

Access to NMOSD care in an Argentinean cohort: real world patient experiences



V. Tkachuk^{1,2}, M.E. Balbuena Aguirre¹, R. Alonso³, A. Barboza⁴, S.d.V. Liwacki^{5,6}, C. Mainella⁷, J.I. Rojas^{8,9}, B.A. Silva^{3,10}, D. Tavolini¹¹, G. Zanga¹², P.A. López¹³, E. Carnero Contentti¹³



1-Neuroimmunology Section, Department of Neurology, Hospital de Clínicas "José de San Martín", Buenos Aires, Argentina, 2-Multiple Sclerosis Clinic CED Accord/Union Personal 3-Neurology Department, Hospital J.M. Ramos Mejía, Buenos Aires, Argentina, 4-Hospital Central de Mendoza, Argentina, 5-Clinica Universitaria Reina Fabiola and Neurology Unit, Córdoba, Argentina, 6-Hospital de Córdoba, Argentina, 7-Hospital Español, Rosario, Santa Fe, Argentina, 8-CEMIC, Ciudad de Buenos Aires, Argentina, 9-CEMBA, Buenos Aires, Argentina, 10-Neurology Department Hospital Italiano de Buenos Aires, Argentina, 11- INECO Neurociencias Oroño, Rosario, Santa Fe, Argentina, 12- Hospital Cesar Milstein, Ciudad de Buenos Aires, Argentina 13-Neuroimmunology Unit, Department of Neuroscience, Hospital Alemán, Buenos Aires, Argentina

INTRODUCTION

Neuromyelitis optica spectrum disorders (NMOSD) is an emergent disease in Latin America (LATAM), which raises substantial socioeconomic challenges. NMOSD has a high burden of disease, which comprises frequent neurological visits, magnetic resonance imaging (MRI) use, long-term medication, and utilization of NMOSD care services during follow-up, with a high impact on healthcare system. We aimed to evaluate barriers in the access to healthcare of NMOSD patients in an Argentinean cohort stratified by health coverage.

METHODS

This is a cross-sectional study based on a self-reported survey conducted in Argentina. NMOSD patients were divided into three groups regarding coverage: prepaid health insurance (PHI), social health insurance (SHI) and state-run health insurance (SRHI, Public Health Ministry) in order to detect differences in access and barriers (neurological visit, MRI use and long-term medication).

Table 1. Demographic and general characteristics

Variable	No	% o DS
No	100	-
Age at disease onset (mean, + DS)	38,77	+ 15,01
Age at first manifestation	36,62	+ 15,38
Female N (%)	74	74%
Live alone N (%)	13	13%
Spouse or partner	85	85%
Primary education N (%)	15	15%
High School education N (%)	39	39%
Tertiary education N (%)	23	23%
University education N (%)	23	23%
Employment N (%)		
Employed	40	40%
-Full time	23	57.5%
-Part-time	17	42.5%
Unemployed	11	11%
Self-employed	11	11%
Housewife	17	17%
Currently studying	8	8%
Retired N (%)	11	11%
Retired due to NMOSD N (%)	13	13%
Health care insurance coverage		
-Private Health Insurance	22	22%
-Social Health Insurance	57	57%
-State-Run Health Insurance	22	22%
Reduction of working hours in the last 3 months N (%)	33	33%
Mean time reduction of working hours (months)	7,82	+12, 95
Permanent reduction of working hours (%)	50	50%
Permanent change work (%)	20	20%
Percentage of reduction of incomes (mean, DS)	52,50	+34,48
No of NMOSD who reduced more than 50% N (%)	14	14%
Disability support pension N (%)	19	19%
Mean time with disability support pension (years)	6	+4,1
Certified disability retirement N (%)	47	47%
Mean time with certified disability (years)	5,04	+3,87

CONCLUSION

These findings suggest that barriers to access and utilization of NMOSD care services in Argentina are common. NMOSD patients experienced problems to receive NMOSD medication properly, especially those from the public sector (SRHI).

Table 2. NMOSD-related resources utilization according to medical insurance coverage

Variable	PHI n=22	SHI n=57	SRHI n=22	p
EDSS	2.6 + 2.4	3.1 + 2.4	2.5 + 1.9	0.58
Outpatient neurology visit (at least 2 times) in the last year, N (%)	20 (91)	46 (80)	15 (68)	0.13
Mean time between request medical appointment and neurological visit (weeks)	3.7 + 2.9	3.8 + 3.2	7 + 5.4	0.008
MRI use in the last 12 months N (%)	17 (80)	49 (85)	15 (68)	0.79
Mean time between MRI request and MRI study (weeks)	4.5 + 10.7	5.3 + 9.1	9.3 + 13.4	0.005
Received 1ST as prescribed by their neurologists in the last year (ie, with no interruptions) N (%)	20 (95)	49 (85)	11 (50)	0.004

PHI: prepaid health insurance, SHI: social health insurance, SRHI: state-run health insurance, EDSS: Expanded Disability Status Scale, MRI: magnetic resonance imaging, DMDS: disease modifying drugs. Significant p values are indicated in bold.

