Evidence for mobilizing policy on haemophilia in India: II. An estimate of treatment gap in Maharashtra

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Introduction

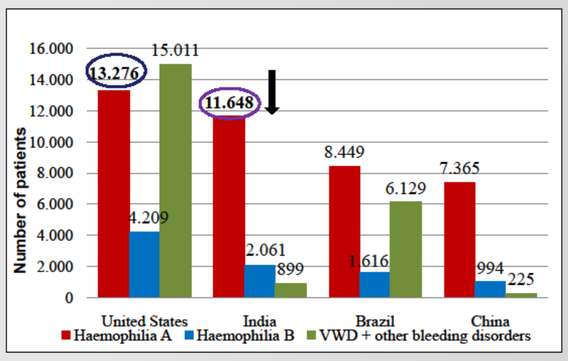


Fig 1: Number of patients with bleeding disorders by country

India reports the second largest burden of haemophilia patients [1]

Case diagnosis rate for haemophilia A in India is *0.99* per 100000 as compared to *4.28* per 100000 for the USA indicating only one fourth cases have been diagnosed

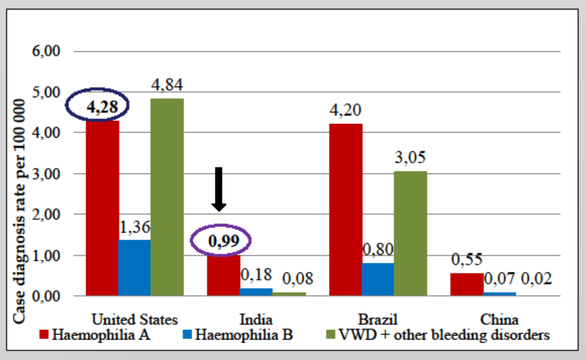
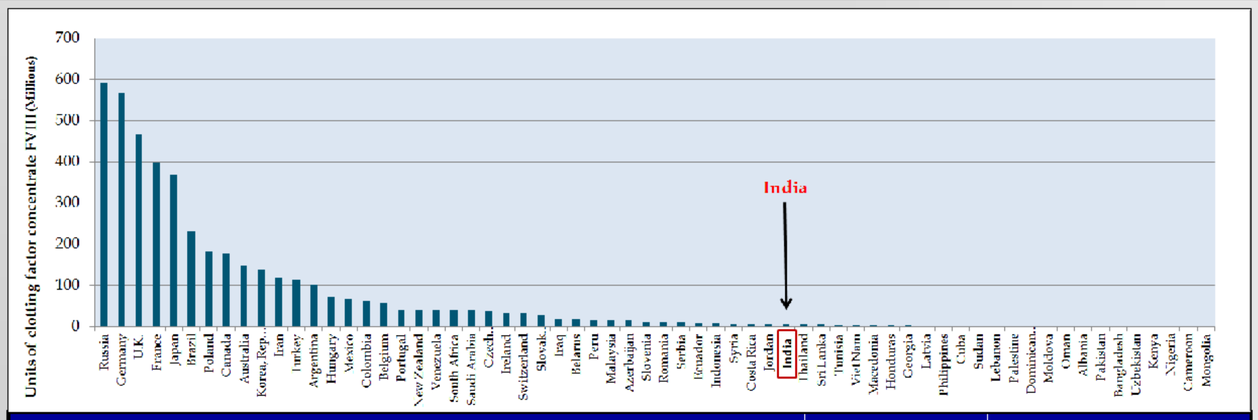


