Results of a national registry for hemophilia A and B: Situation of the disease in Colombia

INTRODUCTION AND OBJECTIVE

To understand the situation of hemophilia by determining the characteristics of the disease which allows presenting those responsible for the care of these patients the results of their actions and expand the landscape of the disease at national and international level. The objective of this study was to analyze demographic and clinical variables in the national registry of information reported to the High Cost Account.

MATERIALS AND METHODS

Retrospective observational study. All reported patients diagnosed with hemophilia A or B were included, univariate and bivariate analysis were carried out of the 64 variables defined in the information registry.

RESULTS

1,832 patients were reported with hemophilia. The prevalence in men and women was 3.8 *100.000, being 6.28*100.000 for men with hemophilia A and 1.24 for men with hemophilia B; the Adjusted Prevalence for men was 7.55*100.000. The age group with the highest concentration of hemophiliacs is between 10 to 19 years old (26.4%); 56.5% of patients with hemophilia A are severe versus 41.7 % of patients with hemophilia B. 59.7 % of hemophiliacs are in prophylaxis, 36.6 % in on demand and 3.7 % being in prophylaxis required additional doses of factor demand. 20 % of hemophiliacs with inhibitors which 29 % are high responders, 34 % of patients have chronic hemophilic arthropathy, 4.9 % hepatitis C, 0.6 % hepatitis B and 0.7 % HIV infection.

CONCLUSIONS

Data from the first record in Colombia at a national level allows sizing disease 's current state for both governmental decision makers and those who take action for the patient. These results are comparable with estimates for the country made by other authors and they are the base line founded on real data for health care planning and for the implementation of actions for approaching and care of this population in the health care system of Colombia

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Illustration 1: Distribution of cases according to severity of haemophilia

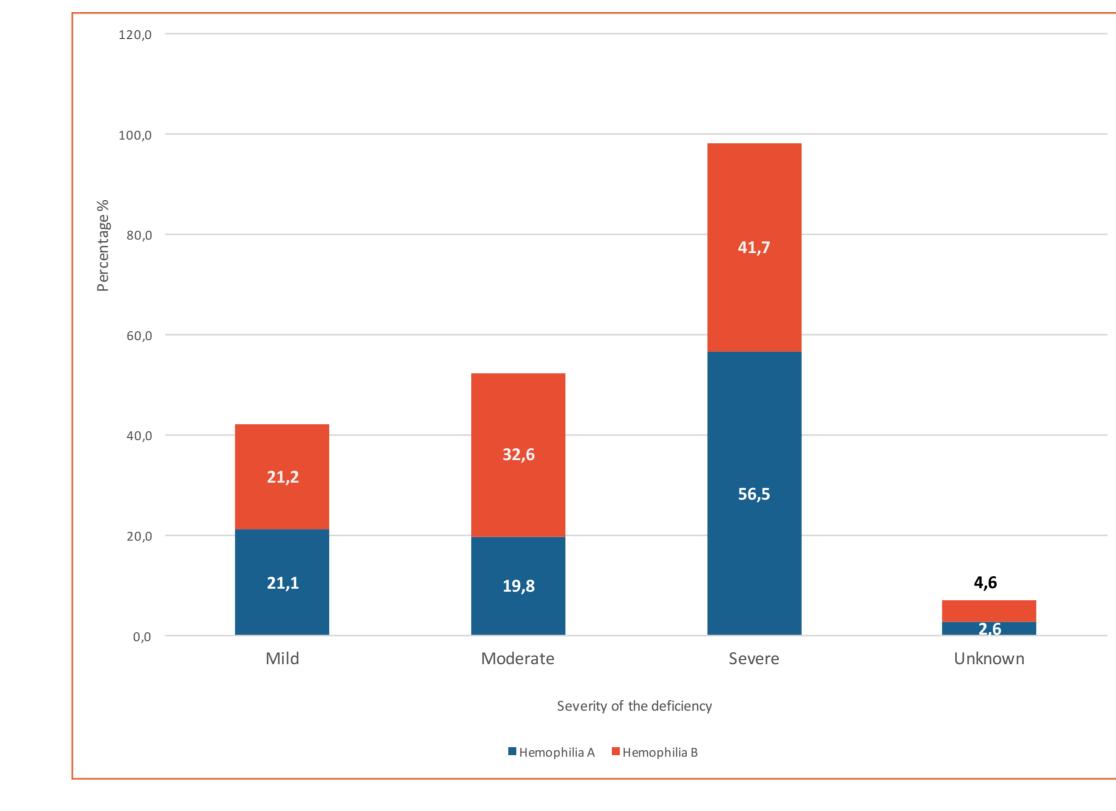


Table 1 : Prevalence of hemophilia in Colombia per 100,000 people

Pathology		Adjusted rate	IC (95%)	
Hemophilia A	Women	0,12	0,05	0,19
	Man	6,13	5,82	6,47
	Total	3,12	2,94	3,29
Hemophilia B	Women	0,05	0	0,09
	Man	1,22	1,08	1,39
	Total	0,63	0,54	0,74

