ISPOR-EU 2023, RWD 166

Assessment of Haemophilia in Algeria: Challenges and Perspectives

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BACKGROUND & OBJECTIVES

Background

- In Algeria, the number of patients with haemophilia recorded in 2021 was 2634.[1] Given the worldwide prevalence of 400,000 patients, the number of people with haemophilia in Algeria is expected to be higher
- In addition to the challenges associated with the identification of patients in Algeria with rare inherited bleeding disorders, there are also barriers to treatment access. Without treatment, haemophilia causes crippling pain, severe joint damage, disability and death
- The patient registry study "Barometer" under the ownership of the Algerian Ministry of Health was designed to collect local real-world evidence on the management of rare bleeding disorders, including haemophilia

Objective

- The objective of this analysis was to evaluate the current management of patients with haemophilia in Algeria over a 3-year period

MATERIALS & METHODS

Study design

- "Barometer" is a national, multicentre, observational study that included patients with haemophilia A and B and other congenital bleeding disorders at 10 participating centres in Algeria between 01 July 2018 and 24 April 2022
- Input from cases was captured by the different study centres using a platform developed for this analysis. Epi-Info 7 and R software were used for data analysis
- Parameters collected and evaluated by a multidisciplinary team included demographic and geographical characteristics, haematological diagnoses, haemophilia type, severity and disease management. Informed consent was obtained from the patient or legal representative prior to any study-related activities

Descriptive analysis

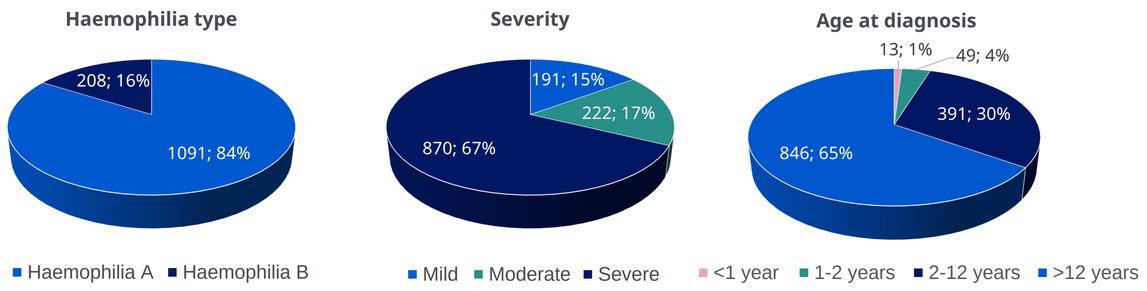
- Qualitative parameter results were expressed as percentages calculated based on the total sample number with a confidence interval of 95%
- Quantitative variable results were expressed as means with the standard deviation

RESULTS

Patient distribution

- 1299 patients (1286 male; 13 female) with haemophilia were reported. The majority of cases were haemophilia A (n = 1091, 84%), whereas haemophilia B was less prevalent (n = 208, 16%)
- The severe form of both haemophilia types was predominant, affecting more than two-thirds of the cases (n = 870, 67%)
- Patient distribution according to haemophilia type, severity and age at diagnosis and age at inhibitor discovery are presented in **Figure 1** and **Table 1**

Figure 1: Patient distribution according to haemophilia type, severity and age at diagnosis



- Inhibitors were reported in 152 (11.71%) patients (95% confidence interval: 10.07; 13.57)

Table 1: Distribution of patients by age at inhibitor discovery

Age at inhibitor discovery	Number of patients	Percentage	Cumulative
<1 year	6	0.46%	0.46%
1–2 years	23	1.77%	2.23%
2–12 years	66	5.08%	7.31%
>12 years	37	2.85%	10.16%
Missing	1167	89.84%	100.00%
Total	**1299**	**100.00%**	**100.00%**

- The distribution of patients by age at diagnosis and degree of severity is presented in **Table 2**. The severe form predominated in children aged >12 years and in children ≤1 year (84.6%). Among children aged 1 to 2 years, the severe form accounted for 81.6%

Table 2: Distribution of patients by age at diagnosis and degree of severity

Age range	Minor	Moderate	Severe	Not specified	Total number of haemophilia patients
<1 year	0	1	11	1	13
1–2 years	5	3	40	1	49
2–12 years	50	57	275	9	391
>12 years	136	161	544	5	846
Total number of haemophilia patients	**191**	**222**	**870**	**16**	**1299**

- The distribution of haemophilia patients according to the circumstances under which patients were diagnosed is presented in **Table 3**. The circumstances leading to diagnosis were most commonly due to a haemorrhagic event or family investigation

