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Original Scientific Paper

ADAPTATION AND VALIDATION OF THE CAMBRIDGE PULMONARY HYPERTENSION OUTCOME REVIEW (CAMPHOR) FOR CROATIA

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SUMMARY – Pulmonary hypertension (PH) is a chronic disease which severely impairs quality of life (QoL). The Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR) is the first disease-specific tool to assess patient-reported symptoms, functioning and QoL in PH patients. The aim of this study was to adapt and validate the CAMPHOR for use in Croatia. The adaptation process involved three stages: translation (bilingual and lay panel), cognitive debriefing interviews with patients and psychometric validation. For the latter stage, a postal survey was conducted with 50 patients to examine the reliability and validity of the adapted scale. All three scales of the Croatian CAMPHOR demonstrated excellent internal consistency (Symptoms = 0.93; Activity limitations = 0.94; QoL = 0.92) and test-retest reliability correlations (Symptoms = 0.90; Activity limitations = 0.95; QoL = 0.90). Predicted correlations with the SF-36 scales provided evidence for construct validity of the CAMPHOR scales. Evidence for known group validity was shown by the ability of the scales to distinguish between participants based on patient-perceived general health and disease severity. The Croatian version of the CAMPHOR is a valid and reliable tool for use in clinical routine and clinical research.

Key words: *Hypertension, pulmonary; Quality of life; Croatia; Reproducibility of results; Surveys and questionnaires*

Introduction

Pulmonary hypertension (PH) is an umbrella term which describes the pathophysiological state characterized by elevation of the pulmonary artery pressure (PAP). It is diagnosed when the mean PAP is ≥25 mm Hg at rest[1]. The increase in pressure is progressive and leads to right ventricular failure[2]. The main symptoms of PH in the initial stages are nonspecific, such as exertional dyspnea, fatigue, angina, syncope or abdominal distension. Disease-specific pharmacotherapy can improve patient prognosis, but no cure is possible for primary PH[3].

Traditionally, large-scale clinical trials in PH have relied on clinical outcomes as endpoints[4], but these are impractical in everyday practice. The six-minute walk test (6MWT) has often been used as a primary endpoint, yet the test is not capable of providing an accurate reflection of the patient experience of living with PH[5].

More recently, clinical studies in PH have included health-related quality of life (HRQL) instruments such as the 36-item Short-Form Health Survey (SF-36)[6-9],

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EuroQoL[9,10], and Nottingham Health Profile[11]. These measures focus on the measurement of symptoms and functioning[12]. However, generic instruments are of limited value as they are likely to miss issues pertinent to specific patient populations and include questions that are not relevant to different groups of respondents[13]. Furthermore, these instruments demonstrate poor responsiveness[14-16].

Pulmonary hypertension has a significant impact on the lives of patients, and PH-specific outcome measures are required to determine these effects accurately. PH symptoms such as exertional dyspnea and fatigue have a major impact on physical activity, functioning and working ability, which affects HRQL[17]. Associated conditions such as systemic sclerosis and side effects of pharmacological treatment (e.g., subcutaneous or parenteral prostacyclin) also affect HRQL of pulmonary arterial hypertension (PAH) patients. There is also the psychological impact of PAH, which includes feelings of social isolation. Approximately half of patients with PAH have symptoms of anxiety and about one-third experience symptoms of depression[18].

The Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR) has been developed to assess both HRQL and quality of life (QoL) in patients diagnosed with PH[19]. Consequently, it provides an overall picture of how PH affects the lives of patients. The CAMPHOR is a needs-based outcome measure[20]. Its underlying theory is that QoL represents the capacity of individuals to fulfill their basic human needs. Over 20 disease-specific measures have been developed that apply the needs-based model.

The CAMPHOR was developed using qualitative interviews conducted with PH patients. This ensured that only the most appropriate and relevant concerns of the patients rather than health professionals were included in the measure. The CAMPHOR has been shown to have excellent psychometric properties, maximizing its ability to detect changes in QoL[21]. Following the development of the CAMPHOR, two other PAH specific patient-reported outcome measures have been developed: emPHasis-10 questionnaire and Pulmonary Arterial Hypertension-Symptoms and Impact Questionnaire (PAH-SYMPACT)®[22,23]. These measures assess patient perceived health status but do not collect information on QoL. Therefore, the CAMPHOR is the only PAH specific measure that integrates the assessment of true QoL.

