Content validity of a patient-reported experience measure (CQRA-PREM) for patients with rheumatoid arthritis in Portugal

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Key messages

. Patient Reported Experience Measures (PREM) collect perceptions of the patients to improve their overall healthcare experience.

. The CQRA-PRE is validated to evaluate the experience of RA patients with the healthcare services.

. The Portuguese version of CQRA-PREM has an acceptable content validity to be used on daily clinical practice.

Abstract

Background: The evaluation of perceptions of patients with rheumatoid arthritis (RA) has a positive influence in their health outcomes and overall experience of care. The Commissioning for Quality in Rheumatoid Arthritis Patient-Reported Experience Measure (CQRA-PREM) was developed to provide the perceptions and the feedback of the patients with RA to the health professionals team. This PREM is already validated and in use in the United Kingdom (UK) and Netherlands. In Portugal, there is no validated PREM to evaluate the experience of patients with RA. Objective: To translate, cultural adapt and validate the content of the CQRA-PREM for the Portuguese population. Methods: A qualitative study using focus groups was conducted to evaluate CQRA-PREM content validity. The CQRA-PREM was first translated and cultural adapted to Portuguese by two researchers, and after back translation, a panel of experts agreed on the preliminary Portuguese version of CQRA-PREM. Patients with RA were recruited from a rheumatology center at a tertiary university hospital center to participate in focus group meetings. Before the focus group they filled in the preliminary version of CQRA-PREM, with its 7 domains and 24 items (Likert scale 1-5). Results: Twelve participants (median 54 (45-58) years old; 92% female) were included in two focus groups. All domains of the questionnaire had medians of 3 or above. Seven major themes and six subthemes emerged. Participants considered the questionnaire as very clear and simple and with adequate questions. Patients pointed as extremely important being treated with dignity and respect and considered the awareness of the multidisciplinary team and the presentation of support programs and organizations as areas for improvement. Conclusion: The Portuguese version of the CQRA-PREM is acceptable and its content is valid in the perspective of patients with RA to assess the quality of care provided by the healthcare services.

Keywords: Education (patients); Rheumatoid arthritis; Quality of life; Quality of healthcare; Attitude of health professionals.

Introduction

Rheumatoid arthritis (RA) is a major global public health challenge[1], with significant morbidity and mortality[2]. This condition is one of the most prevalent chronic inflammatory diseases worldwide[3], with estimates between 0.13% and 0.35%[4]. In Portugal, based on the EpiReumaPt, a national health survey, the prevalence of RA was estimated in 0.7%[5]. RA was considered the 42nd highest contributor to global disability with a negative impact on patient's quality of life[4]. Furthermore, RA has a significant economic burden. In Portugal, treating one patient with RA has an estimated annual mean cost of 3.415€[6]. To address this relevant burden, it is crucial that patients with RA are provided with quality healthcare addressing their multiple needs.

As a fundamental determinant of healthcare quality, the World Health Organization (WHO) advocates the people-centeredness[7]. The inclusion of the perspective of patients with RA plays a fundamental role in communicating the impact of their disease and in promoting the effectiveness of healthcare through shared-decisions[8]. Previous research in RA showed that the involvement of patients in their care improves adherence to treatment, brings positive changes on treatment outcomes (safety, effectiveness and costs) and allows the definition of therapeutic priorities[8,9]. Despite these known benefits, people-centered care is sometimes challenging to be applied in clinical practice. Thereby, it is essential to assess the perspective and personal experience of patients with RA about the healthcare received using validated measures.

Patient-reported experience measures (PREM) can be used to provide the perceptions and the feedback of the patients to the health professionals team in order to improve the care offered and the overall patient experience[10]. In the United Kingdom (UK), the Commissioning for Quality in Rheumatoid Arthritis (CQRA) have developed, piloted and validated a PREM for patients with RA - the CQRA-PREM[11]. This PREM is considered a valuable tool with a good construct validity that evaluates seven domains for capturing the patient experience[11]. This PREM showed to be able to provide feedback to rheumatology teams and to contribute for the improvement of the overall patients' experience and the healthcare[11]. Due to its relevance, CQRA-PREM was already validated in the Netherlands and its feasibility in clinical practice studied[12].

In Portugal, rheumatology services do not have yet a standardized measure to evaluate the patients' experience. The use of CQRA-PREM in the Portuguese population may contribute for a realistic characterization of the experiences of patients with RA and for the identification of opportunities for improvement of the RA care delivery. Therefore, the main aim of this study was to translate, cultural adapt and validate the content of the CQRA-PREM for the Portuguese population with RA. As a secondary aim, we explored if patients' experience of care were covered by the CQRA-PREM items.

