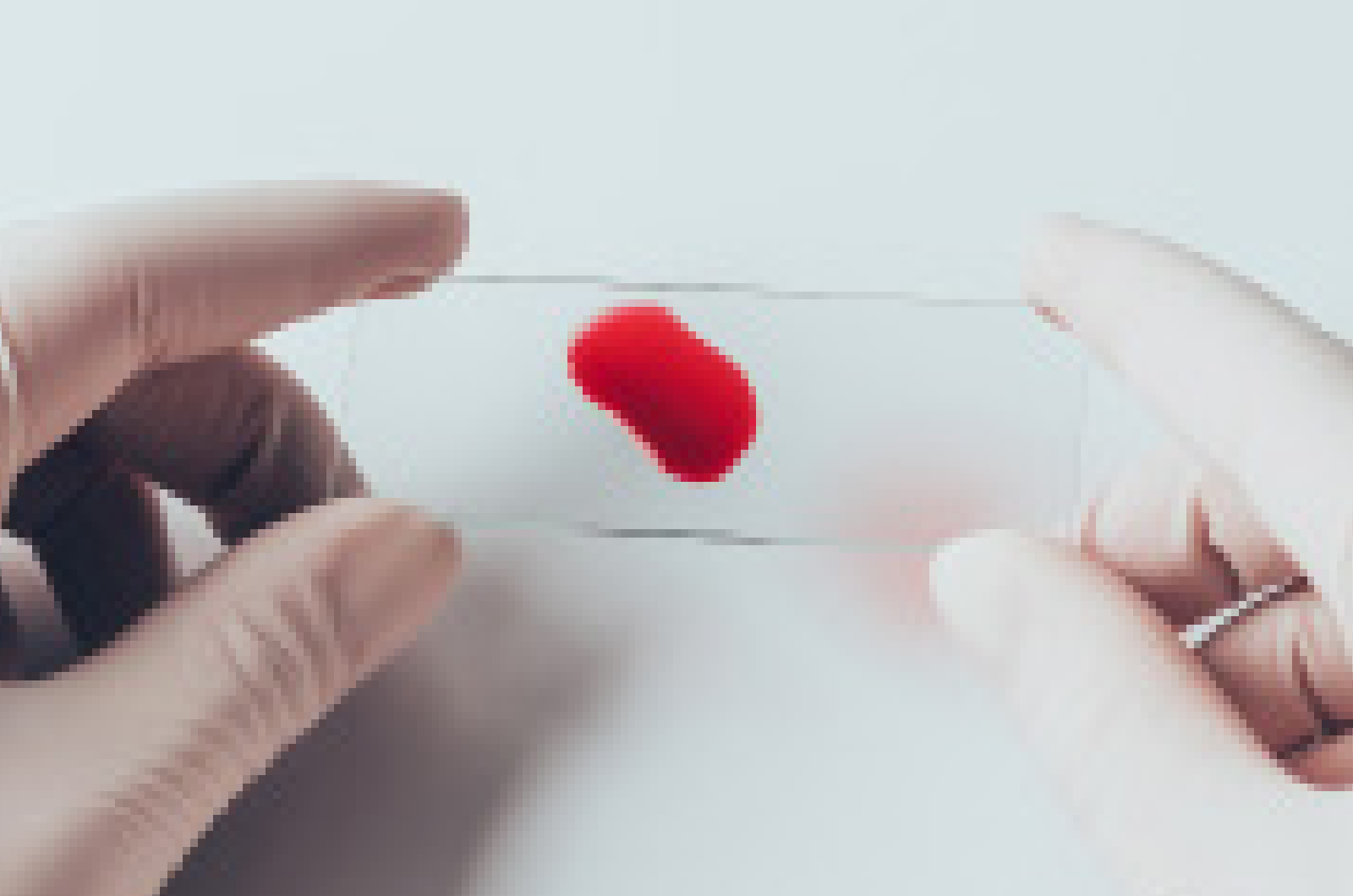
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Fondo Colombiano de Enfermedades de Alto Costo

Annual periodicity
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1. CHARACTERIZATION OF HEMOPHILIA AND OTHER COAGULOPATHIES NEW CASES



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CHAPTER 1 AT A GLANCE

Chapter 1: Characterization of hemophilia and other coagulopathies new cases

Period: February 1, 2020 to January 31, 2021.



