

How Thalassemia is prevented in China: A Policy review and international comparison

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OBJECTIVES

- This study aims to explore the policies on Thalassemia prevention in China, also to **propose potential improvements** by comparing with the policies carried out in other countries.

METHODS

- The literatures **on Thalassemia** and policy documents **in China** were searched, selected and reviewed for international comparison and suggestions proposing.
- The search for the **literatures**, published after 1999, was implemented in PubMed and EMBASE with the keywords: Thalassemia, prevention, and policy.
- Policy documents** were collected from the official websites of National (Local) Health Commission of the People’s Republic of China and National (Local) Healthcare Security Administration.

RESULTS

- 21 academic publications and 149 policy documents from the high-Thalassemia-incidence provinces were included.
- The review indicates that China has launched the **pilot project** for Thalassemia prevention and control in 2012, with the financial support from the central government.
- This project contributes to the **three-level prevention and control system (Figure A)** of Thalassemia, including promoting disease education, premarital medical examination as well as treatment and relief services.
- The **continuing declining birth rate of children with Thalassemia** since 2015 demonstrates its effective achievements^[1].
- Europe and the Mediterranean coastal regions (Cyprus, Greece, Italy) have **well-established system (Table 1)**^[2,3,4], containing the national screening program, registration system, and reimbursement mechanisms.
- In comparison**, China currently mainly focuses on pilot regions, so only a few regions have established a relative perfect system, and lacks provisions to maintain the transfusion accessibility and reimbursement mechanisms (**Figure B**) to protect the patients from **catastrophe payments**, even if the reimbursement proportion exceeds 50% in most cases (**Figure C&D**)^[1].

CONCLUSIONS

- Thalassemia prevention system has been rapidly improved in China since 2012, but there is still a **gap** between China and European countries on **screening strategy** and **reimbursement policies**.
- Increasing capital investment to improve reimbursement policies, carrying out the entire population screening strategy, establishing a mechanism to ensure transfusion accessibility and developing The Belt and Road initiative, strengthening international cooperation should be the next policy focus for China.

Table 1: Thalassemia prevention and control measures (Europe and the Mediterranean coastal regions)

National health service network	Screening	Public awareness	Counseling	Treatment
Gene screening, prenatal diagnosis, genetic counseling and registration system	Screening strategy based on community population (large-scale), including premarital, prenatal and neonatal	Thalassemia related education courses in secondary schools	Prenatal diagnosis, preimplantation diagnosis, termination of pregnancy	Free treatment, standardized and effective blood transfusion (Hemoglobin<90g/L in Cyprus, <60g/L in China)

Figure A: Prevention and control system of Thalassemia in China

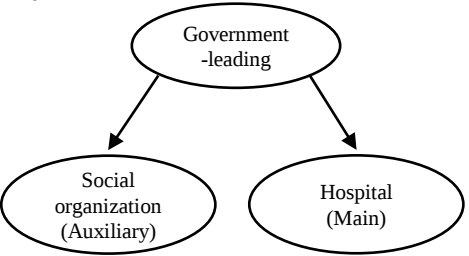


Figure B: Reimbursement proportion of Thalassemia in China (difference between different provinces and cities)

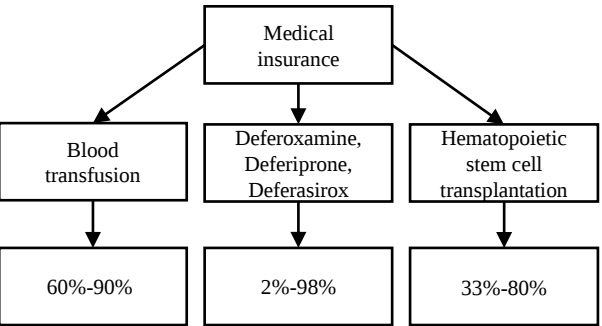


Figure C: Annual income of the patients’ family in China (Unit: RMB)

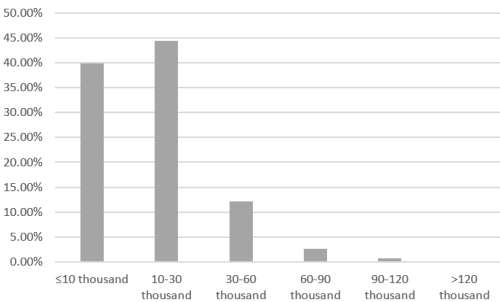
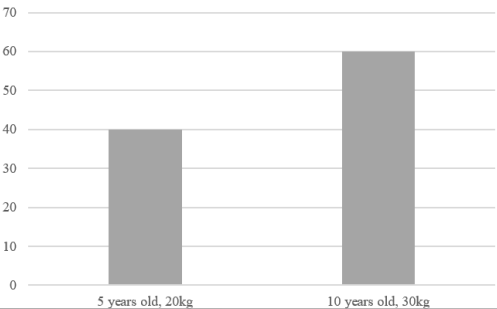


Figure D: Annual treatment cost of patients in China (Unit: thousand RMB)



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