Table 3. Results of logistic regression analysis including potential variables associated with appropriate delivery of NMOSD medications

Variable	OR	Logistic Regression CI95%	P
Age	1.02	0.93-1.06	0.15
Gender	0.40	0.10-1.51	0.17
NMOSD duration	1.04	0.92-1.19	0.47
Education (college or not)	1.10	0.34	0.34
Employment	2.82	0.93-8.51	0.06
EDSS	0.85	0.70-1.05	0.14
Health insurance type (private vs. Public)	3.84	1.34-10.97	0.01
Certified disability retirement	1.38	0.53-3.59	0.50

EDSS: Expanded Disability Status Scale, Significant p values are indicated in bold.

Table 4. NMOSD related resources utilization in this Argentinean cohort

Variable	N	% o DS
NMOSD duration (years)	5,28	+4,02
EDSS (mean, DS)	2,8	+2,3
EDSS (median, IQR 25-75)	2	1-5
Requires a walking aid (i.e. cane or crutch) N (%)	22	22%
Restricted to wheelchair N (%)	2	2%
Restricted to bed N (%)	5	5%
Time between first symptom and NMOSD diagnosis (months), N (%)		
0-6	44	44%
6-12	22	22%
12-24	7	7%
>24	27	27%
Number of specialists visited before NMOSD diagnosis is (neurologists), N (%)		
<1	18	18%
Between 2-3	55	55%
>3	27	27%
MRI use for NMOSD diagnosis	99	99%
Health insurance coverage paid MRI		
Fully	77	78%
Partially	15	15%
No (paid by patient)	7	7%
LP use for NMOSD diagnosis	86	86%
Health insurance coverage paid LP		
Fully	69	80%
Partially	9	11%
No (paid by patient)	8	9%
EP use for NMOSD diagnosis	78	78%
Health insurance coverage paid EP		
-Fully	59	75%
-Partially	11	14%
-No (paid by patient)	7	11%
Serum test for NMOSD diagnosis	100	100%
Health insurance coverage paid lab		
-Fully	76	76%
-Partially	19	19%
-No (paid by patient)	5	5%
AQP4-Ab and MOG-Ab use for NMOSD diagnosis	91	91%
Health insurance coverage paid AQP4-Ab and/or MOG-Ab testing		
-Fully	44	49%
-Partially	14	15%
-No (paid by patient)	30	33%
Not done due to not having the money	3	3%
DMDS use N (%)	92	92%
Never received DMDS: N (%)	7	7%
Current DMF use	92	92%
RTX	57	62%
AZA	20	22%
MMF	4	4%
Eculizumab	1	1%
Satralizumab	2	2%
Otros	8	9%
BURDEN OF NMOSD		
Neurological visit (at least 2 times) in the last year N (%)	81	81%
Mean time among request medical visit and neurological visit (weeks)	4,4	+3,9
MRI use in the last 12 months N (%)	88	88%
MRI use as properly as required by their neurologist N (%)	67	68%
Mean time among MRI request and MRI use	5,9	+10,4
Received the DMDS as properly as prescribed by their neurologists month to month N (%)	68	74%
Do you know any specialized NMOSD center in your city? N (%)		
Yes	29	29%
I do not know	9	9%
Public	15	52%
Private	14	48%
Are you receiving rehabilitation?		
Yes	24	24%
It was not prescribed	13	13%
Health insurance coverage paid rehabilitation		
Yes	46	46%
No	29	29%
I do not know	25	25%

RESULTS

We surveyed 100 NMOSD patients (74% female, mean age at diagnosis 38.7 years, mean EDSS 2.8 and a mean of follow-up time of 5.2 years), 40% were employed (full-time: 57.5%), 11% were currently unemployed and 13% were retired due to NMOSD. More than half (55%) of patients visited between 2-3 specialists before NMOSD diagnosis was performed, and Aquaporin-4 antibody and/or MOG-Ab tests were requested in 91% (health coverage paid partially in 15.3% and in 32.9% they were paid by the patient). NMOSD patients receiving care from the private sector (PHI and SHI) reported greater access to MRI (80% and 85% vs. 68%), neurological visits (91% and 80% vs. 68%, p=0.79) and fewer problems obtaining NMOSD medications compared to those treated at public institutions (95% and 85% vs 50%, p=0.005), respectively. We also observed a longer mean time to access to MRI (9.3 ± 13.4 vs 4.5 ± 10.7 and 5.3 ± 9.1 p=0.005) and neurological visits (7 ± 5.4 vs 3.7 ± 2.9 and 3.8 ± 3.2, p=0.008) in the SRHI group when compared with PHI and SHI, respectively. Regression analysis showed that having private insurance (PHI and SHI) (OR=3.84, p=0.01) was the only factor associated with appropriate delivery of NMOSD medications.