Methods

Study Design

A qualitative study using focus groups was conducted to evaluate CQRA-PREM content validity. This work is part of a larger study[13]. Patients with RA were recruited from a rheumatology center at a tertiary university hospital center located in the northern region of Portugal. Focus groups were the method selected as they ensure a good assessment method of content validity of PREMs[14]. The study was approved by an Ethic Committee (18/12/2020, reference 489/20). All participants signed a written informed consent previously to any data collection. This study follows the Consolidated Criteria for Reporting Qualitative Research (COREQ)[15].

Participants

Patients with RA were conveniently recruited during appointments by their rheumatologist, which explained the purpose of the study and evaluated patients' willingness to participate. Rheumatologists recruited patients with different ages, disease duration and treatments (use/not use of targeted or conventional synthetic or biologic Disease-Modifying Antirheumatic Drugs – csDMARDS or tsDMARDS or bDMARDS, respectively) to obtain a heterogeneous sample with different care experiences. Patients were eligible if they i) had 18 years old or older; ii) were diagnosed with RA at least for 1 year; and iii) were followed up for RA in the rheumatology center in the last year. Patients with psychiatric or cognitive disorders, and those unable to speak Portuguese were excluded.

Data collection

CQRA-PREM translation and cultural adaptation

The CQRA-PREM includes seven domains for people-centered care, namely: 1) Needs and preferences (5 questions); 2) Coordination of care and communication (4 questions); 3) Information, education, and self-care (4 questions); 4) Daily living and physical comfort (2 questions); 5) Emotional support (2 questions); 6); Family and friends (1 question); 7) Access to care (5 questions). The answers to these 23 questions are given on a 5-point Likert scale ("1-strongly disagree" to "5-strongly agree")[11]. An additional question at the end of the questionnaire is related to the overall experience of the care provided, answered using the same Likert scale.

Firstly, authorization for the Portuguese adaptation by the original authors of the CQRA-PREM was obtained. The translation was performed independently by two native Portuguese researchers fluent in English (one rheumatology resident-D.O. and one physiotherapist-C.J.). Disagreements between the two translations were discussed domain by domain during an

online meeting with a panel of experts. The panel of experts included the two translators (D.O. and C.J.), two specialists in rheumatology (M.B. and C.V.) and two experts on questionnaire development/validation (an allergy specialist (J.A.F.) and a psychologist (E.M.)) . A synthesis of the discussion produced a common version, that was back translated to English by a native speaker, who had no clinical background nor previous knowledge of the original questionnaire. The back translated version was assessed and compared with the original questionnaire by the panel of experts. A copy of the English consensus version was sent to the original authors, which was approved without suggestions. The preliminary Portuguese version of CQRA-PREM was then used.

Focus groups

The CQRA-PREM was sent to the participants so they could read carefully and filled in before the focus group to have a first and unbiased opinion about the questionnaire. They also completed questions regarding their socio-demographic (gender, age, occupation, education), and clinical (duration of the symptoms and the disease, use/not use of tsDMARDS, csDMARDS or bDMARDS) characteristics. Two focus groups interviews with 6 participants each were conducted via teleconference (Zoom), due to the restrictions imposed during the COVID19-pandemic. One moderator (C.J.) conducted the two focus groups using a semi-structured guide[13]. C.J. is a physiotherapist and has extensive knowledge in comprehensive interventions for chronic diseases and qualitative studies. One group assistant (R.R.) was present to help the participants with technologies' difficulties in accessing the online meeting and to take notes of the group interaction and of the main topics addressed.

Before the study, there was no relationship established between the moderator, group assistant and the participants. During the focus group, patients were asked, in a non-directive manner, to give their opinion about each question of the questionnaire, to talk about their experience related to the care received, to identify words or expressions that they did not understand and to suggest other relevant topics that were not included in the questionnaire. Each question of the CRQA-PREM questionnaire was presented visually to the participants by a Microsoft PowerPoint presentation. At the end of each focus group, a summary of the main results was given back to the group to enable the participants to verify and amend emergent issues. Both the audio and video were recorded. Focus groups lasted on average 96 minutes (88 and 103 minutes). Focus groups were transcribed (R.R.) and checked for accuracy (C.J. and D.O.). The transcripts did not return to participants for eventual comments and or corrections.

