

Press release

The unbearable weight of being rare: Results from the first national survey among people living with rare diseases in China

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As the world's most populous country, China however does not have epidemiological or registry information about people affected by rare diseases. In February 2016, the Illness Challenge Foundation in collaboration with Hong Kong Baptist University conducted the first national survey among rare disease patients in China. In total, 1,771 valid questionnaires were collected, among which 1,195 were answered by patients themselves.

The 1,195 patients were affected by a total of 102 distinctive rare diseases. The onsets of their diseases were quite early. Almost 60% of the patients had started to show certain symptoms or being diagnosed before their adulthood began. More than 60% of the patients had been misdiagnosed. Even for those who had a diagnosis, about 20% had not received any type of treatment.

Most of the patients had to fully rely on the supports from family members or limited sources from social welfare. Among the 508 unemployed patients, 62.6% had lost their abilities to work (such as disabled or too sick to work). Across all four areas of quality of life (i.e., physical, psychological, social and environmental), the patients were scored much lower even than patients with pneumoconiosis. They received much less social support than, for instance, people with HIV. In addition, their lifestyles are very sedentary. The four most frequently participated activities were: surfing online, watching TV or videos at home, listening to music at home, and read print media. As a result, they became extremely isolated from the society and gradually lost their visibility.

The survey results revealed the urgency of initiating legislation on specific rare diseases in China. Many of the difficulties, barriers, and problems that the Chinese rare disease patients encounter on a daily basis are outside of the scope of medical science. Hence the Illness Challenge Foundation, as Beijing's first foundation focusing on rare diseases, urges all stakeholders to work together to remove the burdens that Chinese rare disease patients have been shouldering via all possible means including policy advocacy and legislation at the national level.