

ORIGINAL ARTICLES

Measurement properties of the Portuguese version of the rheumatoid arthritis patient-reported experience measure (CQRA-PREM): a cross-sectional single center study

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ABSTRACT

Aims: to test the measurement properties of the Portuguese version of the Commissioning for Quality in Rheumatoid Arthritis Patient-Reported Experience Measure (CQRA-PREM) for patients with rheumatoid arthritis (RA).

Methods: This cross-sectional clinical field study recruited adult patients with RA during rheumatology appointments of a Portuguese rheumatology center. Patients completed the Portuguese version of CQRA-PREM, composed of 7 domains and 24 questions. Sociodemographic characteristics, symptoms/disease duration, current treatment, Pain-Visual Analog Scale (VAS), Patient Global Assessment (PGA)-VAS and Health Assessment Questionnaire (HAQ) were also collected from the patient. Disease Activity Score for 28 joints with C-reactive Protein (DAS28-CRP) was recorded by the rheumatologist. The assessment of CQRA-PREM measurement properties followed the Consensus-based Standards for the Selection of Health Status Measurement Instruments (COSMIN) recommendations.

Results: A total of 61 patients with RA were included. The domains in which patients showed better experience were the "Needs and preferences", followed by "Coordination and Communication". The domain "Information, education and self-care" was an identified area of improvement for providing patient-centered care. Ceiling effects were found in four domains of the CQRA-PREM. Internal consistency of all domains was considered good (α >0.7). Homogeneity was considered good for each question in all domains analyzed (0.30 \leq rp \leq 0.70). The divergent validity of the PREM was good, revealing that the domains were not correlated (Pain-VAS, HAQ, DAS28-CRP) or only weakly (PGA-VAS) correlated with clinical outcomes.

Conclusions: The CQRA-PREM showed acceptable measurement properties and is a useful tool for evaluating quality of healthcare provided in daily practice, as perceived by RA patients in Portugal.

Keywords: Outcome measures; Patient reported experience measure; Patient-centered care; Quality of health care; Validation; Rheumatoid arthritis

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic inflammatory condition, often debilitating, that affects around 0.5–1% of the worldwide population¹. In 2020, the global age-standardized disability-adjusted life-year rate for RA was 36.4 per 100 000 population, and this rate is

projected to continue its upward trend². To reduce this growing burden, it is imperative that greater emphasis is placed on early diagnosis and effective treatment for RA

The management of RA currently involves a comprehensive approach aimed at controlling inflammation, preserving joint function, and improving patients' overall quality of life. Regular monitoring of disease activity, adjustment of treatment plans and patient education about self-management strategies are cornerstones of the standard of care to achieve better long-term outcomes in RA³. Moreover, a multidisciplinary approach, engaging different healthcare providers such as rheumatologists, specialist nurses, physiotherapists, among others, is paramount for optimizing clinical outcomes and addressing the diverse needs and experiences of patients living with RA ^{3, 4}.

Understanding patients' experience with their dis-

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ease and healthcare is beneficial for uncovering areas where care can be improved, identifying best practices, and encouraging the development and implementation of innovative care approaches 5. Previous qualitative studies have highlighted that the impact of patients' prior healthcare encounters and their health status significantly affect their attitudes toward health professionals and treatments, including self-medication 6, ⁷. Another recent qualitative study found that patients with RA value when their individual experiences with the disease are taken into account during discussions about symptom relief and treatment options 8. Therefore, it is crucial for healthcare providers to actively listen to the concerns of the patient, improve communication, and adopt a patient-centered approach 8. By addressing these issues, healthcare providers can enhance the overall patient experience and satisfaction.

Patient-Reported Experience Measures (PREMs) have emerged as valuable tools to measure patients' experiences regarding both the structure and process of healthcare delivery 9. These self-reported measures enable the evaluation of patients' perspectives on healthcare which prioritize aspects of care that are meaningful to patients, helping to identify areas for improvement in healthcare services 9, 10. Different PREMs have been developed to assess the patient's experience with RA 11-15. The Commissioning for Quality in Rheumatoid Arthritis Patient-Reported Experience Measure -CQRA-PREM is one of the most well-studied, originally developed in English and with Dutch and Portuguese versions available 9, 11. A recent qualitative study conducted by our research team, demonstrated that the Portuguese version of CQRA-PREM is acceptable, and its content valid from the patients' perspective for assessing the quality of healthcare 16, 17. The CQRA-PREM Portuguese version might be used to assess acceptability of treatments in future clinical trials and to routinely assess experience of patients with RA in clinical practice, yet its measurement properties require further validation. Therefore, the main aim of this study was to test the measurement properties, namely internal consistency, interpretability, homogeneity and validity, of the Portuguese version of the CQRA-PREM in patients with RA through a clinical field testing.

