

Patient Activation, Social Support, and Health Outcomes in Three Sleep Conditions: Comparison of People Diagnosed With Idiopathic Hypersomnia, Narcolepsy, and Sleep Apnea in Five European Countries

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Background

Sleep disorders, such as idiopathic hypersomnia (PwIH), narcolepsy (PwN), and sleep apnea (PwSA), significantly impact health and quality of life. While PwSA is prevalent, PwIH and PwN present unique challenges that are less understood.^{1,2} Patient activation—the ability to manage one's health—and social support are crucial for positive health outcomes. Research indicates that higher activation and strong social networks are associated with improved health-related quality of life.³ Limited comparative studies exist on patient activation and social support among these specific sleep disorders. This study aims to address this gap by evaluating factors across PwIH and PwN compared to PwSA in five European countries, providing insights to inform targeted healthcare interventions.

Objective

To evaluate patient activation, social support, and health outcomes among people diagnosed with rare sleep-related disorders, PwIH and PwN, compared to the more prevalent PwSA.

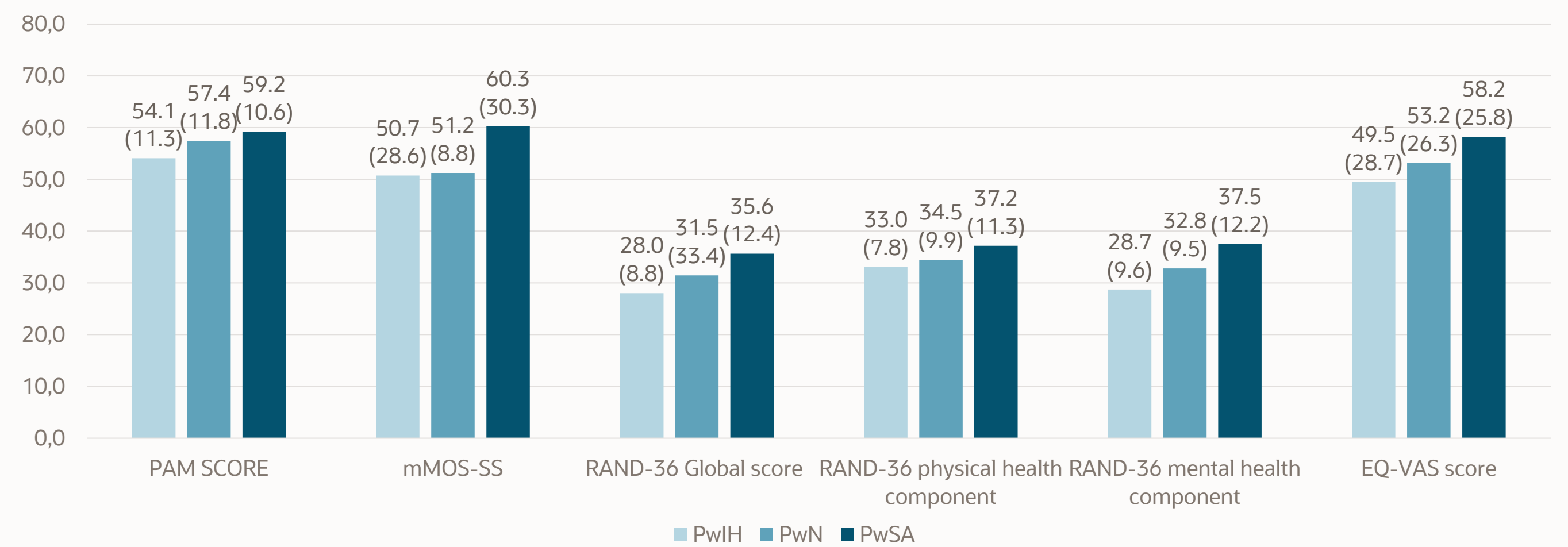
Results

A total of 76 individuals with PwIH, 171 with PwN, and 4,289 with PwSA were included in this study. The mean age for PwIH was 34.2 years, with 68% being female and a Charlson Comorbidity Index (CCI) of 1.3. For PwN, the mean age was 31.5 years, with 60% female and a CCI of 1.1. In contrast, PwSA had a mean age of 50.1 years, with 55% female and a CCI of 0.9.

