

Validation of the Slovenian Version of Patient Assessment of Chronic Illness Care (PACIC) in Patients with Coronary Heart Disease

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ABSTRACT

The Chronic Care Model (CCM) is a conceptual framework that supports the evidence-based proactive and planned care of chronic diseases. Our aim was to validate a Slovenian translation of Patient Assessment of Chronic Illness Care (PACIC) – a self-reported instrument designed to measure the extent to which patients with chronic illnesses receive care congruent with CCM – on a sample of patients with coronary heart disease. Secondary analysis of patients' evaluation of general practice care (EPA Cardio study) was done in patients with coronary heart disease in Slovenia. Patients completed a written questionnaire, which included the instrument for assessing chronic illness care (PACIC), the EUROPEP questionnaire and demographical data. Internal consistency was expressed in terms of Cronbach's α . Reliability was expressed as the intra class correlation coefficient (ICC). Correlation between PACIC and EUROPEP was considered as a measure of construct validity. Factor analysis was done to identify number and types of domains in the instrument. Questionnaires of 843 patients were analysed. The mean age was 68.2 (SD 11.1) years, 34.6% of participants were female. 32.7% of PACIC questionnaires were not completely fulfilled. The internal consistency of the entire questionnaire assessed by Cronbach's α was 0.953 and reliability was 0.937. Construct validity was confirmed with important and significant correlation between PACIC and EUROPEP questionnaire (Spearman's correlation coefficient = 0.60, $p < 0.001$). Principal component factor analysis identifies two major factors which we labeled according to the PACIC domains as »Patient activation, decision support and problem solving« and »Goal settings and coordination«. A translated and validated Slovenian version of PACIC questionnaire is now available. Further research on its validity in other groups of chronically ill patients and the use of instrument for monitoring changes of chronic care over time is recommended.

Key words: chronic diseases, patient perspective, PACIC, validation, Slovenia

Introduction

Most adult patients with major chronic diseases have more than one chronic condition and only a primary care team which is familiar with the patient and her or his family is able to communicate and coordinate medical activities across settings and caregivers¹.

The Chronic Care Model (CCM) is a conceptual framework that supports the evidence-based, proactive and planned care for chronic diseases²⁻⁴. Measures of chronic care delivery are required to target efforts to improve chronic care and to monitor change of chronic care over time.

It has been confirmed that the care of patients according to the principles of CCM leads to higher quality of care and better patients-level assessment of health care. Implementation of CCM was associated with a higher level of recommended procedures and a better intermediate outcome in patients with diabetes⁵, was recognized by patients as more structured and at larger extent reflect evidence-based counseling than usual care⁶, improves self-reported quality of chronic health care for multimorbid older persons⁷ and was positively associated with self-management behaviors, self-reported adheren-

ce to medication, patient rating of their health care and quality of life⁸.

Several means are being developed to assess the effect of CCM implementation on system of care. The assessment of chronic illness care (ACIC) and the patient assessment of chronic illness care (PACIC) instruments have been developed to assess chronic care model implementation at the level of provider and patient. The ACIC instrument was developed to measure the extent to which a health care team employs CCM elements with their patients and it is completed by the health care providers⁹.

The patient assessment of chronic care model (PACIC) has been designed to assess the implementation of the CCM from the patient's perspective that focuses on the receipt of patient-centered care and self-management behaviours¹⁰. Using a patient-level assessment of health care such as PACIC is consistent with calls for both practical tools for evaluating chronic care management and for quality measurement tools that are patient-centered and focus on patient perspectives.

The PACIC is a 20-items questionnaire, divided into five domains. Patients fulfill the questionnaire, which intends to measure chronic care delivery¹⁰. It has been validated in many countries in Europe^{11–17} in groups of different chronically ill patients: diabetes^{11,13,15}, osteoarthritis¹⁴ and mental disorders¹².

In Slovenia most of the chronically ill patients were treated by general practitioners, taking into account the main principles of CCM. Until now, we have not had yet an instrument for evaluation of chronic care delivery from the patient's perspective. Therefore, the aim of our study was to develop a Slovenian version of the PACIC instrument and test it on patients with coronary heart disease in general practice.