Data Analysis

A thematic analysis was performed independently by two researchers (R.R. and D.O.) based on CQRA-PREM domains, the semi-structured guide and the collected data, which resulted in a coding tree scheme with seven major themes. The NVivo software (version 1.6.1, QRS international, Massachusetts, USA) was used and the researchers code the statements of the patients in themes and subthemes, accounting more than one statement for the same code, by

the same participant if it was the case, in order to promote reflexivity, the authors conducted regular group meetings to discuss questions related to codification. Relevant aspects of care for patients were summarized and interpreted.

A descriptive analysis was performed to characterize the sample. For continuous variables we used median and first and third quartiles (Q1, Q3) and for categorical variables we used absolute and relative frequencies. Medians were also calculated for each CQRA-PREM question and domain[16]. The quantitative analysis was performed using SPSS Statistics (version 27.0, IBM Corporation Software Group, New York, USA), with the statistically significant level at p<0.05

Results

Participants

A total of 21 patients were invited to participate, 14 agreed but only 12 participated (median 54, Q1-Q3 44.5-58 years old; 92% female). Most participants have at least secondary school (75%). Median symptom duration and median disease duration were quite similar, 15 (6.5-21.3) years and 15 (6.5-20.5) years, respectively. Half (50%) of the participants were using bDMARDS. Participants' characteristics are shown in Table I.

CQRA-PREM responses

Median's responses for each domain of CQRA-PREM are presented on Table II. All domains of the questionnaire had medians of 3 or above. The domain 7 (Access to care) was the one better classified (median 4.5 (Q1-Q3 2.75-5)). The overall experience was rated as 4 (Q1-Q3 4-5).

CQRA-PREM content validity

As shown in Table III, seven major themes and six subthemes emerged during the analysis of the focus groups. A brief description of each theme and subtheme is provided below and in Table IV.

Clearness and Feasibility of the PREM

Patients defined the questionnaire CQRA-PREM as very clear and simple with instructions and items obvious and objective. The patients agreed that they could easily answer all the items, and the type of questions and their content were appropriate. They also considered that the five possible answer options were adequate, properly worded and corresponding very well to the type of the questions. They believed that the questionnaire was suitable and made sense

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according to their experience within the hospital. Some explained that when the questions did not fit their situation, they simply selected the discord option.

Suggestions

Patients suggested some possible additions. Some suggestions were related to the use of a more specific temporal or local framework in certain questions, namely the substitution of "Always" for "Last year" or "In this rheumatology department" (question 1a). Other suggestions were to add information in few expressions to a better comprehension of the topic, specifically to include together with the expression "self-management program" its definition "program to help me managing my needs and emotions" (question 3d) and to the expression "controlled enough" the explanation that was related to the normal daily activities (question 4). Finally, they suggested, if there was room for the addition of open questions to have the possibility to add qualitative information also.

Patient' needs and preferences

The patients considered that being treated with respect as a person in each visit to the healthcare service was an essential indicator of the quality of healthcare received. For them, it was relevant that their personal circumstances were taken into account and it was essential to trust in physicians advise and in proposed treatment options. All the patients were extremely satisfied with the way personal circumstances were considered and felt comfortable exposing their most intimate and personal problems to their physician. Patients also considered crucial to receive the desired information (disease, treatments and prognosis) at the appropriate time to be capable to make autonomous decisions about their healthcare.

Patients also reported as an essential need the environmental conditions of the treatment's room. They appreciate and value their privacy, dignity and a peaceful environment, characterizing the ideal treatment's room as quiet and clean.

Involvement of Family and Friends

The support of family and friends was considered extremely pertinent to the patients, who believed family members should be integrated in medical appointments. Patients feel satisfied when their problems, treatments and changes in the course of the disease are explained and approached with their loved ones.

Information and education

Information about disease

Patients considered that the information given should be easily and simply understandable, regardless of the format of information (oral or written). During both exacerbation and stable periods of the disease, it is imperative for the patients to have a good understanding about the treatments proposed or received because they believe that this type of information can be easily and quickly given. In case of disease exacerbation, the patients needed extra care, so they considered crucial to receive information about how to manage the exacerbation, who to contact and where to go for immediate care.

Shared decision

The patients appreciated the effort of the physician to identify their current clinical situation and to transmit to them the amount of information required at each moment so they could participate in the healthcare decisions. However, this is not the case for all patients, with two of them preferring to receive less information, mainly regarding long-term options.

