

# Cultural adaptation and validation of the Polish version of the Pulmonary Arterial Hypertension-Symptoms and Impact (PAH-SYMPACT) questionnaire

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## INTRODUCTION

Pulmonary arterial hypertension (PAH) is a disease that leads to the development of right ventricular failure and death despite optimal treatment [1]. A study published by Kopeć et al. [2, 3] in 2020 shows that the estimated prevalence of patients with PAH in Poland is 30.8 per million adults. Recent advances in therapy have improved symptoms severity, functional capacity and survival, but PAH still remains an incurable disease [4].

The main symptom of PAH is dyspnea. However, the experience of this, as well as other symptoms, is subjective, so there is a need to adapt specific tools to assess the severity of symptoms and their impact on patients' functioning. Recommendations for a PAH study endpoint now emphasize the importance of measuring patient-reported outcomes as a secondary endpoint in clinical trials [5, 6]. In the few studies carried out so far in Poland among patients with PAH, only generic tools have been used, i.e. general tools for quality-of-life assessment regardless of the type of disease entity [7], which may not reflect the symptoms and effects of PAH and their impact on quality of life (QoL). Due to the need for research in this group of patients, we have undertaken to translate and validate a tool that can be used to assess QoL and relate it to data presented by other centers in Europe and worldwide.

## METHODS

### *Questionnaires used in the psychometric validation process*

- The Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR) questionnaire is a specific, standardized tool (Polish version) for assessing the quality of life in patients with pulmonary hypertension [8];
- WHO-QOL BREF — a standardized, abbreviated Polish version of the generic questionnaire — assessing the QoL of a patient with any disease entity [9];
- PAH-SYMPACT (Pulmonary Arterial Hypertension-Symptoms and Impact) is a specific questionnaire to assess the quality of life of patients with pulmonary arterial hypertension [5].

### *Patients*

The study included 55 patients who met the inclusion criteria: >18 years, diagnosis of PAH, entry into the national pulmonary hypertension database, written informed consent of the patient for participation in the study, health condition allowing participation in the study, and completion of questionnaires. All questionnaires were administered twice approximately 2–4 weeks apart.

### *The process of cultural adaptation of the Polish version of the PAH-SYMPACT questionnaire*

Permission to translate and validate the English version of the PAH-SYMPACT ques-

**Table 1.** Scores for each subscale of the PAH-SYMPACT questionnaire, Cronbach's alpha, and Spearman correlation coefficient

PAH-SYMPACT questionnaire subscales	Cronbach's alpha (n = 55)	Median (IQR)	Min-max	Spearman correlation coefficient (n = 52)	P-value in Spearman correlation
Cardiopulmonary symptoms	0.706	1.00 (0.50–1.38)	0.00–2.17	0.945	0.001
Cardiovascular symptoms	0.806	0.40 (0.20–0.85)	0.00–2.0	0.911	0.001
Physical effects	0.904	1.14 (0.54–2.0)	0.14–3.86	0.993	0.001
Psychological effects	0.817	0.75 (0.50–1.25)	0.00–2.75	0.935	0.001

Abbreviations: IQR, interquartile range; PAH-SYMPACT, Pulmonary Arterial Hypertension-Symptoms and Impact

tionnaire was obtained from the MAPI Research Gate. The procedure for the cultural adaptation of the Polish version of the PAH-SYMPACT questionnaire was conducted in 3 stages:

- Step 1: Translation process (Questionnaire forward translation, Questionnaire back translation);
- Step 2: Cognitive debriefing interviews;
- Step 3: Psychometric validation.

To determine the construct validity of the translated Polish version of the PAH-SYMPACT (PL) questionnaire, the reliability coefficient (Cronbach's alpha) for each subscale was calculated. Moreover, the internal consistency of the translated version using the test-retest method was determined.

