PB3657

Multidomain Patient-Reported Outcome Impairment in Adults with Antiphospholipid Syndrome Using PROMIS-29+2: An International Cross-Sectional Study

Chanakya Nayudu[1], Christina Pohlman[2], Charlotte Story[3], Amma Amoah[3], Andrew Song[4], Shruti Chaturvedi[3]

[1] Horace Greeley High School, Chappaqua, NY, United States, [2] APS Foundation of America, La Crosse, WI, United States, [3] Johns Hopkins University, Baltimore, MD, United States, [4] Massachusetts General Hospital, Boston, MA, United States

Background
Antiphospholipid syndrome (APS) is a chronic autoimmune disorder characterized by recurrent thrombosis and pregnancy morbidity. Although APS is associated with significant clinical complications, its impact on patients' quality-of-life remains underrecognized.

Aims
To evaluate patient-reported quality-of-life outcomes in adults with APS.

Methods
We administered online Patient-Reported Outcomes Measurement Information System (PROMIS) instruments to adults with self-reported APS, assessing nine domains using PROMIS-29 v2.0 (including physical function, fatigue, pain interference, depression, anxiety, sleep disturbance, and social participation), the PROMIS Cognitive Function 8a and the PROMIS Illness Burden 6a instruments. Continuous variables were presented using mean ± SD or median (IQR) and categorical variables as counts and percentages. One-sample t-tests were used to compare PROMIS T-scores with population norms, and subgroup analysis was conducted using two-sided t-tests and ANOVA. Statistical significance was defined as $p < 0.05$.

Results
A total of 697 out of 706 respondents completed ≥1 PROMIS instrument and were included in analysis. Mean age was 49.7 ± 13.4 years, 89.2% were female, and 56.3% were from the United States. Baseline characteristics of the cohort are summarized in Table 1. Individuals with APS demonstrated significantly worse T-scores than population norms across all domains ($p < 0.0001$) (Figure 1). On subgroup analysis, individuals with secondary APS had worse T-scores than those with primary APS in all domains except cognition. Thrombosis history was associated with worse T-scores for physical function, social participation, pain interference, and illness burden. Individuals with thrombosis ≤ 1 year vs. > 1 year had worse T-scores in all domains except sleep and cognition. The type of anticoagulant did not affect T-scores. Pregnancy history was linked to greater fatigue, sleep disturbance, pain interference, and reduced social participation, and modestly improved (though still impaired) cognitive function.

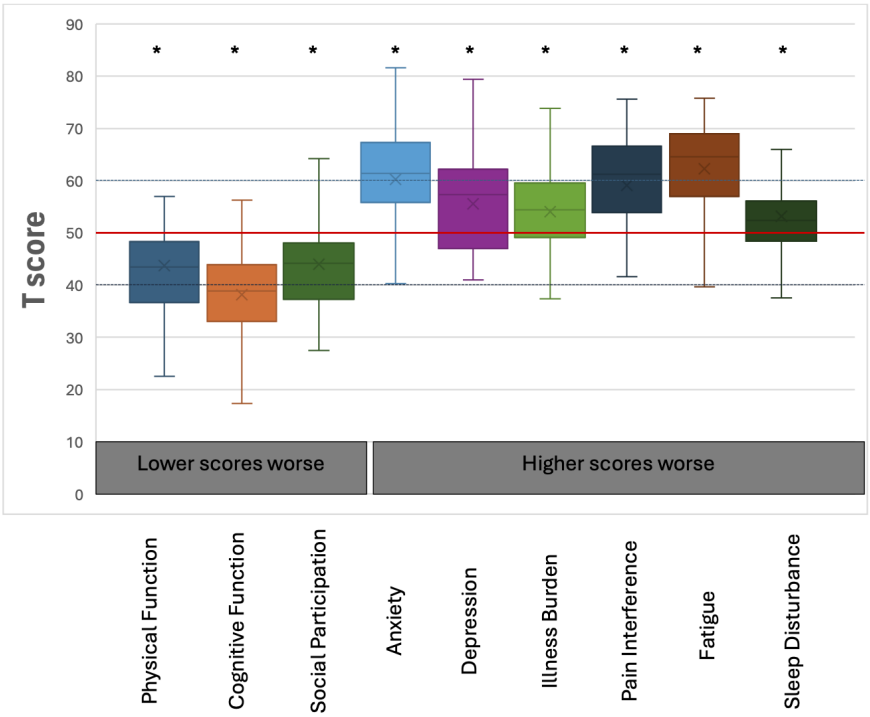
Conclusions
In this large, international, multi-domain study assessing patient-reported outcomes in adults with APS, APS was associated with several quality-of-life impairments, particularly in secondary APS and those with thrombosis or pregnancy history. These findings demonstrate the importance of incorporating validated quality-of-life assessments into APS clinical care to provide better patient-centered care and the need for further investigation into contributors to persistent functional impairment.

Table or Figure Upload (1)

Table 1: Baseline Characteristics (n = 697)		
Characteristic		Value
Age (years, SD)		49.7 (13.4)
Sex	Female	89.2%
	Male	9.8%
	Other	1.0%
Race	White	91.4%
	Black	1.3%
	Asian	1.3%
	Other	6.5%
Ethnicity	Hispanic	7.7%
	Non-Hispanic	86.0%
	Unknown	6.3%
Country of Residence	United States	56.3%
	United Kingdom	26.9%
	Canada	2.7%
	Australia	1.6%
	Honduras	1.6%
	Other	10.9%
Education Level	High school or below	14.5%
	Undergraduate or below	53.0%
	Professional degree	29.8%
	Unknown	2.7%
Employment Status	Employed	55.9%
	Unable to work due to illness	20.3%
	Retired	15.8%
	Unemployed/student	6.6%
	Unknown	1.4%
Coexisting Autoimmune Disorder	SLE	17.2%
	Rheumatoid Arthritis	4.2%
	Sjogren's Syndrome	4.2%
	Other	22.0%
	None	52.4%
APS Complications	TIA (mini stroke)	26.4%
	Low platelet counts	23.4%
	Livedo reticularis	23.1%
	Bleeding from lungs	2.2%
	Heart attack	6.9%
	Heart valve problems	8.6%
	Hemolytic anemia	6.5%
	Kidney problems	13.2%
	Catastrophic APS	4.6%
	Other	15.8%
History of Pregnancy		70.0%
History of Thrombosis		78.3%
Use of Anticoagulants		82.0%
Use of Antiplatelets		34.2%

Table or Figure Upload (2)

FIGURE 1. Individuals with APS have worse scores on Patient-Reported Outcomes Measurement Information System (PROMIS) instruments across multiple quality-of-life domains compared with a normative reference population (T-score mean ± SD, 50 ± 10). Scores >1 and <2 SD from the mean indicate mild impairment, and scores >2 SD from the mean indicate major impairment. Asterisks indicate statistical significance ($p < 0.05$).



DOI*10.1016/j.rpth.2026.106276