MATERIAL AND METHODS

Study Design

This is a cross-sectional study that was conducted in a single Portuguese rheumatology center at a tertiary Hospital center between March and September 2022. This study is reported according to the Strengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines ¹⁸.

Participants

Adult patients (≥18 years old) with RA according to 2010 American College of Rheumatology (ACR)/ European League Against Rheumatism (EULAR) criteria ¹⁹ and followed up in the rheumatology department in the last year were consecutively included by a rheumatology resident (D.O.) during appointments. Exclusion criteria comprised patients with psychiatric or cognitive disorders potentially impacting data collection, those physically or psychologically incapable of communication, and individuals unable to read/speak Portuguese.

Data Collection and measures

During a rheumatology appointment, the following data were collected: sociodemographic characteristics (sex, age, educational level), symptoms duration, disease duration and current treatment (use of Disease-modifying antirheumatic drugs- DMARDs, including conventional synthetic DMARDs- csDMARD, biologic -bDMARD and targeted synthetic- tsD-MARDs). During this appointment, the patient also completed the following questionnaires: a Visual analogue scale (VAS) to assess pain severity (Pain-VAS) ²⁰, a VAS to assess disease activity (Patient Global Assessment- PGA-VAS) 21 and the Portuguese version of the Health Assessment Questionnaire (HAQ) to assess functional disability 22. Disease Activity Score for 28 joints with C-reactive Protein (DAS28-CRP) was calculated by a rheumatologist to measure disease activity ²³. At the end of the appointment, patients completed the Portuguese version of the CQRA-PREM ¹⁶.

Pain-VAS and PGA-VAS

VAS is a tool used to measure subjective experiences such as pain severity, disease activity or global health ^{20, 21}. It consists of a straight line, typically 100 mm in length, with descriptors of the condition being measured at each end. Patients are asked to mark their perceived severity on the line by placing a cross or mark. The distance from the end of the line with the least severity to the marked point is then measured to quantify the severity of the condition. In this study, VAS was used in two distinct questionnaires: Pain-VAS and PGA-VAS 20, 21, both reflecting how the patient has been feeling over the past week. For the Pain-VAS, the chosen descriptors were "no pain" (0 mm) and "unbearable pain" (100 mm) and for the PGA-VAS were "very well" (0 mm) and "very badly" (100 mm). Higher scores indicate greater pain severity or disease activity in each scale.

Health Assessment Questionnaire (HAQ)

This patient-reported outcome measure (PROM) comprises 20 questions pertaining to activities of daily liv-

ing, categorized into eight components. Each question offers four potential responses, corresponding to the following scores: no difficulty (0), some difficulty (1), much difficulty (2), and unable to do (3). The score assigned to each component is determined by the highest score among its questions. Higher scores indicate greater functional disability ²².

DAS28-CRP

This disease activity metric was calculated according to an already established and complex equation that includes the following variables: number of tender and swollen joints (total of 28 joints), PGA-VAS and CRP-mg/dL 24 .

CQRA-PREM

This PREM includes seven domains: 1) Needs and preferences; 2) Coordination of care and communication; 3) Information, education, and self-care; 4) Daily living and physical comfort; 5) Emotional support; 6) Family and friends; 7) Access to care; and one question for evaluating the overall experience of the care provided. The questionnaire includes 23 questions and answers are given on a 5-point Likert scale, ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Additionally, there is an extra question at the end regarding the overall experience of the care provided, also to be answered using the same Likert scale ^{11,16}. The final PREM score takes into account the median of each domain, with higher values representing a better patient experience.

