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# Clinico-Demographic Profile and Management Scenario of Hemophilia Patients in a Tertiary Care Centre of North Bengal – A Cross-Sectional Study

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## ABSTRACT

**Background**: Haemophilia is the most common inherited severe bleeding disorder, with limited data available from resource-constrained regions of North Bengal. The establishment of the Hemoglobinopathies and Hemophilia Control Unit (HHCU) has enabled structured diagnosis and management in this sub-Himalayan region.
**Objectives**: To evaluate the clinico-demographic profile, severity distribution, clinical manifestations, and management practices of haemophilia patients attending a tertiary care centre in North Bengal.
**Methods**: A hospital-based cross-sectional study was conducted at Jalpaiguri Government Medical College and Hospital from 2022 to 2025. All diagnosed haemophilia patients attending the HHCU during the study period were included. Clinical details, family history, PT/INR, aPTT, factor assays, and treatment data were analysed.
**Results**: A total of 66 patients were enrolled, of whom 61 (92.5%) had haemophilia A and 5 (7.5%) had haemophilia B. The majority belonged to the 11–25-year age group (68.2%). Severe disease was observed in 34 (55.7%) patients, moderate in 23 (37.7%), and mild in 4 (6.6%). Hemarthrosis was the most common presentation (50%), followed by gum bleeding (24.2%), epistaxis (13.6%), and joint deformities (12.2%). The knee joint was most frequently affected (45%). Prolonged aPTT was noted in most cases, whereas PT/INR remained normal. Recombinant factor concentrates were administered on-demand in 58 patients, and prophylactic therapy was initiated in five children without established joint deformities. All patients received government-issued unique identification cards.
**Conclusions**: Haemophilia A with severe factor deficiency constituted the predominant disease pattern in this cohort. The HHCU has significantly improved diagnostic access, factor replacement therapy, prophylactic care, rehabilitation support, and patient awareness in North Bengal. Despite recent advances, substantial unmet needs remain in specialized diagnostic facilities and long-term comprehensive care for the rural population of this region.

***Keywords:*** Haemophilia A, Haemophilia B, hemarthrosis, factor assay, prophylaxis, North Bengal, HHCU.

## INTRODUCTION

Haemophilia is the commonest severe hereditary hemmorhagic disorder with an overall prevalence of 1 in 10,000 individuals.. Globally, the prevalence of haemophilia A is about 1 in 5,000 , wheres haemophilia B occurs in approximately 1 in 30,000 individuals [1]. Yet a very little is known about the clinical manifestations and diagnostic protocols of the condition in areas with limited resources. In India, the estimated prevalence is around 0.9 per 100,000 populations. A

significant proportion of patients reside in developing countries, where access to adequate healthcare and social support remains limited[1,2,3].Due to lack of awareness, underdiagnosis, and underreporting, a substantial burden of the disease remains unrecognised, thereby increasing both physical and psychological morbidity, in addition to financial constrains faced by affected families.

At the sub-Himalayan region, there is notable paucity of studies in haemophilia and with this scenario at a remote tertiary care centre in this belt like ours (Jalpaiguri Govt. College and Hospital,West Bengal), the journey for comprehensive management of Hemophilia patients goes back to 2022, following incorporation of Hemophilia in Hemoglobinopathies Control Unit (HCU), now designated as Hemoglobinopathies and Hemophilia Control Unit, (HHCU), as a part of National Health Program. However, due to Covid-19 Pandemic, its effectiveness in managing People with Hemophilia (PwH) has been reflected only in last couple of years among the populations of Northern part of West bengal, popularly known as North Bengal.

However, due to the lack of structured studies, the true burden of hemophilia in Jalpaiguri district remains unclear. Currently, patients are diagnosed primarily at North Bengal Medical College and other tertiary centers and are subsequently referred to JGMCH for counseling and management. This study represents a pioneering effort in this region to assess disease burden and evaluate the effectiveness of existing management strategies. It will also provide insight into the necessity and utility of specialized investigations such as factor assays and inhibitor assays in this setting.

Factor VIII (haemophilia A), Factor IX (haemophilia B) deficiency are the most common inherited coagulation defects. Both show X linked recessive inheritance. Both can be further classified as mild (5-40%), moderate (1-5%) and severe (<1% of normal) depending on the factor levels.

