

OBJECTIVES

- Paroxysmal nocturnal hemoglobinuria (PNH) is a rare, clonal, complement-mediated hemolytic anemia with protean manifestations.
- PNH and a series of complications have brought a heavy economic burden on patients and their families, however, there are few studies on the economic burden of PNH patients in China.
- This study aimed to evaluate the economic burden of patients with PNH in China.

METHODS

- The data was conducted by Shandong University in collaboration with the PNH China from May to June 2023, and patients with PNH who were clinically diagnosed for one year or more were included in the survey.
- Direct medical costs, direct non-medical costs and indirect costs were investigated.
- Descriptive analyses were conducted to analyze the annual average of various costs.

RESULTS

- A valid sample size of 303 PNH patients was analyzed.
- There was 43.7% of patients were jobless or unemployed, and 93.5% of them were unemployed due to having PNH.
- The annual direct medical cost per capita was ¥45,779, while the direct non-medical cost per capita was ¥13,628, and the indirect cost per capita was ¥46,738.
- In the composition of direct medical costs, outpatient and emergency costs accounted for 31%, and hospitalization costs accounted for 46%. Among the components of direct non-medical costs, transportation costs (35%) and nutrition costs (33%) accounted for the largest proportion. In the composition of indirect costs, the cost of missed work caused by family members to care for patients far exceeds the cost of missed work of patients.
- The average annual direct medical cost for the 185 patients with comorbidities was ¥58,942, more than twice the cost for patients without comorbidities. In terms of cost components, the largest differences between the two groups of patients were found in hospitalization costs and the costs of family members' lost wages.
- Among the comorbidities in PNH patients, bone marrow failure had the highest number of annual occurrences (4) and the highest average annual out-of-pocket costs (¥ 59,400).
- The average annual out-of-pocket comorbidities related medical costs for patients with combined thrombus and kidney injury were ¥33,000 and ¥15,900, respectively.
- 57.8% of patients spent more than 40% of their total annual household income on direct medical care, which means catastrophic household health expenditures were incurred.

Table 1 Overall economic burden of PNH patients in China

Type of cost		Average cost (¥)	Total cost (¥)
Direct medical cost	Outpatient and emergency costs	14136	45779
	Hospitalization costs	21126	
	Purchasing medication costs	10517	
Direct non-medical cost	Transport costs	4820	13628
	Meal costs	2475	
	Accommodation costs	1748	
	Nutrition costs	4486	
	Caregivers costs	98	
Indirect cost	Patient's lost wages	9988	46738
	Family members' lost wages	36750	

CONCLUSION

The economic burden of disease for Chinese PNH patients is high, especially in terms of hospitalization costs, transportation costs, and indirect costs. The existence of comorbidities is the main reason for the high economic burden of PNH patients.