Methods

We performed a secondary analysis of patient evaluation of general practice care, using data from EPA cardio study for patients with coronary heart disease in Slovenia. The detailed description of EPA cardio study protocol has been published¹⁷.

Study population and settings

For the cross-sectional validation study we included Slovenian speaking primary care patients with coronary heart disease (with the diagnosis of ischemic heart disease in the medical record, with or without heart attack in the past), treated by 36 general practitioners in Slovenia. The general practitioners were selected randomly from a stratified sample of general practices, based on the proportion of urban and rural general practices and proportion of solo and group practices (mainly in health care centres)¹⁷. 36 out of 56 (64.3%) invited general practitioners accepted invitation.

1080 randomly selected patients with ischemic heart disease were invited (30 per practice) and 863 participated (79.9%). 20 (2.3%) questionnaires were excluded

from the analysis due to incomplete data in five or more items in PACIC. The final sample consisted of the questionnaires of 843 patients.

Measures

Patient assessment of chronic illness care (PACIC) was measured with a 20-items questionnaire, which used a five point response scale (ranging from 1 – »almost never« to 5 – »almost always«). Higher score means more frequent presence of the aspect of structured care. The PACIC instrument has five pre-defined domains: patient activation (3 items), delivery system/practice design (3 items), goal setting/tailoring (5 items), problem solving/contextual (4 items), and follow up/coordination (5 items)¹⁰.

Patient evaluation of general practice was measured with the EUROPE instrument, a 23-items international standardized and validated questionnaire (with a five point ranking scale from 1 – poor to 5 – excellent)¹⁸. The instrument has been already validated in Slovenian language¹⁹.

Finally, the questionnaire contains questions on patient's age, gender, level of education, marriage status, employment status and overall health status (from poor to excellent).

PACIC questionnaire translation

Using accepted guidelines for translation – back translation was used²⁰. The English version of the questionnaire was translated into Slovenian by two native Slovenian speakers, fluent in English and medical terminology. Two different translators then independently translated back into English. Any differences were resolved by consensus. The back translated English version was compared with the original English version to ensure that no loss of meaning or context occurred during the translation process.

Data analysis

We used descriptive statistics ($\bar{X} \pm SD$) for the description of the sample and distributions of scores of the overall PACIC and its 5 subscales. The interpretability of the instrument (the extent to which a qualitative meaning can be assigned to the qualitative scores) was based on the percentages of the chronic patients who provided valid responses on each on the items. In addition, we checked for the floor and the ceiling effect in terms of percentage of patients using the most extreme (upper and lower) response categories.

With the multivariate analysis we analyzed the influence of demographical factors on the overall PACIC score.

Internal consistency (the extent to which items measure the same concept) was expressed in terms of Cronbach's α for the total PACIC and its subscales. Reliability was expressed as the intra-class correlation coefficient (ICC), which is based on variation between patients divided by total variation.

Cronbach's α coefficient and ICC for overall scale can be considered as low in case of lower than 0.80, satisfactory when between 0.80 and 0.90 and high in case of larger than 0.90. For subscales, a minimum value of 0.70 was regarded as acceptable. We assumed the same levels of acceptable internal consistency and reliability as in another study¹².

The analysis of construct validity was based on the hypothesis that a higher overall PACIC score reflected that the patient perceived presence of structured care of his or her chronic disease. We considered that a higher overall PACIC score would be positively correlated with the patient's overall evaluation of general practice assessed by EUROPEP instrument. To verify this expectation, we used the Spearman's rank-order correlation due to non-normal distribution of the variables.

Factor analysis using the principal components extraction method with varimax rotation (factors with eigenvalue >1) was applied to examine the number and the type of domains in the instrument. We determined the Kaiser-Meyer-Olkin measure of sampling adequacy and the Barlett's test of sphericity.

All calculations were conducted by using SPSS, version 21 for Windows (SPSS Inc, Chicago, Illinois, USA).

We considered p values less than or equal to 0.05 to be significant.

Ethical approval

The study was presented to the national ethical committee and got its approval.