Other forms of information

Information about patient's associations and support programs were rarely provided, although patients recognized the importance of these strategies to manage their disease.

Control of disease

During the course of the disease, patients with RA have to adjust their daily activities for the disease itself. During "flares"/exacerbations", they experienced more severe and incapacitating articular complaints. Some referred to deal with "flares" taking drugs for exacerbations and some trying to seek medical help: at the primary healthcare, with their rheumatologist or at the emergency department.

Coordination of healthcare

Availability of health professionals

The availability of the physicians was pointed by the patients as a critical characteristic that contributed to a good patient-physician relationship and, consequently, to the success of the treatment. The patients believed that all the rheumatologists were available, however they had some access difficulties related to excessive time for the first appointment when they were referred to other specialists.

Access to healthcare

Patients considered there is a need to improve the access to the healthcare service, namely when they have an exacerbation or have doubts about the disease or treatment. They suggested the creation of a telephonic support line as a possible solution.

The time management of routine appointments is an essential factor to the global experience with healthcare. Patients think that the physicians have few available time to hear them because appointments are always very time restricted. Further, sometimes, they wait more than six months for an appointment, and they refer difficulties on rescheduling a cancelled appointment. In terms of waiting time for medications, patients using biological agents, report some obstacles regarding bureaucratic issues to access these drugs.

Multidisciplinary team and referral

The patients considered relevant the existence of a multidisciplinary health team involved in the care of their rheumatic condition. Nevertheless, almost all patients felt that the rheumatologist was the "face" of the team and they were unaware that there is a team of different health professionals behind it. A minority reported that they were referred to different health professionals (e.g., psychologist, physiotherapist, nutritionist), according to their needs.

The preliminary version of the CQRA-PREM is provided in supplementary material.

Discussion

We demonstrated that the Portuguese version of CQRA-PREM is acceptable and its content is valid in the perspective of Portuguese patients with RA. This qualitative study allowed us to assess the perspective of the Portuguese patients from a tertiary hospital across the several domains of the CQRA-PREM questionnaire.

To the best of our knowledge, there are four validated PREMs for patients with RA, namely CQRA-PREM[11], Patient-Reported Experience Measures questionnaire[9], The Consumer Quality Index Rheumatoid Arthritis (CQ-Index-RA)[17] and QUOTE-Rheumatic-Patients Instruments[18]. Nonetheless none of these PREMs are validated to Portuguese. The authors choose the CQRA-PREM as it was more recently developed and it included a domain related to family and friends, topic that we considered essential. Besides that, CQRA-PREM showed good psychometric properties for patients with RA in the original study in the UK and in the recent validation in Netherlands[11,12], one more reason to reinforce the importance of this adaptation to the Portuguese population.

During the focus groups, patients clearly highlighted the importance of valuing their personal circumstances and being treated with respect and dignity in order to feel satisfied with the care provided. This finding is in line with previous studies which suggested that psychological and relational factors play a key role in the rehabilitation of rheumatic patients[19]. The environmental conditions of the treatments' rooms were also linked to privacy and dignity, with patients taking intravenous agents preferring a quiet and clean room. Similarly, previous research showed that patients receiving biological agents for inflammatory rheumatic diseases value a safe atmosphere, with appropriate temperature and comfortable furniture for their wellbeing during the treatment[20]. However, the question related to privacy during the treatments sometimes is not seen as a realistic option[20]. The patients also seemed to prioritize sharing the treatments' rooms with patients with similar diseases, yet there is limited literature about this topic.

Portuguese patients considered that is crucial and essential for their satisfaction, the involvement of family and friends in their care and treatments options. Patients with RA from the original study of CQRA-PREM on the UK had similar considerations and this was somewhat expected as corroborates the findings of other qualitative studies where patients with RA believed that the social support (family and friends) is crucial for their wellness and coping [11,21].

Patients stated that the information about their disease and treatments should be simple, well explained and discussed by the healthcare provider to potentiate conscious, autonomous and well-informed decisions. These results were also reported on other qualitative studies, where the adherence to lifestyle measures, medications and therapeutics interventions are more likely if patients understood their disease, the treatments received and if they had confidence in their healthcare team[14]. Previous literature showed that shared-decision between physicians and patients is considered the best available evidence to account for patient preferences and to increase treatment adherence [22]. Furthermore, the 2022 update of EULAR Recommendations for the management of RA emphasizes the importance of provide the best care through a shared decision [23].

