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The Polish adaptation of the CAMbridge Pulmonary Hypertension Outcome Review (CAMPHOR)

Katarzyna Malaczynska-Rajpold[1], Anna Smukowska-Gorynia[1], Alice Heaney[2], Stephen P. McKenna[2, 3], Magdalena Janus[1], Aleksander Araszkiewicz[1], Stanislaw Jankiewicz[1], Sylwia Slawek-Szmyt[1], Iga Tomaszewska[1], Tatiana Mularek-Kubzdela[1]

[1]1st Department of Cardiology, Poznan University of Medical Sciences, Poland
[2]Galen Research Ltd., Manchester, United Kingdom
[3]School of Health Sciences, University of Manchester, United Kingdom

Abstract

Background: *Pulmonary hypertension (PH) results in severely impaired quality of life (QoL) in people with this condition. The CAMbridge Pulmonary Hypertension Outcome Review (CAMPHOR) is the only questionnaire providing a disease-specific measurement of symptoms, functioning and QoL in PH patients. It has already been adapted for use in several countries. The aim of this study was to adapt and validate CAMPHOR for the Polish-speaking population.*

Methods: *Two panels (bilingual and lay) were conducted to translate CAMPHOR into Polish. This new version was then tested by cognitive debriefing interviews with 15 patients. Finally, a postal validation survey was conducted with 56 patients on two occasions 2 weeks apart to assess its psychometric properties.*

Results: *No problems were experienced in producing a Polish translation of CAMPHOR. Interviewees responded well to the Polish CAMPHOR, finding it relevant, comprehensible and easy to complete. For all three CAMPHOR scales (Symptoms, Activity, QoL), The Cronbach alpha coefficients were above 0.8 at both time points, indicating high internal consistency. Test-retest reliability for the three scales achieved a value above 0.80. Predicted correlations with the Nottingham Health Profile provided evidence of the construct validity of CAMPHOR scales. The Polish CAMPHOR could distinguish between patients who differed according to their perceived general health and perceived disease severity. No significant differences in scores were found between participants grouped by gender or age.*

Conclusions: *The Polish version of CAMPHOR demonstrated good psychometric properties and is recommended for use in clinical practice.* (Cardiol J 2020; 27, 5: 608–615)

Key words: adaptation, CAMPHOR, quality of life, patient reported outcome, pulmonary hypertension

Introduction

Precapillary pulmonary hypertension (PH) is a condition, when mean pulmonary artery pressure increases significantly (≥ 25 mmHg) whereas the capillary wedge pressure remains within normal values (≤ 15 mmHg). It is represented in the clinical classification as group 1 — pulmonary arterial hypertension (PAH), group 3 — PH due to lung diseases and/or hypoxia, and group 4 — chronic thromboembolic PH (CTEPH). In Poland, the prevalence of PAH in adults is about 19.6 cases per million population. The number of patients increases year by year, suggesting that the disease is becoming better diagnosed [1]. A number of trials are in progress to improve life expectancy

Address for correspondence: Katarzyna Malaczynska-Rajpold, MD, PhD, 1st Department of Cardiology, Poznan University of Medical Sciences, ul. Długa 1/2, 61–848 Poznań, Poland, tel: +48 61 854 91 46, fax: +48 61 854 90 94, e-mail: k.malaczynska-rajpold@rbht.nhs.uk

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in this disease. However, the main problems that investigators face in planning such trials is a lack of ideal endpoints [2].

Recent clinical studies have assessed Health Related Quality of Life (HRQL) using generic patient-reported outcome measures, such as the SF-36 [3–5], EuroQol [6, 7] and Nottingham Health Profile [8]. HRQL provides information that is of interest to clinicians with a focus on symptoms and functional limitations resulting from a disease [9]. However, these measures demonstrate relatively low responsiveness, especially with PH patients [10]. For example, to obtain a minimally important difference on the SF-36 domains, scores must improve between 13 and 25 points on a scale of 0–100. A modified version of the Minnesota Living with Heart Failure Questionnaire [11, 12] has also been used [13, 14]. However, the questionnaire was not designed for patients with PH and so it cannot be concluded that changes in score are valid.

Comprehensive disease-specific measures that directly address PH characteristics are required. The CAMbridge Pulmonary Hypertension Outcome Review (CAMPHOR) is the first disease-specific questionnaire to assess both health-related QoL (symptoms and activity limitations) and QoL in patients diagnosed with PH [15]. CAMPHOR consists of three sections; symptoms (25 items), activities (15 items) and QoL (25 items). Quality of life is concerned with measuring how these symptoms and functioning affect the lives of patients, for example, whether they are able to fulfil their roles in life, communicate with others or interact socially. The measurement model, the needs-based model of QoL, argues that quality of life is the extent to which an individual is able to meet his or her basic human needs [16].

