

BACKGROUND

Neuromyelitis optica (NMOSD) is a rare disease that disabling central nervous system disease characterized by acute or subacute demyelinating lesions involving the optic nerve and spinal cord simultaneously or successively.

OBJECTIVES

The study aims to investigate the basic characteristics ,disease characteristics, healthcare resource utilization, current treatment,satisfaction with current treatment,the most important factoe in treatment and health-related quality of life (HRQoL) among NMOSD patients in China.

METHODS

- ✓ An online survey of patients recruited from a national NMOSD patient association was conducted from May to June 2024.
- ✓ Patients' demographic and clinical characteristics, healthcare resource utilization and cost, health utility measured by the EQ-5D-5L, and aspects they deemed as critical for the treatment were collected.
- ✓ Descriptive analyses were conducted in the total sample. Subgroup analysis stratified by the disease relapse was then conducted.

RESULTS

- ✓ **Basic characteristics, disease characteristics**

➤ A total of 366 patients (mean age **40.3 ± 12.7** years, 40.3% female) were included. **71.1%** of patients live in city. **(Table 1)**

➤ The average delay of confirmed diagnosis was **2.6 ± 4.9** years. The average delay of duration in treatment was **2.3 ± 4.1** years. **(Table 1)**

➤ All subgroups showed long duration of delay in diagosis and treatment among NMOSD patients,The proportion of relapsed patients who had a disability and who had an affected walking condition was much higher than those of relapse-free patients . **(Table 1)**

RESULTS

- NMOSD can affect the vision of patients. More than **50%** of patients have different types of vision-related diseases, and the proportion of relapsed patients with vision problems is higher than that of relapse-free patients .**(Table1)**
- NMOSD can have an impact on the mental health of patients, with more than **20%** suffering from anxiety or depression.**(Table1)**

Table 1 Basic characteristics and disease characteristics of NMOSD patients

Variables	Total population N=336	Relapsed N=204	Relapse-free N=132
Females,n (%)	300(89.3%)	183 (89.7%)	117(88.6%)
Age,years,mean (SD)	40.3 (12.7)	40.7(12.2)	39.6(13.5)
Place of residence,n(%)			
City	239 (71.1%)	140 (68.6%)	99 (75%)
Countryside	97 (28.9%)	64 (31.4%)	33(25%)
Duration of delay in diagnosis, years, mean, (SD)	2.6(4.9)	3.4 (5.4)	1.4 (3.6)
Duration of delay in treatment, years, mean, (SD)	2.3 (4.1)	2.9(4.6)	1.4(3.5)
Disabled certificate ,n(%)			
Yes	53(15.8%)	45(22.1%)	8(6.1%)
No	283(84.2%)	159(77.9%)	124(93.9%)
Walking is affected, n (%)	66 (98.5%)	17 (94.4%)	17 (100.0%)
Yes	142(42.3%)	98(48.0%)	44(34.1%)
No	194(57.7%)	106(52.0%)	88(65.9%)
Blurred vision,n(%)	197(58.6%)	127(62.3%)	70(53%)
Loss of vision,n(%)	193(57.4%)	129(63.2%)	64(48.5%)
Visual field defects,n(%)	161(47.9%)	105(51.5%)	56(42.4%)
Double vision,n(%)	72(21.4%)	53(26%)	19(14.4%)
Anxiety,n(%)	140(41.7%)	87(42.6%)	53(40.2%)
Depression,n(%)	76(22.6%)	51(25%)	25(18.9%)

- ✓ **Current treatment, satisfaction with current treatment, and most important factors in treatment**

➤ The current treatment mentioned in the table below refers to the use of drugs recommended in the sequential treatment phase of the latest edition of the Chinese Guidelines for the diagnosis and treatment of Neuromyelitis optica Spectrum disorders proposed by the Chinese Society of Immunology and Neuroimmunology.**(Table2)**

➤ At present, mycophenolate mofetil is the most commonly used drug, accounting for more than **40%**, which belongs to immunosuppressive drugs.; **(Table 2)**.

