The Diagnosis and Treatment Status of Children Hemophilia in China —Multicenter data analysis

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Objectives: Collect and analyze the data of children hemophilia in multiple centers in order to investigate the diagnosis and treatment status of children hemophilia in China, and to provide evidence for authorities to make policy.
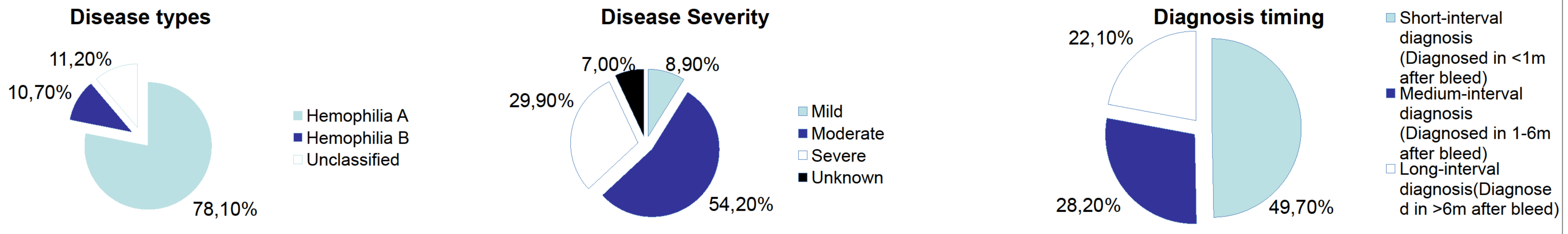
Methods: The data of diagnosis and treatment for children hemophilia in twelve hemophilia centers around China from Jan 1, 2008 to Mar 30, 2014 were collected via questionnaires.

Results: Data of 616 children hemophilia were collected. Median age: 7.05 years old(0.1-17.9 years old).185(30.0%) patients had family history. Disease types : hemophilia A 481 patients(78.1%), hemophilia B 66(10.7%), unknown because of data missing or disremember 69(11.2%).Severity of hemophilia: mild 55 patients(8.9%), moderate 334(54.2%),severe 184(29.9%),and factor activity unknown 43 cases(7.0%). First bleeding occurred at median age of 9.0 months(0.0-180 months). And the median age of diagnosis was 12 months(0-168 months), in which 306 patients(49.7%) had been diagnosed less than one month after first bleeding, 174(28.2%) between 1 month and 6 months,136(22.1%)after six months. There was no relationship between diagnosis timing (interval between first bleeding and the diagnosis) and disease severity((P=0.212),while significantly relation with severity of first bleeding. Only 32.5% of patients had received optimal dosage of factor replacement in acute bleeding, others received low dosage of factors or even no treatment. 268 patients(42.6%) had target joints. 37.5% of patients had ever received prophylactic treatment, however, 57.4% of them discontinued due to economic pressure, factors shortage or venous access difficulty.

GRAPHS AND TABLES

Disease types
- 78,10% — Hemophilia A
- 10,70% — Hemophilia B
- 11,20% — Unclassified

Disease Severity
- 8,90% — Mild
- 54,20% — Moderate
- 29,90% — Severe
- 7,00% — Unknown

Diagnosis timing
- 49,70% — Short-interval diagnosis (Diagnosed in <1m after bleed)
- 28,20% — Medium-interval diagnosis (Diagnosed in 1-6m after bleed)
- 22,10% — Long-interval diagnosis(Diagnosed in >6m after bleed)

Conclusions: This result, to some extent, could represent national hemophilia diagnosis and treatment status in China. Moderate and severe hemorrhage were diagnosed timely. But still a part of children had a delayed diagnosis. Hemophilia treatment lagged behind the developed country, with higher suboptimal treatment, joint damage, and lower prophylaxis.