Rheumatol Int (2014) 34:1299–1309
DOI 10.1007/s00296-014-2997-z

ORIGINAL ARTICLE

Culture-sensitive adaptation and validation of the Community-Oriented Program for the Control of Rheumatic Diseases methodology for rheumatic disease in Latin American indigenous populations

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Received: 13 January 2014 / Accepted: 18 March 2014 / Published online: 29 March 2014

Abstract The purpose of the study is to validate a culturally sensitive adaptation of the community-oriented program for the control of rheumatic diseases (COPCORD) methodology in several Latin American indigenous populations. The COPCORD Spanish questionnaire was translated and back-translated into seven indigenous languages: Warao, Kariña and Chaima (Venezuela), Mixteco, Maya-Yucateco and Raramuri (Mexico) and Qom (Argentina). The questionnaire was administered to almost 100 subjects in each community with the assistance of bilingual translators. Individuals with pain, stiffness or swelling in any part of the body in the previous 7 days and/or at any point in life were evaluated by physicians to confirm a diagnosis according to criteria for rheumatic diseases. Overall, individuals did not understand the use of a 0–10 visual analog scale for pain intensity and severity grading and preferred a Likert scale comprising four items for pain intensity (no pain, minimal pain, strong pain, and intense pain). They were unable to discriminate between pain intensity and pain severity, so only pain intensity was included. For validation, 702 subjects (286 male, 416 female, mean age 42.7 ± 18.3 years) were interviewed in their own language.

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In the last 7 days, 198 (28.2 %) subjects reported having musculoskeletal pain, and 90 (45.4 %) of these had intense pain. Compared with the physician-confirmed diagnosis, the COPCORD questionnaire had 73.8 % sensitivity, 72.9 % specificity, a positive likelihood ratio of 2.7 and area under the receiver operating characteristic curve of 0.73. The COPCORD questionnaire is a valid screening tool for rheumatic diseases in indigenous Latin American populations.

Keywords Ethnic groups 1 · Screening 2 · COPCORD 3 · Rheumatic diseases 4 · Cross-cultural validation 5

Introduction

Musculoskeletal (MSK) disorders and rheumatic diseases are a major cause of morbidity in the general population. Although most rheumatic diseases do not increase short-term mortality, they do lead to disability and impaired quality of life [1].

In 1981, the International League of Associations for Rheumatology, together with the World Health Organization, initiated a program for the prevention and control of rheumatic diseases at the community level called the community-oriented program for the control of rheumatic diseases (COPCORD). This program seeks to obtain reliable epidemiological information through low-cost studies conducted in the community [2, 3]. The COPCORD is comprised of three stages: Stage 1 comprises an epidemiological study of rheumatic disease; Stage 2 includes treatment and educational strategies; and Stage 3 determines the environmental and genetic risk factors underlying rheumatic disorders. The COPCORD Core Questionnaire (CCQ) is applied in Stage 1 for the screening and detection of rheumatic diseases [2, 3].

COPCORD methodology has been employed to determine the prevalence of MSK disorders and rheumatic diseases in some Latin American countries, where the participating population was predominantly of Mestizo origin [4–12]. Indigenous Latin American populations are located in remote areas and have limited access to health care. It has been reported that there are cultural differences among populations between and within countries in relation to concepts of health and disease, literacy and reading levels, agreement between written and oral languages, and taboo topics, and these differences influence the way that health parameters are measured or estimated among different cultures [13–15]. Recently, a new COPCORD study conducted in Mexico demonstrated that there were differences in reporting MSK conditions across populations with different cultural and socioeconomic characteristics [7, 16]. This study supported the findings of previous genetic and epidemiologic studies that certain rheumatic diseases occurred with greater prevalence and/or severity in indigenous populations [17, 18].

To address these regional differences, the Latin American Study Group of Rheumatic Diseases in Indigenous Peoples (*Grupo Latino-Americano de estudio De Enfermedades Reumáticas en Pueblos Originario,* GLADERPO) was created. This project is part of the initial stages of a regional effort to address the health issues of indigenous populations. In order to achieve this, it is necessary to create community programs that adapt efficiently to the beliefs, perceptions and cultural values of each community, i.e., the programs should be culturally sensitive. Multicultural countries such as the those found in Latin America need to have epidemiological instruments validated for each indigenous community in order to obtain reliable and comparable measurements across populations [13–20].

We hypothesized that pain, swelling, and stiffness, which are important features in rheumatic diseases, may be conceptualized and expressed differently in each indigenous groups. To be certain that we are measuring identical or semantically close concepts in indigenous populations, it is necessary to formulate and validate a culturally sensitive adaptation of the measurement instrument for effective use in each specific culture [21, 22].