Prior to this study, the CAMPHOR was not available in Croatian. We report on the adaptation of the CAMPHOR into Croatian and its subsequent validation. It was intended that the adaptation would produce a reliable and valid outcome measure for use in PH studies in Croatia.

Patients and Methods

Three stages were employed in adapting the CAMPHOR:

- translation,
- interviews with relevant patients, and
- psychometric validation.

Patients were invited to take part in the interviews and postal validation survey if they were aged at least 18 years, were monolingual Croatian speakers, met the World Health Organization (WHO) definition of PH, and could understand and provide written informed consent. Patients were recruited from the Zagreb University Hospital Centre in Zagreb. Following the Ethics Committee approval, all patients provided their written informed consent prior to inclusion in the study.

Stage 1: Translation

The CAMPHOR was translated into Croatian using two separate translation panels[24]. Firstly, a bilingual panel was held. This consisted of Croatian individuals whose first language was Croatian and who were also fluent in English. The task of this panel was to work as a team to translate the UK English version of the CAMPHOR into Croatian. The focus was on producing conceptual equivalence and a translation that would be comprehensible and acceptable to Croatian respondents. If the group differed on the most appropriate wording for an item, alternative potential translations were sent to a second panel.

Secondly, a lay panel was held, consisting of six monolingual Croatian individuals who were less well educated. This panel was employed to ensure that the items sounded 'natural' and were simple enough for a range of potential respondents to understand. The instructions and items translated by the bilingual panel were presented to members of the lay panel and they were asked to check on ease of understanding, and whether the wording was appropriate. Where alterna-

tive translations were presented, participants selected the most acceptable one. Both panels were led by the same Croatian researcher.

Stage 2: Cognitive debriefing interviews

Ten face to face interviews were conducted with relevant patients to determine the face and content validity of the translated scale. The respondents filled in the CAMPHOR in front of the interviewer before answering a series of questions about its acceptability and comprehensiveness.

Stage 3: Psychometric validation survey

The reliability and validity of the Croatian CAMPHOR was tested by means of a postal survey. PH patients were invited to take part in the survey. Demographic data and illness information were collected from eligible patients attending the outpatient clinic for pulmonary disease at the hospital. At the first administration (Time 1), the Croatian CAMPHOR and the Croatian version of the SF-36[25] were included in the postal survey. Respondents who completed and returned both questionnaires were administered the CAMPHOR again approximately two weeks later (Time 2), to assess reproducibility.

Measures

The CAMPHOR has three individual scales: Symptoms (25 items), Activities (15 items) and QoL (25 items) (Table 1). The Symptoms scale employs "Yes"/"No" format that measures the presence of PH symptoms (from 0 to 25). A higher score indicates higher symptomatology. The Activities scale assesses the extent to which the patient's daily functioning is affected by PH. Each item in the scale has three response options: "Able to do on own without difficulty", "Able to do on own with difficulty", and "Unable to do on own". Each item is scored 0 to 2, giving a total score of 0 to 30. Poor physical functioning is indicated by high scores. The QoL scale uses a "True"/"Not true" response format that indicates that PH interferes with need fulfillment. Again, a high score indicates poorer QoL.

The 36-item Short-Form Health Survey (SF-36)

The SF-36 is a generic HRQL measure containing 36 items falling into eight sections (physical functioning, social functioning, physical role limitations, emotional role limitations, mental health, energy, pain, general health and health transition). Each section is scored from 0 to 100, but for this measure, a higher score indicates better HRQL.

Table 1. Example CAMPHOR items and Croatian translation

Symptoms scale	I get tired very quickly (Croatian: Jako brzo se umaram) I get breathless without doing anything (Croatian: Nedostaje mi daha i kad ne radim ništa)
Activities scale	Stand for a short time (Croatian: Kratko stajati) Lift heavy items (Croatian: Podizati teške predmete)
Quality of Life scale	It feels like my body has let me down (Croatian: Osjećam kao da me tijelo iznevjerilo) I feel as if I am a burden to people (Croatian: Osjećam kao da sam teret drugim ljudima)

Statistical analyses

Descriptive statistics: Median and inter-quartile range [IQR]) scores were calculated for CAMPHOR responses, together with floor and ceiling effects.