Table 1. Demographics and Clinical Characteristics

		PwIH n = 76	PwN n = 171	PwSA n = 4289	p-value
Age	Mean (SD)	39.84 (17.0)	44.18 (16.9)	58.46 (13.4)	<.001
Gender (n, %)	Male	27 (35.5%)	96 (56.1%)	2,691 (67.4%)	<.001
	Female	49 (64.5%)	75 (43.9%)	1,598 (32.6%)	
Marital Status (n, %)	Married/Living with Partner	37 (48.7%)	98 (57.3%)	2,860 (66.7%)	<.001
	Divorced/Widowed/Separated	14 (18.4%)	28 (16.4%)	828 (19.3%)	
	Never Married	25 (32.9%)	45 (26.3%)	592 (13.8%)	
	Decline to answer	0 (0.0%)	0 (0.0%)	9 (0.2%)	
University Education (n, %)	University education or higher	30 (39.5%)	83 (48.5%)	1,607 (37.5%)	0.063
	Less than University education	45 (59.2%)	86 (50.3%)	2,639 (61.5%)	
	Decline to answer	1 (1.3%)	2 (1.2%)	43 (1.0%)	
Insurance coverage (n, %)	Yes	76 (100.0%)	171 (100.0%)	4,289 (100.0%)	n/a
	Underweight (<18.5 kg/m2)	0 (0.0%)	6 (3.5%)	19 (0.4%)	
Body Mass Index (n, %)	Normal weight (18.5 to <25.0 kg/m2)	0 (0.0%)	30 (17.5%)	329 (7.7%)	<.001
	Overweight (25 to <30.0 kg/m2)	0 (0.0%)	20 (11.7%)	616 (14.4%)	
	Obese (30.0 kg/m2 and above)	0 (0.0%)	34 (19.9%)	982 (22.9%)	
	Unknown	76 (100.0%)	81 (47.4%)	2,343 (54.6%)	
Smoking Status (n, %)	Current	34 (44.7%)	77 (45.0%)	1,065 (24.8%)	<.001
	Former	27 (35.5%)	37 (21.6%)	1,755 (40.9%)	
	Never	15 (19.7%)	57 (33.3%)	1,469 (34.3%)	
	None	15 (19.7%)	34 (19.9%)	1,061 (24.7%)	
Alcohol (n, %)	Less than daily	54 (71.1%)	121 (70.8%)	2,822 (65.8%)	0.525
	Daily	7 (9.2%)	16 (9.4%)	406 (9.5%)	
	0	39 (51.3%)	65 (38.0%)	1,905 (44.4%)	
CCI score category (n, %)	1	13 (17.1%)	42 (24.6%)	1,075 (25.1%)	0.012
	2	6 (7.9%)	26 (15.2%)	670 (15.6%)	
	3+	18 (23.7%)	38 (22.2%)	641 (14.9%)	
	Mean (SD)	5.92 (8.45)	7.09 (8.79)	6.05 (8.34)	
Days of exercise in past 30 days	Mean (SD)	5.92 (8.45)	7.09 (8.79)	6.05 (8.34)	0.279

Figure 1. Outcome measures (on a 0-100 scale) across sleep cohort, Mean (SD)



Footnote: All p-values were <0.01. Numbers in parentheses represent standard deviations. Higher PAM score conveys higher activation. Higher mMOS-SS score conveys higher social support. Higher RAND-36 Global score composite, RAND-36 mental health component, EQ-VAS score indicate higher quality of life.

Conclusion

Individuals with rare sleep conditions, specifically idiopathic hypersomnia and narcolepsy, experience a significantly greater burden of symptoms compared to those with the more prevalent sleep apnea. Both idiopathic hypersomnia and narcolepsy patients reported higher levels of daytime sleepiness, depression, and anxiety, alongside lower levels of social support and health-related quality of life (HRQoL). Patients diagnosed with idiopathic hypersomnia demonstrated the lowest patient activation levels, with a significant portion classified as "disengaged and overwhelmed." These findings highlight the critical need for targeted interventions to address the unique challenges faced by patients with idiopathic hypersomnia and narcolepsy. Future research should explore the underlying factors contributing to these disparities, aiming to improve patient activation and overall well-being in this population.

Methods

This study utilized retrospective, cross-sectional, de-duplicated data from the 2022 and 2020 National Health and Wellness Survey (NHWS) conducted in France, Germany, the UK, Italy, and Spain. Participants were identified based on self-reported diagnoses of PwIH (n=76), PwN (n=171), and PwSA (n=4289). Validated measures were employed to assess key variables.

- Daytime sleepiness was evaluated using the Epworth Sleepiness Scale (ESS), range: 0 to 24, higher scores indicate greater daytime sleepiness; scores of 11 or higher = excessive daytime sleepiness.
- Patient activation was assessed with the Patient Activation Measure (PAM), a 13-item scale (range: 0 to 100); higher scores indicate higher activation.
- Social support was measured with the Modified Medical Outcomes Study Social Support Survey (mMOS-SS), yielding scores from 0 to 100; higher scores indicate greater social support.
- Depression was evaluated using the Patient Health Questionnaire-9 (PHQ-9), range: 0 to 27, and anxiety was assessed with the Generalized Anxiety Disorder Assessment-7 (GAD-7), range: 0 to 21; higher scores indicate greater severity of symptoms.
- Health-related quality of life (HRQoL) was measured using the RAND-36 mental and physical health composites (0 to 100), the EQ-5D index (0 to 1.0), and the EQ visual analog scale (VAS), which ranges from 0 to 100; higher scores are indicative of better HRQoL.

Bivariate analyses were conducted to compare these measures across the three sleep conditions, with statistical significance set at p < 0.05.

Patient Activation and Social Support: The mean Patient Activation Measure (PAM) score was significantly lower for PwIH compared to PwN and PwSA, p < .001 (**Figure 1**).

- A higher proportion of PwIH (25.0%) were classified at Level 1 compared to PwN (15.8%) and PwSA (8.9%).
- Social support scores were also significantly lower for PwIH.