The aim of this study was to adapt and validate the Spanish COPCORD methodology and CCQ for screening of MSK disorders and rheumatic diseases in seven indigenous groups from three Latin American countries, and to determine the performance of the CCQ as a screening tool for diagnosis of rheumatic diseases in these populations.

Method

Population

The study included subjects older than 18 years of age who belonged to an indigenous group (as defined in the Constitution or the pertinent legislation of each participating country). The participating indigenous groups were Qom from Argentina; Mixteco, Maya-Yucateco, and Raramuri from Mexico; and Warao, Kariña, and Chaima from Venezuela. Their characteristics are described below:

Argentina: the Qom or Toba live in the city of Rosario, province of Santa Fe, and are migrants from their native

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Chaco region, with which they maintain important migratory movement. Their language belongs to the Guaycurú family and lacks a written format [23].

Mexico: Mixteco group: residents of the Mixteco Alta community (San Antonio Huitepec), which is located in the Sierra area of the state of Oaxaca. Maya-Yucateco group: residents of Chikindzonot, which is in the state of Yucatan in southeastern Mexico. Raramuri or Tarahumara group: residents are dispersed throughout the Sierra Tarahumara in the state of Chihuahua in northern Mexico. All these communities are classified as highly marginalized by the INEGI (National Institute of Statistics and Geography) and are highly monolingual [24].

Venezuela: Warao group: residents of the region called "Los Caños" in the state of Monagas, who live along the Morichal River in stilt houses, move around in canoes and are mostly monolingual. Chaimas group: residents of the Caripe municipality in the state of Monagas who are in the process of recovering their language and culture, as they have become highly westernized. Kariñas group: residents from the town of Guamo (Cedeño municipality) in the state of Monagas, who, like the Chaimas, are in the process of recovering their indigenous language, Kariña [25]. In the last two indigenous groups, only one cross-cultural adaptation was performed. The full translation process was deemed unnecessary because of their high proficiency in Spanish.

The groups of participants were selected for convenience and study feasibility. The participants varied between the validation stages, with the criteria being detailed for each phase.

Cross-cultural adaptation

Instrument adaptation was performed following the guidelines proposed by Beaton et al. [14]. These authors defined cultural adaptation as a process that observes both parties to the cultural and linguistic adaptation (translation) in the process of preparing a questionnaire for use in other contexts. They also suggested that this process should be tailored to 4 different situations, as defined by the target population (native inhabitants, established immigrants, and new immigrants), culture, language, and country. The translation process includes seven stages: (1) translation, (2) translation abstract, (3) back-translation, (4) review by an expert committee, (5) pre-final version testing, and (6) documentation review for developers [14]. This process includes the evaluation of conceptual, semantic, items, and operational equivalences [19]. Phase 7 is validating the adaptation to evaluate the measurement equivalence (clinimetric and psychometric properties of the questionnaire) [14, 19].

The study was conducted in each of the indigenous communities following the process of COPCORD methodology.

COPCORD–CCQ: the questionnaires were administered in the participants' households [2, 3] by bilingual staff members, who received standardized training, administered a cross-culturally validated version of the COPCORD questionnaire to the adult population of the 7 communities. Version 2 of the Mexican Spanish COPCORD–CCQ was used in the cross-cultural adaptation process [7, 20]. This version has the following sections: (a) self-reported illnesses, (b) work history, (c) MSK pain during the past 7 days, measured as pain intensity, and perceived severity, MSK pain for any period of time in the past, (d) coping, and help-seeking behavior (including treatment patterns like biomedical, surgical, and traditional care), and (e) functional ability as measured by the amended Health Assessment Questionnaire Disability Index (HAQ-DI). Also added were a section on cultural affiliation, i.e., elements of linguistic competence in the native language as well as in Spanish, genealogy (whether the respondent's parents were indigenous) and whether the respondent considered themselves indigenous. The questionnaire was fully administered to the participants with the exception of the treatment and treatment-seeking sections, which were not administered in negative cases (i.e., MSK disorders).

Translation of the Mexican Spanish text into indigenous languages

Phase 1

Initial translation of the CCQ: for each participating indigenous group, the questionnaire was translated directly and interpretively. The methodology varied in each group. The Warao, Maya-Yucateco, and Raramuri have predominantly oral cultural traditions and are highly monolingual; therefore, we used qualitative techniques such as group discussions and semi-structured interviews. The purpose of this phase was to understand the concepts explored by the questionnaire, including their interpretation by each population to reflect what was required for clinical evaluation. Three to five individual translations were performed by community translators, bilingual community teachers, and cultural facilitators and were recorded in the case of Warao, Raramuri, and Qom groups. In the case of Maya-Yucateco, they were also written because this language can also be expressed in the written form.