The opportunity to join a self-management program and to be introduced to patients' associations are areas that Portuguese patients thought as fundamental, but which are clearly insufficient and must be drastically improved in clinical practice. In Portugal, there are two national associations for patients with RA (ANDAR – Associação Nacional de Doentes com Artrite Reumatóide and LPCDR- Liga Portuguesa contra as Doenças Reumáticas), however most of the patients did not know about their existence. This may be due to a number of reasons, perhaps the activity of this association is not country widespread for the general population or there is a lack of awareness of healthcare professionals for the topic. During these focus groups, we also could understand that, when presented, the patients express their willingness and curiosity about the activities developed by these associations. This is extremely relevant because it is well known that structured group interventions improve psychological wellbeing and improve quality of life, coping and mental adjustment[24]. Furthermore, the healthcare professionals should be aware of the resources available to signpost patients to, in order to enhance and support self-management[25].

Regarding the multidisciplinary team, this topic emerged as a possible point to improve in rheumatology Portuguese's centers since most of the patients did not recognize the existence of different health professionals on a team in the current clinical practice, but only the rheumatologist. This contrasts with the results of the CQRA-PREM validation in UK, in which 92% of the participants were aware that a team was looking after them[11]. Indeed, according to EULAR Recommendations, the multidisciplinary team of the rheumatology services should include a rheumatologist, a specialist nurse, a physiotherapist, an occupational therapist, a podiatrist, a psychologist, a nutritionist and any other healthcare professionals involved in the care of patients with RA[25]. However, although the majority of participants in UK were aware of the existence of a multidisciplinary team, this team is only really complete in 17% of the UK rheumatology centers[26]. In Portugal, according to conclusions published in 2021 by the Rheuma SPACE Study Group, the multidisciplinary coverage is still a domain to improve, which corroborate the vision of the Portuguese patients[27].

In general, CQRA-PREM's content validity was good due to the similar aspects rated as relevant by the Portuguese patients and the patients in the UK. Only additions to better explain some expressions were added to the Portuguese preliminary version, as can be seen in the supplementary material. The choice of including open questions when applying this PREM may be decided by each healthcare center, depending on whether resources are available to analyse this qualitative information. In this study, due to the small sample size, internal consistency was not calculated. However, the results obtained in the UK and Netherlands are quite promising, with Cronbach's alpha coefficient ranging from 0.61 to 0.90 and from 0.65 to 0.93, respectively, for the several domains of the CQRA-PREM[11,12].

Authors acknowledge some strengths and limitations in this study. We can highlight the combination between translation, cultural adaptation of the CQRA-PREM based on a panel of experts and the content validation grounded on rich focus groups discussions. Focus groups discussions are extremely relevant to obtain particular perceptions about the healthcare provided. These interviews were performed by a trained moderator, capable of orientate and direct the discussion to obtain high quality data. The heterogeneity between the participants is also a component that enriches the obtained conclusions. In terms of limitations, we know that the recruitment of the participants was made during appointments by rheumatologists, so it is possible that a selection bias was introduced. First, rheumatologist could be biased to select a younger sample with a higher education level. Second, as patients who accepted to participate were possibly more interested because they felt that their disease had a huge impact in their life. Third, since the focus group discussions were performed via teleconference, patients with few experience with the use of IT technologies or with no familiar support to help them possibly were the ones refusing to participate. There were only 12 effective participants, being only 1 participant a man, which may not be representative of all patients with RA. Nevertheless, we need to consider that RA is more prevalent in women and that men in general are underrepresented in qualitative research [28] An additional limitation is related to the inclusion of only one participant with primary education, which can limit the representation of the comprehensibility and completion of the questionnaire by patients with lower educational levels. So, the small sample size and its process of recruitment imply more confirmatory evidence with a larger and diverse sample to demonstrate the validity of CQRA-PREM. Furthermore, this questionnaire was filled at home and then sent to the research team by email,

reason for what the median completion time was not measured, so we cannot take objective conclusions about the feasibility of the CQRA-PREM to be used in routine clinical practice. Nevertheless, a study to assess CQRA-PREM internal consistency, validity and feasibility in clinical practice is ongoing to bring more information about its psychometric properties. Another limitation of this study is related to the lack of a patient partner research in the design and implementation of the study, as it promotes a patient centered approach to research and enhance the validity of the findings, through helping bridge the gap between patients and researchers. Therefore, future studies in this area of knowledge should consider patient and public involvement.

