



Diagnostic Delay of Multiple Sclerosis in China: A Nationwide Cross-Sectional Study

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BACKGROUND

- Multiple sclerosis (MS), a chronic neurologic disorder, induces a worldwide challenge due to delay in diagnosis.
- Diagnostic delay of MS can adversely affects the timeliness of treatment and prognosis.
- However, in China, where MS is classified as a rare disease, the existence and factors contributing to diagnostic delay are not well studied.

OBJECTIVE

- This study aimed to evaluate the prevalence of diagnostic delay of MS in China and identify its associated factors.

METHODS

- Data sources:**
- We conducted a nationwide cross-sectional study in July 2022 using online surveys.
- Our study included individuals over the age of 18, had a confirmed MS diagnosis, and had consented to participate in the research.
- Patients provided information including detailed socio-demographic information, disease status, and diagnostic-related experiences.
- Measurements:**
- Diagnostic delay was defined as > 3 months elapsing between symptom onset to final diagnosis.
- The delay was further categorized into patient delay which reflected barriers at the patient level and system delay which reflected barriers within the healthcare delivery system.
- Patient delay was defined as > 1.5 months elapsing between the symptom onset to initial clinical consultation.
- Similarly, system delay was defined as > 1.5 months elapsing between initial clinical consultation to final diagnosis.
- Statistical analysis**
- Continuous variables were described by their means and standard deviations (SDs). Categorical variables were presented as frequencies and percentages.
- We conducted the Mann-Whitney U test to compare differences between patients with and without diagnostic delay.
- Binary logistic regression analyses were employed to examine the factors associated with diagnostic delay, patient delay, and system delay, considering various socio-demographic and diagnosis-related variables.

RESULTS

- 722 patients (female 67.6%; mean age 34.6 years old, SD 9.9) were finally included in the analysis. The average age of symptoms onset was 28.47 years old (SD 8.37).
- Overall, 48.48% experienced diagnostic delay, with 22.58 % attributed to patient delay and 44.74% to system delay. The average duration from symptom onset to final diagnosis was 16.23 months (SD 35.33). The average duration from symptom onset to initial clinical consultation was 11.27 months (SD 27.83). The average duration from initial clinical consultation to final diagnosis was 4.97 months (SD 19.16).
- Mann-Whitney U tests suggested unadjusted associations between diagnostic delay and age, year at symptom onset, initial department visited(Table 1).
- Regression analyses indicated that patients with moderate level of disease knowledge(OR=0.407, p<0.05), who initially consulted neurology/neurosurgery department (OR=0.188, p<0.01), or whose symptoms started after 2017 (OR=0.487, p<0.01) were less likely to face diagnostic delay. Older patients at symptom onset were less prone to patient delay (OR=0.964, p<0.05). Those choosing neurology/neurosurgery department initially (OR=0.089, p<0.01), or with symptoms beginning post-2017 (OR=0.574, p<0.01) were less likely to encounter system delay(Table 2).