For the Mixteco and Qom groups, the questionnaire was translated for subjects older than 60 years because they were monolingual. The Mexican Spanish version was adapted for the population under 60, who were bilingual and had a good command of Spanish. In the Kariña and Chaima groups, translation was not required as these participants were Spanish speakers. Each translation was recorded for analysis and synthesis of the translation.

Phase 2

Translation synthesis: A report was drafted after the qualitative phase of the study for all translations and discussed by an expert committee comprising community translators, bilingual community teachers, cultural facilitators, and health professionals (physicians, anthropologists, primary health care providers, and rheumatologists). Differences were resolved by consensus. Given the cultural and linguistic difficulties, we decided to make another change to the methodology [14]. We conducted a pretest in 10 subjects in each monolingual community by administering the translated questionnaire and conducting a short interview with the help of bilingual interviewers from the community. The purpose of this phase was to evaluate the clarity of the questionnaire and its culturally appropriate conceptualization to form version 1.

Phase 3

Back-translation: Three back-translations of the CCQ were performed by two bilingual community subjects and by one bilingual teacher who did not belong to the community, but was certified by the bilingual system of each country. All back-translations were reviewed and recorded for analysis.

Phase 4

Committee review process: Discussion sessions were held with an expert committee to obtain version 2 of the questionnaire, verifying it for culturally appropriate semantic, idiomatic, conceptual, and cultural equivalence. In addition, we submitted version 2 of the questionnaire for review and evaluation by anthropologists and linguists specialized in the study of the participating indigenous groups and who were not participating in the project. The comments and suggestions of this external review process were used to create version 3 of the questionnaire.

Phase 5

Testing the pre-final version: We did another pre-pilot test with version 3 on a convenience sample of 20 monolingual individuals from each indigenous group (except Kariña and Chaima groups) in order to validate the process of administration of the instrument. This was done to ensure that accessibility, traditions, and customs of the indigenous groups were considered and respected in applying the questionnaire in the field.

Phase 6

Presentation to the committee of experts and participating investigators: Focus groups were held by the expert committee. The meetings were recorded and transcribed to make sure all changes and suggestions made by the committee were implemented in version 4 of the questionnaire. This version was then presented and discussed with the entire group of researchers involved in the study in order to approve the final version of the instrument.

Phase 7

Validation of the final version: The purpose of this phase was to evaluate all psychometric characteristics of the CCQ (see Fig. 1). We administered the final version of the questionnaire (version 5) to a convenience sample of 100 subjects in each indigenous community. This sample size was based on the proposal of Terwee et al., who suggested that at least 100 subjects were required to measure the internal consistency and construct validity of a questionnaire [26]. Subjects with positive manifestations (pain, stiffness and swelling in any part of the body in the last 7 days and/or at some point in life) were also assessed by a group of family physicians, internists, and rheumatologists to provide a diagnosis according to international criteria for rheumatic diseases. For the diagnosis of osteoarthritis (OA), rheumatoid arthritis (RA), fibromyalgia, and systemic lupus erythematosus (SLE), the American College of Rheumatology criteria were used [27–31]; for gout, we used the Wallace criteria [32]; and for ankylosing spondylitis (AS), the modified New York criteria [33]. For nonspecific cases of MSK disorders, we used the International Classification of Diseases, 10th revisión [34].