Conclusion

The Portuguese version of the CQRA-PREM is acceptable and its content is valid in the perspective of patients with RA to assess the quality of care provided. This study is the first to adapt and validate the content of a Portuguese version of a PREM to be used in Portuguese rheumatology services. In future, the CQRA-PREM can be used to characterize Portuguese rheumatology services and help to identify the areas needing improvement, contributing for the increase in the global quality of patient-centered care in RA patients in Portugal.

Tables and Figures

Table I. Participants' sociodemographic and clinical characteristics (n=12).

Characteristics	
Gender, n (%)	
Female	11 (92)
Age (years) Median (Q1-Q3)	54 (44.5-58)
Employment Status, n (%)	
Employed	7 (59)
Retired	4 (33)
Unemployed	1 (8)
Education Level, n (%)	
Primary Education	1 (8)
Basic Education	2 (17)
Secondary	3 (25)
Higher	6 (50)
Symptoms duration (years), n (%)	
5-9	4 (33)
10-19	4 (33)
20-29	3 (25)
≥30	1 (9)
Diagnosis duration (years), n (%)	
<5	2 (17)
5-9	3 (25)
10-19	3 (25)
≥20	4 (33)
Drugs, n(%)	
bDMARD	6 (50)
csDMARD	4 (33)
tsDMARD	2 (17)

Legend: Q1-first quartile; Q3-third quartile; bDMARDS-Biologic Disease Modifying Antirheumatic Drugs; csDMARDS-Conventional Synthetic Disease Modifying Antirheumatic Drugs; tsDMARDS-Targeted synthetic Disease-Modifying Antirheumatic Drugs.

Table II. Median's responses for each CQRA PREM domain (n=12).

PREM domains	Number of questions	Median (Q1-Q3)
1.Needs and preferences	5	4 (4-5)
2.Coordination of care and communication	4	4 (3-5)
3.Information, Education and Self-care	4	3 (2-4)
4.Daily living and physical comfort	2	3 (2.75-4)
5.Emotional support	2	3 (3-4.35)
6.Family and friends	1	4 (3-4)
7.Access to care	1	4.5 (2.75-5)

PREM: Patient-Reported Experience Measures; Q1: first quartile; Q3: third quartile.

Table III. Themes and subthemes emerged on Focus Groups.

Themes	Subthemes	Absolute Frequency
Clearness and Feasibility of the PREM		157
Suggestions		46
Patients' needs and preferences (CQRA-PREM Domain 1 and 5)		80
Involvement of family and friends (CQRA-PREM Domain 6)		14
Information and Education ((CQRA-PREM Domain 3)	Information about disease	11
	Shared decision	53
	Other forms of information	27
Control of Disease (CQRA-PREM Domain 4)		19
Coordination of healthcare (CQRA-PREM Domains 2 and 7)	Availability of health professionals	35
	Access to healthcare	35
	Multidisciplinary team and referral	48

PREM: Patient-Reported Experience Measures

Table IV. Patients' citations in each theme and subtheme.

Themes and Subthemes	Citations
Clearness and Feasibility of the PREM	"To me, it makes perfect sense." (Female, 43y, 26y of disease) "I think your questionnaire is very clear." (Female, 55y, 22y of disease) "I've been thinking about each situation that has arisen over the years and I've been fitting in, and I've always been answering based on my experience." (Female, 47y, 16y of disease)
Suggestions	"My suggestion is about reschedule, why? (…) when I can't go [to the appointment] and I want to reschedule or call to let them know, I have no way of communicating." (Female, 58y, 7y of disease) "I think that perhaps the most correct here is "in the last year", "in the place where it is usually done, where your support is assured". We have been in several places throughout our history." (Female, 55y, 16y of disease) "I always had a hard time answering questionnaires because there should be an open question (…) Because it is like this: a person often neither agrees nor disagrees (…)." (Female, 60y, 8y of disease)
Involvement of family and friends	"My husband, whenever he could, he went with me and gave his opinion." (Female, 53y, 14y of disease) "Yes, I went to the appointments always with someone [from my family]." (Female, 71y, 27y of disease)
Information and Education	
Information about disease	" (…) I never leave an appointment without knowing the why and how, and therefore, I am always clarified and I have no type of complaint in this regard. I know what I am taking, how I am taking it and why I am taking this medication." (Female, 43y, 20y of disease) "They have to explain things to us in a simple way, in a way that we can understand it." (Female, 43y, 26y of disease)
Shared Decision	"So I think here it's really very important that things are explained to us, so that we can really make the decision (…), we have to understand it in depth." (Female, 43y, 26y of disease) "I'm very silent when I go to the physicians. I hear what I want to know. I don't worry too much and I don't want to know a lot of information about my disease." (Male, 45y, 5y of disease)
Other forms of information	"And she [the nurse] went to get a little alert card with information about what I was going to take, what I was going to do." (Female, 55y, 22y of disease) "In Portugal, we have few [associations]." (Female, 43y, 20y of disease)
Control of Disease	"Our disease is never effectively controlled and the called habitual and diary activities are adapted to our quotidian." (Female, 53y, 14y of disease) "Whenever I had a crisis, I had to go to the hospital to receive intravenous drugs so I could restore my movements, I had to go to the Primary HealthCare to ask for a "sick leave" and I had to go to the rheumatologist to receive an adequate treatment." (Female, 53y, 14y of disease)
Coordination of healthcare	
Availability of health professionals	"(…) and she [the rheumatologist?] tried within her possibilities to help and make some kind of contact and give as much information as possible." (Female, 47y, 16y of disease)