: Resolution 0123 CAC: Database 2015. Information date: January 2015. DANE Population database: 31 June 30, 2015

Table 2: Presence of some complications in hemophilia population

Complications		Hemophilia A (N=1.527)		Hemophilia B (N=307)		Hemophilia	
						(N=1.832)	
		n	%	n		n	%
Chronic hemophilic arthropathy	No	984	64,5	216	70,4	1.200	65,5
	Yes	541	35,5	91	29,6	632	34,5
Infection Hepatitis C virus	No	1.445	94,8	297	96,7	1.742	95,1
	Yes	80	5,3	10	3,3	90	4,9
Infection Hepatitis B virus	No	1.518	99,5	304	99	1.822	99,5
	Yes	7	0,5	3	1	10	0,6
HIV infection	No	1.514	99,3	306	99,7	1.82	99,3
	Yes	11	0,7	1	0,3	12	0,7

Source: Resolution 0123 CAC: Database 2015. Information date: January 2015. DANE Population database: 31 June 30, 201

Illustration 2: Distribution of cases according to the presence of inhibitors

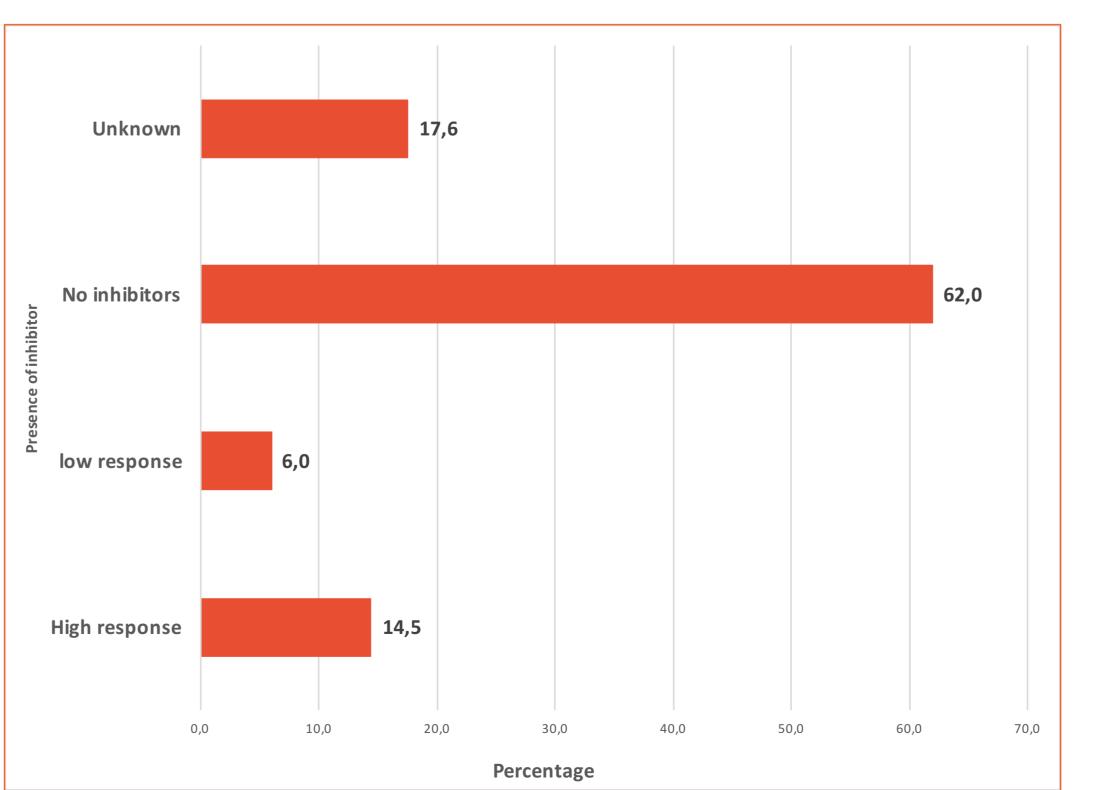


Illustration 3: Distribution interdisciplinary team care for hemophilia population