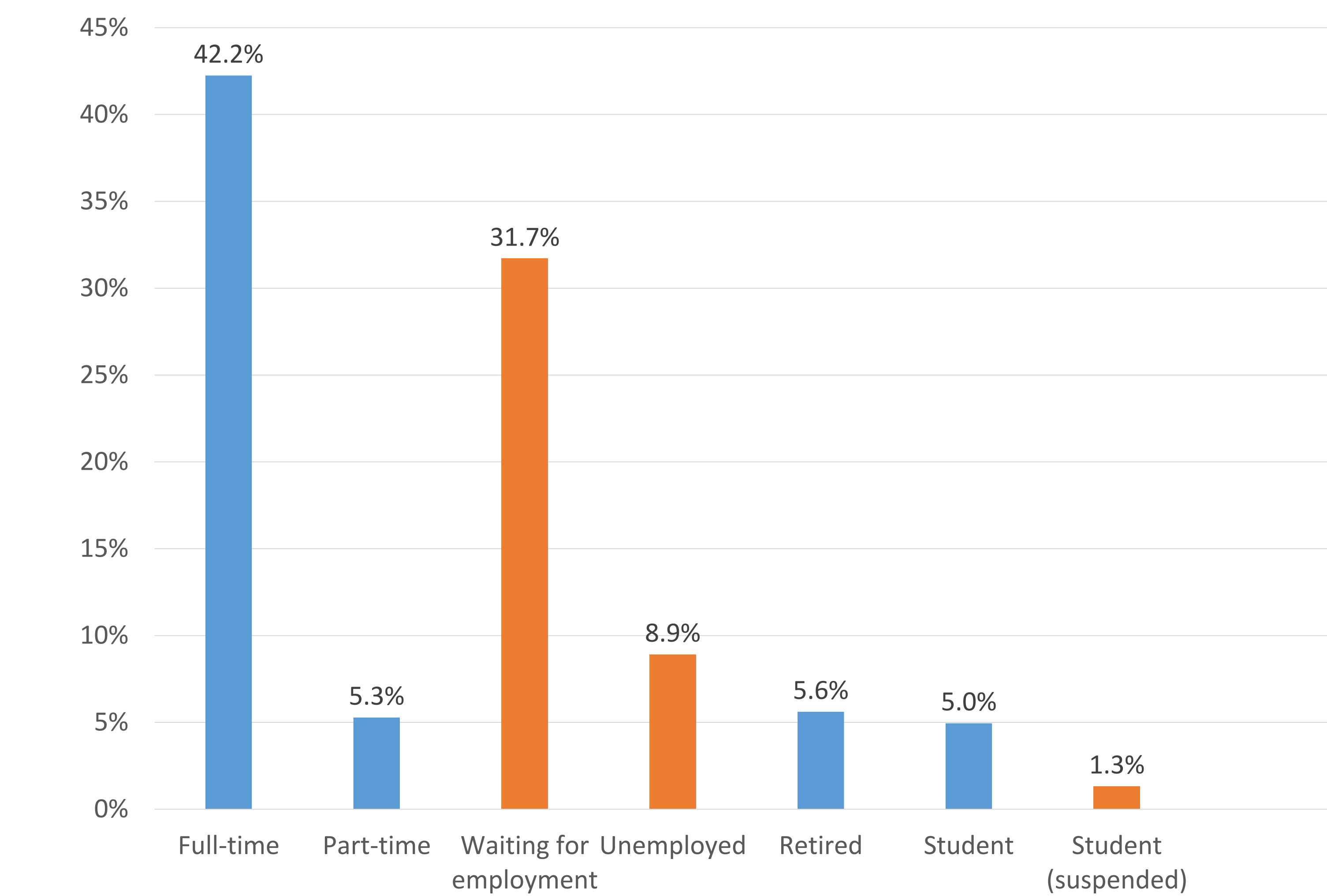


Figure1 Work and study status of patients with PNH

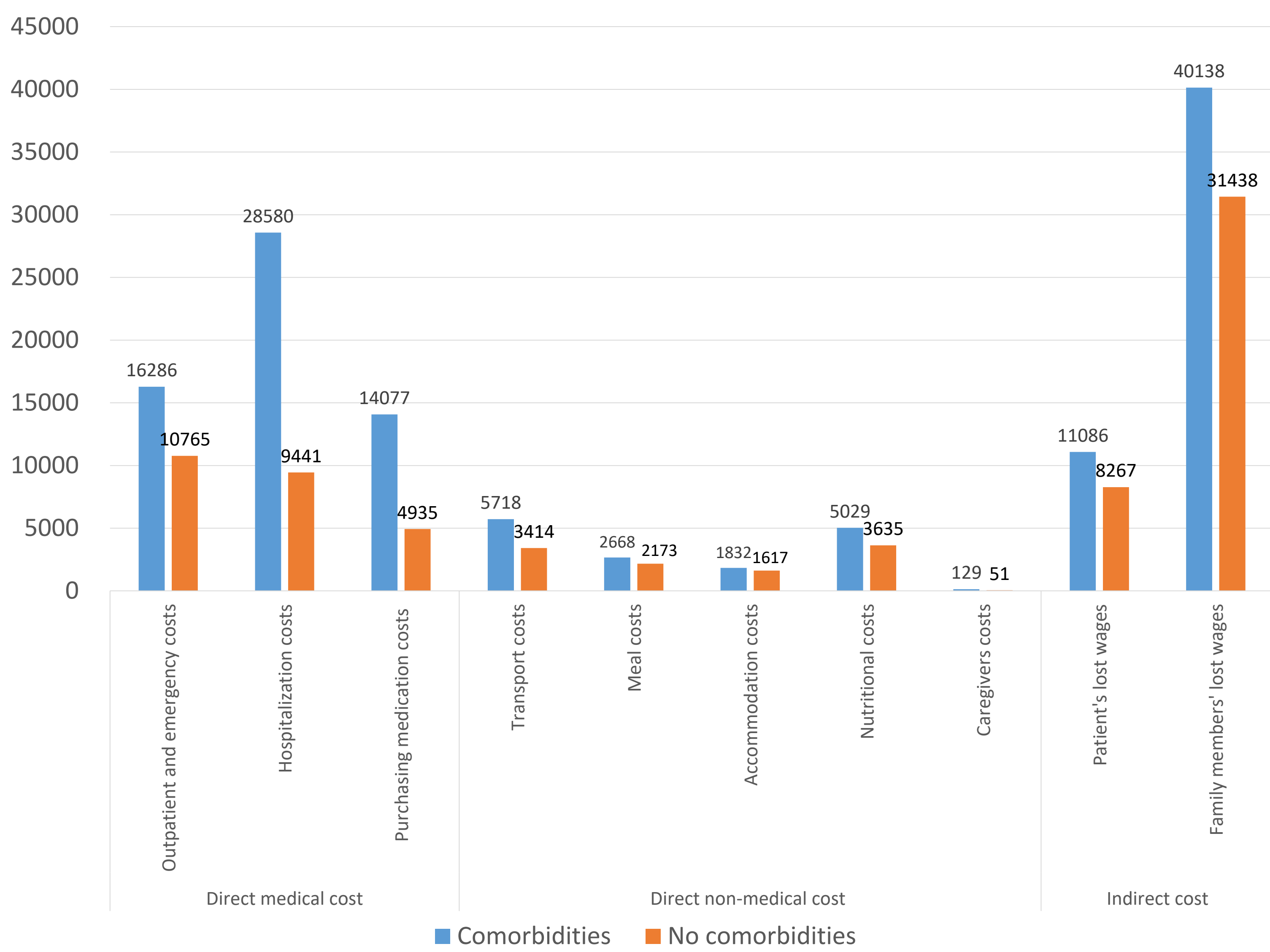


Figure2 Average annual