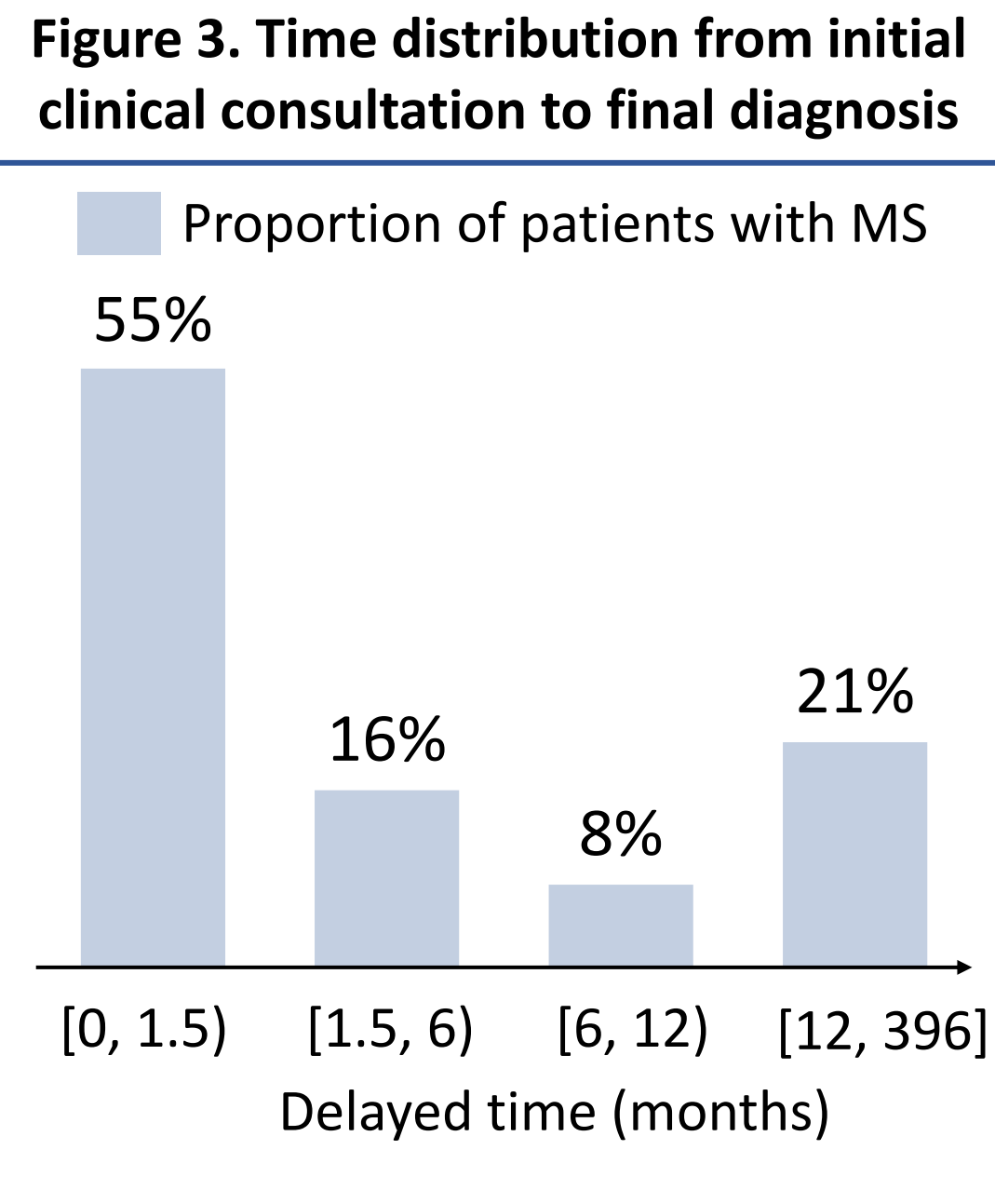
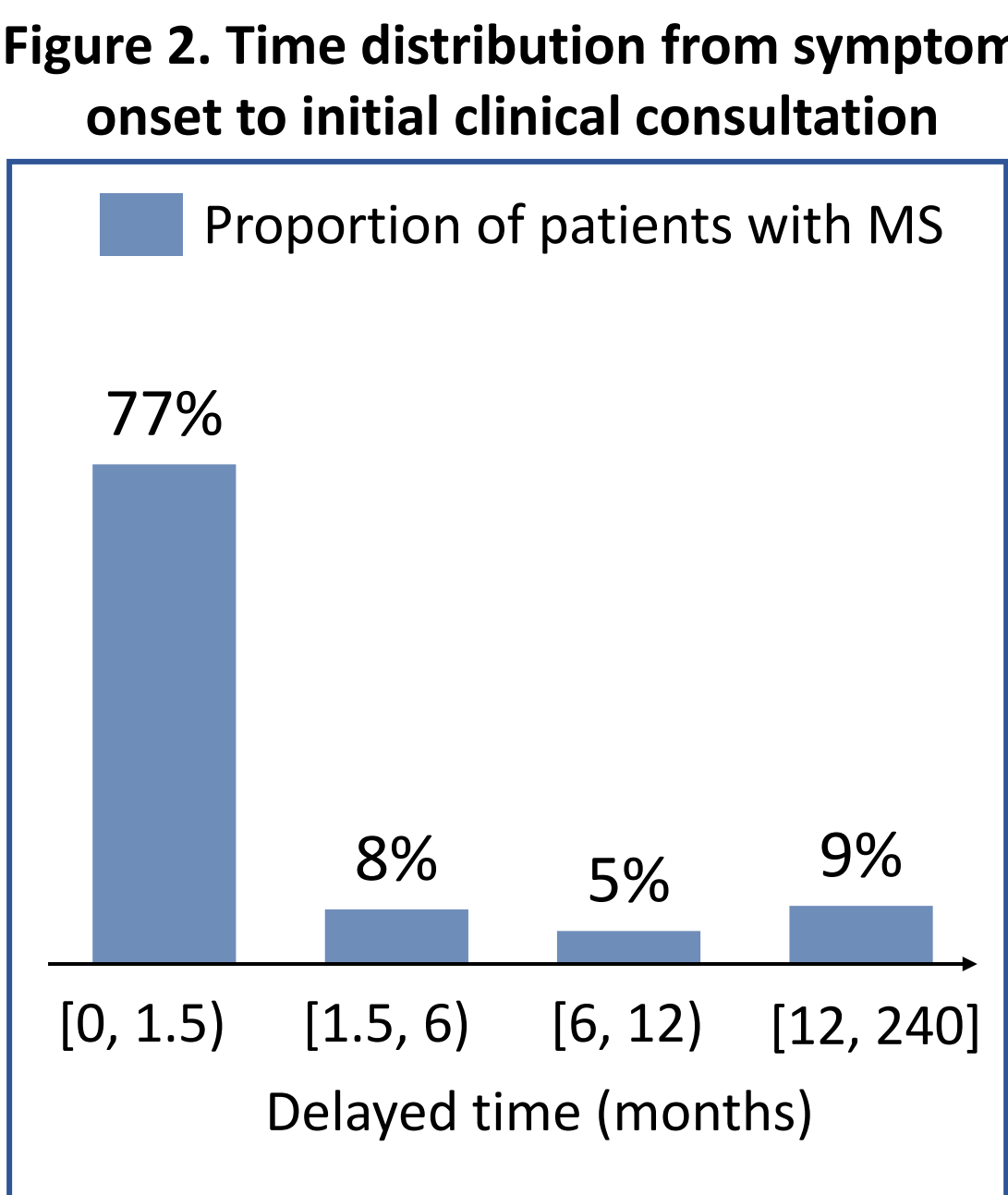