Internal consistency: Internal consistency was assessed using Cronbach's alpha, with values below 0.70 indicating that it would be inappropriate to sum item scores[26].

Reproducibility: Spearman's rank correlation coefficient was calculated to establish the test-retest reliability of the CAMPHOR. This estimate of reproducibility should be 0.85 or above[27].

Convergent validity: Convergent validity was determined by correlating scores on the SF-36 sections with those on the CAMPHOR scales. It was expected that QoL scores would be moderately highly correlated with the HRQL scores, particularly energy level and physical limitations.

Known group validity: Known group validity was assessed using Mann-Whitney U tests. These examined whether the CAMPHOR was able to show meaningful differences in score between respondents who differed by self-perceived general health ('very

good or good' and 'fair or poor') and disease severity ('mild or moderate' and 'quite severe or very severe').

Scores of patients who differed by age (below *versus* above median age) and gender were also examined for differences in CAMPHOR scores. As the data collected were at the ordinal level of measurement, non-parametric statistical tests were employed. The Statistical Package for the Social Sciences version 23.0 was used on analyses[28].

Results

Stage 1: Translation

Bilingual panel: Two males and four females participated in the bilingual panel. They were aged between 22 and 35 years. The panel found little difficulty in producing translation of the CAMPHOR, with most items considered straightforward. For some items, direct translation of the item was not appropriate. For example, for the item: 'I feel worn out', the bilingual panel suggested the translation 'I feel drained/spent' to capture the intended meaning of the item.

Lay panel: One male and five females made up the lay panel. Their ages ranged from 30 to 76 years. Changes were made to the translations where the lay panel felt the item could be expressed in more commonly used language. For example, 'I get out of breath when I stand up' from the Symptoms scale was improved by the lay panel. The phrase 'kad ustanem ostanem bez daha' was replaced with 'kad ustanem ponestane mi daha' in the lay panel, as the latter was considered a more natural expression in Croatian.

Stage 2: Cognitive debriefing interviews

Ten cognitive debriefing interviews were performed (seven female; mean age 39 years). Eight patients had idiopathic pulmonary arterial hypertension and two had pulmonary hypertension resulting from congenital heart disease. Interviewees completed the questionnaire between 6 and 11 minutes (mean = 8.8 minutes).

The mean time taken to complete the CAMPHOR was 8.8 (range 6 to 11) minutes. Respondents considered the questionnaire to be clear, comprehensible and relevant. Due attention was paid to three items in the cognitive debriefing interviews (CDIs), in which both the bilingual and lay panel translations were presented

Table 2. Demographic and disease information (N=50)

Age		**Years**	
Mean (SD)		52.8 (14.4)	
Median (IQR)		52.2 (43.1-65.7)	
Range		24.1-78.2	
Gender		**n**	**%**
Male		15	30
Female		35	70
Marital status			
Married/living as married		30	60
Divorced		4	8
Widowed		2	4
Single		14	28
Work status			
Working full-time		6	12
Homemaker		2	4
Retired		29	58
Long-term sick leave		3	6
Unemployed		7	14
Student		2	4
Other		1	2
Diagnosis			
Idiopathic PAH		13	26
PAH due to congenital heart disease		14	28
PAH due to connective tissue disease		10	20
Chronic thromboembolic pulmonary hypertension		13	26
Patient-perceived disease severity			
Mild		5	10
Moderate		21	42
Quite severe		21	42
Very severe		2	4
Missing		1	2
Patient-perceived general health			
Very good		2	4
Good		13	26
Fair		21	42
Poor		14	28

SD = standard deviation; IQR= interquartile range; PAH = pulmonary arterial hypertension