During the period, 135 new cases with coagulopathies, 49 with hemophilia, and 15 new carriers were reported.



Compared to 2020, there was a decrease of 3.85% in incident cases of coagulopathies and 14.29% for hemophilia.



The median age at diagnosis for hemophilia A is 6 years (IQR: 1.00 - 28.00), while for hemophilia B is 2 years (IQR: 1.00 - 9.00).



48.98% of the new cases were between 0 and 4 years old. In the case of females, the majority were between 25 to 29 years old.



32.50% of the new cases of hemophilia A cases lived in the central region, followed by the caribbean region (25.00%).



55.00% of the new cases of hemophilia A were affiliated to the third payer insurance.



52.50% of the new cases with hemophilia A had mild disease, while the 44.44% of hemophilia B had a severe form.



Most of the new cases with hemophilia and carriers had a family history of coagulopathy.

IQR: Interquartile range.



2. CHARACTERIZATION OF HEMOPHILIA AND OTHER COAGULOPATHIES PREVALENT CASES



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CHAPTER 2 AT A GLANCE

Chapter 2. Characterization of hemophilia and other coagulopathies prevalent cases

Period: February 1, 2020 to January 31, 2021.



By 2021, 4,863 people with any coagulopathy were reported to the national registry, which corresponds to an increase of 5.58% over the previous year.



The most frequent coagulopathy was hemophilia A, with 67.82% of prevalent cases, followed by hemophilia B (14.57%).



The median age of the prevalent cases was 25 years (IQR: 14.00 - 40.00), while female carriers had a median age of 39.00 years (IQR: 29.00 - 49.00).



56.19% of males with hemophilia A were between 5 to 29 years old (n=1130). In the case of females, the most frequent age group was 10 to 14 years old.



Bogota C.D. and Antioquia registered the highest proportion of cases with hemophilia.



The highest proportion of persons with coagulopathies were affiliated to the third payer insurance (68,11%).



55.83% of people with hemophilia A and 35.78% of people with hemophilia B were classified as severe.



The most frequent presentation was mild disease in women. For men, the severe form was the most frequent.

IQR: Interquartile range.



3. MORBIDITY AND MORTALITY IN PEOPLE WITH HEMOPHILIA AND OTHER COAGULOPATHIES



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CHAPTER 3 AT A GLANCE

Chapter 3. Morbidity and mortality in people with hemophilia and other coagulopathies

Period: February 1, 2020 to January 31, 2021.



The crude incidence of coagulopathies was 2,68, for hemophilia A and B was 0.79 and 0.18 new cases per 1,000,000 people, respectively.



There was a decrease in the crude incidence of hemophilia A, while for hemophilia B there was a slight increase compared with 2020.



There was a lower incidence for females compared with males. The latter presented severe forms of the disease in the total new cases.



Antioquia and Bogotá, C.D had the highest age-standardized incidence rate of coagulopathies with 5.42 and 4.10 new cases per 1,000,000 people, respectively.



The standardized incidence rate of hemophilia was higher in people affiliated to the third payer than those with the state insurance. 1.26 vs. 0.91 new cases per 1,000,000 affiliates, respectively.



The crude prevalence of coagulopathies was 9.65, and for hemophilia A and B were 4.29 and 0.92 cases per 100,000 people, respectively.



Bogotá, C.D. and the central region had the highest age-standardized prevalence of hemophilia with 8.16 and 5.60 cases per 100,000 people.