Results

Description of the sample

Patients' characteristics are presented in Table 1. Due to the high average age of the participants, 77.5% of them had already retired. 1.9% of patients were unemployed. Only 4.2% of the participants assessed their health status as very good or excellent, 31.5% as good, 46.1% as fair and 18.2% as poor.

Descriptive information on PACIC items

Descriptive information on PACIC items is presented in Table 2. Information about PACIC domains and overall PACIC scores are given in Table 3. For overall PACIC we found an excellent internal consistency, assessed by

Cronbach's α (0.95), a reliability assessed with ICC (0.94) and a very good correlation with EUROPEP questionnaire (0.60), that confirmed also the validity of the instrument.

Table 4 shows correlations between each PACIC domain and EUROPE domains. The correlations between similar domains in PACIC and EUROPEP were good.

Association between patients' characteristics and overall PACIC score

Using multivariate regression, taking into account all the observed demographical variables (age, gender, years of education, marriage status, employment status), we found that only 'more than 9 years of education' is significantly correlated with higher score in overall PACIC ($b = 0.093$, 95% CI 0.004–0.351, $p = 0.045$).

Instrument properties from explanatory factor analysis

Using the factor analysis with varimax rotation, we identified two factors, explaining 60.5% of the total variance. The first component with eigenvalue 10.65 explains 53.2% of the total variance (87.9% of the explained variance) and the second factor only 7.3% of the total variance (12.1% of the explained variance). Table 5 shows the results of the factor analysis. We labeled the two factors according to the PACIC domains as composite factors:

Patient activation, decision support and problem solving

Goal settings and coordination

The first two predefined domains loaded completely to the first factor and partly also the fourth domain. The fifth domain and partly the third domain loaded with the second factor.

Discussion

Main findings

Slovenian version of PACIC questionnaire is reliable and internally consistent instrument. A strong positive correlation between the overall PACIC instrument and the EUROPEP questionnaire and strong positive correlations between the equivalent domains in both two questionnaires confirmed the validity of instrument for measuring patient reported structured care. We did not

TABLE 1
PATIENTS' CHARACTERISTICS

Characteristics	Values
Age	68.2 (SD 11.1), Range: 34–98
Proportion of female patients	34.6%
Proportion of patients with 9 or more years of education	60.6%
Proportion of married/cohabitated	74.9%
Proportion of employed	20.6%

TABLE 2
DESCRIPTIVE INFORMATION ON PACIC ITEMS

Domains	Items	Number (%) of patients who did not answer the particular question	Floor effect (%)	Ceiling effect (%)	\bar{X} (SD)
Patient activation					
	Asked for my ideas when we made a treatment plan.	140 (16.6)	7.3	23.9	3.57 (1.18)
	Given choices about treatment to think about.	154 (18.3)	8.7	27.7	3.54 (1.28)
	Asked to talk about any problems with my medicines or their effects.	137 (16.2)	4.4	45.4	4.06 (1.12)
Delivery system design/decision support					
	Given a written list of things I should do to improve my health.	157 (18.6)	15.2	26.2	3.31 (1.40)
	Satisfied that my care was well organized.	133 (15.8)	1.4	41.5	4.60 (0.89)
	Shown how what I did to take care of myself influenced my condition.	157 (18.6)	6.2	28.6	3.57 (1.24)
Goal setting/tailoring					
	Asked to talk about my goals in caring for my condition.	162 (19.2)	10.7	22.2	3.26 (1.30)
	Helped to set specific goals to improve my eating or exercise.	145 (17.2)	4.6	34.8	3.78 (1.18)
	Given a copy of my treatment plan.	157 (18.6)	22.2	21.7	2.91 (1.47)
	Encouraged to go to a specific group or class to help me cope with my chronic condition.	176 (20.9)	30.1	14.5	2.51 (1.41)
	Asked questions, either directly or in a survey, about my health habits.	152 (18.0)	4.6	39.5	3.15 (1.33)
Problem solving/contextual					
	Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.	144 (17.1)	10.3	31.2	4.00 (1.10)
	Helped to make a treatment plan that I could carry out in my daily life.	150 (17.8)	10.8	31.5	3.58 (1.32)
	Helped to plan ahead so I could take care of my condition even in hard times.	159 (18.9)	11.1	27.8	3.44 (1.32)
Follow-up/coordination					
	Asked how my chronic condition affects my life.	144 (17.1)	23.8	16.7	3.47 (1.31)
	Contacted after a visit to see how things were going.	153 (18.1)	13.9	20.9	2.75 (1.42)
	Encouraged to attend programs in the community that could help me.	164 (19.5)	30.7	10.1	2.38 (1.31)
	Referred to a dietitian, health educator, or counselor.	164 (19.5)	36.8	12.6	2.28 (1.38)
	Told how my visits with other types of doctors, like an eye doctor or surgeon, helped my treatment.	154 (18.3)	17.2	22.0	3.15 (1.42)
	Asked how my visits with other doctors were going.	150 (17.8)	21.6	29.9	3.46 (1.41)