"(..) However, nobody calls me from there [other hospital service], nobody answers the phone. (…) It does not give any information to the patient [about the first appointment in the other hospital service]." (Female, 42 years, 1.5 years of disease)

Access to healthcare	*"I think there should be a support line for us to clear these doubts." (Male, 45y, 5y of disease)*

"If I'm in a distressing situation, I know I won´t be able to call anywhere, so one of two things: either I go there or we can not (…). (…) urgent or not, you can't do it, which is it what scares me a little." (Female, 43y, 26y of disease)

"The hospital has already cancelled me appointment and I had to wait nearly four months for the next one." (Female, 55y, 22y of disease)

"Go to the pharmacy to buy a pill is fast, the difficult is receive the biological treatments from the hospital. The biological treatments are the ones which are difficult and it is needed a wait time." (Female, 53y, 14y of disease

Multidisciplinary Team and referral	*"This multidisciplinary team, I really think it is essential and it really needs to become a reality." (Female, 43y, 20y of disease)*

"I also didn't know that there were so many professionals to give us support in case of need, such as the physiotherapist support." (Female, 53y, 14y of disease*)*

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Supplementary Material

Supplementary Material – Preliminary Portuguese version of CQRA-PREM

Cuidados na Artrite Reumatoide: questionário ao doente	
Introdução Instruções:	**Este questionário é sobre o quê?** Este questionário é sobre a sua experiência com os serviços e tratamentos de reumatologia do hospital onde recebe cuidados para a sua artrite reumatoide. O objetivo do questionário é fornecer feedback à sua equipa de reumatologia sobre a sua **experiência** como doente, de forma a melhorar a sua experiência no futuro. Algumas questões poderão estar relacionadas com outros profissionais que lhe prestam cuidados de saúde. As suas respostas são anónimas e não podem ser identificadas. As suas respostas são extremamente importantes para ajudar a equipa de reumatologia a melhorar os cuidados a todos os doentes.
	Quem deve preencher o questionário? Este questionário é para pessoas a quem foi diagnosticada artrite reumatoide há pelo menos um ano. Se precisar de ajuda a preencher o questionário, as respostas devem ser dadas de acordo com o seu ponto de vista - não sob o ponto de vista de quem o(a) está a ajudar a preencher o questionário. O questionário demora cerca de 5 a 10 minutos a ser preenchido.
	Como preencher o questionário? Para cada afirmação, **coloque um X dentro de um dos círculos**. Se responder em papel, use uma caneta azul ou preta. Caso se engane, não se preocupe – apenas risque e coloque o **X** no círculo correto. Por favor **não escreva** o seu nome, morada ou qualquer informação pessoal no questionário. As suas respostas são anónimas e serão tratadas de forma confidencial. Por favor entregue o questionário completamente preenchido – obrigado.

Secção	Afirmação	Concordo totalmente	Concordo	Não concordo nem discordo	Discordo	Discordo totalmente
1. As suas necessidades e preferências	a) Sempre que fui atendido(a) num serviço, sentia que era tratado(a) com respeito como pessoa	◯	◯	◯	◯	◯
	b) Fui envolvido(a), tanto quanto queria, nas decisões sobre o meu tratamento e cuidados	◯	◯	◯	◯	◯
	c) As minhas circunstâncias pessoais (ver nota 1 abaixo) e preferências foram tidas em consideração ao planear e decidir o meu tratamento e cuidados	◯	◯	◯	◯	◯
	d) Foi-me fornecida informação de forma a que eu a pudesse compreender	◯	◯	◯	◯	◯
	e) Foi-me fornecida informação suficiente para me ajudar a tomar decisões quanto ao meu tratamento	◯	◯	◯	◯	◯

Nota 1: Exemplos de "circunstâncias pessoais" podem ser uma atividade profissional ou ser cuidador de alguém.