Table 3. Questionnaire descriptive statistics

	n	Median (IQR)	Min - Max	% scoring minimum	% scoring maximum
Time 1					
CAMPHOR Symptoms	47	9 (4-13)	0-24	6	0
CAMPHOR Activities	50	8 (4-13)	1-25	0	0
CAMPHOR QoL	48	5 (2-13)	0-21	13	0
SF-36 sections (Time 1)					
Physical functioning	48	55 (30- 69)	0-90	6	0
Physical role limitations	50	25 (0-100)	0-100	36	32
Bodily pain	50	62 (41-100)	12-100	0	28
General health	48	35 (25-59)	5-87	0	0
Vitality	50	53 (40-70)	5-90	0	0
Social functioning	49	63 (50-88)	0-100	4	14
Emotional role limitations	50	100 (33-100)	0-100	22	54
Emotional well-being	50	68 (51-77)	24-100	0	2
Time 2					
CAMPHOR Symptoms	49	11 (4-17)	0-25	6	4
CAMPHOR Activities	50	10 (5-14)	0-29	2	0
CAMPHOR QoL	48	7 (2-17)	0-25	15	2

IQR = interquartile range; CAMPHOR = Cambridge Pulmonary Hypertension Outcome Review; QoL = quality of life

to patients for consideration. For two of the items, interviewees felt that the translation generated by the lay panel sounded more natural in Croatian. For the item 'My condition limits the places I can go', interviewees preferred the bilingual panel's translation for clarity and understanding.

Stage 3: Psychometric validation

All the patients invited agreed to participate in the postal validation survey (n=50). Table 2 provides demographic information on the sample and ratings of perceived disease severity and general health. Most respondents were female and married or living as married. More than half the sample were retired. Most patients perceived their disease severity to be 'moderate' or 'quite severe' and rated their general health as 'fair'.

Descriptive statistics

Table 3 shows scores obtained on the outcome measures. Large proportions of respondents scored at the minimum or maximum on the physical role limitations and emotional role limitations sections of the SF-36. The pain section also demonstrated ceiling effects, indicating that these subscales are not well targeted to PH patients.

Internal consistency and reproducibility

Alpha coefficients and test-retest reliability for the CAMPHOR are shown in Tables 4 and 5, respectively. All values achieved were well above the required values.

Table 4. Cronbach's alpha coefficients

	Time 1	Time 2
Symptoms	0.93	0.94
Activities	0.94	0.94
Quality of life	0.92	0.95

Table 5. Test-retest reliability (reproducibility)

	Symptoms (n=46)	Activities (n=50)	QoL (n=46)
Correlation coefficient	0.90	0.95	0.90

QoL = quality of life

Table 6. Correlation between CAMPHOR scales and SF-36 section scores at Time 1

	Symptoms	Activities	Quality of life
SF-36			
Physical functioning	-0.54	-0.74	-0.62
Physical role limitations	-0.75	-0.64	-0.64
Bodily pain	-0.62	-0.51	-0.59
General health	-0.58	-0.51	-0.64
Vitality	-0.74	-0.62	-0.72
Social functioning	-0.69	-0.60	-0.79
Emotional role limitations	-0.51	-0.33*	-0.49
Emotional well-being	-0.66	-0.53	-0.78

All correlations significant at the 0.01 level (2-tailed) except where marked; *significant at the 0.05 level (2-tailed)

Convergent validity

Table 6 shows the association between CAMPHOR scale scores and those on the SF-36 sections at Time 1. CAMPHOR Symptoms were moderately highly associated with the SF-36 vitality and physical role limitations sections. As expected, CAMPHOR Activities were most strongly associated with physical functioning. CAMPHOR QoL was most closely related to scores on the emotional well-being and social functioning sections of the SF-36.

Known group validity

There were statistically significant differences in scores on all three CAMPHOR scales related to both self-perceived disease severity (Fig. 1) and perceived overall health (Fig. 2).

Association with demographic factors

Table 7 shows CAMPHOR scores for patients grouped by gender and age (below *versus* above median age). Scale scores did not differ by gender.

A statistically significant difference between older and younger patients was found for the CAMPHOR Activities scale. Older patients scored higher on the scale than younger patients. This difference was not related to perceived severity of PH (χ^2 (49)=0.53; p=0.47). Similarly, no significant relation was found between age and perceived overall health (χ^2 (50)=2.38; p=0.12).