Data analysis

Descriptive statistics included mean and standard deviation or median and quartiles for continuous variables (depending on the distribution) and frequencies for categorical variables. Considering the CQRA-PREM 5-point Likert scale for each response, primarily relative frequencies were used for each category. To simplify the reporting and description of CQRA-PREM, the frequencies of "Strongly agree" and "Agree" were combined (hereafter referred as "agreed") and the frequencies "Strongly disagree" and "Disagree" (hereafter referred as "disagreed"). Median of the responses per domain together with respective quartiles (quartile 1-Q1, quartile 3-Q3) were also produced.

The assessment of the Portuguese CQRA-PREM measurements properties was conducted in accordance with the Consensus-based Standards for the Selection of Health Status Measurement Instruments (COSMIN) recommendations ²⁵. The measurement properties assessed were internal consistency (reliability across items), interpretability, homogeneity and construct validity (divergent validity). Internal consistency was as-

sessed using Cronbach's alpha coefficient (α) and was considered good if $0.70 \le \alpha \le 0.95^{-26}$. Interpretability of the CQRA-PREM involved testing for floor and ceiling effects in the median scores of different domains. Floor and ceiling effects were considered to be present if 15% or more of the patients had the lowest or highest possible median domain score²⁷. Homogeneity within domains containing more than two questions was explored through corrected item-total correlations (rp) to identify questions with either very weak or very strong correlations within their respective domains. Homogeneity was deemed good when the corrected item-total correlation fell within the range of 0.30≤rp≤0.70. Divergent validity was assessed using either Spearman's rank (rs) or Pearson correlation coefficients (rp), depending on the sample distribution. Given that PREMs are presumed to encompass more than just the patient's condition or treatment outcomes, correlations between CQRA-PREM with clinical outcomes (Pain-VAS, PGA-VAS, DAS28-CRP, HAQ) were expected to be weak at most $(-0.30 \le r_s \le 0.30)^{28,29}$.

The statistically analysis was performed using IBM SPSS Statistics version 27.0 for Windows (IBM Corporation Software Group, New York, United States of America). The statistical significance set was p<0.05.

Ethics

The Guideline for Good Clinical Practice of the International Conference on Harmonization and the ethical principles of the Declaration of Helsinki was followed ³⁰. Approval from the local Ethical Committee was obtained (18/12/2020, reference 489/20). All patients signed an informed consent previous to any data collection.

RESULTS

Participants

Sixty-five patients with RA were invited to participate. A total of 61 patients accepted and were enrolled, with the majority being female (89%). The mean age was 58.8±9.6 years old (Table I). The mean symptoms and diagnosis duration were 20.3±12.5 and 17.4±11.2 years, respectively. A total of 39 (64%) patients were treated with bDMARDs. Pain severity and disease activity were moderate (median of 50[40-70] and mean of 2.9±1.1, respectively). Patients included experienced mild difficulties in physical function (median 1.5[0.75-1.88]).

CQRA-PREM responses by domain

The scores of CQRA-PREM are shown in Table II. Almost all (95.4%) of patients agreed that their "Needs

TABLE I. CHARACTERISTICS OF PARTICIPANTS (N=61)

Sociodemographic and clinical variables	
Age (y) ^a , mean±SD, min-máx	58.8±9.6 (36-81)
Female, n (%)	54 (89%)
Education ^b , n(%)	
Primary	19 (34%)
Lower secondary	17 (30%)
Upper secondary	9 (16%)
University	11 (20%)
Symptoms duration (y) ^c , mean±SD, min-máx	20.3±12.5 (1-50)
Diagnosis duration $(y)^c$, mean \pm SD, min-máx	17.4±11.2 (1.5-47)
DMARDs (current)	59 (1.6)
csDMARDs, n (%)	55 (90.2)
bDMARDS, n (%)	39 (64)
tsDMARDs, n(%)	2 (3.3)
Pain-VAS, median (Q1-Q3)	50 (40-70)
PGA-VAS, median (Q1-Q3)	52.5 (40-74.8)
DAS28-CRPd, mean±SD, min-máx	2.9±1.1 (1.3-6.7)
HAQ, median (Q1-Q3)	1.5 (0.75-1.88)

SD-standard deviation; DMARD- disease-modifying antirheumatic therapy; csDMARDs-conventional synthetic antirheumatic therapy; bDMARD-biologic disease-modifying antirheumatic therapy; tsDMARDs-targeted synthetic antirheumatic therapy; VAS-Visual analogue scale; PGA-Patient Global Assessment; Q-quartile; DAS28-CRP- Disease Activity Score for 28 joints with C-reactive Protein; HAQ- Health Assessment Questionnaire. a missing information for 1 patients. b missing information for 5 patients. c missing information for 3 patients. d missing information for 12 patients.

and preferences" were being addressed, while 88.3% of patients agreed that "Coordination of care and communication" were good. While 94.3% of patients agreed that they had received timely information and had a good understanding of the treatments they were being offered, only 46% were informed about "Patient organizations or groups", and one third had been offered an opportunity to attend a "Self-management program" (32.8%).

