

Update of National Hemophilia Registry of China

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INTRODUCTION and OBJECTIVES

To Share the data, experience and shortcoming of the China national registry as having established for three years. The data presented here are from January 2010 to October 2013.

METHODS

- A Web-based Registry authorized by Ministry of Health of China.
- Aim to collect the data of hemophilia patients of China mainland.
- “Hub and Spoke” model:
 - 1 National haemophilia registry centre—to pool and analyzed the data uploaded from spoke centres
 - 31 provincial registry centres(treatment centres) ----responsible for collecting data of each province
- The privacy of patients are preserved for the detailed information cannot be accessed openly.
- Report will be generated and provided to authority upon demand.

RESULTS

Table 1: Overall distribution of bleeding disorders recorded in database

Type	n	%
Hemophilia A	9675	84.7
Hemophilia B	1433	12.5
vWD	58	0.5
Other hereditary factor deficiency	261	2.3
Total No	11427	100

Table 2: Age distribution of Hemophiliacs registered in China database

Age	<14 n(%)	14-18 n(%)	19-44 n(%)	>45 n(%)	Unknow n(%)
Hemophilia A (n=9675)	2563(26.5)	1074(11.1)	4709(48.7)	1206(12.5)	123(1.2)
Hemophilia B (n=1433)	330(23)	150(10.5)	713(49.8)	231(16.1)	9(0.6)

Table 3: Children/ Adult ratio in country with variant income economy

	High income economy	Upper middle income economy	PR, China	Lower middle income economy	Lower middle income economy
Children	19	22	27	30	40
Adult	80	72	72	67	60
Ratio	0.24	0.31	0.38	0.45	0.47

Age distribution of Haemophilia A according to world bank ranking. WFH Haemophilia report on the Annual GLOBAL SURVEY 2009.

Table 4 Clinical phenotype of Hemophilia A and B

Phenotype	Severe(<1%) n(%)	Moderate(1-5%) n(%)	Mild(>5%) n(%)	Unknow n(%)
Hemophilia A (n=9675)	7046(72.8)	1825(18.9)	703(7.3)	101(1)
Hemophilia B (n=1433)	934(65.2)	330(23.0)	159(11.1)	10(0.7)

Table 5 The prevalence of HBV and HCV infection in Haemophilia patients: Among the small population with information of blood borne viral infection, the proportion of HCV infection is higher than HBV infection.

	Sum of Pts tested	Positive n(%)	Negative n(%)	Sum of pts unknow
HBs-Ag	2302(20.7%)	147(6.4)	2155(93.6)	8806
HCV-Ab	1455(13.1%)	203(14.0)	1252(86.0)	9653
HIV-Ab	2243(20.2%)	32	2211	8865

Shortcoming and further improvement for the National Registry

- Current registry does not provide information on death and mortality.
- Does not allow a continuous vigilance on the treatment regimen, concentrate consuming, joint health, inhibitor development and other adverse effects.
- The quality of data need to be increased and validated.
 - For improving the system:
 - New software containing more detailed information is under designed.
 - More education aim to raise the awareness of the importance of registry should be held to ensure more patients be registered.

CONCLUSIONS

According to the 1.3 billion population of China mainland, there are about 100,000 people estimated having Haemophilia. The Current Registry contains only 10% of estimated population. In light of the fact that severe and moderate- severe patients are more prone to be diagnosed especially in areas with better economy and high healthcare rank, the large population of Hemophiliacs unidentified may located in economy less development area especially rural area. What we should do next is to identify more patients. The data in registry is essential for assisnting policy decision, resourse distribution and construction of Hemophilia treatment centre in China.

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The authors declare no conflict of interest.