Discussion

The CAMPHOR proved straightforward to adapt into Croatian and was found to be easily and quickly completed by, and relevant and comprehensive to, local PH patients. The adapted CAMPHOR demonstrated

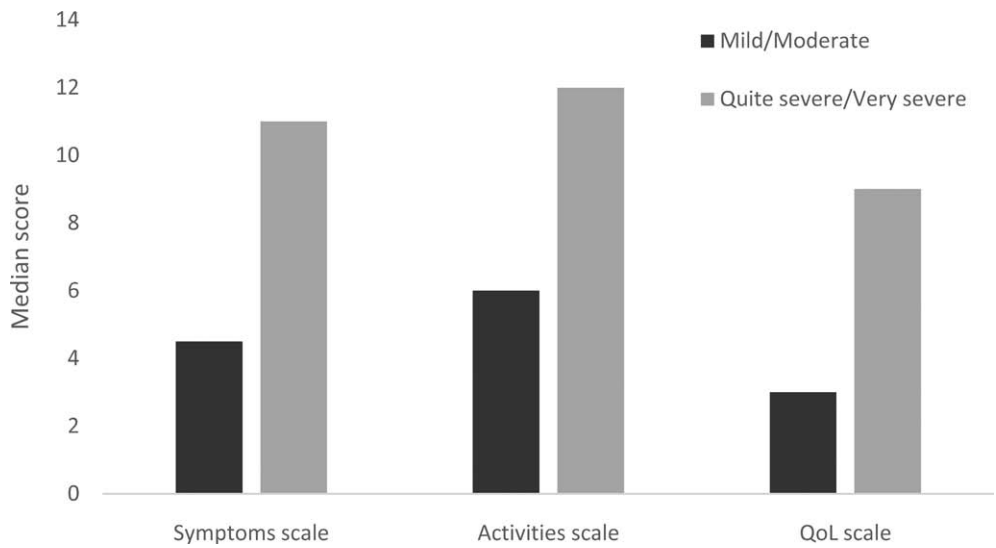

Fig. 1. Median CAMPHOR scale scores by perceived disease severity.

All comparisons statistically significant (p<0.01; 2-tailed); QoL = quality of life

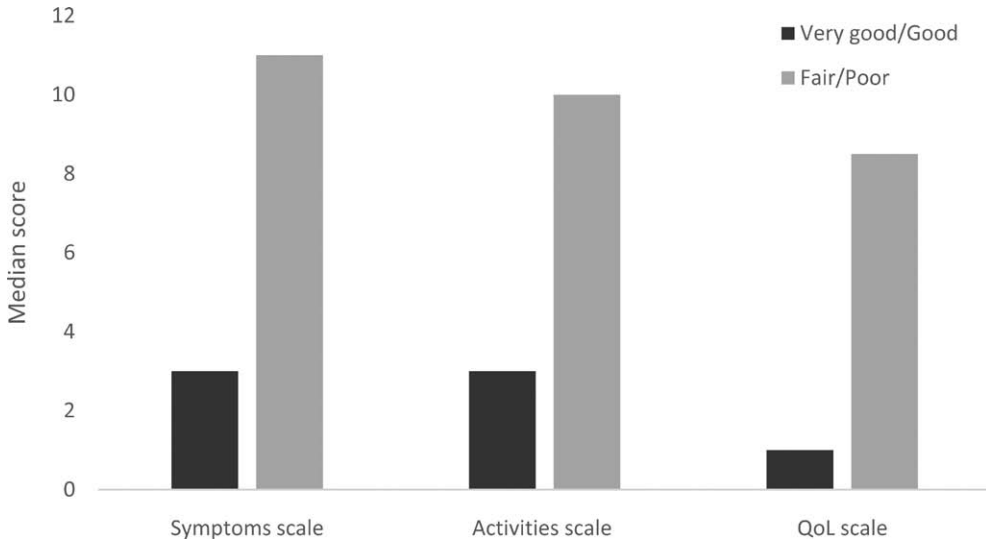

Fig. 2. Median CAMPHOR scale scores by perceived general health.

All comparisons statistically significant (p<0.001; 2-tailed); QoL = quality of life

Table 7. CAMPHOR scale scores by gender and age group

		Symptoms		Activities		QoL
	n	Median (IQR)	n	Median (IQR)	n	Median (IQR)
Gender						
Male	15	9 (6-17)	15	12 (7-15)	14	10 (3-17)
Female	32	9 (3-13)	35	7 (4-11)	34	5 (2-11)
p	47	0.42	50	0.14	48	0.26
Age						
Below median	25	7 (4-13)	25	6 (3-9)	24	5 (1-10)
Above median	22	10 (6-18)	25	12 (7-17)	24	7 (4-16)
p		0.25		<0.05		0.07

IQR = interquartile range; QoL = quality of life

good psychometric properties, with excellent consistency and test-retest reliability. Tests of validity showed that CAMPHOR scale scores correlated as expected with SF-36 section scores and were able to distinguish between groups of patients who varied by perceived disease severity and general health.