In terms of daily living and physical comfort, 70.5% of patients agreed that their RA was sufficiently controlled to enable them to carry out their usual daily activities, and a comparable proportion (70.4%) agreed that they were able to promptly access assistance when experiencing a flare.

Regarding emotional support, 82% of patients agreed that they could approach a member of their healthcare team to discuss any worries, while 75.4% agreed that they could approach a team member with personal or intimate issues about relationships. The majority of patients (86.9%) agreed that they felt capable of involving family in care decisions during outpa-

tient appointments.

In relation to access to care, the majority of patients (91.8%) agreed that their appointments were long enough and did not have clinic appointments unexpectedly cancelled (80.3%). Overall, 91.8% of patients had a good overall experience of RA care over the past year.

Measurement properties

Median's responses for each domain of CQRA-PREM and its interpretability, internal consistency, homogeneity are presented in Table III. All domains of the PREM had medians of 3.75 or above. Interpretability assessed by floor and ceiling effects showed ceiling effects (≥ 15%) in the domains "Needs and preferences", "Coordination and communication", "Daily living and physical comfort" and "Emotional support". Internal consistency of all domains was good (α >0.7). The "Needs and preferences" domain had the highest α coefficient (0.886), while domain "Information, education and self-care" had the lowest α coefficient (0.732). Homogeneity was considered good for each question in all domains analyzed (0.30≤rp≤0.70). When considering the domains, homogeneity exceeded the threshold (rp≥0.70) in "Needs and preferences" and "Coordination and communication".

Divergent validity is described on Table IV. The divergent validity showed that all CQRA-PREM domains were not correlated or weakly correlated with Pain-VAS, PGA-VAS, disease activity (DAS28-CRP) and functional disability (HAQ).

DISCUSSION

In this study, we demonstrated that the Portuguese version of the CQRA-PREM has acceptable measurement properties to be used in daily clinical practice. In addition, data from this study indicated that this PREM is capable of identifying areas for improvement in Portuguese rheumatology field.

The overall experience of patients with RA health-care was positive, yet also highlighted areas where changes in clinical practice may be necessary to enhance the patient experience. The domains in which patients showed the better experience were the "Needs and preferences" followed by "Coordination and communication". Previous qualitative research has concluded that patients with RA appreciate a good dialogue and personalized interaction with the rheumatologist, taking into account their personal circumstances and preferences 8. Another recent study aimed to explore the real-world experiences of patients receiving outpatient rheumatology care concluded that personalized

TABLE II. RESULTS OF THE CQRA-PREM IN PATIENTS WITH RA (N=61).