CAMPHOR is widely used in international clinical studies for evaluating the benefits patients gain from alternative treatments for the condition. It is also used to monitor the progress as well as response to treatment of individual patients in clinical practice. It is an outcome measure that shows the effects of treatment from the viewpoint of the patient. Research has shown that CAMPHOR scales are responsive to change, with effect sizes ranging from 0.31 to 0.69. It should be noted that CAMPHOR is at least as responsive as the 6-min walking test. This is often used as a primary endpoint in clinical trials, having demonstrated effect sizes that range from 0.16 to 0.34 [17].

CAMPHOR was developed in the United Kingdom (UK) and has since been adapted into 18 additional languages [18–25]. This report describes the adaptation of CAMPHOR into Polish and includes results from the translation, field-testing and psychometric evaluation of the new language version. A successful adaptation would provide a valid and reliable outcome measure for use in PH clinical practice and trials in Poland.

Methods

The process of adaptation of CAMPHOR questionnaire consisted of three main stages: translation (by means of a bilingual and lay panel), cognitive debriefing interviews with patients and a postal validation survey. Local ethics committee at Poznan University of Medical Sciences approved the study (resolution No. 728/16).

Stage 1: Translation process

The dual-panel methodology was used to translate CAMPHOR into Polish [26]. The bilingual translation panel consisted of 5 native Polish speakers (3 females and 2 males; aged from 26 to 51 years) with competence in English at the C2 level (proficient user) according to the Common European Framework of Reference for Languages (CEFR). They were asked to translate the UK English CAMPHOR into Polish, while keeping the following requirements in mind: capturing the same concepts as the original version and producing a comprehensible formulation of the concepts. Conceptual equivalence is of primary importance in this methodology. All items were discussed until an agreement was reached. A separate lay panel consisted of 5 monolingual Polish participants (4 females and 1 male; aged from 22 to 48 years). Individuals included to the lay panel were of an average to lower than average education level to ensure that the wording of the questionnaire is at an appropriate level for typical patients. Participants were presented with the translations made by the bilingual panel and asked to decide whether the phrasing and language were acceptable and sounded 'natural'. The purpose of this second panel was to ensure that the wording of items was appropriate to respondents from all educational backgrounds. The lay panel was provided with alternative formulations of items in which a consensus could not be reached by the bilingual panel participants.

Stage 2: Cognitive debriefing interviews

Cognitive debriefing interviews were conducted with PH patients from Warsaw. The patients were recruited through convenience sampling

from a single center. Eleven of the interviewees had idiopathic pulmonary arterial hypertension (IPAH), one chronic thromboembolic pulmonary hypertension (CTEPH), one had PH associated with scleroderma and two had congenital heart disease. The aim of these interviews was to check the applicability, comprehension, relevance and comprehensiveness of the translated scales with appropriate patients. The semi-structured interviews were conducted face-to-face. Respondents completed the questionnaire in the presence of an interviewer and were then asked to answer specific questions about the measure.

Stage 3: Validation

To further validate the Polish version of CAMPHOR, PH patients of mixed etiology treated in 1st Department of Cardiology, Poznan, Poland in 2016 were recruited. Pulmonary hypertension was diagnosed according to the standard criteria [27] and confirmed by right heart catherization. Detailed demographic and disease information is shown in Table 1. The CAMPHOR was administered twice by mail approximately 2 weeks apart. Patients also completed the Nottingham Health Profile questionnaire (NHP) [27] at the first administration. Demographic (sex, age, marital status, occupation) and disease information (time since diagnosis, perceived general health and disease severity) was also collected.

Statistical analyses

Non-parametric statistical tests were used throughout the analyses due to the ordinal nature of the data. Internal consistency of CAMPHOR scales was evaluated by determining the Cronbach alpha coefficients. Test-retest reliability was examined using the Spearman rank correlation coefficients. Convergent validity was assessed by comparing scores on CAMPHOR scales with those on the NHP sections.

Known-group validity is the ability to distinguish between groups of patients who differ according to some known factor. The following variables were used for this purpose: patient-perceived general health (very good/good/fair/poor) and patient-perceived disease severity (mild/moderate/quite severe/very severe). P-values < 0.05 were considered statistically significant.