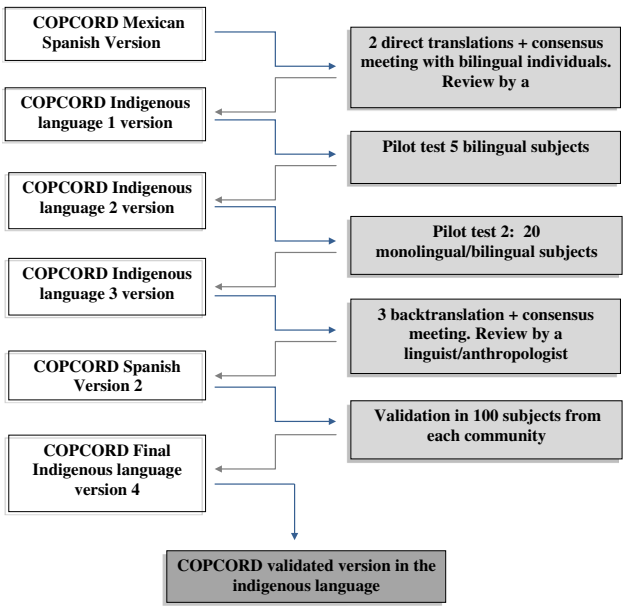

Fig. 1 Cross-cultural validation process

Ethical aspects

We obtained approval from the appropriate ethics committee of each participating country, as well as approval by the community and indigenous authorities of each participating group. After a detailed explanation of the study, each participant gave his/her approval for participation in the study in their own language. This consent was recorded and authorized by a signature or fingerprint in a written informed consent form.

Analysis

Qualitative analysis was performed using a thematic analysis [35]. The results of this phase will be published in full in another publication.

Statistical analysis

Analyses included descriptive statistics of all the study variables, which are reported as measures of central tendency and dispersion and proportions for dichotomous or ordinal variables. The Cronbach α coefficient was measured considering a criterion of dimensionality; lower values were interpreted as multidimensional, and values larger than 0.70 were interpreted as one-dimensional [36]. Correlation matrices were performed using Spearman's rank test for the dimensions of the CCQ.

Performance as a screening test: pain symptomatology (in the last 7 days and historical pain) was compared with the clinical assessment and the final diagnosis provided by a rheumatologist by assessing sensitivity, specificity, likelihood ratio, and areas under the receiver operating characteristic (ROC) curves and their 95 % confidence intervals (CI) [37].

The predictive validity was assessed by multiple regression analyses, in which the dependent variables were the frequency of MSK disorders and the presence of a rheumatic disease as diagnosed by a rheumatologist. The variables with significant odds ratio (OR) values ($P \leq 0.005$) were included in a final multiple forward logistic regression to explore the contribution of significant variables to establishing a diagnosis. Responsiveness was not measured, since the purpose of the instrument was not the detection of change. The analysis was performed with Stata v.11.0 (Stata Corp, College Station, TX, USA).

Results

The questionnaire was amended according to the findings of the qualitative analysis (30 subjects from each community participating in the two pre-pilot testing phases 2 and 5). These amendments were as follows: (a) the 0–10 visual analog scale (VAS) for pain intensity, and severity was removed as respondents had difficulty in understanding this scale and were more comfortable using a Likert scale with four options (no pain, minimal pain, strong pain, and intensive pain); for the Warao indigenous group, a scale of three options was suggested (no pain, minimal pain, strong pain); (b) the concepts of pain intensity and severity were not distinguishable in any of the participating groups, so only pain intensity was included; (c) all work activities and HAQ-DI questions were adapted to the lifestyle of each group, for instance, fishing and farming for the Warao group, hammock weaving and embroidery for the Maya-Yucateco group, and cirujeo (garbage collection) for the Qom group; (d) a section on cultural affiliation was added, including elements of kinship, language proficiency in the native language of both parents and their degree of bilingualism; (e) comorbidities were based on local morbidity and mortality statistics and the information provided by the respondents to identify diseases that are categorized locally but may not have a counterpart in the general biomedical nomenclature.

For validation of the CCQ, 702 subjects (286 male, 416 female, mean age 42.7 $\pm$ 18.3 years) were surveyed (95 Warao, 100 Chaima, 97 Kariña, 103 Qom, 106 Maya-Yucateco, 100 Mixteco, and 101 Raramuri); 244 (65.3 %) had a partner; median duration of education was 1 year (inter-quartile range 0–6 years); 496 (70.6 %) declared they were engaged in a productive activity; and 499 (71.1 %) spoke an indigenous language. A comparison of sociodemographic characteristics of participants revealed statistically significant differences between groups across all variables (Table 1).

Table 2 shows the results of the pain and disability domains of the CCQ. In the last 7 days, 198 subjects (28.2 %) reported having MSK pain unrelated to injury. The most common MSK pain locations were the knees (21.7 %), lower limbs (11.0 %), shoulders (13.3 %), hands (9.5 %), elbows (6.0 %), and hips (5.0 %).

Of 705 respondents, 195 (27.7 %. 95 % CI 24.4–31.2) were diagnoses during the survey. The most frequent being osteoarthritis, back pain, and nonspecific cases of MSK disorders (see Table 3).

An analysis of the internal consistency of the COPCORD questionnaire dimensions gave values for Cronbach α ranging from 0.77 for the pain path to 0.20 for the course of treatment (Table 4).