The crude all-cause mortality rate in people with coagulopathies was 0.48 and for hemophilia was 0.34 deaths per 1,000,000 people.



4. TREATMENT IN PEOPLE WITH HEMOPHILIA



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CHAPTER 4 AT A GLANCE

Chapter 4. Treatment in people with hemophilia

Period: February 1, 2020 to January 31, 2021.



71.15% (n=1,199) of the people with hemophilia and inhibitor measurement were under prophylaxis at the cutoff date.



72.63% (n=146) of the people with hemophilia on prophylaxis, had high inhibitor titers during the period.



85.28% (n=898) of the people with hemophilia on prophylaxis and no inhibitors had severe disease.



In people with hemophilia and no inhibitors, standard half-life recombinant factor VIII and IX were the most frequently reported medications as part of prophylaxis. In those with inhibitors, Emicizumab was the most prescribed medication for prophylaxis during the period.



54.76% of the people with hemophilia without inhibitors receiving episodic treatment had mild disease. 83.33% of the people with high inhibitor titers had a severe disease.



Most people with hemophilia treated with induction to immune tolerance received Plasma factor VIII, followed by bypass agents.



5. INTERDISCIPLINARY MANAGEMENT OF PEOPLE WITH HEMOPHILIA



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CHAPTER 5 AT A GLANCE

Chapter 5. Interdisciplinary management of people with hemophilia

Period: February 1, 2020 to January 31, 2021.



In 95.60% (n=2,501) of people with hemophilia, the healthcare team was led by the hematologist.



The main medical specialties reported were hematology and orthopedics with 2,489 and 1,921 patients with at least one consultation during the period, respectively.



The average number clinical appointments with hematology went from 2.47 in mild hemophilia and 7.85 in severe forms.



The average number clinical appointments with dentistry went from 1.32 in mild hemophilia and 2.31 in severe forms.



81.15% (n=2,123) and 73.54% (n=1,924) of the people with hemophilia were evaluated at some time by nursing and physiotherapy professionals, respectively.



The average number clinical appointments with psychology went from 1.65 in mild hemophilia and 3.54 in severe forms.



The average number clinical appointments with social work went from 1.83 in mild hemophilia and 2.97 in severe disease.



6. BLEEDING EVENTS IN PEOPLE WITH HEMOPHILIA



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Situación de la hemofilia y otras coagulopatías en Colombia 2021

CHAPTER 6 AT A GLANCE

Chapter 6. Bleeding events in people with hemophilia

Period: February 1, 2020 to January 31, 2021.

Hemarthrosis



During the period, 539 cases with hemarthrosis were reported, 85.34% (n=460) had hemophilia A.



The median age of people with hemarthrosis was 24 years (IQR: 13.00 - 35.00).



The majority of cases with hemarthrosis were treated with some type of prophylaxis (64.38%).



5.19% of people with hemarthrosis had high inhibitor titers.



In 59.74% of the cases of hemarthrosis were traumatic.

Extra-articular bleeding



24.58% of people with hemophilia had some type of extra-articular bleeding during the period.



62.48% of people with hemophilia and extra-articular bleeding had severe disease.



The annual extra-articular bleeding rate from traumatic origin was 1.16 bleeds/person, while annual extra-articular bleeding rate from spontaneous origin was 0.64 bleeds/person.



7. COMPLICATIONS IN PEOPLE WITH HEMOPHILIA



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CHAPTER 7 AT A GLANCE

Chapter 7. Complications in people with hemophilia

Period: February 1, 2020 to January 31, 2021.

Inhibitors



Inhibitors incidence for hemophilia A during the period was 7.71% (n=166), while in hemophilia B was 1.51% (n=7).



A direct relationship was observed between the frequency of high-response inhibitors and severity.

Chronic hemophilic arthropathy



Presence of hemophilic chronic arthropathy was reported in 37.50% (n=981) of people with hemophilia. From those, 83.79% (n=822) had hemophilia A.