Outcome measures

CAMPHOR. The CAMPHOR was originally developed and validated in the United Kingdom [15]. It consists of a 25-item symptom scale (scored 0–25), a 15-item functioning scale (scored 0–30) and a 25-item QoL scale (scored 0–25). For all scales, a low score indicates better status. All validated language versions demonstrate good internal consistency, reproducibility and validity [18–25].

Nottingham Health Profile. The NHP is a 38-item questionnaire of perceived distress that has been widely used in health research [28]. It

Table 1. Demographic and disease information of the validation sample (n = 56).

Age [years]	
Median	57.1
IQR	43.6–69.1
Gender	
Male	17 (30.4%)
Female	39 (69.6%)
Marital status	
Married/Living as married	33 (58.9%)
Divorced	5 (8.9%)
Widowed	8 (14.3%)
Single	10 (17.9%)
Work status	
Full-time	4 (7.1%)
Part-time	1 (1.8%)
Retired	21 (37.5%)
Homemaker	5 (8.9%)
Long-term sick leave	18 (32.1%)
Student	2 (3.6%)
Unemployed	5 (8.9%)
Cause of PH	
Idiopathic PAH	17 (30.4%)
Associated PAH	18 (32.1%)
Connective tissue disease	4 (7.1%)
Congenital heart disease	14 (25.0%)
CTEPH	21 (37.5%)
Patient-perceived general health	
Very good	1 (1.8%)
Good	19 (33.9%)
Fair	24 (42.9%)
Poor	12 (21.4%)
Patient-perceived disease severity	
Mild	2 (3.6%)
Moderate	11 (19.6%)
Quite severe	32 (57.1%)
Very severe	11 (19.6%)

CTEPH — chronic thromboembolic pulmonary hypertension; IQR — interquartile range; PAH — pulmonary arterial hypertension; PH — pulmonary hypertension

Table 2. Questionnaires descriptive statistics.

	N	Median	Interquartile range	Minimum–Maximum	% scoring minimum	% scoring maximum
CAMPHOR Time 1						
Symptoms	56	11	7–18	0–25	3.6	1.8
Activities	55	9	6–13	0–22	3.6	0
QoL	56	8	3–13	0–25	5.4	3.6
NHP Time 1						
Energy	53	33.3	0–100	0–100	28.6	26.8
Pain	52	12.5	0–25	0–100	42.9	1.8
Emotional reactions	53	22.2	0–44.4	0–100	33.9	3.6
Sleep	53	40	0–80	0–100	30.4	10.7
Social isolation	53	0	0–20	0–80	62.5	0
Physical mobility	51	37.5	12.5–50	0–87.5	12.5	0
CAMPHOR Time 2						
Symptoms	56	10.5	6–16	0–25	5.4	1.8
Activities	56	11.5	7–14.8	0–23	3.6	0
QoL	56	8	3–13.8	0–25	7.1	1.8

NHP — Nottingham Health Profile; QoL — quality of life

includes 6 sections, evaluating: energy level, pain, emotional reactions, sleep, social isolation and physical mobility. All sections are scored 0 to 100 with a lower score indicative of better health status.

Results

Translation

No significant difficulties were present during the translation process. In the adaptation process every additional step checks the correctness of previous stages and the results of the postal validation survey demonstrate whether the newly adapted version is reliable and valid. Therefore, no other investigations were required. Additionally, it is possible that certain words or concepts could not have been translated in a reasonable way however we did not find this to be the case. Where more than one translation was proposed by the bilingual panel, the lay panel generally reached agreement with little discussion. For example, the lay panel felt that the translation "Mam dosyć swojej choroby" expressed the feeling of being fed up more clearly than the alternative "Jestem zmęczony moją chorobą". For the item 'I feel guilty asking for help', the bilingual panel suggested three translations ("Czuję się źle/ /zawstydzony/zażenowany, prosząc o pomoc"). The lay panel considered that "zawstydzony" could be misinterpreted as meaning shyness, while the word "zażenowany" was thought to be too complicated. Therefore, the panel agreed that "źle" was the most appropriate translation for this item.

Cognitive debriefing interviews

Fifteen cognitive debriefing interviews were conducted with patients. All patients understood clearly the purpose of the interview. Most of the patients responded well to the questionnaire, they thought it was simple and easy to complete. The items were clear and comprehensible. Interviewees felt that the items reflected their situation well, that they could relate to the ideas expressed and felt that no part of their experience of PH was missing. No changes were made to the questionnaire as a result of the cognitive debriefing interviews.

Validation

Fifty-seven participants were recruited at Time 1. Of these 56 (98.2%) patients completed and returned the questionnaire at Time 2. Table 2 shows descriptive statistics for the questionnaires at both time points. High floor effects (high number of patients scoring the minimum) were observed for most NHP sections. This indicates that the NHP is not well targeted to PH patients in this sample.