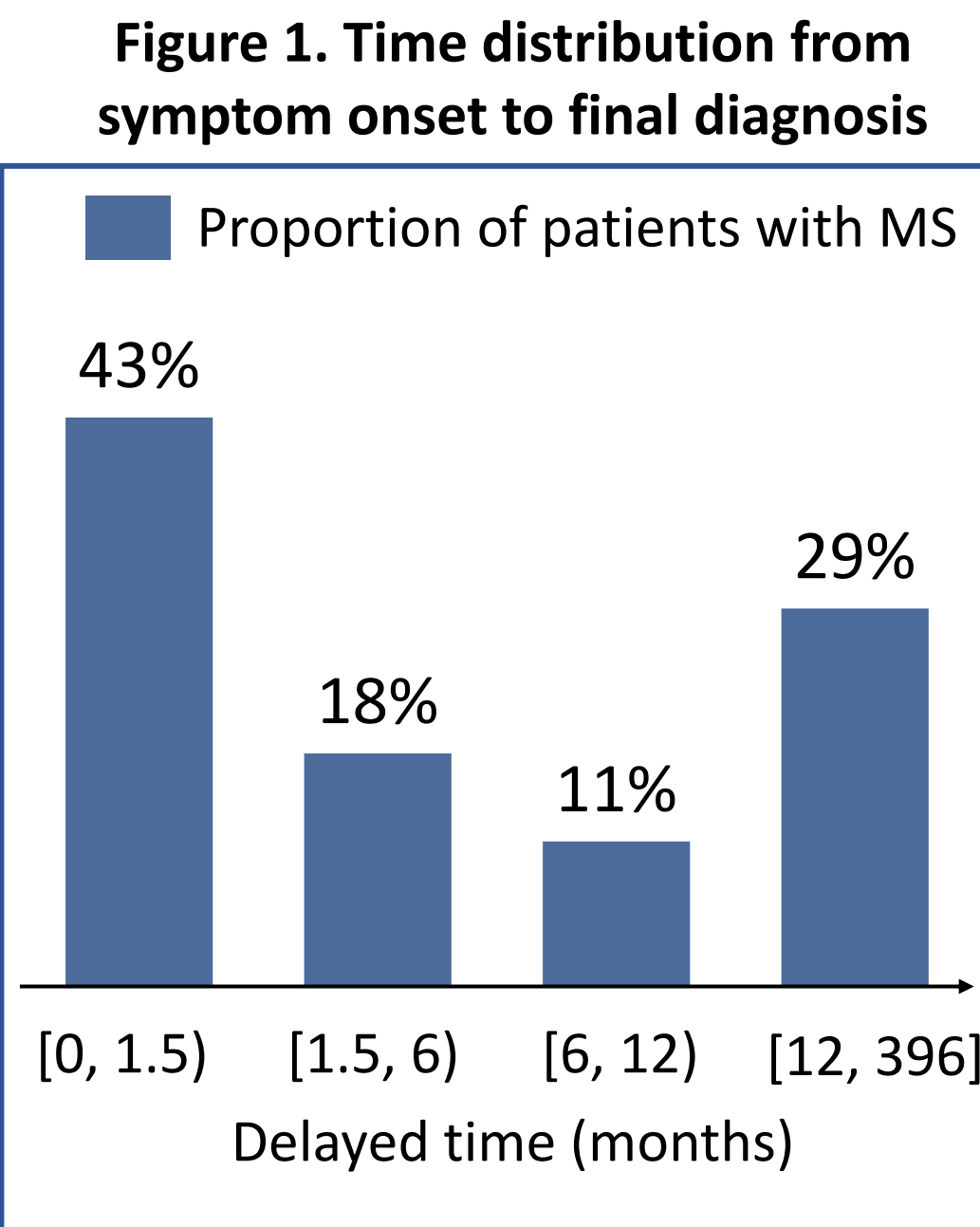