a) Whenever I attended a clinic, I feit that I was treated respectfully as an individing preferences b) I was involved as much as I wanted to be in decisions about my treatment and care. d) I was given information in a way that I could understand e) I was given enough information to help me make decisions about my treatment and care. d) I was made aware that there is a team of health professionals looking after me ³ communication communication b) When I needed help, I was able to access different members of my health team who can help me to see other specialists: d) I feel that the people I see at the clinic are fully up to date with my current situ al feel that I have a good understanding of the treatments I am on or being offer education and self-care d) I have been told about patient organizations or groups that can help me ³ and physical comfort a) I feel that my rheumatic condition is being controlled enough to let me get on a usual activities comfort a) I feel that my rheumatic condition is being controlled enough to let me get on usual activities b) If have been offered an opportunity to attend a self-management program suital all three had a 'flare' (when my symptoms get much worse), I have been able to approach a member of my health team to discuss any worries about my treatment or their effect on my life b) I feel able to discuss personal or intimate issues about relationships with my he about my care if I want to about my care if I want to all feel that I have enough time with the health care profession I want to discuss b) I have had clinic appointments cancelled unexpectedly 7. Access to care c) If yes, how long have you had to wait for a new appointment?	 a) Whenever I attended a clinic, I felt that I was treated respectfully as an individual b) I was involved as much as I wanted to be in decisions about my treatment and care c) My personal circumstances and preferences were taken into account when planning and deciding on my treatment and care.^a d) I was given information in a way that I could understand e) I was given enough information to help me make decisions about my treatment 	٠	,00			
s and dination nication mation, on and sical ional so to care ss to care	o be in decisions about my treatment and care rences were taken into account when planning and deciding on t I could understand the make decisions about my treatment		1.6%	1.6%	26.2%	70.5%
dination mication mation, on and living sical ional sy and sy and	rences were taken into account when planning and deciding on 1 could understand the make decisions about my treatment		1	1.6%	27.9%	70.5%
dination nication mation, on and living sical ional sy and ss to care	r I could understand elp me make decisions about my treatment	1	ı	8.2%	34.4%	55.7%
dination nication mation, on and sical ional so to care	elp me make decisions about my treatment	1	1.6%	1.6%	36.1%	%2.09
dination nication mation, on and living sical ional so to care		1	3.3%	1.6%	26.2%	%6.89
dination nication nication and e living sical ional sy and ss to care	ı of health professionals looking after me $^{\scriptscriptstyle a}$	1.6%	8.2%	%8.6	29.5%	49.2%
mation, on and living sical ional si to care	cess different members of my health team	•	8.2%	11.5%	26.2%	54.1%
mation, on and by and living ional sto care	c) There is a member of my health team who can help me to see other specialists in the team if I need to	1	1.7%	92.9	30.0%	61.7%
mation, on and living sical ional set to care	d) I feel that the people I see at the clinic are fully up to date with my current situation	1	1.6%	4.9%	26.2%	67.2%
mation, on and living sical ional ly and ly sad	the time I needed it		4.9%	1.6%	34.4%	29.0%
living sical ional	b) I feel that I have a good understanding of the treatments I am on or being offered		1.6%	3.3%	36.1%	26%
living sical ional ional ss to care	zations or groups that can help mea	14.8%	26.2%	11.5%	26.2%	19.7%
living sical ional ly and ss to care	o attend a self-management program suitable to my needs b	18%	24.6%	21.3%	16.4%	16.4%
ional ly and ss to care	a) I feel that my rheumatic condition is being controlled enough to let me get on with my daily life and usual activities	3.3%	13.1%	13.1%	36.1%	34.4%
ional ly and ss to care	toms get much worse), I have been able to get help quickly ^a	1.6%	%9.9	19.7%	31.1%	39.3%
ly and	a) I feel able to approach a member of my health team to discuss any worries about my condition and my treatment or their effect on my life	1.6%	4.9%	11.5%	37.7%	44.3%
ly and	b) I feel able to discuss personal or intimate issues about relationships with my health team if I want to		4.9%	19.7%	45.6%	32.8%
	a) I feel able to take members of my family to outpatient appointments to become involved in decisions about my care if I want to	1	4.9%	8.2%	45.9%	41%
	a) At appointments, I feel that I have enough time with the health care professional to cover everything I want to discuss	1	4.9%	3.3%	24.6%	67.2%
	elled unexpectedly	Yes 19.7%	No 80.3%			
	t for a new appointment?	<1 week 16.7%	1-3 weeks 8.3%	4-6 weeks 33.3%	7-12 weeks 33.3%	>12 weeks 8.3%
d) I have needed extra treatment or a change of	nange of treatment	Yes 60.7%	No 39.3%			
e) If yes, how long did it take for this to happen?	, happen?	<1 week 27.8%	1-3 weeks 13.9%	4-6 weeks 19.4%	7-12 weeks 33.3%	> 12 weeks 5.6%
8. Overall a) Overall, in the past year, I have had a ge experienced care	a) Overall, in the past year, I have had a good experience of care for my rheumatoid arthritis $^{\scriptscriptstyle \perp}$,	1.6%	4.9%	27.9%	63.9%

TABLE III. INTERPRETABILITY, INTERNAL CONSISTENCY AND HOMOGENEITY OF CQRA-PREM IN PATIENTS WITH RA (N=61).