Correlation analysis between the diagnosis of any rheumatic disease pain and pain-related variables in the CCQ showed a significant positive correlation ranging from 0.42 for pain in the last 7 days to 0.16 for current physical impairment (Table 5).

Predictive analysis using the best multivariate model of simple and multiple logistic regression showed that

Table 1 Socio-demographic characteristics of the indigenous group validation study sample

Variable	Total $n = 702$	Warao $n = 95$ (13.5 %)	Chaima $n = 100$ (14.5 %)	Kariña $n = 97$ (13.8 %)	Qom $n = 103$ (14.6 %)	Yucatec Maya $n = 106$ (15.1 %)	Mixtec $n = 100$ (14.2 %)	Raramuri $n = 101$ (14.3)	p
Age mean (SD, range)	42.7 (18.3, 18–99)	35.2 (15.9; 18–74)	41.2 (17.4; 18–85)	40.5 (19.0; 18–92)	35.2 (13.1; 18–69)	45.3 (16.7; 20–88)	42.3 (19.3; 18–99)	57.8 (15.4; 21–86)	<0.01
Gender (female) *n* (%)	416 (59.2)	51 (53.6)	53 (53.0)	52 (53.6)	69 (66.9)	73 (68.8)	72 (72.0)	46 (45.5)	<0.01
Marital status (married/ co-habiting) *n* (%)	459 (65.3)	79 (83.1)	53 (54.6)	58 (59.7)	54 (52.4)	94 (88.6)	64 (64.0)	57 (56.4)	<0.01
Work (yes) *n* (%)	496 (70.6)	69 (72.6)	50 (50.0)	58 (59.7)	49 (47.5)	97 (91.5)	100 (100.0)	73 (72.2)	<0.01
Indigenous language speaker (%)	499 (71.1)	89 (94.6)	6 (6.0)	22 (22.6)	74 (71.8)	100 (100.0)	100 (100.0)	100 (100.0)	<0.01
Median years of education (IQR)[a]	1 (0–6)	1 (0–5)	5.5 (1–13)	0 (0–1)	6 (0–6)	1 (1–2)	2 (1–3)	1 (0–3)	<0.01

IQR interquartile range, *SD* standard deviation

[a] Kruskal–Wallis rank test

the variables in the CCQ that most successfully predicted the probability of having a rheumatic disease (R^2 29.83, $P \leq 0.01$) were the following: belonging to the Raramuri or Qom indigenous groups (OR 1.55, 95 % CI 1.37–1.76), presence of pain in the last 7 days (OR 3.30, 95 % CI 1.76–4.35), presence of pain at some point in life (OR 2.78, 95 % CI 1.71–4.53), and not adapting to pain (OR 2.66, 95 % CI 1.87–3.79). These factors were found to be independent predictive variables for having a specific clinical rheumatic diagnosis.

A performance assessment of the COPCORD questionnaire using the two questions about "pain in the last 7 days" and "historical pain plus pain in the last 7 days" as a screening tool for a final specific rheumatologic diagnosis established by a rheumatologist showed that a positive response for both resulted in a sensitivity of 73.8 %, specificity of 72.9 %, positive likelihood ratio (LR±) of 2.7, and an area under the ROC curve of 0.73 (95 % CI 0.69–0.77) (Table 5). For each diagnosed rheumatic disease, sensitivity varied from 60 to 100 % and specificity varied from 60 to 66 % (Table 6).

Discussion

The COPCORD methodology and the modified CCQ showed good performance as a screening test for MSK disorders and rheumatic diseases in rural and urban Latin American indigenous communities. Other cross-cultural validations of the COPCORD methodology and instrument performed in Latin American Mestizo populations from Mexico, Brazil and Chile showed higher sensitivity (84 %) and specificity (80.2 %) rates than those found in this study [38]. However, in the CCQ validation in these three countries, ethnic groups were mentioned only in the background descriptive information [38]. No pain intensity cutoff point was used in the present study as suggested in the first validation in Spanish by Bennet et al. [38], as we believe that the perception of the severity or intensity of pain varies between cultures.

A previous COPCORD validation conducted in a Mexican Mestizo population reported lower sensitivity (51.7 %), higher specificity (80.1 %), similar LR ± (2.6) and slightly lower ROC (0.65) than the present study. These results differ in that sensitivity was higher in the present study (73.8 %), while specificity was slightly lower (72.9 %), ROC was higher (0.73) and the LR ± was similar (2.7) [20]. In light of the above, we can conclude that our validation of the CCQ has shown adequate performance and greater sensitivity than in previous validations performed in the Mestizo population at least in Mexico [20]. We have no comparators with other countries (Argentina and Venezuela) since any validation studies had been conducted on Mestizo populations in those countries.

