

Economic Burden of Patients with Hemophilia in China

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Introduction/Objectives

Hemophilia is a rare hereditary bleeding disorder caused by deficiency of a coagulation factor. Patients with hemophilia usually experience repeated bleeding which could lead to severe long-lasting clinical consequences. Life-long and standard treatment for hemophilia is required, which result in substantial economic burden on patients and their families. In China, approximately 65,000 patients live with hemophilia, while less consideration was given to economic burden of hemophilia. This research aims to determine the economic burden of patients with hemophilia in China from societal perspective.

Methods

A nationwide, online, cross-sectional survey was conducted with collaboration with Hemophilia Home of China, the biggest hemophilia patient organization in China in July 2021. Data on demographic characteristics, healthcare-related transportation expense and loss of labor productivity were obtained from questionnaires completed by patients or their caregivers.

Results

- **Sample population**

A total of 694 patients were included in the analysis, with adults accounting for 38.33% and hemophilia A accounting for 83.00%.

- **Health care utilization**

25.1% of patients had experienced hospitalization at least once last year and 14.5% of patients or their caregivers had missed work due to hemophilia in the past week. The survey represented that inadequate drug use and healthcare utilization of patients mainly resulted from financial difficulty.

- **Direct economic burden**

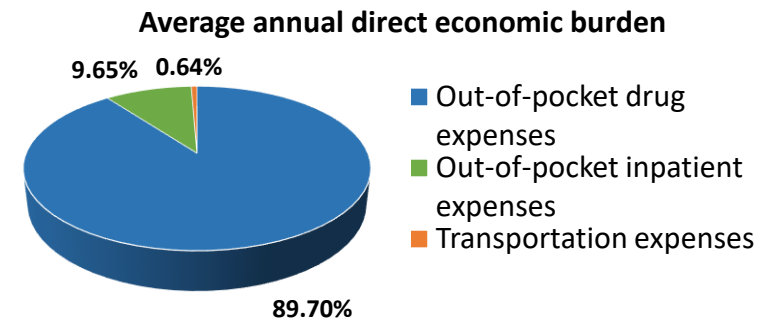
The average annual direct economic burden per patient associated with hemophilia was \$9,425, with out-of-pocket drug expenses, inpatient expenses and transportation expenses respectively accounting for 89.7%, 9.65% and 0.64%.

- **Productivity loss**

The average annual loss of labor productivity driven by patients missing work for hemophilia-related treatment or caregivers caring for the patients was estimated as \$578.

- **Catastrophic Health Expenditure**

80.62% of hemophilia patients' families encountered catastrophic health expenditure, meaning that annual hemophilia related costs exceeded 40% of their annual non-food household expenditure.



Conclusions

Hemophilia is associated with a substantial economic burden for hemophilia patients in Chinese setting. More measures should be taken to enhance health security for hemophilia patients to further relieve their economic burden.