Secção	Afirmação	Concordo totalmente	Concordo	Não concordo nem discordo	Discordo	Discordo totalmente
2: Coordenação de cuidados e comunicação- Cuidados entre serviços	a) Fui informado(a) de que existe uma equipa de profissionais de saúde (ver nota 2 abaixo) a cuidar de mim	◯	◯	◯	◯	◯
	b) Quando precisei de ajuda, consegui ter acesso a diferentes membros da minha equipa de saúde	◯	◯	◯	◯	◯
	c) Há um membro na minha equipa de saúde que me pode encaminhar para outros especialistas, caso eu precise	◯	◯	◯	◯	◯
	d) Sinto que as pessoas que me atendem no serviço conhecem bem a minha situação atual	◯	◯	◯	◯	◯

Nota 2: O tipo de profissionais de saúde na equipa pode variar de região para região e deveriam incluir um médico de família, reumatologista, enfermeiro, fisioterapeuta, terapeuta ocupacional, nutricionista, farmacêutico e assistente social.

Secção	Afirmação	Concordo totalmente	Concordo	Não concordo nem discordo	Discordo	Discordo totalmente
3. Informação, educação e cuidados pessoais	a) Sinto que recebi informações no momento em que precisei	○	○	○	○	○
	b) Sinto que tenho uma boa compreensão acerca dos tratamentos que estou a receber ou que me foram propostos	○	○	○	○	○
	c) Fui informado(a) sobre associações de doentes ou grupos que me possam ajudar	○	○	○	○	○
	d)Foi-me dada a oportunidade de frequentar um programa de apoio para me ajudar a gerir as minhas necessidades *1	○	○	○	○	○
4. Vida diária e conforto físico	a) Sinto que a minha artrite reumatoide está controlada o suficiente para que eu possa continuar com a minha vida diária e as minhas atividades habituais *2	○	○	○	○	○
	b) Quando tenho uma "crise" (quando os meus sintomas pioram muito), tenho conseguido ajuda rapidamente	○	○	○	○	○
5. Apoio Emocional	a) Sinto que posso falar com um membro da minha equipa de saúde para discutir quaisquer preocupações sobre a minha	○	○	○	○	○

Secção	Afirmação					
	condição e o meu tratamento ou os seus efeitos na minha vida					
	b) Sinto que posso discutir com a minha equipa de saúde questões pessoais ou íntimas, caso o queira	○	○	○	○	○
6.Família e amigos	a) Sinto que, se eu quiser, posso ser acompanhado(a) por familiares nas minhas consultas para que estes sejam envolvidos nas decisões sobre os meus cuidados	○	○	○	○	○

*1: A program to help me managing my needs and emotions

*2: Controlled enough accordingly to your typical daily activities

7. Acesso aos cuidados	a) Nas consultas, sinto que tenho tempo suficiente com o profissional de saúde para falar sobre tudo o que quero discutir	○	○	○	○	○
	b) Já tive consultas canceladas de forma inesperada	Sim ○	Não ○			
	c) Se sim, quanto tempo teve de esperar por uma nova consulta?	Até 1 semana ○	1 a 3 semanas ○	4 a 6 semanas ○	7 a 12 semanas ○	Mais de 12 semanas ○
	d) Já necessitei de tratamentos extra ou de mudanças no meu tratamento	Sim ○	Não ○			
	e) Se sim, quanto tempo demorou para que isso acontecesse?	Até 1 semana ○	1 a 3 semanas ○	4 a 6 semanas ○	7 a 12 semanas ○	Mais de 12 semanas ○

Secção	Afirmação	Concordo totalmente	Concordo	Não concordo nem discordo	Discordo	Discordo totalmente
8. Experiência global com os cuidados	a) Globalmente, no último ano, tive uma boa experiência com os cuidados de saúde para a minha artrite reumatoide	◯	◯	◯	◯	◯
Obrigado pelo tempo despendido a preencher este questionário. **Por favor, entregue o questionário completamente preenchido - obrigado.**						