confirm the predefined five domains structure. Slovenian version of PACIC has only two dimensions.

Comparison with existing literature

A substantial number of patients did not provide answers to the PACIC questionnaire, although they returned the questionnaires and completed other parts of the questionnaire well. In the original version of PACIC validation, only a few percent of the responders did not

answer all the questions¹⁰. It seems that the questionnaire was not easy to understand for the elderly patients, participating in the survey. A possible problem for high percentage of patients, mentioned in the research made by Wensing et al. in Netherlands, is probably attributed to translation problems¹¹ or differences in the health care systems regarding the care of chronically ill patients between US and European countries¹⁶. Patients' expectations toward general practitioners and general practice may be different in different cultures.

TABLE 3
INFORMATION ON THE PACIC DOMAINS ABOUT OVERALL PACIC SCORES

	Overall PACIC score	Patient activation	Delivery system design/decision support	Goal setting/tailoring	Problem solving/contextual	Follow-up/coordination
Number of questions	20	3	3	5	4	5
Available sample for data analyses	567	677	666	629	656	567
Proportion of incompletely fulfilled questionnaires	32.7%	19.7%	21.0%	25.4%	22.2%	32.7%
Mean value (SD) for responders	3.26 (0.94)	3.72 (1.03)	3.67 (1.00)	3.01 (1.04)	3.60 (1.06)	2.77 (1.09)
Item to scale correlation		0.57–0.72	0.69–0.76	0.64–0.78	0.66–0.76	0.61–0.73
Cronbach's α	0.95	0.83	0.79	0.84	0.86	0.85
ICC (Intra-class correlation coefficient)	0.94	0.81	0.73	0.81	0.85	0.81
Effect of aggregated EURO-PEP score (Spearman's rank correlation coefficient, p value)	0.60 p<0.001	0.59 p<0.001	0.56 p<0.001	0.53 p<0.001	0.59 p<0.001	0.49 p<0.001

TABLE 4
CORRELATIONS BETWEEN PACIC AND EUROPEP DOMAINS

EUROPEP	PACIC				
	Patient activation	Delivery system design/decision support	Goal setting/tailoring	Problem solving/contextual	Follow-up/coordination
Access to assistance facility	0.414	0.380	0.348	0.432	0.339
Information and support	0.564	0.502	0.465	0.545	0.411
Medical care	0.549	0.522	0.474	0.554	0.428
Doctor-patient relationship	0.498	0.542	0.449	0.500	0.392
Service organisation	0.519	0.480	0.439	0.513	0.398

All the correlations were statistically significant at level $p < 0.05$

The overall PACIC score in a population of patients with coronary heart disease was 3.26. The score was higher than in the population of patients with cardiovascular disease in Netherlands²¹, patients with chronic illnesses in England¹⁶, and patients with osteoarthritis in Germany¹⁴. Our results are more comparable with the results of patients with diabetes in Netherlands and Spain^{11,13} and patients with mental disorders in Germany¹².

The high PACIC score for patients with coronary disease in Slovenia could be a result of the program of cardiovascular prevention in Slovenia, which started in 2001 and resulted in a high level of cardiovascular risk factors recording in patients at high risk²² and based on quality indicators successful cardiovascular risk management in patients with coronary disease²³.

