The Disease Burden of Beta-Thalassemia in China: A Systematic Review

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BACKGROUND & OBJECTIVES

- Thalassemia is a genetic blood disorder. It has become a **public health problem** in southern China because of the high genetic carrier rate and the large population.[1]
- Due to the **blood supply shortage** and the **high cost of iron chelation**, the disease poses a serious risk to the health of patients and gives rise to a substantial emotional and financial burden on families and also society.[2]
- Prevention of thalassemia is a crucial strategy to reduce birth defects in areas with a high prevalence of thalassemia in China.[1]
- This study aims to understand the **epidemiological burden**, **economic burden**, and **health service utilization of β-thalassemia in China**.

METHODS

- *Database*: PubMed, Web of Science, China National Knowledge Infrastructure, Wanfang Data, and Chinese BioMedical Literature Database.
- *Publication Date*: up to 31 Dec 2021.
- *Search Condition*: the main inclusion criteria were studies on the **epidemiological features and economic burden** of β-thalassemia disease, **life quality of patients**, and **utilization of health services** in China.

RESULTS

- In China, the **prevalence** of β-thalassemia ranged from **1% to 6%**, and the patients were mainly concentrated in the **southern area.** The overall **gene carrier rate** of β-thalassemia in southern China was between **1% and 8%**.[3] **(Figure 1)** Approximately 90% of intermediate and serious β-thalassemia patients were aged between 0 and 15 years old. Children with severe β-thalassemia usually developed symptoms at **3-6 months**, with an average age of 13.1 months, and **died before 5 years old if untreated**.[1]
- Children with β-thalassemia started transfusion therapy from 2 months to 6 years of age and terminated at (6.23 ± 4.86) years old.[4-5] The treatment costs were higher. The monthly expense of treatment was within **(3,803.91±1,976.99) CNY** given they received regular blood transfusion and iron chelation.[6] The iron chelation cost was significantly higher than the blood transfusion. **(Table 1)** The **disease burden** of β-thalassemia increased from **1.38% to 17.12%** in Guangdong.[7]
- Due to the lack of adequate blood supply, 44.1% of the children were **rejected by the hospital**.[6] Technical interventions were offered in some areas, but there was still a shortage of medical professionals and funding.[8] More than 90% of thalassemia patients lacked knowledge about thalassemia and they did not receive any genetic screening.[9] In addition, the disease itself, the side effects of treatment, as well as the **physical and social limitations** caused by the chronic disease, seriously affected the mental health of patients.[10]

DISCUSSION & CONCLUSIONS

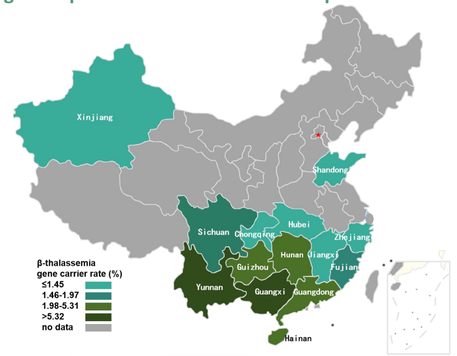
- The prevalence of thalassemia varies widely among provinces in China. Generally, the **gene carrier rates are higher in low-latitude regions**. The patient population is mostly children.
- Unable to afford the **high medical expenses** caused by long-term treatment and lack of qualified blood sources, some patients cannot undergo blood transfusion and iron chelation treatment on schedule, which seriously affects their survival rate and life quality.[11]
- Inadequate publicity and education, as well as limited awareness of prenatal and postnatal diagnosis in the public, also add difficulty to intervene and prevent the occurrence of the disease effectively. β-thalassemia potentially induces a more severe disease burden than other hematologic diseases.

Table 1. β-Thalassemia economic burden in representative provinces of China from 3 identified studies

Region	Patient type	Sample size	Data source	Cost (CNY/Month)		
				Direct*	Blood transfusion**	Iron chelation**
Guangxi[9]	Serious	300	Tertiary hospitals	1000-3000	1211.89	2030.34
Guangdong[6]	Serious	249	Tertiary hospitals	1938.51	391.75	1345.31
Chongqing[4]	Serious	41	Tertiary hospitals	1500-3000	767.00	1414.00

*Direct Cost: the total cost of direct use in the prevention and treatment of β-thalassemia per month, including blood transfusion cost and iron chelation cost.
**Average value. Generally, patients under two years old don't need iron chelation. The patient's weight was positively correlated with transfusion amount, transfusion cost, iron chelation drug dosage, and iron chelation cost.

Figure 1. β-Thalassemia carrier rate in provinces of China [3,12-13]



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