Table 1 Association of socio-demographic and diagnostic-related experience of MS patients with diagnostic delay				
Variables	Total sample(N=722)	Not delayed(N=372)	Delayed(N=350)	P value*
Age group, n				
18-24	90	53	37	0.01
25-39	320	177	143	
40-59	282	126	156	
≥60	30	16	14	
Gender, n				
Male	234	121	113	1.00
Female	488	251	237	
Educational level, n				
High school or below	235	113	122	0.16
Bachelor	442	233	209	
Master or above	45	26	19	
Health insurance, n				
UEBMI	452	233	219	0.80
URBMI/NCMS	220	117	103	
Other insurance	21	11	10	
Not insured	29	11	18	
Year at symptom onset, n				
Before 2017	356	142	214	0.00
After 2017	366	230	136	
Initial department visited, n				
Neurology/Neurosurgery	543	332	211	0.00
Other departments	157	36	121	
Forgotten	22	4	18	

*Mann-Whitney U test

Table 2 Results of binary logistic regression analysis on diagnostic delay of MS(N = 722)						
Variables	Diagnostic delay		Patient delay		System delay	
	OR	Robust SE	OR	Robust SE	OR	Robust SE
Age group (ref: 18-24)						
25-39	1.204	0.387	1.317	0.433		
40-59	1.675	0.736	1.825	0.724		
≥60	0.776	0.578	2.251	1.731		
Gender (ref: male)						
Female	0.970	0.182	1.051	0.21		
Residence (ref: urban)						
rural	0.678*	0.155	0.865	0.209		
Marital status (ref: married)						
Unmarried	0.961	0.193	0.766	0.162		
Educational level (ref: High school or below)						
Bachelor	0.760	0.159	1.172	0.267		
Master or above	0.753	0.287	0.652	0.327		
Employment status (ref: Employed)						
Long absence from work	1.161	0.321	1.569	0.455		
Retired	1.576	0.795	1.046	0.577		
Unemployed	1.150	0.267	1.318	0.32		
Health insurance (ref: UEBMI)						
URBMI/NCMS	0.833	0.182	1.145	0.268		
Other insurance	0.857	0.41	1.152	0.627		
Not insured	1.711	0.771	1.753	0.783		
Age at symptom onset	0.977	0.018	0.964**	0.015		
Ln(Household Income Per Capital)*	1.027	0.07	0.989	0.054		
Disease knowledge level (ref: Low)						
Moderate	0.407**	0.15	0.669	0.253		
High	0.495*	0.21	0.883	0.399		
Clinical classification (ref: RRMS)						
SPMS	0.926	0.317	1.554	0.543		
PPMS	1.875	0.865	1.890	0.923		
CIS	0.097*	0.115	0.423	0.436		
Not know	0.562*	0.189	1.214	0.437		
Initial department visited (ref: Other departments)						
Neurology/Neurosurgery	0.188***	0.042			0.089***	0.021
Forgotten	1.563	0.925			1.057	0.714
Year at symptom onset (ref: Before 2017)						
After 2017	0.487***	0.105			0.574***	0.097
Constant	15.987***	15.690	0.558	0.479	6.938***	1.630

*** p<0.01, ** p<0.05, * p<0.1 ; *The natural logarithm of household income per capita
OR: odds ratio; SE: standard error; UEBMI: Urban Employee Basic Medical Insurance; URBMI: Urban Residence Basic Medical Insurance; NCMS: New Cooperative Medical Scheme; RRMS: relapsing-remitting MS; SPMS: secondary progressive MS; PPMS: primary-progressive MS; CIS: clinically isolated syndrome.

CONCLUSIONS

- The increased policy focus on rare diseases in China since 2018 had a positive impact on the timely diagnosis of MS. However, diagnostic delay of MS remains a significant concern, predominantly attributed to system delay.
- Given the absence of a primary health gatekeeping system in China, patients' reliance on self-assessment to choose their initial consultation department poses a significant barrier to early diagnosis.
- There is a pressing need to enhance disease awareness among the general public and improve diagnostic capabilities among physicians, to ensure timely referrals and minimize MS diagnostic delay.