

Perceived barriers to treatment of hemophilia –a survey among parents of persons with hemophilia



Mrs. Anjalín D'souza¹, Dr.Dinesh Nayak², Dr.Annamma Kurien³

¹Asst.professor-selection grade,Manipal College of Nursing Manipal; ²HOD, Paediatrics, MMMC (Manipal campus), Dr. TMA Pai Hospital, Udupi;

³Associate Dean & Professor of Pathology, MMMC, Manipal University, Manipal.

Introduction and objectives

- Hemophilia is an inherited X-linked coagulation disorder caused by deficiencies of the clotting factor VIII (FVIII: hemophilia A) or of factor IX (FIX: hemophilia B). Hemophilia occurs in approximately 1 in 5,000 live births.^[1,2]
- Early treatment of bleeds in hemophiliacs has shown to be of immense benefit in the overall clinical outcome. But in a developing country like India there is little or no access to factor replacement therapy leading to greater mortality and morbidity. People with hemophilia have many barriers related to financial, educational and treatment. Identification and addressing these barriers will result in better joint health, early treatment which eventually leads a better quality of life ².
- This study was conducted to explore the barriers experienced by the parents of people with hemophilia in one of the treatment centres of South India .

Methods

- This survey was conducted at hemophilia treatment centre. Kasturba Hospital among parents of 50 persons with hemophilia. Parents of PWH were selected by convenient sampling.
- Data was collected from parents by using self-administered questionnaire, which consisted of demographic proforma with disease variables and a five point likert scale on perceived barriers to hemophilia treatment which was developed by the researcher based on literature review. Barriers included were contextual(access to hospital),financial (cost of treatment) and educational (awareness of disease) ³
- Content validity was done based on expert opinion. The tool had two sections, section 1 had three open ended questions. Section 2 had 16 items with 5 to 1 scoring,(always, very often, sometimes, rarely and never) that gives a maximum score of 80 and minimum of 16. Higher the score, more is the perceived barrier.
- Reliability of the tool on Perceived barriers to hemophilia treatment was established by administering the tool to 20 parents & internal consistency (r) was 0.79.

Results

Table 1. Sample Characteristics of persons with hemophilia (n=50)

Sample Characteristics	Frequency	Percentage
1.Age in years		
6-7	7	14
8-12	15	30
13-16	13	26
17-24	15	30
2.Education		
Primary school	18	36
Higher primary	6	12
High school	14	28
PUC	7	14
Degree	5	10
3.Family history		
Yes	28	56
No	22	44

Table 2.Sample characteristics of parents

Sample Characteristics	Frequency	Percentage
1.Monthly income in rupees		
> 50000	15	30
30,000 - 49,999	25	50
10,000 - 29,999	7	14
5,000 - 9,999	3	6
2.Father's education		
Primary school	19	38
Higher primary	14	28
High school	11	22
PUC	4	8
Degree	2	4
3.Mother's education		
Primary school	17	34
Higher primary	16	32
High school	12	24
PUC	4	8
Degree	1	2