Excessive Daytime Sleepiness: A significant difference in excessive daytime sleepiness was observed across the groups (p < .001).

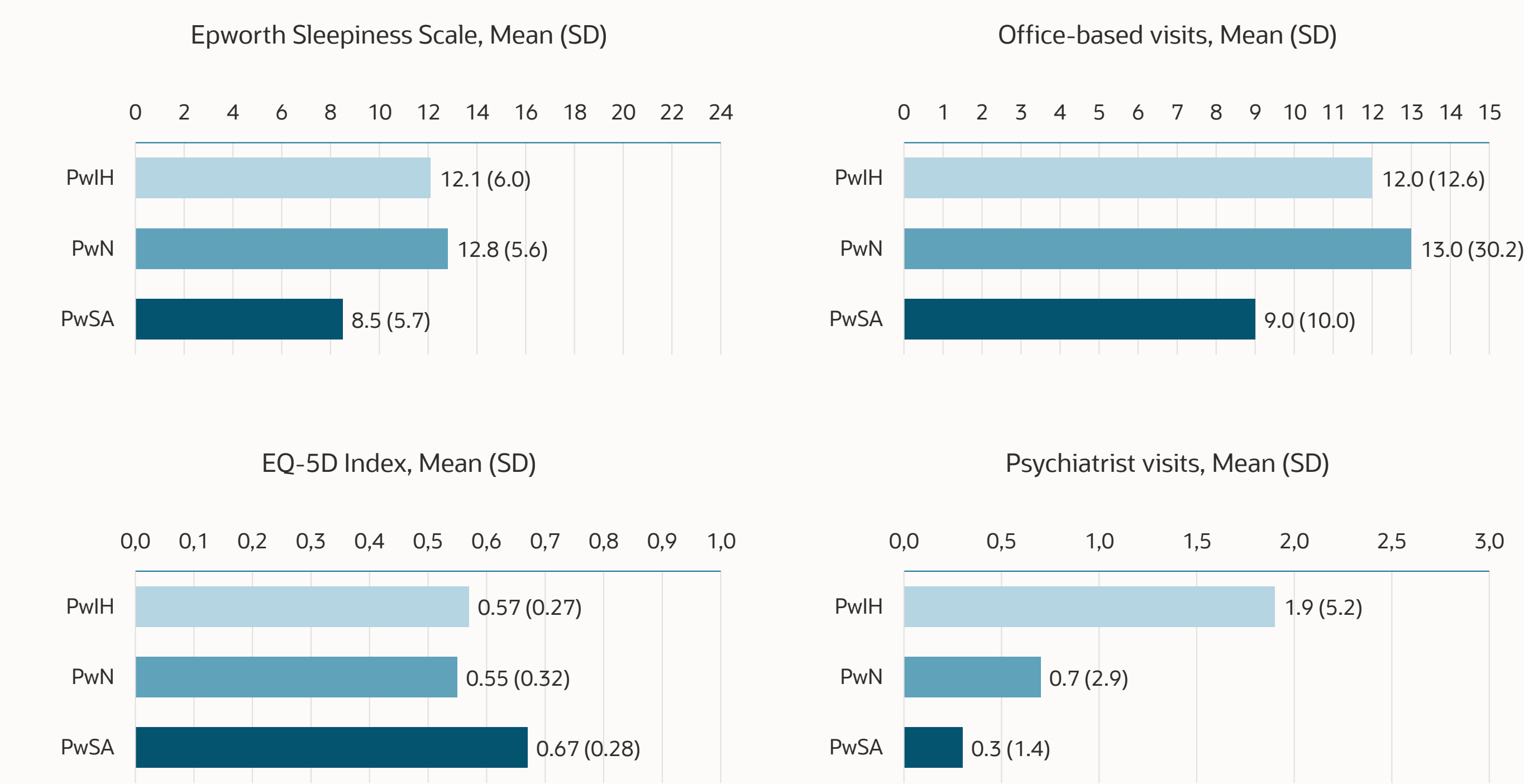
- Only 35.5% of PwIH reported no excessive daytime sleepiness (EDS), compared to 31.0% of PwN and 66.0% of PwSA. The mean Epworth Sleepiness Scale (ESS) score was higher for PwIH and PwN than for PwSA (**Figure 2**), with all groups showing a significant difference (p < .001).

Health-Related Quality of Life: The RAND-36 global, mental health component, and physical health component scores were significantly lower for PwIH and PwN compared to PwSA, p < .001.

Healthcare Utilization: PwIH and PwN had a significantly number of healthcare visits compared to PwSA, with PwIH averaging 12.0 visits in the past six months, p < .001.

Mental Health: PwIH reported higher depression and anxiety compared to PwN and PwSA, p < .001.

Figure 2. ESS, EQ-5D index, and Resource Utilization (# of visits in past 6 months) across sleep cohort, Mean (SD)



Footnote: All p-values were <0.001. Higher PAM score conveys higher activation. Higher ESS score conveys higher daytime sleepiness. Higher EQ-5D-5L score indicate higher quality of life. Resource utilization was self-reported visits in the past 6 months.

References

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