81.96% of the people with chronic hemophilic arthropathy had a severe disease.

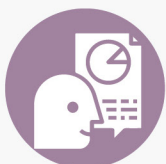
Other complications



3.90% of the people with hemophilia had a history of hepatitis C virus infection.



Complications such as pseudotumors, fractures or anaphylaxis were reported in less than 1%.



1.95% (n=51) of people with hemophilia reported some type of disability. The most frequent type was related to limb mobility (54.90%).



8. RISK MANAGEMENT INDICATORS



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CHAPTER 8 AT A GLANCE

Chapter 8. Risk management indicators

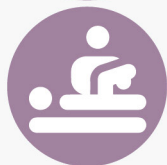
Period: February 1, 2020 to January 31, 2021.



General bleeding rates in people with hemophilia treated with prophylaxis with and without inhibitors decreased with compared to 2020.



59.14% of the people with hemophilia treated with prophylaxis during the period had chronic arthropathy.



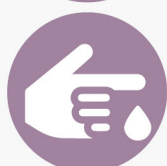
96.51% of the people under 18 years of age with severe hemophilia and no inhibitors were treated with prophylaxis during the period. 90.33% of the people over 18 years with severe hemophilia were treated with prophylaxis.



57.53% received care by interdisciplinary team, with an increasing trend since 2019.



The annual average of clinical appointments with hematology was 7.81 in people with severe hemophilia.



14.11% of the people with hemophilia were infused independently, while 41.86% were infused with nursing assistance at home.



39.71% of the people with mild to moderate hemophilia treated with prophylaxis, were adherent to an integral healthcare, whereas, among those with a severe disease, adherence was 29.17%.



9.VON WILLEBRAND DISEASE



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CHAPTER 9 AT A GLANCE

Chapter 9. Von Willebrand Disease

Period: February 1, 2020 to January 31, 2021.



During the period, 1,678 people were identified with VWD, among them, 60 were incident cases.



There was an 9.09% decrease in incident cases of VWD compared to the 2020 period. In the case of prevalent cases, there was an increase of 8.68%.



The Central region had the highest proportion of incident cases with 33.33%.



The majority of incident cases were diagnosed within the reproductive ages, with a median of 22.50 years (RIC: 14.50 - 36.00).



Among incident cases, 76.67% had measurement of VWF:Ag, VWF:RCo and factor VIII coagulant activity.



VWD type 1 was the most frequent (50.24%) among the prevalent cases.



The most frequent pharmacological combination in cases of VWD under treatment was plasmatic FVIII + antifibrinolytic.

VWD: Von Willebrand Disease.

VWF:Ag: VWF antigen.

VWF:RCo: Ristocetin cofactor assay.



10. EFFECT OF THE COVID-19 PUBLIC HEALTH EMERGENCY ON THE MANAGEMENT OF PEOPLE WITH HEMOPHILIA



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CHAPTER 10 AT A GLANCE

Chapter 10. Effect of the COVID-19 public health emergency on the management of people with hemophilia

Period: February 1, 2020 to January 31, 2021.



During the period, a notable decrease of incident case reporting was observed from March to August compared to 2020 and 2019, which is consistent with the initial period of the declaration of the health emergency in Colombia.



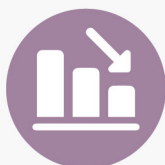
There was an increase in the proportion of people with hemophilia with home or self-administered treatment, from 45.90% in 2020 to 52.92% in 2021.



There was an increase in the total interdisciplinary team management in 2021 compared to 2020.



At the regional level, there was a widespread reduction in the rates of general and articular bleeding in people with hemophilia treated with prophylaxis.



No significant differences with the 2020 period were observed in the measurement of inhibitor titers in people with hemophilia. However, there was a decrease in the number of tests taken between March and June, which coincides with the first months after the declaration of the COVID-19 public health emergency.