When comparing the performance of CCQ as a screening test across different ethnic groups, we found that certain sensitivities (true positives as identified by a rheumatologic clinical assessment) were low in the Kariña (20 %),

Table 2 Description of pain, functional capacity, and physical impairment

Variable	Total $n = 702$ n (%)	Warao $n = 95$ (13.5 %) n (%)	Chaima $n = 100$ (14.5 %) n (%)	Kariña $n = 97$ (13.8 %) n (%)	Qom $n = 103$ (14.6 %) n (%)	Yucatec Maya $n = 106$ (15.1 %) n (%)	Mixtec $n = 100$ (14.2 %) n (%)	Raramuri $n = 101$ (14.3) n (%)	p
MSK pain 7 days	281 (40.0)	57 (60.0)	42 (42.0)	25 (25.7)	39 (37.8)	25 (23.8)	39 (39.0)	54 (53.4)	<0.01
MSK pain 7 days associated with trauma	85/281 (30.2)	20/57 (35.0)	8/42 (19.0)	17/25 (68.0)	7/39 (17.9)	9/25 (36.0)	12/39 (30.7)	12/54 (22.2)	<0.01
MSK pain 7 days not associated with trauma (COPCORD±)	198 (28.2)	37 (38.9)	34 (34)	8 (8.2)	32 (31.0)	16 (15.0)	28 (28)	43 (42.5)	<0.01
Chronic pain[a]	195 (27.8)	30 (31.5)	32 (32.0)	17 (17.5)	37 (35.9)	21 (19.8)	29 (29.0)	29 (28.7)	0.03
Pain degree (strong)[b] Strong-severe pain	90/198 (45.4)	23/37 (62.1)	0	0	22/32 (68.7)	7/16 (6.6)	28/28 (100)	10 (23.2)	<0.01
Historical pain	331 (47.1)	37 (38.9)	62 (62.0)	57 (58.7)	65 (63.1)	30 (28.3)	50 (50.0)	30 (29.7)	<0.01
Current impairment for Work	26 (3.7)	0	0	1	7 (6.8)	12 (11.3)	7 (7.0)	0	<0.01
HAQ-DI median (IQR)[c]	0.08 (0–0.41)	0.16 (0–0.5)	0.16 (0–0.5)	0.16 (0–0.41)	0.33 (0–0.58)	0 (0–0.1)	0 (0–0)	1.5 (1–2)	<0.01

COPCORD the Community-Oriented Program for the Control of Rheumatic Diseases, *MSK* musculoskeletal, *HAQ-DI* Health Assessment Questionnaire Disability Index

[a] Chronic pain: pain in the last 7 days and historical pain were constructed as a proxy for the presence of chronic pain

[b] Categories of strong/severe were combined

[c] Kruskal–Wallis rank test

Table 3 Rheumatic diseases identified in the evaluation by rheumatologists

Osteoarthritis	93 (13.2;10.8–15.9)
Back pain	56 (7.9;6.0–10.2)
MSK disorders	55 (7.8;5.9–10.0)[a]
Regional pain	22 (3.1;1.9–4.7)
Rheumatoid arthritis	11 (1.5; 0.7–2.7)
Undifferentiated arthritis	7 (1.0;0.4–2.0)
Fibromyalgia	5 (0.7;0.2–1.6)
Spondyloarthritis	2 (0.2; 0.03–0.1)

[a] MSK disorders (other joint disorder according to M20-25 code by ICD-10)

Table 4 COPCORD internal consistency

Dimensions of COPCORD	Cronbach α	Items
MSK pain path[a]	0.77	6
Comorbidity[b]	0.34	13
Work[c]	0.30	5
Cultural affiliation[d]	0.43	5
Functional capacity HAQ-DI[e]	0.92	10
Course of treatment[f]	0.20	4

$P \leq 0.001$

[a] Pain path: pain in the last 7 days, historical pain, severity of pain, pain intensity, and pain coping

[b] All comorbidities common to each population

[c] All questions regarding work and activity

[d] Affiliation to an indigenous group and linguistic competence

[e] All questions from HAQ-DI and related to functional impairment

[f] Course of treatment

Chaima (30 %) and Maya-Yucateco (36 %) groups. These groups also exhibited a lower prevalence of rheumatic diseases, which would explain the low sensitivities observed, because sensitivity depends on the prevalence [37, 39]. The specificities were high (above 80 %) in all ethnic groups except the Qom group (73 %). Therefore, we calculated the LR± for the relationship between sensitivity and specificity, which expressed how many times more (or less) a subject with MSK pain in the last 7 days or chronic MSK pain could have a rheumatic disease compared with individuals without pain. This study yielded LRR± values ranging between 2.4 and 16.6, which predicted the likelihood of a subject having a rheumatic disease based on the risk of the source population [37, 39].