Internal consistency

For all CAMPHOR scales, the Cronbach alpha coefficients were above 0.8, indicating high internal consistency (Table 3).

Table 3. Cronbach's alpha coefficients at Time 1 and Time 2.

CAMPHOR	Time 1	Time 2
Symptoms	0.94	0.92
Activities	0.89	0.91
QoL	0.94	0.94

Test-retest reliability

Test-retest reliability for the three scales was 0.81 for Symptoms, 0.89 for Activities and 0.96 for QoL. These values suggest that the measure produces low levels of measurement error.

Convergent validity

Evidence of convergent validity can be seen in Table 4 where significant correlations between scores on CAMPHOR and NHP sections at Time 1 are shown.

Association with demographic factors

Table 5 shows CAMPHOR scores for patients grouped by gender and age (below vs. above median age). No significant differences in CAMPHOR scores were found between participants grouped by gender. The Mann-Whitney U test revealed there was a significant difference found between older and younger individuals for CAMPHOR Activities and QoL scales. Older patients had significantly worse scores on these two scales compared to younger patients. The χ^2 test of independence was performed to investigate age differences in greater detail. A significant association was found between age and perceived disease severity (χ^2 (1) = 4.9, p = 0.04). Similarly, a significant relation was found between age and perceived general health (χ^2 (1) = = 7.8, p = 0.008).

Known group validity

Mann-Whitney U tests demonstrated statistically significant differences in CAMPHOR scores between patients who differed according to their perceived general health (Fig. 1) and disease severity (Fig. 2).

Patients who rated their disease severity as quite or very severe had significantly worse scores on all CAMPHOR scales than patients who rated their disease severity as mild or moderate. Respondents who

Table 4. Correlation coefficients between CAMPHOR scale scores and Nottingham Health Profile (NHP) section scores.

NHP	Symptoms	Activities	Quality of life
Energy	0.75	0.55	0.72
Pain	0.48	0.43	0.48
Emotional reactions	0.54	0.23*	0.72
Sleep	0.39	0.05*	0.45
Social isolation	0.48	0.19*	0.58
Physical mobility	0.69	0.86	0.70

Note: p = 0.01 (2-tailed) for all correlations except where marked. *Correlation is not significant at 0.05 level (2-tailed).

Table 5. Median scores by demographic factors.

	Symptoms		Activities		QoL	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
Gender						
Male	17	10.0 (7.0–17.5)	17	10.0 (7.0–15.0)	17	8.0 (3.5–15.5)
Female	39	11.0 (6.0–19.0)	38	8.5 (5.8–12.3)	39	8.0 (3.0–11.0)
P	56	0.80	55	0.22	56	0.46
Age						
Below median	28	10.5 (3.3–17.8)	28	7.0 (5.0–10.8)	28	5.5 (2.0–10.5)
Above median	28	11.0 (7.3–19.8)	27	12.0 (8.0–15.0)	28	9.0 (5.0–15.8)
P	56	0.30	55	0.008	56	0.04

P value (2-tailed); IQR — interquartile range; QoL — quality of life

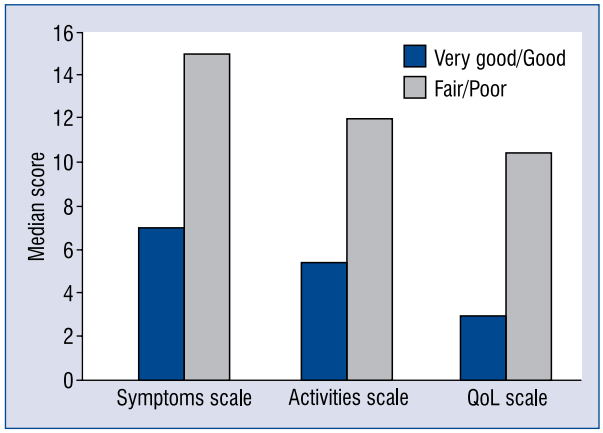

Figure 1. Median CAMPHOR scale scores by perceived general health. Note: All comparisons significant at $p < 0.01$ (2-tailed); QoL — quality of life.

