Overview of Hemophilia in Béchar

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Introduction:

Hemophilia is a rare hereditary disorder characterized by a deficiency in coagulation factors: factor VIII for hemophilia A or factor IX for hemophilia B. This deficiency leads to an inability of the blood to clot properly, resulting in prolonged internal and external bleeding. Although hemophilia is widely studied and managed in developed countries, the challenges related to its management are more pronounced in southern regions of Algeria.
This poster aims to provide an overview of hemophilia in Béchar, highlighting the challenges encountered.

Patients and Methods:

This is a descriptive study that reports on the epidemiological, clinical, and evolutionary profiles of hemophiliac patients followed in the hematology department at EHS-CLCC and the pediatric department at EHS Mother and Child in Béchar.

Results:

We identified 28 hemophiliacs: 14 adults aged 19 to 84 years and 14 children aged 2 to 17 years, all residing in Béchar and its surroundings. None had comorbidities, except for one child with well-controlled epilepsy under treatment. Of these, 27 were diagnosed with hemophilia A (70% with a severe form and 30% with a moderate form), and one had severe hemophilia B. The age of diagnosis ranged from a few days to 21 years. The circumstances of diagnosis were circumcision (32%), post-vaccination hematoma (25%), post-minor trauma hemorrhage (22%), and spontaneous bleeding (11%).
Clinically, hemarthrosis was the most common hemorrhagic manifestation (75%), affecting primarily exposed joints (knees 60%, elbows 25%, and ankles 10%). Soft tissue hematomas were observed in 20% of cases, and externalized bleeding in 5%, with a frequency ranging from 1 to 10 episodes per year depending on disease severity.
Management mainly involves substituting the deficient factor during bleeding episodes. None of the hemophiliacs received primary prophylaxis. One child was placed on tertiary prophylaxis after developing hemophilic arthropathy, and eight patients are on secondary prophylaxis. Six others refused prophylaxis due to the recurrence of intra-hospital injections. The inhibitor assay (ACC), unavailable locally, was only performed in five patients at northern university hospitals, with one testing positive and subsequently placed on bypassing agent prophylaxis. Regarding complications, two brothers developed hemophilic arthropathy, and one patient contracted hepatitis B. All patients receive their treatment in a hospital setting, as none have benefited from a therapeutic education program.

Conclusion:

In Béchar, the management of hemophilia faces several challenges, such as limited access to specialized care and a lack of awareness within the population. This situation impacts not only the quality of life of patients but also their families, especially since the disease requires rigorous and continuous multidisciplinary care.