

Evaluation of pulmonary hypertension patients’ knowledge about the disease and their information needs

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Background: Adequate medical information is crucial for ensuring proper healthcare literacy and better self-management in patients with pulmonary hypertension (PH).

Objective: To assess how patients with PH receive medical information and what their information needs are.

Methods: We conducted an online survey of 40 Ukrainian patients with PH from December 2024 to January 2025. The survey was distributed among patients via patients' instant messaging app groups.

Results: The average age of the patients was 43.8 ± 12.0 years, 35 women (87.5 %) and 5 men (12.5 %). The average disease duration was 12.4 ± 12.9 years. Most of the patients (28 patients (70 %)) stated that their knowledge of PH is sufficient. Sources of medical information about PH were next: healthcare staff – 87.5 % (35 patients); social media – 57.5 % (23 patients); other patients – 57.5 % (23 patients); websites – 40.0 % (16 patients). 67.5 % of patients (n=27) considered that healthcare staff provided them with the appropriate amount of medical information about PH. 70 % of patients (n=28) highlighted that medical information was understandable. 62.5 % of patients seek general information about PH, 42.5 % - treatment strategies, 12.5 % - physical activity recommendations, 10 % - financial support, 7.5 % - psychological support, and 5 % - nutrition recommendations.

Conclusion: Most of the PH patients considered their knowledge about the disease as sufficient. The most popular sources of medical information were consultations with healthcare staff and social media. Most popular information requests were seeking general information about PH, treatment strategies and physical activity recommendations.

Footnotes

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