It would be interesting to know whether the overall PACIC score in Slovenia would be as high also for other chronically ill patients for whom we had not organized such a structured and comprehensive model of care.

We found high floor and ceiling effects, like in Danish and Dutch study^{11,15}. It is a question how the items in PACIC cohere with the present opportunities for chronic

care within health care system in primary care is Slovenia and some other European countries.

Similar to validation study¹⁰, we also found that demographical characteristics have little influence on PACIC scores. Using multivariate regression we found that only a higher level of education is related to a higher PACIC score. The possible explanation is that a better educated patient wishes to be more involved in its treatment. More detailed explanations for this result require further investigation.

The Slovenian version of the PACIC questionnaire has very good internal consistency, reliability and external validity. Internal consistency of the overall PACIC was very high and comparable to the original PACIC instrument and to most of the national validations of PACIC in various European countries^{11,15,16}. Internal consistency of the domains of five predefined domains of the PACIC questionnaire was also acceptable (from 0.79 to 0.86) and comparable to original instrument and national validations^{10,11,15,16}.

The correlation between the overall PACIC and EUROPEP, which had been already validated in Slovenian

TABLE 5
FACTOR ANALYSIS REVEALS TWO-DIMENSIONAL STRUCTURE OF SLOVENIAN VERSION OF PACIC QUESTIONNAIRE

PACIC domains	Items	Factor 1	Factor 2
Patient activation			
	Asked for my ideas when we made a treatment plan.	0.766	0.244
	Given choices about treatment to think about.	0.728	0.305
	Asked to talk about any problems with my medicines or their effects.	0.729	0.089
Delivery system design/decision support			
	Given a written list of things I should do to improve my health.	0.611	0.439
	Satisfied that my care was well organized.	0.775	0.178
	Shown how what I did to take care of myself influenced my condition.	0.688	0.410
Goal setting/tailoring			
	Asked to talk about my goals in caring for my condition.	0.652	0.484
	Helped to set specific goals to improve my eating or exercise.	0.689	0.338
	Given a copy of my treatment plan.	0.513	0.521
	Encouraged to go to a specific group or class to help me cope with my chronic condition.	0.233	0.766
	Asked questions, either directly or on a survey, about my health habits.	0.701	0.266
Problem solving/contextual			
	Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.	0.695	0.402
	Helped to make a treatment plan that I could carry out in my daily life.	0.635	0.476
	Helped to plan ahead so I could take care of my condition even in hard times.	0.630	0.456
	Asked how my chronic condition affects my life.	0.430	0.575
Follow-up/coordination			
	Contacted after a visit to see how things were going.	0.469	0.581
	Encouraged to attend programs in the community that could help me.	0.135	0.853
	Referred to a dietitian, health educator, or counselor.	0.195	0.830
	Told how my visits with other types of doctors, like an eye doctor or surgeon, helped my treatment.	0.449	0.639
	Asked how my visits with other doctors were going.	0.433	0.496

language, was strong and we also found significant correlations between PACIC and EUROPEP domains. The strong correlation between these two instruments could confirm the validity of the Slovenian version of the PACIC instrument. The EUROPEP instrument was built for the assessment of patients' satisfaction with primary care, but now we have a reliable and valid instrument for the assessment of chronic illness care, which should be used for measuring the extent to which patients receive care congruent with comprehensive chronic care model.

Based on confirmatory factor analyses we could not confirm a five dimension structure in the Slovenian version of PACIC. Our patients recognized only two dimensions of care, which explained 60.5% of total variance. From that point of view, our results were in line with the results of PACIC validation from Germany¹², Denmark¹⁵ and the results of Gugiu et al. who did not confirm the original five-factor structure of the PACIC and later developed and validated a shorter version of PACIC with

good psychometric characteristics and only one dimension²⁴.

Strength and limitations of the study

The number of included randomly selected patients was higher than in most of the other validation studies and the response rate was reasonable and in line with other published studies^{11,12,14}. Comparison between the results of EUROPEP, which has been already validated in Slovenia¹⁹, and the PACIC instrument confirmed external validity of the PACIC instrument.