Without careful adaptation, questionnaire items may be interpreted differently by local respondents or the instructions could cause problems. This study employed two translation panels[24]. This approach focuses on conceptual equivalence to the source measure rather than literal equivalence. Consequently, language versions are produced that are more directly comparable. Patients have rated translations produced by this dual-panel methodology as preferable to those developed using forward-backward translations[29]. Because of the numerous dialects in Croatia, it was important that the adaptation was expressed in simple, everyday language. Participants in the bilingual and lay panels were mainly from one region in Croatia, meaning it is possible that the translations would not be appropriate for all regional dialects. However, the psychometric validation stage included participants from throughout the country and no problems with the wording of items were found.

Given that elderly populations tend to have poor physical functioning, it is not surprising that differences in scores on the CAMPHOR Activities scale

were found between older and younger patients. This finding could not be explained in terms of differences in patient-perceived disease severity or general health, suggesting that care should be taken when matching comparison groups in clinical studies.

A limitation of the study was that most of the participants in the bilingual panel were university students. Consequently, it is possible that the first translation produced may have been more appropriate to a younger population. However, any resulting issues were dealt with in the lay panel which consisted of people with a wider range of ages.

The Croatian CAMPHOR is one of many language adaptations that have been produced, all of which have been shown to have good psychometric properties. Results in this study compared well with those for the German[30], Swedish[31], Canadian[32], United States[33], and Australian and New Zealand[34] adaptations of the CAMPHOR. Use of the CAMPHOR in everyday practice may facilitate communication between clinicians and patients.

Conclusion

The newly developed Croatian CAMPHOR represents an accurate and reliable instrument for assessing both HRQL and QoL in Croatian PH patients. The new questionnaire will prove a valuable tool for application in clinical routine and for evaluating clinical and non-clinical interventions.

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Sažetak

HRVATSKA PRILAGODBA I VREDNOVANJE UPITNIKA *THE CAMBRIDGE PULMONARY HYPERTENSION OUTCOME REVIEW* (CAMPHOR)

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Plućna hipertenzija je kronična bolest koja značajno narušava kvalitetu života. *The Cambridge Pulmonary Hypertension Outcome Review* (CAMPHOR) je prvi upitnik specifičan za ovu bolest kojim bolesnici s plućnom hipertenzijom smoprocjenjuju simptome, funkcionalni status i kvalitetu života. Cilj ove studije bio je prilagoditi i vrednovati CAMPHOR za uporabu u Republici Hrvatskoj. Prilagodba je postupak koji uključuje tri koraka: prijevod (dvojezični panel i panel laika), kognitivno ispitivanje i psihometrijsko vrednovanje. U daljnjem tijeku ispitivanje je provedeno na 50 bolesnika kako bi se ispitala pouzdanost i valjanost adaptiranih ljestvica. Sve tri ljestvice hrvatske verzije CAMPHOR-a pokazale su izvrsnu unutarnju konzistenciju (Simptomi = 0,93; Aktivnosti = 0,95; Kvaliteta života = 0,92) i ponovljivost (Simptomi = 0,90; Aktivnosti = 0,95; Kvaliteta života = 0,92). Korelacija sa česticama SF-36 potvrdila je strukturnu valjanost ljestvica CAMPHOR-a. Prema rezultatima ljestvica moguće je razlikovati ispitanike grupirane prema samoprocijenjenom općem zdravstvenom stanju i težini bolesti, čime je dokazana valjanost upitnika za definirane skupine. Hrvatska inačica CAMPHOR-a je valjan i pouzdan upitnik za primjenu u svakodnevnom kliničkom radu i kliničkim ispitivanjima.

Ključne riječi: *Hipertenzija, plućna; Kvaliteta života; Hrvatska; Reproducibilnost rezultata; Ankete i upitnici*