### Statistical analysis

The analysis of quantitative variables was conducted by calculating the mean, standard deviation, median, first and third quartiles, minimum, and maximum. The analysis of qualitative variables was performed by calculating the number and percentage of occurrences of each value. The internal consistency of the PAH-SYMPACT was assessed using Cronbach's alpha. Convergent validity was assessed by correlating all questionnaires. Correlations between test and retest scores were analyzed using Spearman's correlation coefficient. Thus, all *P*-values below 0.05 were interpreted as indicating significant correlations. The analysis was performed in the program R, version 3.6.3 (R Development Core Team, Vienna, Austria).

### Ethical considerations

The study was approved by University Bioethics Committee (approval number 538/2019). All patients provided informed consent. All study participants were informed that the study is conducted anonymously, and participation is voluntary.

## RESULTS AND DISCUSSION

The average age (standard deviation [SD]) of respondents was 56.22 (17.25) years and more than half (69%) were over 60 years. Approximately 85% of participants suffered from idiopathic PAH, and the rest had PAH-related connective tissue disorders.

The study shows that the Polish adaptation of PAH-SYMPACT was successful. Carefully developed QoL scales provide a holistic picture of the impact of disease and its

treatment on patients. The new language version meets the expectations of good internal consistency, test-retest reliability, and convergent and known group validity. The resulting version reliably examines symptoms (resulting from the disease), as well as outcomes (consequences of symptoms) in patients with PAH.

The median (interquartile range [IQR]) on the subscales: cardiopulmonary symptoms, cardiovascular symptoms, physical effects, and psychological effects was 1.0 (0.5–1.38), 0.4 (0.2–0.85), 1.14 (0.54–2.0), and 0.75 (0.5–1.25), respectively (Table 1).

The reliability for each subscale of the translated Polish version of the PAH-SYMPACT questionnaire was determined using Cronbach's alpha. In all 4 domains, all subscales were shown to be reliable. Cronbach's alpha coefficient for each subscale is above 0.7, an alpha above 0.7 is assumed to be a reliable scale [10]. Removing any of the items does not improve the alpha coefficient (Table 1). Therefore, it can be concluded that the created scale is well constructed and does not need to be changed.

Consistency over time was examined by correlating the results of the first and second tests. The result indicated a very high consistency, between the repeated tests performed. Indeed, the correlation coefficient was always above 0.9 and was statistically significant ( $P < 0.05$ ) for each subscale (Table 1). There were no cultural/linguistic differences between Poland and the creators' version in terms of what daily life is like for PAH patients [5]. Validation of the original American version of the PAH-SYMPACT questionnaire demonstrated Cronbach's alpha coefficient  $> 0.8$ , and Spearman's correlation coefficient in the test-retest study  $> 0.7$  (Table 1). The Polish version of the PAH-SYMPACT questionnaire has a good design and is a reliable version of the questionnaire for assessing QoL. Moreover, each domain of the PAH-SYMPACT, correlated with all domains of the CAMPHOR questionnaire, which indicates that both tools can be used interchangeably or concurrently with success in the assessment of the QoL among patients with PAH. However, it should be emphasized that only the PAH-SYMPACT questionnaire is dedicated to a narrow group of PAH patients. An American cultural adaptation of the PAH-SYMPACT questionnaire [5] obtained similar results as the Polish version. Scores for each domain: cardiopulmonary symptoms, cardiovascular symptoms, physical effects, psychological effects: 1.0; 0.4; 1.3; 0.9 correlated with our own results: 1.03; 0.56; 1.32; 0.89, respectively. In both

studies, the results should be interpreted as low severity of symptoms and effects. Only in the study performed by Chin et al. [5], in the subscale of cardiovascular symptoms, the result can be interpreted as the absence of symptoms. However, it should be emphasized that despite the similarities in both studies, such as female predominance in the study group >60% and mean age >55 years, our study included only patients chronically treated for PAH, in contrast to the study by Chin et al. [5] where the included patients were incidental.

### Limitations

The study had some limitations. One of them was a relatively small number of participants, and the other was a single-center study.

### CONCLUSION

Despite the limitations, the cultural adaptation of the Polish version of the PAH-SYMPACT questionnaire demonstrated that it provides a new accurate and reliable instrument for assessing health-related quality of life in Polish patients with PAH.

### Article information

**Conflict of interest:** None declared.

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