➤ The patients' satisfaction with the current treatment regimen was not high, which was just at the pass level.**(Table 2)**

➤ The most important factor for most patients in treatment is whether the treatment can reduce or inhibit the recurrence of the disease, the proportion is accounting for about **70%**. **(Table2)**

Table 2 Current treatment, satisfaction with current treatment, and most important factors in treatment of NMOSD patients

Variables	Total population N=336	Relapsed N=204	Relapse-free N=132
Current medication use (Sequential therapy),n(%)			
Mycophenolate mofetil	141(42.0%)	83(40.7%)	58(43.9%)
Rituximab	59(17.6%)	42(20.6%)	17(12.9%)
Inerizumab	39(11.6%)	27 (13.2%)	12 (9.1%)
Satlizumab	15(4.5%)	4(2.0%)	11(8.3%)
Tocilizumab	2(0.6%)	2(1.0%)	0(0.0%)
Azathioprine	19(5.7%)	13(6.4%)	6(4.5%)
Tacrolimus	8(2.4%)	3(1.5%)	5(3.8%)
With no sequential therapy	109(32.4%)	63(30.9%)	46(34.8%)
Satisfaction with current treatment regimens,(SD)	6.0(2.8)	5.9(2.8)	6.0(3.0)
The most important factor in treatment,n(%)			
Preventing relapse	230(68.5%)	132(64.7%)	98(74.2%)
Preventing symptom deterioation	43(12.8%)	34(16.7%)	9(6.8%)
Safety	42(12.5%)	23(11.3%)	19(14.4%)
Accessibility	13(3.9%)	8 (3.9%)	5(3.8%)
Others	8(2.4%)	7(3.4%)	1(0.8%)

✓ **Quality of life**

- The EQ-5D-5L utility values of NMOSD patients was 0.665 (0.334); Among them, the EQ-5D-5L utility values of relapsed patients was 0.625 (0.338); the EQ-5D-5L utility value of relapse-free patients was 0.728 (0.321); And the utility value (SD) of the general Chinese population was 0.946 (0.096)[1].

