

Current status of prophylaxis in haemophilia children ---a multi-center study in China

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Objectives

To describe the current status of prophylaxis for haemophilia children in China.

Methods

This study was from 1st January 2014 to 1st April 2015. Only patients under 18 years-old were recruited. We collected clinical data including diagnose, treatment pattern and reason for not accepting prophylaxis, from 14 pediatric hemophilia centers in China. These 14 centers are located in different parts of China and present different economic levels.

Figure.

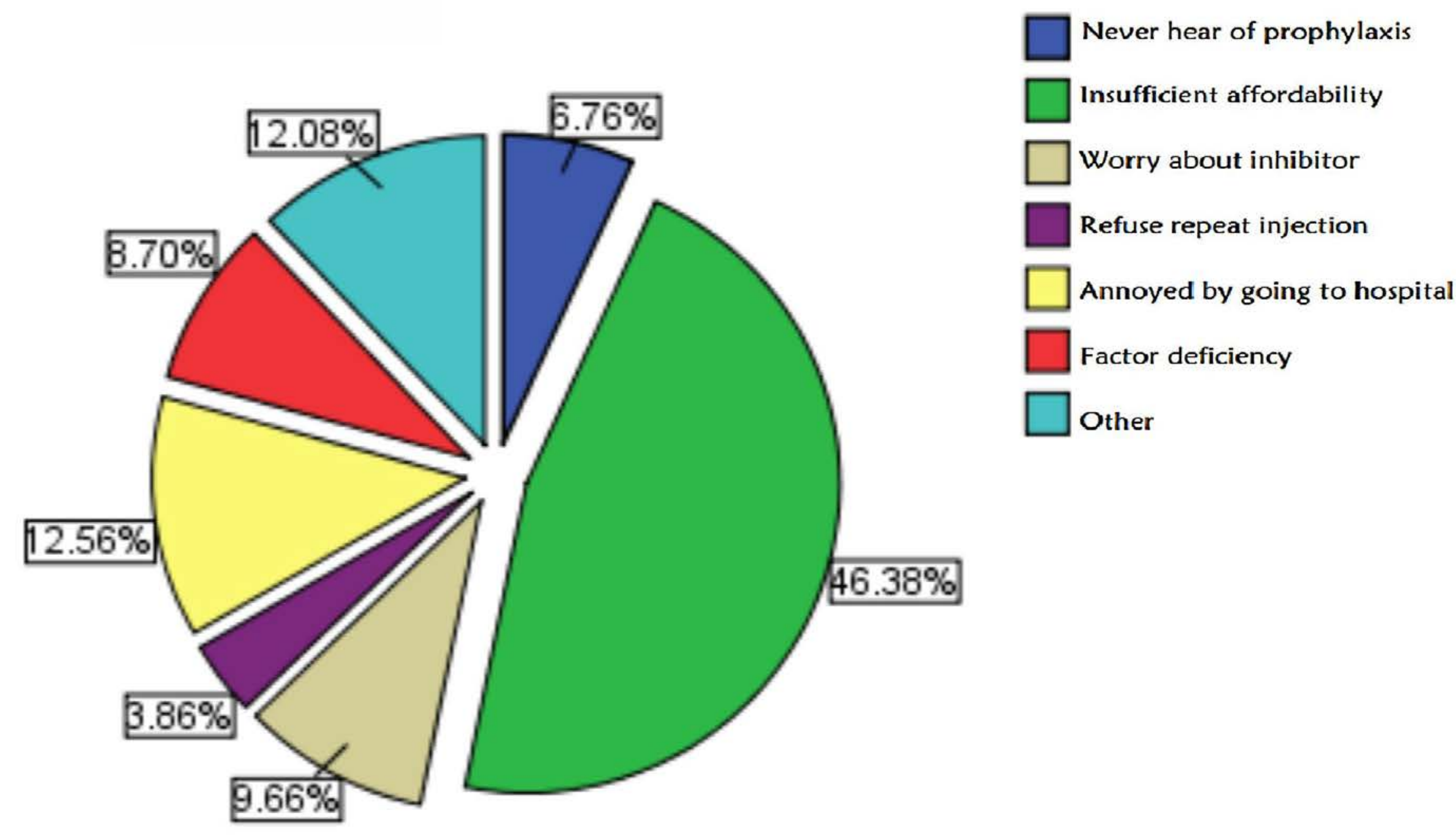


Figure. Several reasons were mentioned for severe/moderate patients not accepting prophylaxis. 6.76% never hear of prophylaxis. This result was not anticipated. And 156 of them chose **insufficient affordability** as reason to refuse prophylaxis. Though health insurance are increasing these years in China, there remain gap between reality and patients' expectation.

Results

- ✓ **595** cases were recruited. The **median age** was 7 (0.1-17.9).
- ✓ 527 (88.6%) were type A, 68 (11.4%) were type B.
- ✓ Mild 49 (8.2%), moderate 341 (57.3%) and severe 205 (34.5%), **192 (32.3%) accepted prophylaxis**.
- ✓ 124 patients's prophylaxis duration longer than 24 weeks consecutively.
- ✓ Average **initial age of prophylaxis** was 57.87 ± 50.90 (0-204) month.
- ✓ **Median dose for single infusion** was 11IU/kg (3-20IU/kg).
- ✓ **The frequency of infusion** varies from 1 to 3 times per week.
- ✓ 61(59.2%)patients terminated prophylaxis due to economic limitation.
- ✓ **7 mild hemophiliac boys had inappropriate prophylaxis**, while 316 boys with moderate/ severe haemophilia did not have.
- ✓ 156 of them chose **insufficient affordability** as reason to refuse prophylaxis.

Table.

Table. Prophylaxis in children with different severity of hemophilia
7 mild hemophiliac boys had **inappropriate prophylaxis**, while 316 boys with moderate/ severe haemophilia did not have.

	Severity of hemophilia			Total
	Mild	Moderate	Severe	
If prophylaxis accepted	No	42	234	403
	Yes	7	107	192
Total	49	341	205	595

Conclusion

Prophylaxis as a new pattern of haemophilia treatment was applied and accepted by part of hemophilia family in China, not all the patients had clear understanding of prophylaxis and the strategy of prophylaxis varied, economic limitation is still obstacle of prophylaxis for Chinese families