Our assessment on acceptability was limited to missing item rates and the floor and the ceiling effect, but we did not explore other aspects, such as patients' view on the scale and cultural accessibility of the scale. A substantial number of responders did not answer to all the items in the questionnaire and there were relatively high floor and ceiling effects, although the reasons for that would benefit from further research.

Due to the cross-sectional design of the study we did not have to estimate some important aspects of reliability and validity, including test-retest reliability or responsiveness to changes.

Implications for future work and research

PACIC questionnaires should be encouraged in quality improvement projects, but also in the further research. The Slovenian version of the PACIC questionnaire could be used for assessment of patients' assessment of care in various chronic diseases and for the monitoring of patients' assessment of chronic illness care over time.

The complexity of proactive and patient-centered care, which also addresses self-management, became more and more in focus in Slovenia in the last two years. With the implementation of »modal practices« – family medicine practices with extended team including also a graduated nurse who is responsible for preventive service and the care of chronically ill patients²⁵ – the care is becoming more and more patient-centered and in line with the concept of chronic care model. In the future, our aim is to monitor the effect of the new concept of work in general practice from patients' perspective using PACIC instrument and quality of care, measured by quality indicators.

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Patients in Slovenia are mostly satisfied with their general practitioners²⁶ and also with nurse practitioners working in modal practices²⁷, but some quality improvement factors are not always in favor with higher satisfaction score²⁸.

It would be interesting to know whether there are any correlations between patients' assessment of chronic care assessed by PACIC and the quality of care accessed by quality indicators.

Conclusion

The Slovenian version of PACIC is a reliable and valid instrument for patients with long-term conditions, treated in general practice.

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VREDNOVANJE SLOVENSKE INAČICE MODELA PATIENT ASSESSMENT OF CHRONIC ILLNESS CARE (PACIC) U PACIJENATA S KORONARNOM BOLESTI SRCA

SAŽETAK

Model kronične njege (CCM) je konceptualni okvir koji podržava na dokazima temeljenu proaktivnu i planiranu brigu o kroničnim bolestima. Naš je cilj bio vrednovati slovenski prijevod Patient Assessment of Chronic Illness Care (PACIC) – osobno prijavljujući instrument konstruiran za mjerenje koliko bolesnici s kroničnim bolestima dobivaju brigu sukladnu s CCM – na uzorku oboljelih od koronarne bolesti srca. Sekundarna analiza evaluacije pacijenata skrbi opće prakse (EPA kardio studija) je učinjena u bolesnika s koronarnom bolesti srca u Sloveniji. Pacijenti su ispunili pismeni upitnik, koji je uključivao instrument za procjenu skrbi kronične bolesti (PACIC), upitnik EUROPEP i demografske podatke. Unutarnja konzistencija izražena je s Cronbach α . Pouzdanost je izražena kao koeficijent unutar klase korelacije (ICC). Korelacija između PACIC i EUROPEP smatra se kao mjera valjanosti konstruiranog instrumenta. Faktorska analiza je učinjena kako bi se identificirali broj i vrsta domena u instrumentu. Analizirani su upitnici od 843 pacijenata. Srednja dob je 68,2 godine (SD 11,1 godina), 34,6% ispitanika bile su žene. 32,7% od PACIC upitnika nisu u potpunosti ispunjeni. Unutarnja konzistentnost cjelokupnog upitnika je ispitana, Cronbach α je bio 0,953 i pouzdanost je bila 0,937. Potvrđena je valjanost konstruiranog kao važan i u značajnoj korelaciji između PACIC i upitnika EUROPEP (Spearmanov koeficijent korelacije =0,60, $p<0,001$). Faktorska analiza Principal Component identificirala je dva glavna faktora koje smo označili prema PACIC domeni kao »Aktivacija pacijenta, podrška u odlučivanju i rješavanju problema« i »postavkama cilja i koordinacije«. Prevedena i ovjerena slovenska verzija upitnika PACIC je sada dostupna. Preporučuju se daljnja istraživanja njegove valjanosti u drugim skupinama kroničnih bolesnika i korištenje instrumenta za praćenje promjena u kroničnoj skrbi tijekom vremena.