

The **economic burden** and its consequences on families with **children** affected by **MYASTHENIA GRAVIS** in China

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Objective

To explore and disclose the economic burden and its consequences for families with children affected by MG in contemporary China.

Method

A national survey was conducted by the Beijing Aili Myasthenia Gravis Rare Disease Care Center in 2014. Parents (n=145) of children (aged below 18) with MG were recruited through the Internet. A cross-sectional study was used to evaluate the economic burden on the families.

Results

Disease onset age, Misdiagnosis, and Parents' knowledge about MG.

Among the 145 families, half of their children's age of disease onset was before two years old (50.1%), with an average of 7.63 months to receive the correct diagnosis.

Although only about 15% of the children had been misdiagnosed, parents' knowledge about the disease was relatively inadequate. About 37% of the parents did not know about the restrictions on medications for MG patients, which however have significant impact on the disease's influence to children's life. **When parents have better knowledge about MG, the odds of serious impact brought to children's life by the disease will decrease** (OR = 0.36, 95% Confidence Interval = 0.17-0.78; p = 0.009).

The economic burden and its consequences for these families were obvious.

More than 58% of the families had to spend more than one third of their total incomes on their child's treatments. Compared with people who spent 10% of their income on children's treatment per month, **when the families spent higher income proportion, the self-reported economic burden increased significantly** (for families spent 10-40% of their incomes, OR=12.7, 95% CI = 1.55-104.30; p=0.018; for families spent more than 40% of their incomes, OR=105.77, 95% CI = 11.09-1008.96; p<0.001).

Regarding the average expenditure on treatment per month, the odds of having a higher level of impact on the child patient's life is 6.3 times for the families spent over 1500 RMB per month than those spent less than 500 RMB (OR = 6.30, 95% Confidence Interval = 1.98-20.05; p<0.001).

Possibly as a consequence, in terms of the willingness of families to **apply for a disability certificate for their children** (which may alleviate some but very limited economic burden), the odds of families with severe economic burden is 3.26 times higher than those who had less (OR = 3.26, 95% Confidence Interval = 1.37-7.75; p = 0.007).

Conclusion

As the first national survey on families with MG children in China, this study reveals that the economic burden on the families are significant and severe. The main problem is that, the country does not provide sufficient and substantial support for these families, nor are the existing policies good enough to provide an economic safe-net for the families. In order to take care of their children, many parents, at least one of the two, have to quit their jobs, which in turn, exacerbates the economic burden on the families. Also, the "money" problem often leads to negative impacts on children's psychological and physical well-beings. Hence we propose that it is more than critical to address these issues, as the study unveils, by the government and other related players in the field of rare disease policy advocacy in China.