Two other COPCORD methodology validation studies conducted in Australian aboriginal groups reported a sensitivity of 86 % and a specificity of 76 %. The differences between these results and ours could be explained by the fact that no cross-cultural validation was performed in the Australian studies since all participants (97 % of whom considered themselves indigenous) spoke English at a native level [11]. Another study in Australia adapted the CCQ to an indigenous group and reported a sensitivity of 81 % and a specificity of 67 % for back pain, neck and shoulder pain. The pain cases were assessed by a chiropractor [12]. In our study, the sensitivity and specificity were similar for MSK disorders. The validation of the CCQ into Arabic in Kuwait revealed a sensitivity of 94.3 % and a specificity of 96.9 %, which is higher than that found in our report [40]. However, our study included not only subjects with pain in the last 7 days but also subjects reporting pain at some point in the past. The reason behind this was our view that symptoms of rheumatic diseases vary over time, so there may be a subject with a rheumatic disease who has had no pain in the last 7 days.

The first COPCORD study was conducted on three different ethnic groups (Chinese, Indian and Malaysian) inhabiting the same region [41, 42]; however, the questionnaires were administered in English and Malay, and no data regarding cultural differences were mentioned.

The results of the dimensionality and internal medical consistency using Cronbach's α were interpreted according to Sijtsma [36]: there were very low scores for multidimensional sections, and very high scores for one-dimensional sections of the questionnaire for pain path (0.77) and functional capacity as measured by HAQ-DI (0.92). There were moderate scores for comorbidities, work and cultural affiliation, and very low scores for the course of treatment. A potential explanation for the low scores is that the data are multidimensional in relation to the traditional treatments and reasons for using different types of treatment

Table 5 Correlation of pain-related variables of COPCORD and a proxy for the gold standard (established by rheumatologist diagnosis)

Dimensions of COPCORD	Rheumatic disease[a]	Osteoarthritis	Rheumatoid arthritis
Pain 7 days	0.42*	0.32*	0.13*
Historical pain	0.34*	0.14	0.11*
Pain severity	0.37*	0.18*	0.16*
Physical impairment	0.16*	0.01	0.17*
Adaptation to pain	0.31*	0.06	0.06
Functional capacity HAQ-DI	0.38*	0.38*	0.17*
Treatment for pain	0.27*	0.19*	0.02

* $P \leq 0.001$

[a] Any diagnosis of rheumatic disease

Table 6 Performance as a screening test for the COPCORD questionnaire for the detection of rheumatic diseases

	Sensitivity (%)	Specificity (%)	Positive likelihood ratio (%)	Area under the curve (95 % CI)
Sensitivity and specificity analyses of the pain in the last 7 days versus clinical diagnosis of rheumatic disease				
Rheumatic disease	73.85	72.98	2.73	0.73 (0.69, 0.77)
Osteoarthritis	80.65	66.17	2.38	0.73 (0.68, 0.77
Back pain	60.71	61.76	1.58	0.61 (0.54, 0.67)
RRPS	72.73	61.03	1.86	0.66 (0.57, 0.76)
Rheumatoid arthritis	90.91	60.78	2.31	0.75 (0.66, 0.84)
Undifferentiated arthritis	83.33	60.34	2.10	0.71 (0.55, 0.88)
Spondyloarthritis	100	60.14	2.50	0.80 (0.78, 0.81)

RRPS rheumatic regional pain syndromes, *CI* confidence interval

(biomedical and traditional), as well as types of work and the concept of cultural affiliation.

Multicultural countries such as the ones found in Latin America need to have instruments validated for each indigenous community in order to obtain reliable and comparable measurements across populations. Furthermore, there is little evidence that different methods have similar results, as this has been tested only empirically on a very limited scale. Further research is needed for this assumption to be accepted [13, 19]. As a prelude to conducting an epidemiological study on indigenous populations, it is necessary to validate the performance of the COPCORD methodology, found to have good performance in detecting rheumatic diseases in Mestizo populations [20], as a screening test.