Fig 2: Case diagnosis rate per 100 000

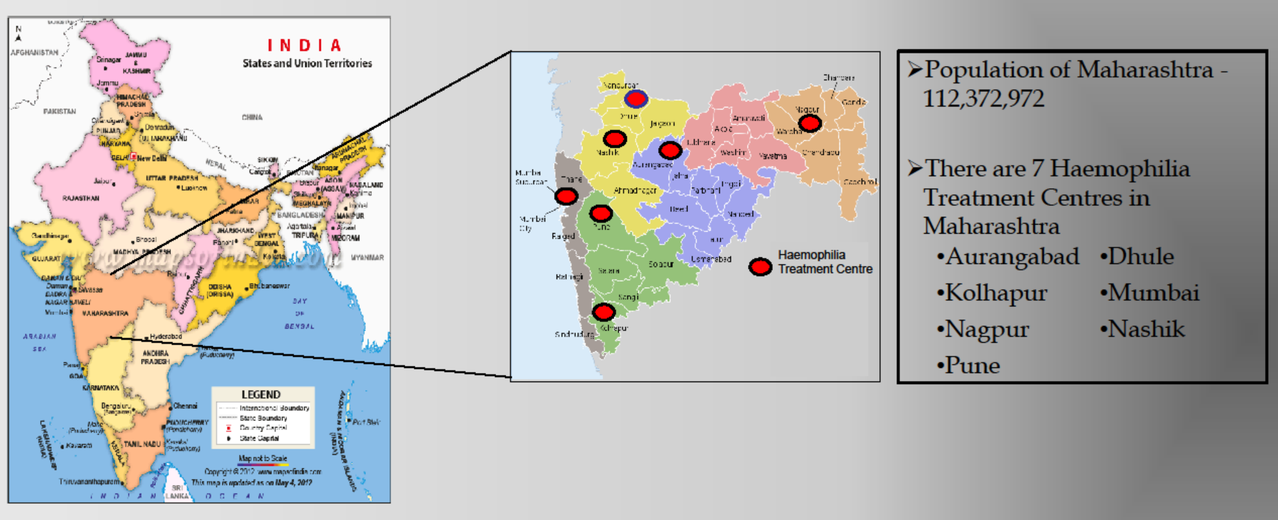


	India	USA
Number of diagnosed patients	11 648	13 276
Total IU of clotting factor VIII concentrate used (IU)	5 350 000	1600 000 000
Per capita consumption (IU)	0.005IU	5.15 IU