			Interpretability		Internal consistency	Homogeneity
PREM domains	Number of questions	Median (Q1-Q3)	Floor effect	Ceiling effect	Cronbach's alpha	rp
1. Needs and preferences	5	4.8 (4.2-5)	0%	44.3%	.886	.562840
2. Coordination and communication	4	4.5 (4-5)	0%	39.3%	.838	.568817
3. Information, education and self-care	4	3.75 (3-4.5)	0%	13.1%	.732	.445663
4. Daily living and physical comfort	2	4 (3-5)	1.6%	31.1%	.825	.706
5. Emotional support	2	4 (4-5)	0%	31.1%	.775	.635
6.Family and friends	1	4 (4-5)	-	-	-	-
7. Access to care	1	5 (4-5)	-	-	-	-
8. Overall experienced care	1	5 (4-5]	-	-	-	-

TABLE IV. DIVERGENT VALIDITY OF CQRA-PREM IN PATIENTS WITH RA (N=61).

PREM domains	Pain-VAS r _s	PGA-VAS r _s	DAS28-CRP ^d r _s	HAQ r _s
1. Needs and preferences	-0.004	-0.043	0.195	-0.156
2. Coordination and communication	-0.072	-0.235	0.053	0.026
3. Information, education and self-care	-0.022	-0.216	0.050	-0.094
4. Daily living and physical comfort	-0.219	-0.293*	-0.128	-0.187
5. Emotional support	-0.065	-0.173	-0.073	0.100
6. Family and friends	0.010	-0.040	0.113	-0.133
7. Access to care	-0.051	-0.039	0.011	0.154
8. Overall experienced care	-0.139	-0.173	-0.024	-0.049

VAS-Visual analogue scale; PGA-Patient Global Assessment; DAS28-CRP- Disease Activity Score for 28 joints with C-reactive Protein; HAQ- Health Assessment Questionnaire. Spearman Coefficient correlation (rs), *significant at 0.05 level. d missing information for 12 patients.

and comprehensive care, alongside effective coordination and information sharing, emerged as crucial elements in healthcare delivery 7. On the other hand, patients with RA find close communication between rheumatologist and specialized nurses useful, as it facilitates direct access to these professionals when their condition worsens 6. The domain "Information, education, and self-care", namely about self-management program suitable to patient needs and patient organizations or groups are important areas of improvement for patients with RA. These findings align with the results of the CQRA-PREM validation study in the UK and other qualitative studies 11, 31. Certainly, previous research reported that patients with RA appreciate the opportunity to receive information about: what to expect with the disease, the medication, responsibilities of different healthcare personnel, how to inform relatives, and which activities to engage in to feel better 8. Education was seen as empowering for patients with RA and enabled them to take care of themselves 7. There-

fore, and according to European Alliance of Associations for Rheumatology recommendations, healthcare professionals should be knowledgeable about available resources to guide patients towards, aiming to improve and support self-management 4. Furthermore, previous research has demonstrated that structured group interventions enhance psychological wellbeing, health related quality of life and coping strategies 32. Similar to previous research, in our study most patients with RA agreed that they were capable of including family members in care decisions during appointments ⁶. In fact, patients with arthritis believe that caregivers should have as much knowledge as they do about the disease and treatments, and possess practical skills, namely in pain management and administering injections 33. In our study, the majority of patients agreed that rheumatology appointments were long enough and included emotional support, aspects particularly appreciated by patients with RA in previous literature ⁶. Certainly, temporal limitations during appointments may prevent the development of a personal connection between the rheumatologist and the patient with RA, thereby inhibiting the patient's ability to inquire about their condition and treatments ⁸. So, appropriate time should be allocated to patients, as well as their families and caregivers, to assess mental health, discuss concerns and explore all management options ⁴.