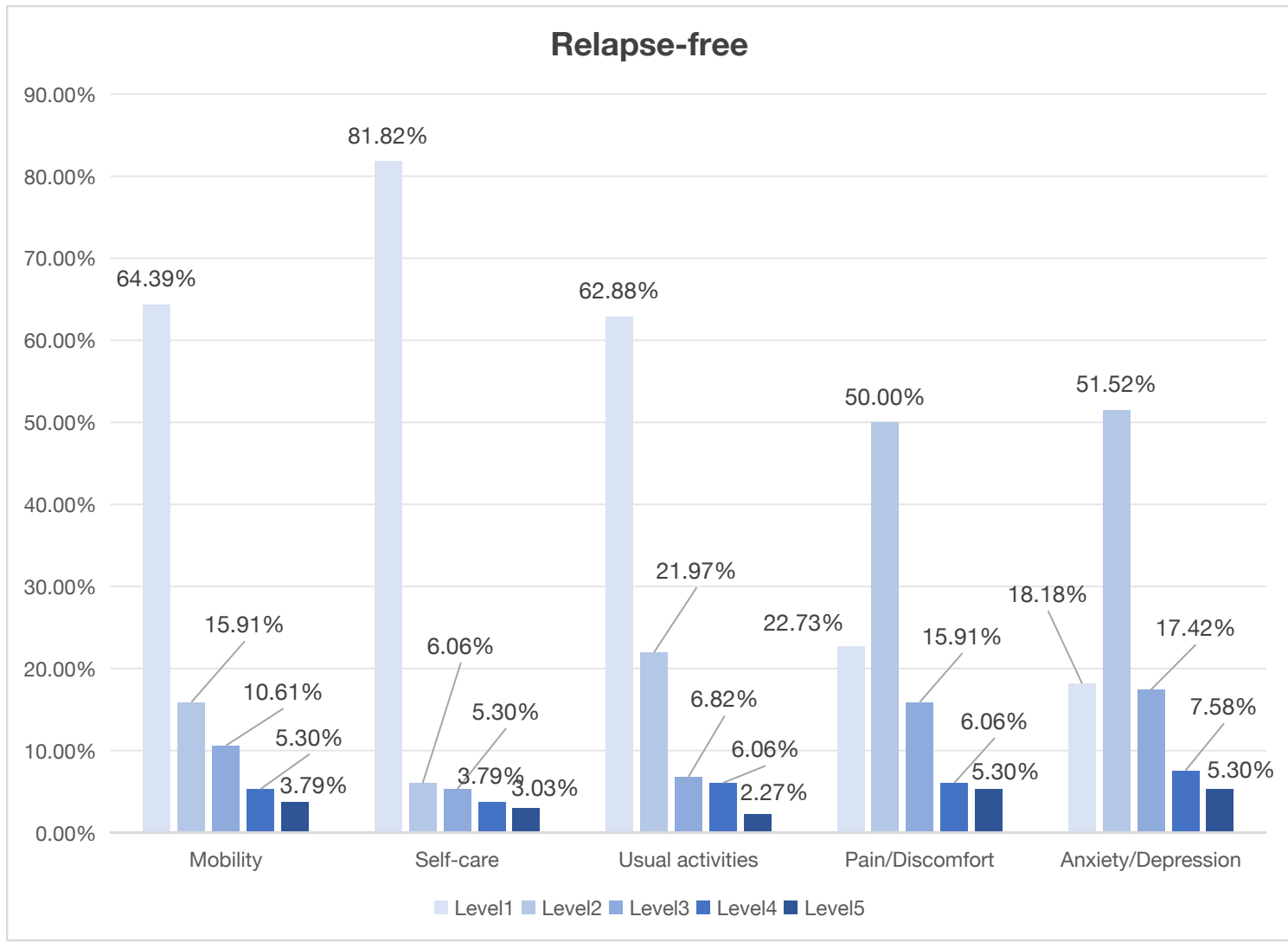
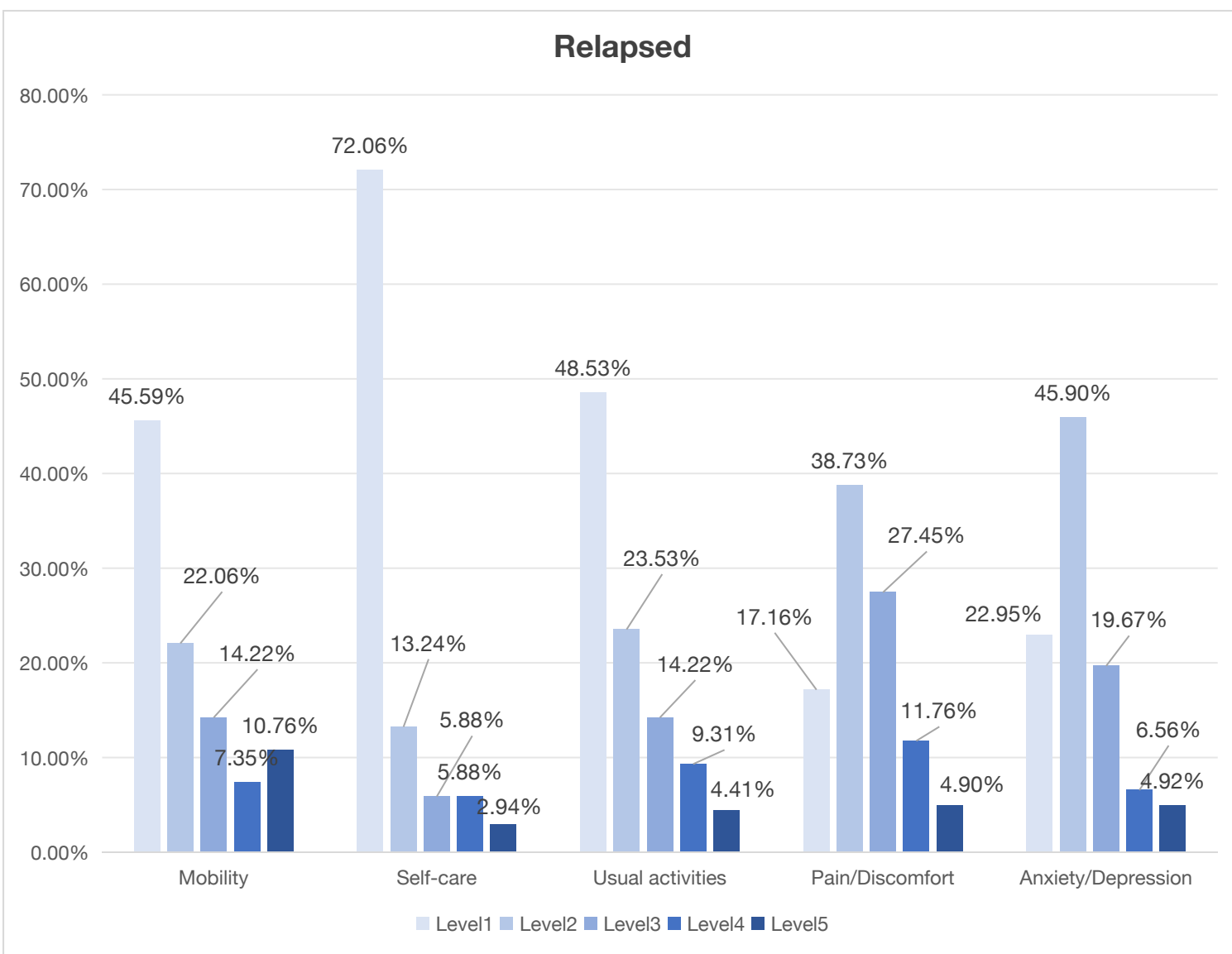
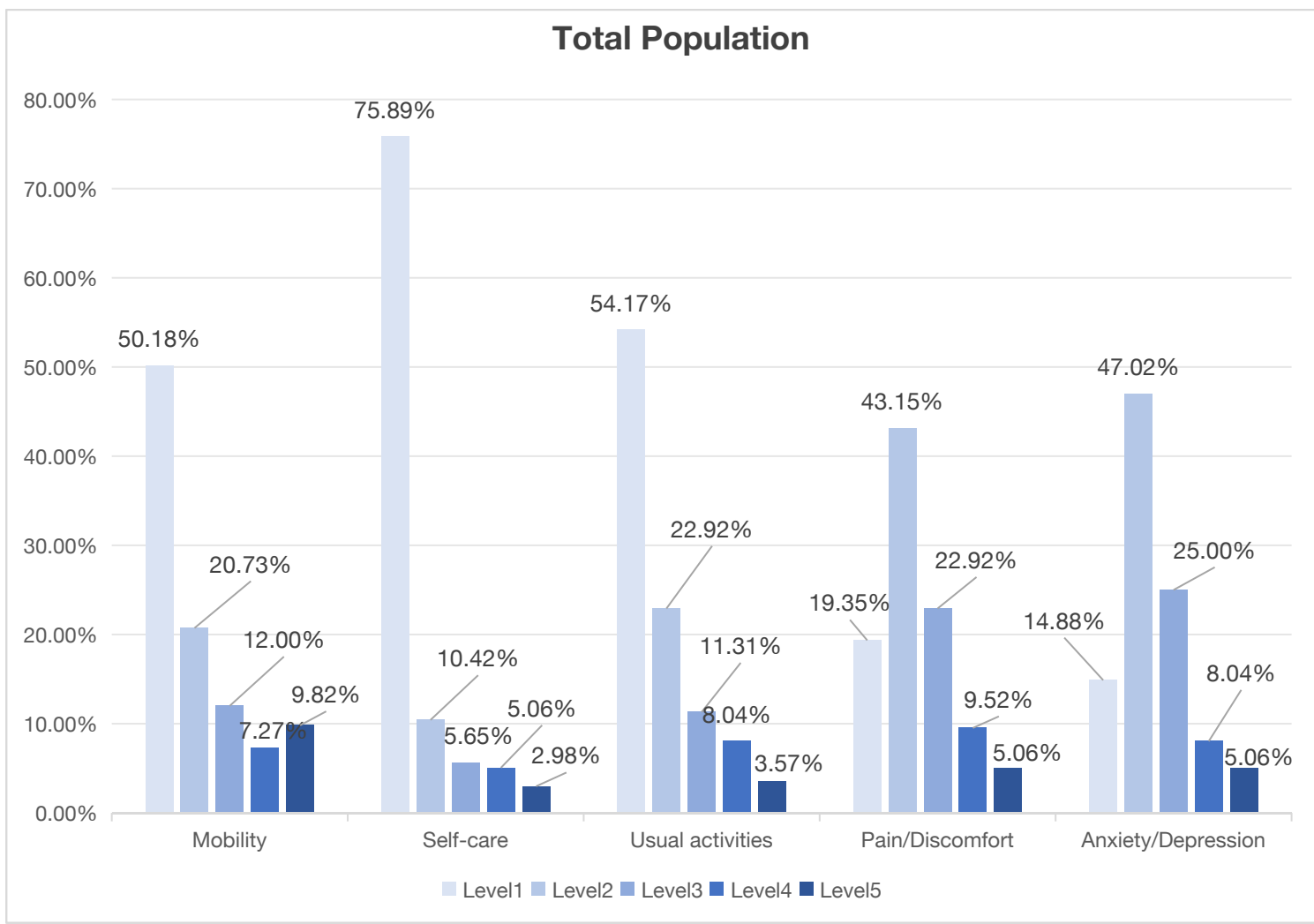


Figure 1-3 Distribution across levels of the EQ-5D dimensions of Total, Unrelapsing and Relapsing patients

CONCLUSIONS

In China, NMOSD patients, especially for patients with disease relapse, experienced a heavy disease burden in terms of long disease period, high proportion of disease relapse, high healthcare resource utilization and cost, and severe impairment of HRQoL.At the same time, patients have high expectations for drugs that can prevent patients from relapse.

Reference

[1]Xie S, Wu J, Xie F. Population Norms for SF-6Dv2 and EQ-5D-5L in China. Appl Health Econ Health Policy. 2022 Jul;20(4):573-585. doi: 10.1007/s40258-022-00715-2. Epub 2022 Feb 8. PMID: 35132573.