The purpose of this study was to fill the information gap by evaluating the clinic demographic profile of haemophilia in patients who presented to this tertiary care institution at the time of diagnosis.

**Aims and objectives**
To study the clinico-demographic profile of patients with hemophilia attending the HHCU at Jalpaiguri Government Medical College and Hospital, including their types and severity grades, and to assess the impact on management practices. Additionally, the study aims to enhance awareness regarding hemophilia among healthcare providers and the general population.

**MATERIAL AND METHODS-**
**Study Design:** Hospital-based, cross-sectional study
**Study Timeline:** 2022 -2025.
**Study Area:** Jalpaiguri Govt. Medical College and Hospital
**Study Population:** Patients who attended Jalpaiguri Govt. Medical College with Hemophilia during this time period.
**Sample Size:** All the patients, who attended and were diagnosed as Hemophilia in HHCU in the study period, will be included in the study after proper consent.

**Inclusion Criteria:** Patients screened and diagnosed with hemophilia, attending Jalpaiguri Govt. Medical College and Hospital during the study period.

**Exclusion Criteria:** Other bleeding disorders were excluded from the study

**Work Plan**
All patients presenting with symptoms suggestive of hemophilia and enrolled in the HHCU were counseled, and informed consents were obtained prior to inclusion in the study. Sociodemographic details, including age, sex, and distance from the institution, were recorded from hospital records and/or direct patient interviews.

Clinical presentation patterns such as gum bleeding, epistaxis, hemarthrosis, joint deformities, and other bleeding manifestations were systematically documented.

Laboratory parameters, including routine screening tests such as Prothrombin Time (PT) and Activated Partial Thromboplastin Time (aPTT), along with specific factor assay results, were recorded. Based on factor deficiency, patients were categorized as Hemophilia A (Factor VIII deficiency) or Hemophilia B (Factor IX deficiency).

The severity of hemophilia will be classified according to plasma factor activity levels as follows: [3,4,5]

- Severe: <1% factor activity
- Moderate: 1–5% factor activity
- Mild: 6–40% factor activity

Details regarding treatment were documented, including the use of recombinant factor concentrates administered on-demand as well as prophylactic therapy. Prophylaxis was typically provided to patients below 10 years of age without established joint deformities.

As part of comprehensive care, the involvement and support from the Department of Physical Medicine and Rehabilitation were assessed and recorded. Documentation also included whether patients had been issued unique identity cards for patients from haemophilia care centre.

To evaluate diagnostic capacity and needs in the region, records of factor assays and inhibitor assays performed at Jalpaiguri Govt. College and Hospital (West Bengal) and other centers weree reviewed. The necessity and utilization of these specialized investigations were analyzed in the context of regional healthcare delivery.

**Data Analysis**

The collected data were analyzed using the Statistical Package for the Social Sciences (SPSS). Data were presented in the form of tables and graphical representations where appropriate.

Continuous quantitative variables (e.g., age) were expressed as mean ± standard deviation (SD) and median (range). Categorical qualitative variables were be expressed as absolute frequencies (numbers) and relative frequencies (percentages).

Appropriate statistical tests were applied to assess significance. A p-value of less than 0.05 will be considered statistically significant.

## MATERIALS AND METHODS

This is a cross-sectional study of Hemophilia patients, visiting the tertiary care centre of North Bengal. We collected the data of Hemophilia patients reporting to HHCU for a period of 3 years. Here we try to describe the types of Hemophilia, degree of severity, clinical profile and management rendered to them.

## RESULTS

**Clinical parameters, family history, PT-INR/APTT, factor studies were done.**

Out of 66 patients 45 were in the age group between 11-25 years and 21 were in the age group between 1-10 years

Out of 66 cases enrolled 61 (92.5%) cases were diagnosed as Hemophilia A while 5 (7.5%) cases were diagnosed as Hemophilia B. According to their factor levels, 34 (55.7%) cases had severe disease, 23 (37.7%) cases had moderate disease and 4 (6.6%) cases had mild disease. Most common clinical presentation was hemarthrosis in 33 (50%) cases, gum bleeding in 16 (24.2%) cases, epistaxis in 9 (13.6%) cases, deformities in joints in 8 (12.2%) cases. Most common joint affected was knee joint in 23 (45%) cases, followed by elbow joint in 13 (25.4%) cases, followed by ankle joint in 11 ( 21.5%) cases, followed by hip joint in 4 (8.1%) cases. Number of patients with O+ blood group were 23 (34.8%), with AB+ blood group were 23 (34.8%), with B+ blood group were 16 (24.2%) and with AB+ blood group were 4 (6.2%).