The interpretability of the CQRA-PREM showed high ceiling effects for the domains "needs and preferences", "coordination and communication", "daily living and physical comfort", and "emotional support", which implies that it can be difficult to discern with this measure all significant differences between patients. However, ceiling effects are common in PREMs ³⁴ and our results for interpretability did not differ from CQRA-PREM adaptation and implementation study in the Dutch population, even though patients have filled out the questionnaire in an online application 9. Indeed, these data may reflect the true experience and perspective of the majority of patients with RA followed in a Portuguese rheumatology centre, translating into true satisfaction with healthcare. Though, it should be emphasized that these results may also be due to the fact that the patients who agreed to participate may be more satisfied with the healthcare provided (selection bias). Additionally, despite patients being informed that their responses were confidential, social desirability bias may have occurred, given that they were invited to fill out CQRA-PREM by the rheumatologist during the end of an appointment. In future, ceiling effects should be tested considering other locations/methods of PREM completion, such as in the waiting room, by telephone, or in an online format (e.g., disease registry).

The homogeneity of the CQRA-PREM was globally considered good, however exceeded thresholds in two domains: "Needs and preferences" and "Coordination and communication" (rp≥0.70), results similar to the Dutch validation study 11. This result may indicate that the items of each domain are highly correlated and may be measuring the same aspect with excessive redundancy. This could suggest a lack of diversity in the items of the measure, which may reduce its sensitivity to capture different aspects of the construct in question. However, the internal consistency of all domains was deemed good (α >0.7), meaning that the items within each assessed domain correlated consistently with each other, reliably measuring the same construct. These findings align with those obtained in the UK and Netherlands, where Cronbach's alpha coefficients ranged from 0.61 to 0.90 and from 0.65 to 0.93, respectively, for the various domains of the CORA-PREM 9, 11.

The divergent validity of the PREM was good, re-

vealing that the domains indicating the quality of healthcare provided are not influenced by outcome measures for pain severity, disease activity and functional disability. Thus, this finding suggests that for patients CQRA-PREM is a unique and useful tool that specifically evaluates a distinct construct (perspectives, values and experiences), without being influenced by unrelated factors. Indeed, previous studies have shown a weak correlation between patient experience and treatment effectiveness in other settings, such as primary healthcare and elective surgery 28, 35. Therefore, in the future, health teams should use PREMs to assess patients' viewpoints on the structure and process of care delivery, in contrast with outcome measures such as PROMs which specifically capture patients' perspectives on the clinical outcomes of care received 9. Although studies vary in the strength of association observed between patient experience and clinical outcomes, it has been suggested that the improvement of patient experience is positively associated with clinical effectiveness and safety of treatments 28, 36. Additionally, patients' perceptions of care quality may differ from those of healthcare professionals. These measures can be used by healthcare professionals themselves to reflect on their own performance and that of their teams, to indicate specific areas of improvement at clinical and organizational levels, and to evaluate the impact of changes introduced within organizations 9. So, these findings support the routine implementation of PREMs in clinical practice to measure and monitor the patient's experience.

To the best of our knowledge, this study is the first to test a rheumatic-specific PREM's measurement properties for clinical use in Portuguese rheumatology centers. However, this study has some limitations. Firstly, the small sample size did not allow for the analysis of CQRA-PREM domains by subgroups, such as different years of disease and patients with or without bDMARDs, with the hypothesis that these patients would have different experiences with provided care. Secondly, it is worth noting that participant recruitment occurred during appointments with rheumatologists, potentially introducing a selection bias. Rheumatologists may have been biased towards selecting participants with higher levels of education, better disease control, and greater satisfaction with healthcare provided. A future multicenter study should be considered to overcome these limitations. This study would demonstrate the capability of the CQRA-PREM to distinguish between rheumatology centers that prioritize patient-centered care to varying degrees. Thirdly, this study did not examine the test-retest and interrater reliability, sensitivity to change over time, and convergent validity of the Portuguese version, neither its measurement properties when applied in distinct forms (paper, telephone, web). These measurement properties could be assessed in future studies.

CONCLUSIONS

Understanding the healthcare experience of Portuguese patients with RA and the impact of this disease on patients' daily life has the potential to improve the management of these patients. The CQRA-PREM demonstrates acceptable measurement properties for evaluating quality of healthcare provided in daily practice as perceived patients with RA in Portugal. The CQRA-PREM is a valuable instrument to enhance patient centered care in rheumatic health care centers. In the future, the integration of CQRA-PREM into the clinical practice should be considered with the aim of characterizing the experience and perspective of patients with RA regarding the care provided. This will help identify areas in rheumatology centers that need improvement, thereby enhancing the overall quality of patient-centered healthcare for patients with RA in Portugal.

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