Letter

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Focusing on basic data and a model of healthcare security for rare diseases: The Multidisciplinary Expert Seminar on Healthcare Security for Rare Diseases in China was held in Beijing

Qi Kang[1], Chunlin Jin[1], Dingguo Li[2,*]

[1] Department of Health Policy Research, Shanghai Health Development Research Center, Shanghai Medical Information Center, Shanghai, China;
[2] Shanghai Foundation for Rare Diseases, Shanghai, China.

Summary **On August 10, 2019, the Multidisciplinary Expert Seminar on Healthcare Security for Rare Diseases in China was held in Beijing. The seminar was organized by the Shanghai Foundation for Rare Disease and Shanghai Health Development Research Center and advised by the China Alliance of Rare Diseases. Participants in this seminar included government officials, experts in clinical medicine, pharmacy, epidemiology, health economics, and law as well as representatives from rare disease patient organizations. The participating experts cited three key elements of healthcare security, including its concept, data, and mechanism, to solve the problem of health care security for patients with rare diseases at the national level. Collection of basic data and creation of a model of healthcare security for rare diseases were discussed. Data collection should be actively promoted. Creation of a special zone to ensure medical care for patients with rare diseases should be considered. Healthcare security should be classified, which means that basic medical insurance provides better care for rare diseases that respond to treatment, and channels should be established for rare diseases that respond poorly to treatment.**

Keywords: Rare disease, healthcare security, multidiscipline, expert discussion

On August 10, 2019, the Multidisciplinary Expert Seminar on Healthcare Security for Rare Diseases in China was held in Beijing. The seminar was advised by the China Alliance of Rare Diseases (CARD) and organized by the Shanghai Foundation for Rare Disease and Shanghai Health Development Research Center. Present at the meeting, were relevant officials from the Department of Drug Policy and Essential Medicine System of the National Health Commission (NHC), the Bureau of Medical Administration of NHC, and members from the Expert Committee on Diagnosis and Treatment of and Care for Rare Diseases of the NHC, experts and scholars from rare disease societies in 14 provinces or municipalities, medical insurance associations, and the fields of clinical medicine, pharmacy, epidemiology, health economics, and law, as well as representatives from rare disease patient organizations. In total, more than 80 experts attended the seminar.

Wenjiong He, vice president of the China Association of Social Security and professor in the School of Public Administration of Zhejiang University, gave a special speech on "Examination and Implementation of Healthcare Security for Rare Diseases in China." His research indicated that medical care for rare diseases in China is expensive, and this burden is mainly borne by patients and their families. He also described healthcare security for rare diseases in Qingdao, Shanghai, and Zhejiang. He interpreted the latest policy of the National Healthcare Security Administration, which calls for the issuance of new policies to be halted in order to expand the scope and increase the level of reimbursement by basic medical insurance at the district level and which proposed a list of ensured medical benefits (*1*). He pointed out that the introduction of this policy meant that issuing new local policies on ensured medical care for rare diseases

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*Address correspondence to:
Prof. Dingguo Li, Shanghai Foundation for Rare Disease, 1477 Beijing Road (west), Shanghai 200040, China.
E-mail: 13901813288@163.com

would be difficult. Therefore, the problem of ensuring medical care for rare diseases needs to be gradually and effectively solved at the national level. The key lies in three aspects: the concept of ensured care for rare diseases, basic data on patients with rare diseases, and a mechanism to ensure care for rare diseases.

Junshuai Liu, vice president of the Qingdao Medical Insurance Research Association of Shandong Province, gave a speech entitled "Some Thoughts on Ensuring Medical Care for Rare Diseases in China." He described the basic aspects of ensured medical care for rare diseases (15 aspects including financing, co-ordination, cataloguing, pricing, and reimbursement) along with healthcare in Qingdao, and he analyzed its relevant points. He pointed out that healthcare security for rare diseases is a condensed version and a touchstone of healthcare reform in China. He recommended that healthcare security for rare diseases be a special zone for reform of healthcare security. The healthcare security should be independently funded. He also pointed out that in the event of a large surplus in national medical insurance (up to 2.3 trillion RMB in 2018) (*2*), allocating part of that surplus would ensure care for patients with rare diseases.

A spirited discussion on ensuring medical care for rare diseases in China was held among participants. The discussion specifically mentioned basic data collection and creation of a model of healthcare security for rare diseases in China, and participants actively made suggestions.

The participating experts fully recognized the significance of basic data to devising policies to ensure medical care for rare diseases in China. Linkang Li, chairman of CARD, mentioned that surveys on the three aspects of healthcare security were currently underway to obtain data and facilitate decision-making, including a health economics evaluation of rare diseases, a survey of doctors' attitudes towards the cooperative network for diagnosis and treatment of rare diseases, and a sociological study of patients with rare diseases through patient organizations. Shuyang Zhang, vice chairman and secretary general of CARD, mentioned that more than 38,000 patients with rare diseases have been registered since December 2016 through precision medicine research plans and cohort studies of rare diseases (*3*). She then appealed for more support from participating institutions to register patients. Ruilin Song, vice chairman of CARD, suggested that a mandatory rare disease reporting system should be established as soon as possible. Yuhui Zhang, deputy director of the National Health and Development Research Center of the NHC, proposed that patients with rare diseases be screened from the health expenditure database and that related research be conducted.

Experts at the meeting had a lively discussion of the model to healthcare security for rare diseases in China. A considerable number of the experts supported creation of a special zone to ensure medical care for rare diseases, a point raised by Junshuai Liu. However, some experts suggested that this may lead to inequity. In addition, some experts suggested increasing the amount of maternity insurance financing to ensure care for patients with rare diseases. Feng Zhang, deputy director of the Department of Drug Policy and Essential Medicine System of the NHC, pointed out that a multi-faceted comprehensive system of healthcare security for rare diseases is required and that it should be tailored to different diseases and areas. Specifically, medical care should be classified based on the response to treatment and cost of rare diseases (basic medical insurance provides better care for rare diseases that respond to treatment, and channels should be established to ensure care for rare diseases that respond poorly to treatment). Differences in policies in different regions should be allowed because of the various socio-economic levels in China.

After the seminar, the Expert Committee on Diagnosis and Treatment of and Care for Rare Diseases of the NHC and CARD held a symposium on the inclusion principle of China's Second List of Rare Diseases.

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