Most patients presented with severe Hemophilia in first few months of life and moderate to mild ones presented in late childhood/ early adolescence.

Family history is positive in one-third of patients and APTT prolonged in most of the cases. PT-INR results were normal. A few patients did inhibitor studies and prophylactic management has also been started on a few patients along with guideline based management on other patients.

All the patients received unique identification cards as per government protocol. Quarterly awareness programmes are held and World Haemophilia day is celebrated on !7 th April every year since the inception of the national programme.

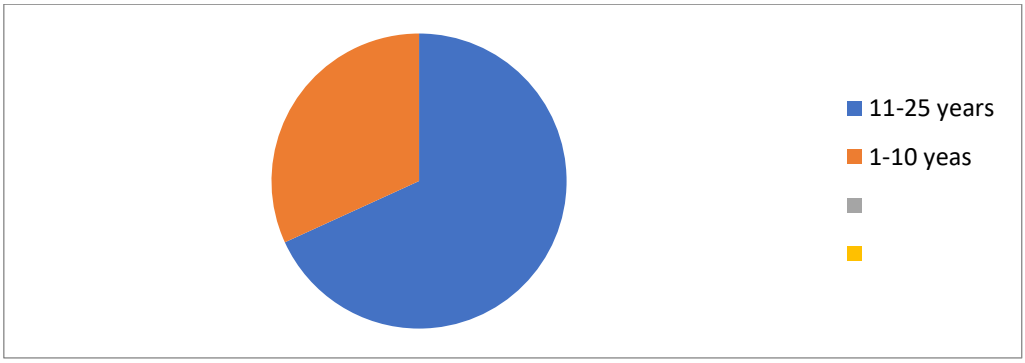


**Figure 1: Distribution of age in Hemophilia patients**

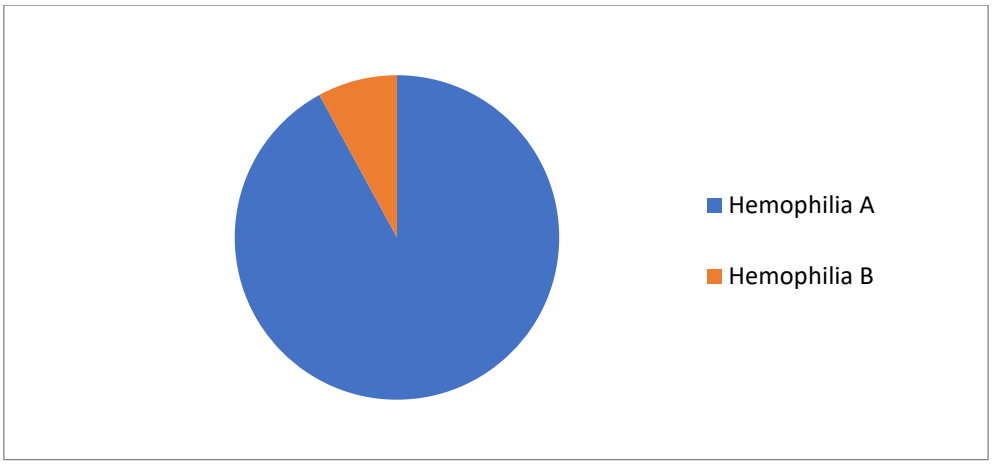


**Figure 2: Distribution of Hemophilia A And Hemophilia B**

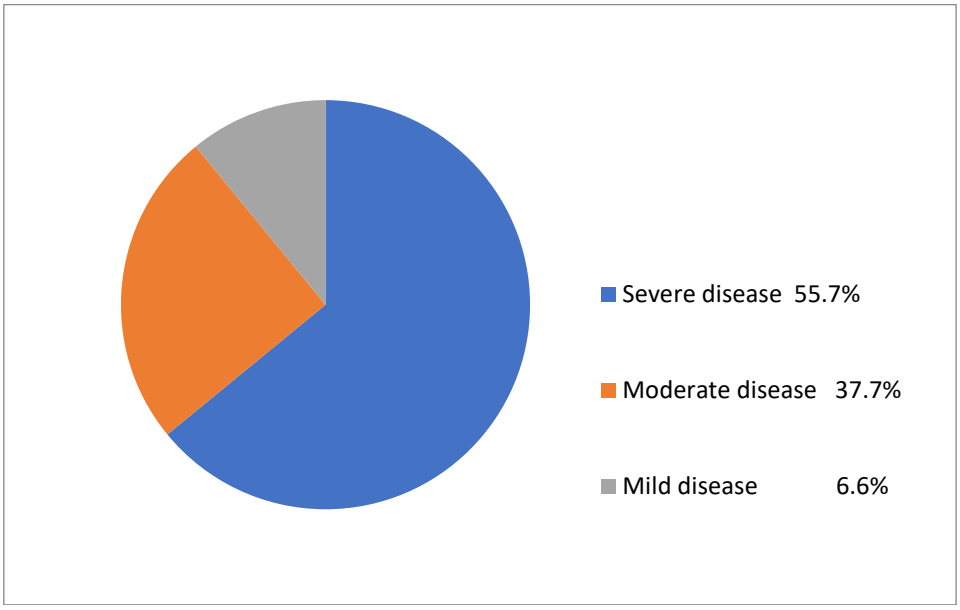


**Figure 3: Distribution of Hemophilia according to Factor levels**

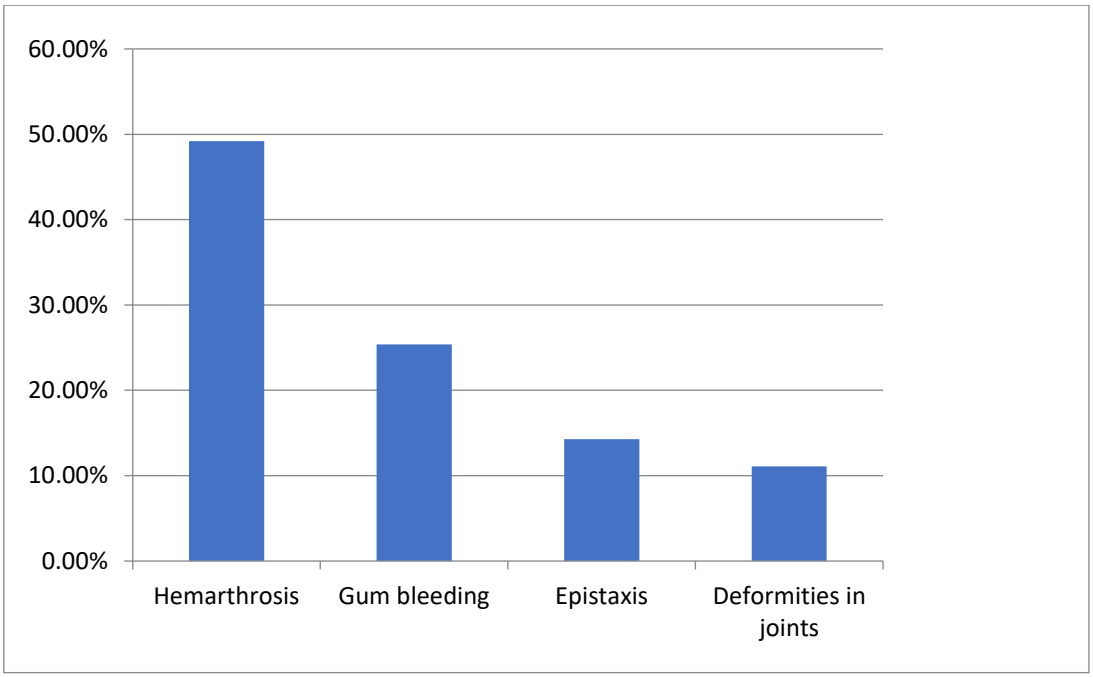


**Figure 4: Distribution of clinical presentations of Hemophilia patients**

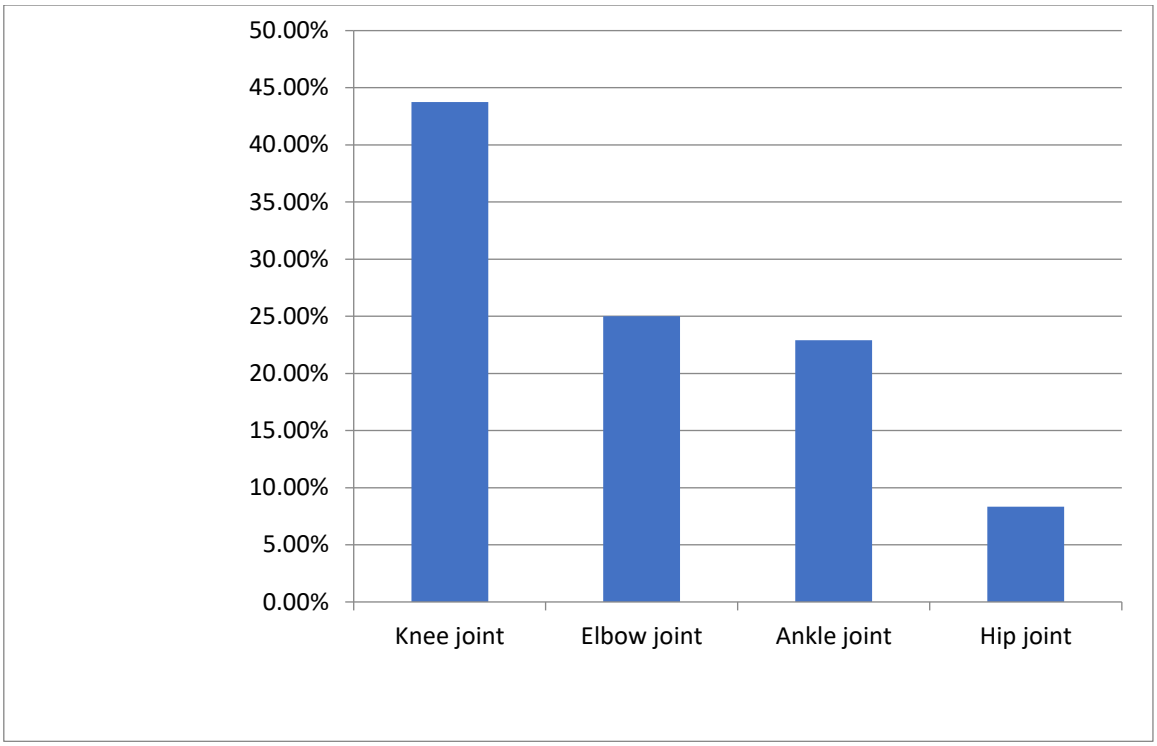


