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## Experiences of Social Isolation among Patients with Neuromyelitis Optica Spectrum Disorder in China: A Qualitative Study

### Background:

Neuromyelitis optica spectrum disorder (NMOSD) is an autoimmune inflammatory demyelinating disease of the central nervous system, which mainly involves the optic nerve and spinal cord and has high recurrence and high disability rate, and patients with this condition are prone to social isolation, which is not widely studied. The purpose of this study was to investigate the experience of social isolation in patients with NMOSD.

### Methods:

A qualitative descriptive approach was used to conduct in-depth, face-to-face, semi-structured interviews. Data were analyzed using thematic analysis.

Results: A total of 20 patients (19 females, 1 male) completed the interview. Patients ranged in age from 14 to 68 years, with disease duration from 1 month to 30 years and Expanded Disability Status Scale scores from 2.0 to 8.0; 60% of patients were unemployed. Four major themes were identified: (1) perception of social isolation, (2) reasons for isolation, (3) impacts of isolation, and (4) potential solutions.

### Conclusions:

Social isolation affects patients of all ages with different levels of disability and duration of NMOSD. Isolation occurs as a result of multiple interactions between bodily functions and structures, the environment, and self-isolation. The effects of isolation are mainly physical, psychological, and familial. Although patients reported receiving good social support, they did not make good use of it. Comprehensive intervention to improve social isolation should be carried out based on these multidimensional influencing factors.

### Biography

[Haifen Liao](#) has received her master's degree in nursing, and is currently studying for her doctor's degree in nursing at [Sun Yat-sen University](#) in China. Her main research interest is the nursing of [neuroimmune diseases](#).



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