Fig 3: Global consumption of clotting factor concentrates FVIII

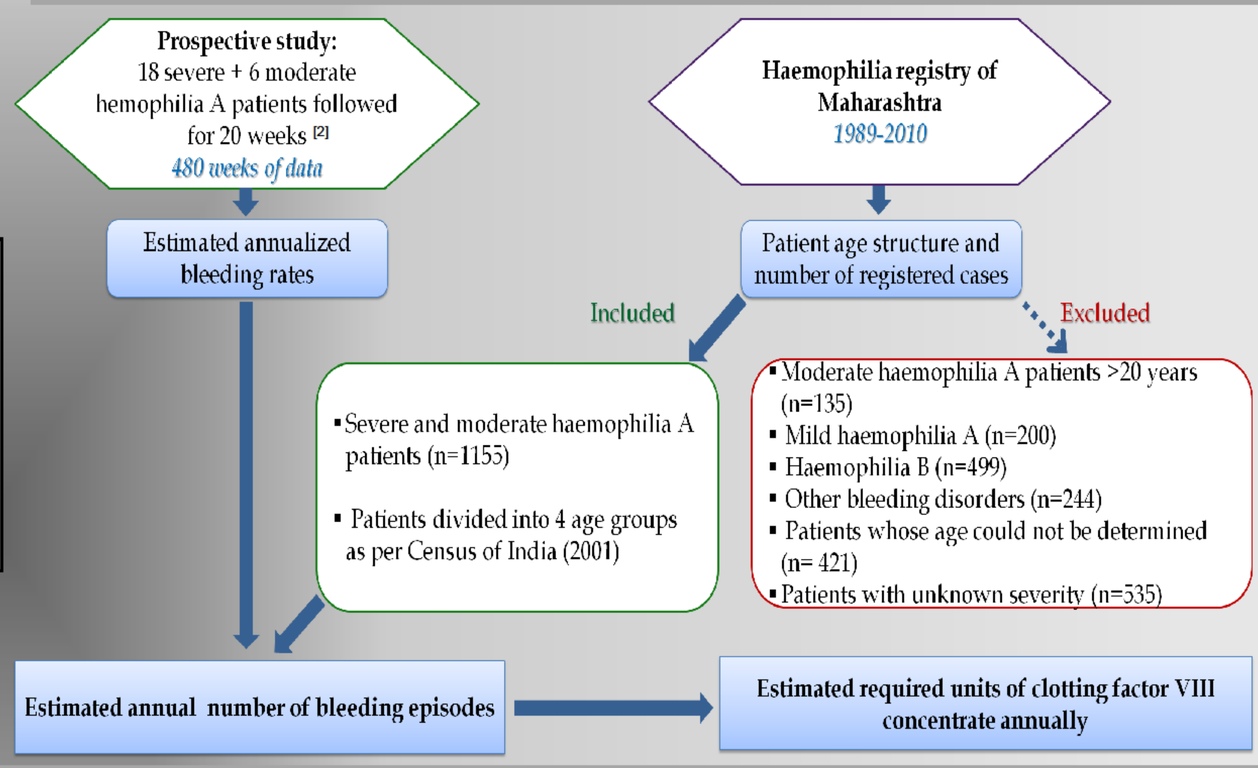
Objective

- **To estimate the annual clotting factor VIII concentrate requirement by patients with severe and moderate haemophilia A in the state of Maharashtra, India and compare it with the amount actually used**



- Population of Maharashtra - 112,372,972
- There are 7 Haemophilia Treatment Centres in Maharashtra
  - Aurangabad
  - Dhule
  - Kolhapur
  - Mumbai
  - Nagpur
  - Nashik
  - Pune

Methodology



Results

Table 1:Estimated number of bleeding episodes and units of clotting factor VIII concentrates required annually

Age groups	Number of patients followed up for twenty weeks		Median annualized bleeding rates		Number of patients in the Haemophilia Registry		Estimated annual bleeding episodes		Units of clotting factor concentrate required for each bleeding episode	Estimated units of clotting factor VIII concentrate required to treat all bleeding episodes* (IU)	
	S	M	S	M	S	M	S	M		S	M
0-9 years	3	3	17	10	207	82	3519	820	500	1759500	410000
10-14 years	4	1	17	12	194	36	3298	432	500	1649000	216000
15-19 years	6	2	12	7	144	31	1728	217	1000	1728000	217000
20+ years	5	-	11	-	461	-	5071	-	1000	5071000	-
Total	**18**	**6**	**-**	**-**	**1006**	**149**	**13616**	**1469**	**-**	**10207500**	**843000**

*Assuming each bleeding episode can be treated with a single infusion of clotting factor VIII concentrate

S- Severe haemophilia A ; M- Moderately severe haemophilia A

Table 2: Per capita and per patient utilization of clotting factor concentrate

Number of patients included in the study	1155
Number of patients excluded from the study (mild haemophilia A, moderate haemophilia A (>20 years), haemophilia B, other bleeding disorders and patients whose age or severity not known)	1887
Estimated total requirement of clotting factor VIII concentrate (n=1155)	**11 050 500 IU**
Estimated per patient utilization of clotting factor VIII concentrate. (The denominator includes all patients with haemophilia A and von Willebrand disease) (n=2412)	891 IU
Estimated per capita utilization of clotting factor VIII concentrate	**0.004 IU**

Estimated treatment gap **81%**

(excluding treatment product required to treat patients with moderate haemophilia A (>20 years), mild haemophilia A and von Willebrand disease) (n=1155)

This data is an underestimate because:

- Clotting factor concentrate requirements have been computed assuming that *each* haemorrhagic episode can be controlled by a *single* infusion of clotting factor VIII concentrate
- The estimate *has not taken into consideration* the clotting factor concentrate requirement for surgeries and emergencies.
- Data was *unavailable* for patients with moderate haemophilia A >20 years of age, mild haemophilia A and patients with von Willebrand disease

Conclusions

- Estimation of lack of treatment has been presented
- Data urges the need for a public policy for haemophilia including
  - Availability of subsidized treatment
  - Genetic counseling for families
- Establishment of a National Rare Disease Register including haemophilia where ongoing haemophilia surveillance data can be submitted for analysis and assessment of needs of patients

References

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2. Dharmarajan S. et al. Treament decision and usage of clotting factor concentrate by a cohort of Indian haemophilia patients. Letter. Haemophilia. 2012; 18: e27.

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