Final comments

One major aspect in the adaptation of the CCQ was the replacement of VAS with a simpler Likert scale with three or four response options. In reviewing the literature of COPCORD methodology, we found that there were only two fully documented studies where the VAS was replaced by a Likert scale, one with five response options [37] and the other with four options [15], but neither article discussed this change. It is important to take into account these psychometric assessments as they may limit the comparability between study populations.

Another important finding was the lack of conceptual distinction between severity and intensity in the original CCQ instrument. The respondents claimed that intense pain was also severe, and therefore, one needed to seek medical treatment in either case.

The concept of "cross-cultural adaptation" is used to encompass a process that considers both language (translation) and cultural adaptation issues in the process of preparing a questionnaire for use in another setting [14]. This methodology does not delve too deeply into the implications of the cultural adaptation. Rather than simple adaptation of a questionnaire, we believe that a community actively changes over time, so we propose that the initial phase should include qualitative methodology allowing for changes, suggestions, and new contributions from the group that can be systematically incorporated into the assessments. We suggest that the concept of "culturally sensitive adaptation" be used for this type of validation adaptation.

Limitations

Test–retest validation could not be performed due to the difficulty involved in performing a second measurement in less than 7 days, remoteness of the populations, and limited human and economic resources.

Conclusions

The COPCORD questionnaire is valid for use in indigenous population, provided that certain adjustments are made such as use of a simplified pain intensity scale as suggested by each population and verbal administration by bilingual health facilitators in communities where the language lacks a written format. The questionnaire was found to have a good performance as a screening test for detecting rheumatologic diseases in the community.

Acknowledgments *Venezuela:* We thank Gean Carlos Martinez (indigenous teacher), Dr. Celenia Rosillo, "Barrio adentro" Health program and Dr. Libya Cabello, Regional Director of Health, State of Monagas, Venezuela, for their technical support in the fieldwork. *Argentina:* Special thanks to Dr. Miguel Angel Cappiello, Ministry of Heath of the Santa Fé Province, Argentina, for his continuous support for the project. We would also like to thank Dr. Lelio Mangiaterra, statistician Alicia Aronna, and other authorities of the Public Health Secretary of the Municipality of Rosario, Santa Fe, Argentina; Dr. Marcela Nuccitelli and Dr. Gustavo Englander, Coordinators of "Nodo Rosario"; Dr. Esteban Ferrandini, Ignacio Gomez, Emilce Beletti and Eduardo Martinez, coordinators of Health District, Rosario, Santa Fe, Argentina; Professor Raul Britos, Dr. Guillermo Marconi, Ricardo Fernandez and Hugo Gordillo, Provincial Directorate of Original (native) Peoples and Equity and Ministry of Social

Development of Santa Fe Province, Argentina; the team of the Primary Health Care Centers: Juana Azurduy and Juan B. Justo, Municipality of Rosario, and Caritas Guadalupe, Toba Nº 47 and Paulo VI, Santa Fe Province; Dr. Carlos Crisci and Dr. Damian Vercenazi, Faculty of Medical Sciences, National University of Rosario, Santa Fe, Argentina; Cecilia Aguado, Israel Albertario, Verónica Cattaneo, Luciano Heredia, medical students, Faculty of Medical Sciences, National University of Rosario, Santa Fe, Argentina; Dr. Julieta Milanesio and Dr. Mariano Palatnik, Hospital Provincial del Centenario, Rosario, Santa Fe, Argentina; Dr. Guillermo A. Berbotto, Hospital Eva Perón, Granadero Baigorria, Santa Fe, Argentina; the Qom Community Center: QADHUOQTÉ, Barrio Los Pumitas, Rosario, Santa Fé, Argentina, and its president Ernesto Oscar Talero; the translators and cultural facilitators: Ana Maria Jerez, Ana Medina, Ezequiel Alvarez, Gertrudis Lazaro, Mirian Alonso, Hector Lopez and Ronaldo Sanchez; the data entry assistants: Antonella Vanucci, Leonardo Grasso and Jorge Melchiori; Maria Cecilia Caffaratti, anthropologist and Vanina García Bianco, psychologist. *Mexico:* We thank Diego Yeh Cen (Community facilitator of Chakom, Yucatán), Maria Lizbeth Escudero, Veronica Hernandez (Health Research assistant, Mexico City) and Mexican College of Rheumatology, Mexico. Ministry of Health of Santa Fe Province, Argentina (by resolution 0127/08 Feb, 2011) and Public Health Secretary, Municipality of Rosario, Rosario, Santa Fe, Argentina. This study was supported by the National Council for Science and Technology and Ministry of Health (Health CONACYT-2007-C01-162154) (Mexico).

Conflict of interest The authors have no conflicts of interest to disclose.

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