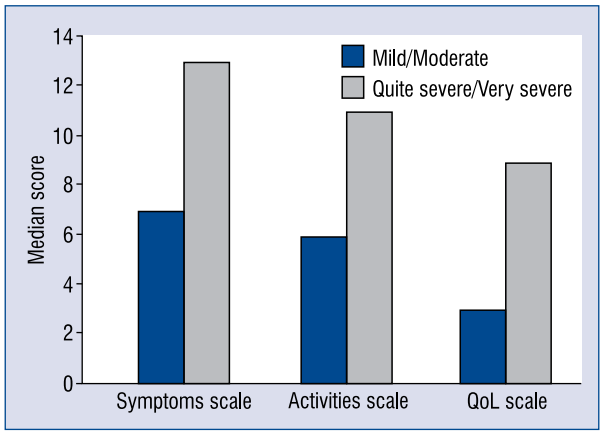

Figure 2. Median CAMPHOR scale scores by perceived disease severity. Note: Activities and quality of life (QoL) comparisons significant at $p < 0.01$ (2-tailed). Symptoms scale comparisons significant at $p < 0.05$ (2-tailed).

considered their general health to be fair or poor had significantly worse CAMPHOR scores than patients who rated their health as good or very good. This demonstrates the ability of the Polish CAMPHOR to detect meaningful differences.

Discussion

This study shows that the Polish adaptation of CAMPHOR was successful. The new language version meets the expectations of good internal consistency, test-retest reliability, and convergent and known group validity. Similar findings have been reported for previous adaptations of the CAMPHOR [18–25].

Translations that are conceptually equivalent make it possible to compare scores across countries and to combine data from different countries in international clinical trials [14]. The dual panel methodology was applied. The translation methodology used in the adaptation of CAMPHOR has been shown to produce more acceptable translations and this method is preferred in the adaptation of all need-based measures [29]. Moreover, this method places great emphasis on achieving conceptual equivalence of translated items to the original. It is important that translated items are expressed in everyday language, so that they are easily understood by future respondents, which is why the lay panel is used. In the next stage of adaptation, patients with PH in cognitive debriefing interviews confirmed the ease of answering particular items and no additional changes were necessary.. Furthermore, the use of a postal system at the validation stage was preferred, because the CAMPHOR is a patient-reported questionnaire, so adding an interviewer might have introduced response bias.

In an evaluation of internal consistency, coefficients of all three CAMPHOR scales (Symptoms, Activities and QoL) were above 0.8, indicating high internal consistency. Moreover, high test-retest coefficients obtained in all CAMPHOR scales confirmed its reproducibility. NHP was used in the validation of the original UK English CAMPHOR [15] and was adapted and validated in Polish for use as a comparator measure in the study of McKenna et al. [30]. The Polish NHP was developed using the same methodology as the Polish CAMPHOR. CAMPHOR consists of three separate sections measuring different types of outcomes: symptoms (impairment), activity limitations (disability) and QoL. The relations between scores on NHP energy section and all three CAMPHOR scales reflect the nature of the disease. Physical mobility (disability) was highly related to CAMPHOR disability and also had an overall impact on QoL scores. Overall, QoL scores were most influenced by energy level, emotional reactions and physical mobility. These results were both expected and matched findings from previous CAMPHOR adaptations [21, 23–25].

The Polish CAMPHOR scales were able to differentiate clearly between groups of patients depending on their perceived general health and perceived disease severity. The finding that older individuals reported significantly worse scores on the Activities and QoL scales was explored further. Investigation of the age differences revealed that older participants experience significantly worse in perceived disease severity and perceived general

health compared to younger individuals. This is in line with previous research that found physical functioning worsened with age in PH patients [31].

Quality of life assessment can serve as an important endpoint especially in patients with an incurable disease. It differs from HRQL in that it assesses outcomes that are of relevance and interest to patients rather than physicians [9]. Carefully developed QoL scales provide a holistic picture of the impact of disease and its treatment on the patient. In the case of chronic or terminal illness where no effective cure is available, emphasis should be placed on improving QoL as the goal of treatment [9].

The Polish CAMPHOR can be applied in both research and clinical settings in the Polish PH population. Previous research has shown that some endpoints do not indicate how patients respond to the illness [14]. This means that it is not possible to determine which interventions are of greatest value to them. Therefore, the wide range of issues covered by the CAMPHOR may support clinicians in the management and monitoring of patients.

Limitations of the study

A limitation of this study is the sample size. However, it was designed to establish the suitability of the Polish CAMPHOR rather than to describe in detail the impact of PH on patients.

Conclusions

The psychometric properties of the Polish version of CAMPHOR indicates that it is a valid and reliable measure of both HRQL and QoL in patients with PH. The new language version is recommended for use in the Polish population who speak Polish.

Acknowledgements

Researchers wishing to use the CAMPHOR questionnaire should contact Galen Research (gr@galen-research.com).

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