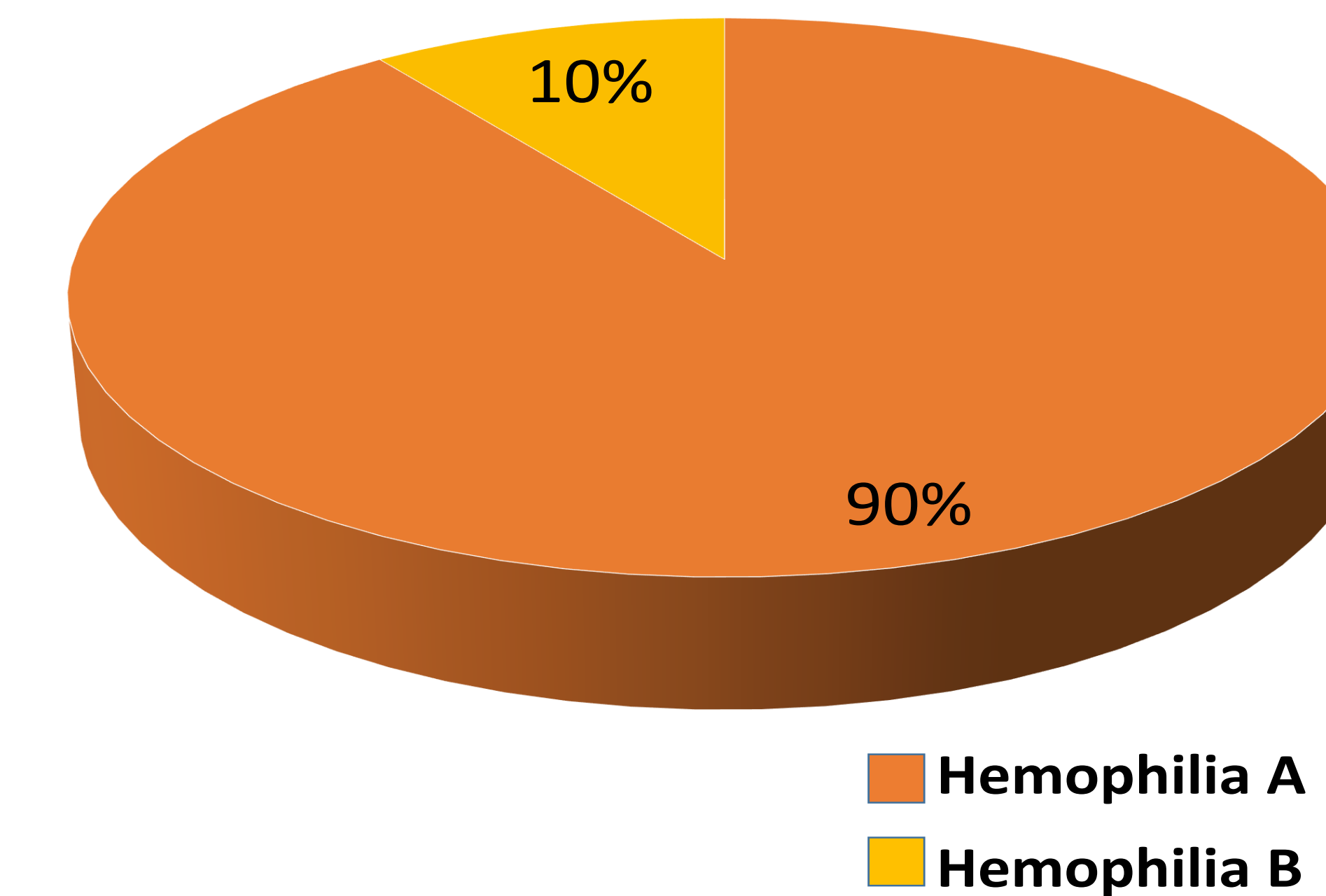


Fig 1. Distribution of sample based on type of hemophilia

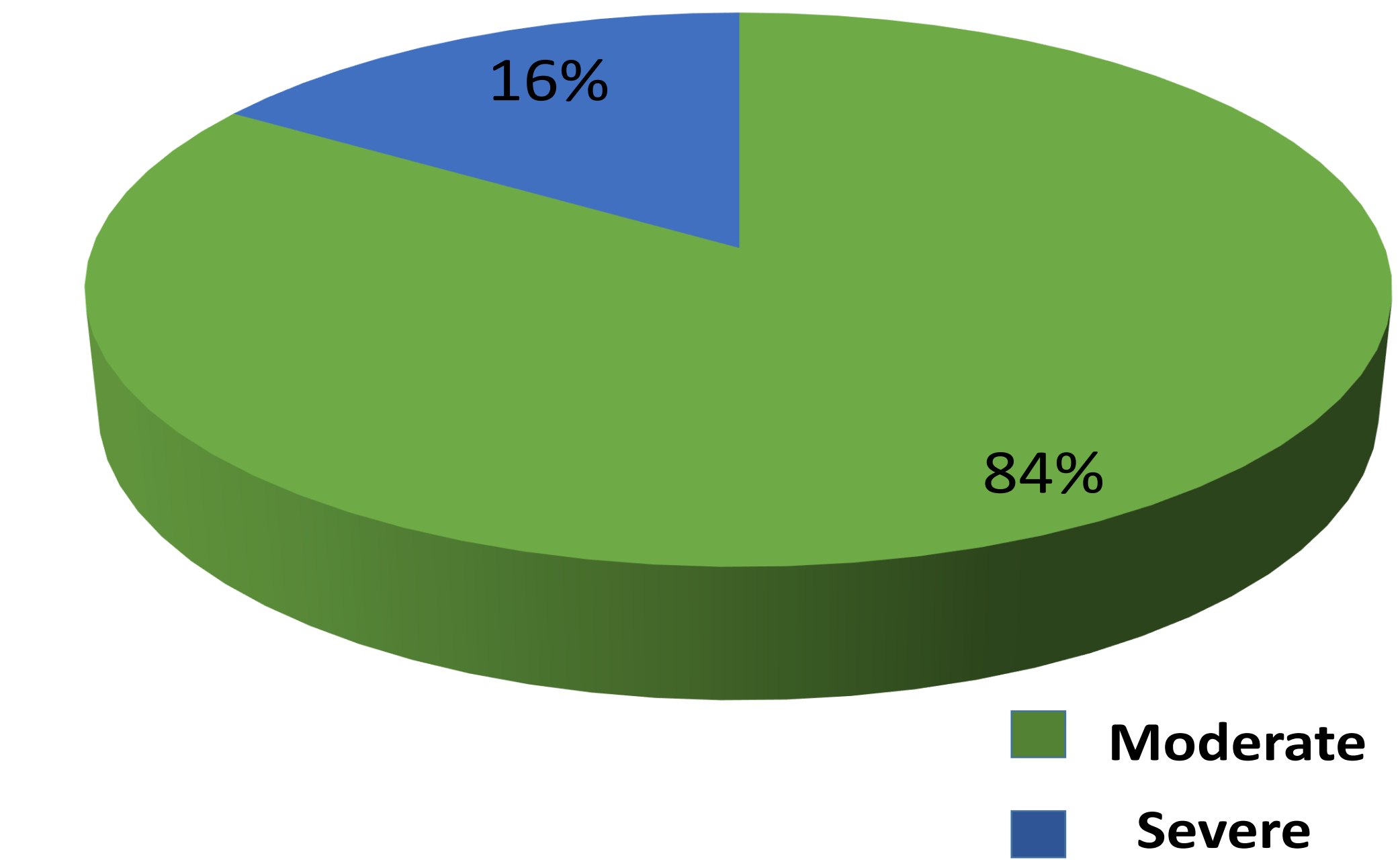


Fig 2. Distribution of sample based on severity of hemophilia

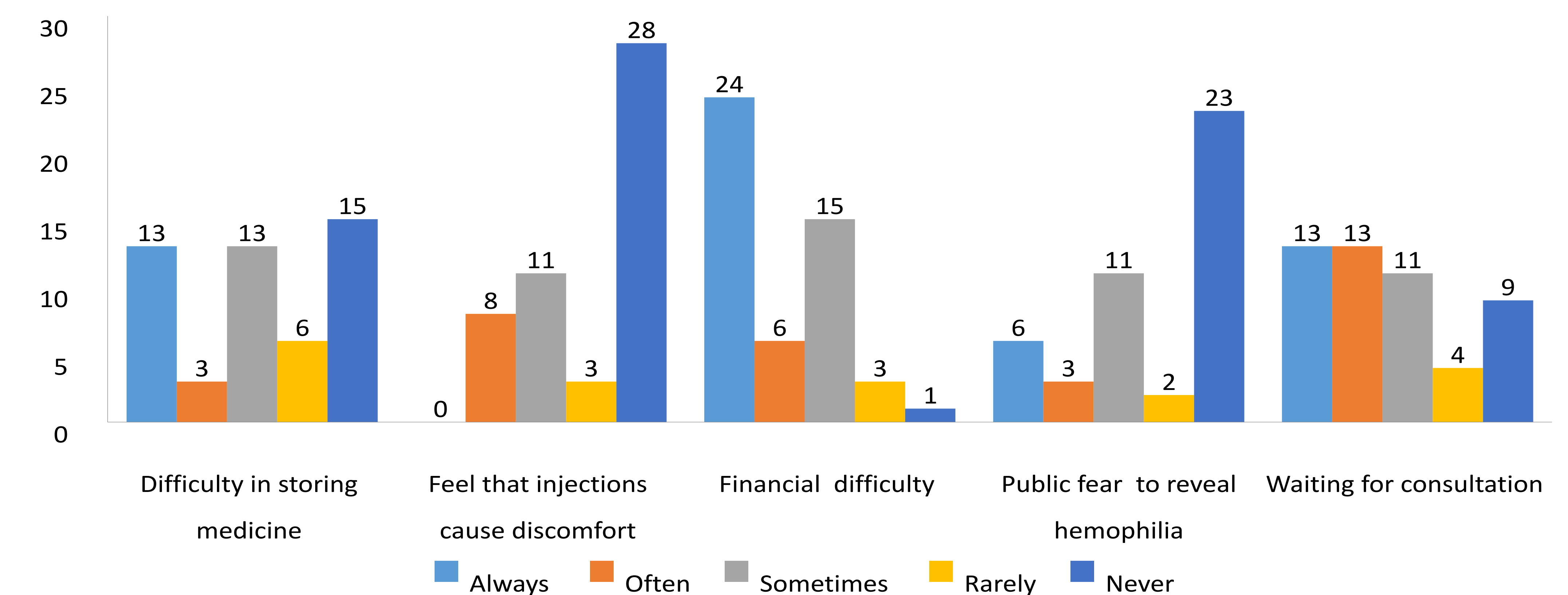


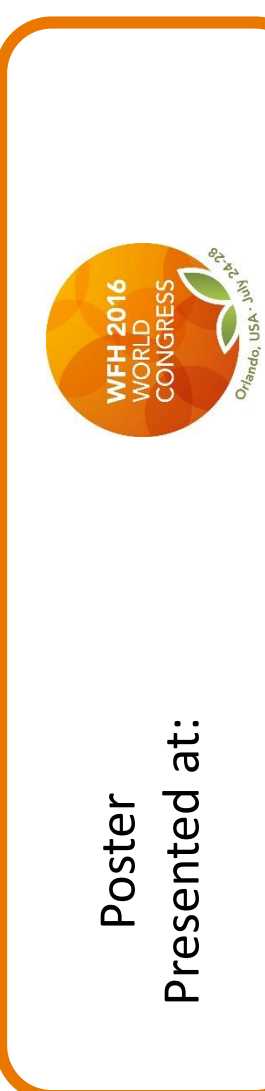
Fig.3 Perceived barriers to hemophilia treatment

Conclusions

The study findings show that people with hemophilia have several barriers related to treatment and financial support. Health care sector in developing countries like India need to develop many strategies to overcome these barriers.

References

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Adherence Anjalín D'souza

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