**Figure 5: Distribution of joints affected in Hemophilia patients**

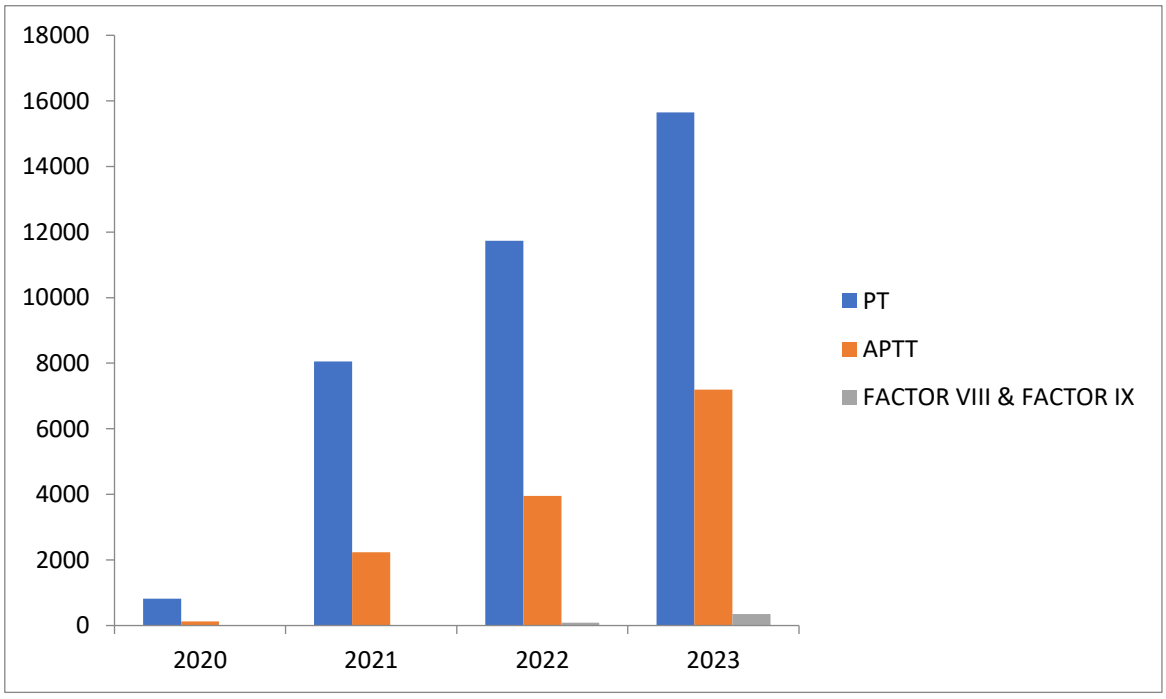


**Figure 6: Distribution of PT APTT Factor VIII and Factor IX assay**

The number of PwH with Inhibitor are very few. However, we have been able to start Assay of Inhibitor.

- As a part of conventional practice, Recombinant Factors were given on demand to 58 of Hemophilia patients
- Prophylaxis has been started to below 10 yrs patients with no deformities and has been given to 5 patients till date.
- As a part of comprehensive management, assistance from Physical Medicine department is available to PwH and has been increased.

## DISCUSSION

A major health issue, coagulopathy causes increased mortality and morbidity as a result of spontaneous and traumatic bleeding events.

Factor VIII or factor IX deficiency is an X linked inherited bleeding condition known as Hemophilia A and B respectively .A lack of these components may cause repeated bleeding into muscles and joints resulting in hemophilic arthropathy and contractures. Developing nations like India are thought to be home to 80% of the world's hemophiliacs because of lack of social awareness about inherited bleeding disorders[ 6,7,8].