out-of-pocket medical expenses for patients with and without comorbidities

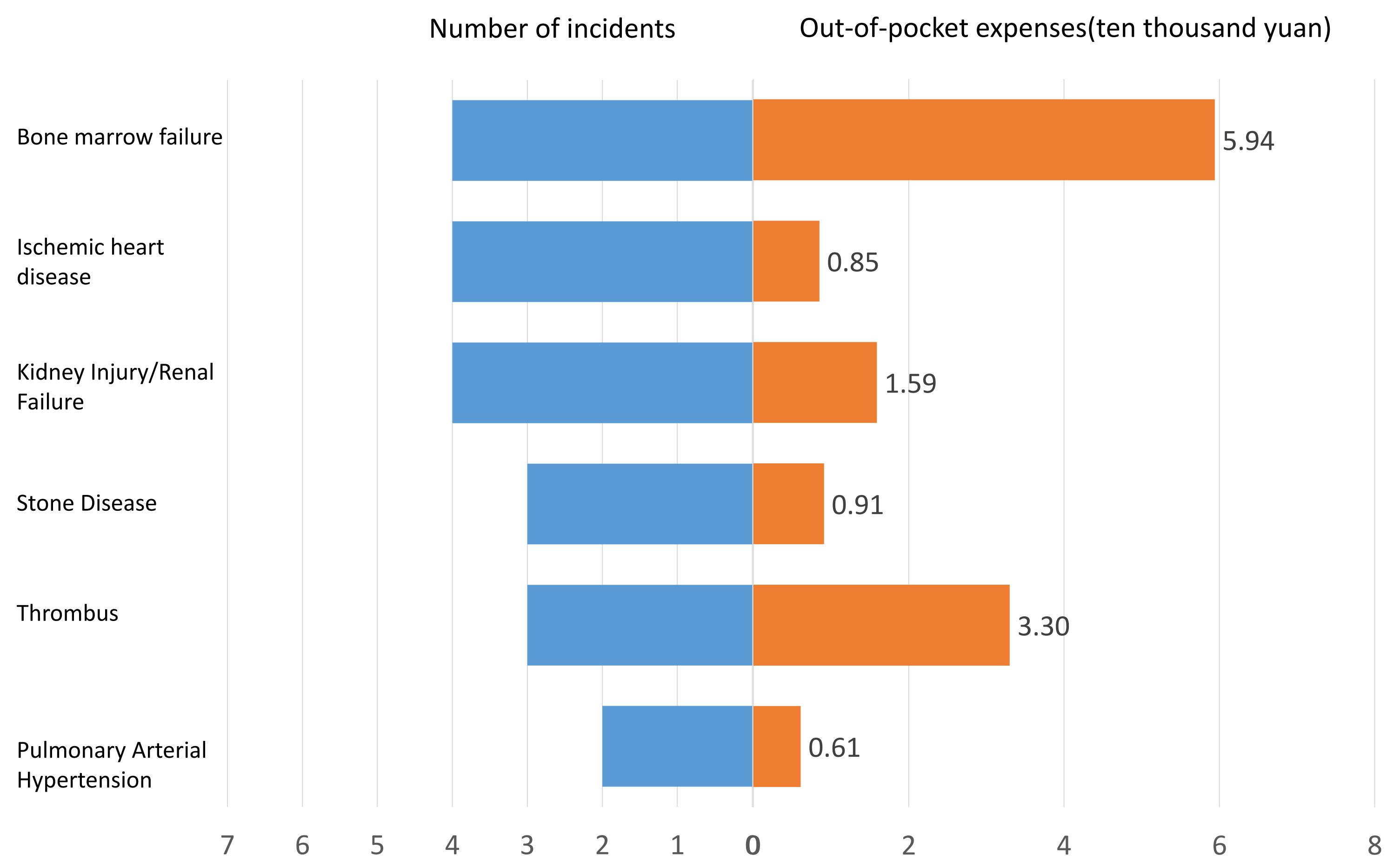


Figure3 PNH Complications and Economic Burden