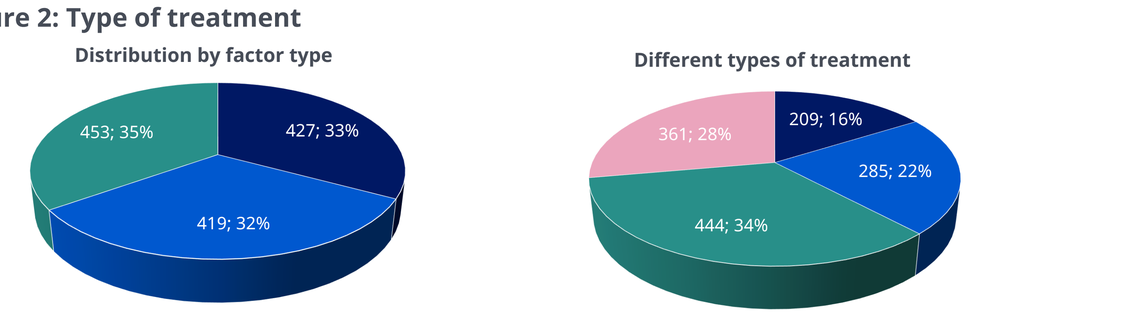
Table 3: Distribution of haemophilia patients according to the circumstances leading to diagnosis

Circumstances leading to diagnosis	Number of haemophilia patients	%
Secondary to a haemorrhagic manifestation	541	66.5
Family investigation	94	11.6
Circumcision	80	9.8
Fortuitously during a haemostasis assessment	63	7.8
Other	24	3.0
During a surgical procedure	10	1.2
Fracture	1	0.1
Total	**389**	**100**

Treatment

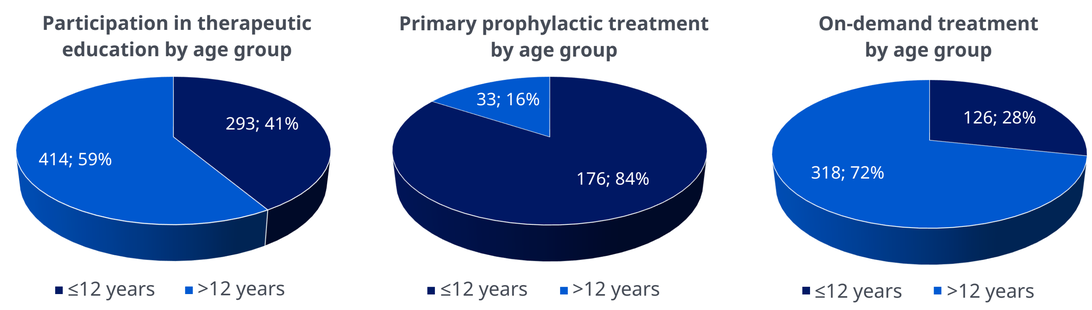
- Approximately one-third of haemophilia patients were treated with plasma-derived factor concentrates (n = 427, 32.9%) and 419 (32.3%) with recombinant products, with the remainder not specified
- On-demand treatment was reported in 444 patients, of which 126 (28.38%) were ≤12 years of age
- Prophylactic treatment was reported in 494 patients, of which 176 (84.2%) ≤12 years and 33 (15.8%) >12 years of age received primary prophylaxis
- Among patients ≤12 years, 64 (22.5%) were reported to receive secondary prophylaxis, with 221 (77.6%) among patients >12 years
- Among patients receiving prophylaxis, 313 (60.4%) of patients were treated at home, predominantly by a nurse (38.8%, the mother (25.7%) or father (11.3%)
- A few cases (n = 4) received no factor replacement therapy and the remainder were missing data (n = 357)
- Details on the type of treatments administered are presented in **Figure 2**
- On-demand treatment and prophylaxis by age group are presented in **Figure 3**

Figure 2: Type of treatment



PPX, prophylaxis; TX, factor therapy.

Figure 3: Therapeutic education, on-demand and primary prophylactic treatment by age group



CONCLUSIONS & PERSPECTIVES

- Although limited by insufficient budgets and the lack of diagnostic infrastructure, continuous efforts are being made to improve treatment and care of haemophilia patients in Algeria
- This study highlights a remaining unmet medical need among patients with haemophilia in Algeria, including the prevalence of on-demand treatment and the use of plasma-derived factor replacement products
- There is an immediate need to align haemophilia care in Algeria, especially in children, with international standards
- Implementation of genetic and molecular research initiatives will help to identify patients at risk of developing inhibitors
- Initiatives to raise awareness of haemophilia management are ongoing and decentralisation of haemophilia management, including respective quality controls, is in progress
- These findings showcase the national "Barometer" registry of rare inherited bleeding disorders that provides a platform within which stakeholders in the haemophilia community throughout Algeria can collaborate to improve the management of rare inherited bleeding disorders

REFERENCES

1. World Federation of Hemophilia. Report on the annual global survey 2021. 2022. https://www1.wfh.org/publications/files/pdf-2324.pdf

ACKNOWLEDGEMENTS AND DISCLOSURES

- The authors thank the patients, their families and all study investigators for their participation and support
- Medical writing support was provided by Ashfield MedComms GmbH (Mannheim, Germany), an Inizio company, and funded by Novo Nordisk
- Presented at ISPOR Europe 2023, 12-15 November 2023, Copenhagen, Denmark, #ISPOREurope