In our study Hemophilia A is contributing more than Hemophilia B patients which is similar to the study by Shastri et al and Verhagen et al.[7,8]

We noticed here that severe deficiency is more common than moderate and mild deficiency and similar data was reported by Kreuz et al, Schieve et al and Kulkarni et al [9,10,11]

**A practical solution can be the concept of prophylaxis therapy.**
A Hemophilia patient can self administer low doses of factor at regular interval at the nearest health centre under supervision of primary care physician.[7]

A haemophilia campaign must be launched among developing nations to raise awareness and a rigorous cautious approach to evaluate bleeding symptoms is necessary to make a conclusive diagnosis of haemophilia. So on World Haemophilia Day we celebrate with much enthusiasm by organising different programmes motivating our enlisted patients and their family members.They participate with all their energy , but within their capacity.

## CONCLUSION

Before the start of proper functioning of HHCU in the year 2023, a systematic approach to the diagnosis and management of Hemophilia was not available.

However, now with a proper functioning HHCU, a systematic diagnostic approach and comprehensive management under one roof can be provided to the Haemophilia patients which is cost effective and of great relief to the patients, of course we must accept, we are miles away to reach our goal.

Hemophilia requires specialized tests for diagnosis and life-long support which is a limitation for the vast rural population in north-east part of India. The role of primary care physicians is extremely important in providing routine care, emergency treatment of bleeding, follow up and check for anemia due to hemorrhage, transfusion transmitted infections and joint deformity. Also, by prophylactic administration of clotting factors in severe hemophilia, physicians can reduce morbidity and mortality related to severe hemophilia.[9]

Although the future looks promising with the recent advances in therapy including gene therapy , there is a huge unmet need of diagnostic and treatment facilities in this part of India.[9]

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