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Brazilian Portuguese version and content validity of the Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH)

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Abstract

Introduction The Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) program is a personalized, progressive 12-week exercise program for people with hand problems due to rheumatoid arthritis (RA). Patients are provided with two guidance documents, the 'Patient Exercise Booklet' and the 'Personal Exercise Guide', to continue the exercises independently at home.

Objective This study aimed to translate and culturally adapt the SARAH protocol into Brazilian Portuguese and validate its content.

Methods The guidance documents 'Patient Exercise Booklet' and 'Personal Exercise Guide' of the SARAH program were translated and culturally adapted to Brazilian Portuguese. The content validity was obtained by calculating the content validity index (CVI).

Results The Brazilian version of the SARAH protocol reached semantic, idiomatic, conceptual, and cultural equivalences. The CVI was greater than 0.8, corresponding to a satisfactory index. The verbal comprehension was 4.9, showing good verbal comprehension of the target population.

Conclusion The Brazilian Portuguese version of the SARAH protocol is available to Brazilian people with compromised hands due to RA with satisfactory content validity.

Keywords Cross-cultural study, Translation, Rheumatoid arthritis, Hand, Strengthening, Stretching

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Introduction

Rheumatoid Arthritis (RA) is an inflammatory, systemic autoimmune, and chronic disease affecting approximately 0.2 to 1% of individuals [1, 2] with an average annual incidence of 13.4/100.000 inhabitants in Brazil [3]. Most of the people with RA present hand involvement, resulting in functional disability and impairment in daily life activities [4, 5] due to stiffness, swelling, pain, deformity, limitation of the range of motion, and muscle weakness [6]. A recent systematic review showed that modifiable factors such as grip strength, disease activity, and pain are the most influential factors on hand function in people with RA [7]. Functional disability reduces their capacity to work, taking to a significant economic impact. In Brazil, the total annual direct cost was approximately one million US dollars, or slightly less than ten thousand US dollars per patient/year [8] (that is mostly absorbable by the Brazilian robust public health system), while the estimated indirect cost was US\$ 466,107.81 or US\$ 2,423.51 per patient/year for this population. [9]

Despite new drug advances and targeted medical treatment, hand function problems for people with RA persist [10, 11]. Exercises aim to improve both the mobility and strength of the hand and therefore improve functional ability. Systematic reviews have concluded that hand exercises may positively affect the strength and aspects of daily functioning without aggravating disease activity or pain [12, 13]. Home hand exercise programs effectively improve hand function, grip strength, and pain in RA. High-intensity resistance exercise programs taught by therapists over at least several sessions, including strategies to promote long-term adherence, seem to be most effective and are cost-effective [14].

The Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) program, recommended by the UK National Institute for Health and Care Excellence (NICE) guidelines [15], is a tailored, progressive 12-week exercise program for people with hand problems due to RA. The SARAH program includes 7 upper limb mobility exercises and 4 strength exercises for the hand against resistance provided by bands, balls, or therapeutic putty. Exercise regimen (intensity and volume) are modified according to patient's response. The program includes six sessions of face-to-face contact with a physiotherapist or occupational therapist. Patients are encouraged to continue the exercises independently and daily at home. They are provided with a discharge advice sheet, exercise booklet, and copies of exercise diary, personal exercise guide, and barriers and facilitators form during their final clinical appointment. [16–18]

The SARAH program has been safe, cost-effective, and effective in improving overall hand function and self-efficacy compared to the control group [18, 19]. Hall et al.

demonstrated that the effect of the SARAH intervention is due in part to physical factors, specifically grip strength [20]. Although participants who perform the SARAH exercise program improved hand function compared to baseline >2 years after randomization, there were no statistical differences between groups, indicating that the program effect decreased over time. This reduction in hand function compared to previous follow-up points coincided with decreased self-reported hand exercise performance, highlighting the importance of supporting RA patients to maintain regular exercise [21]. In the English language, there is also a web-based training program (iSARAH) [22] and an online version (mySARAH) [23, 24] of the SARAH program.

However, the SARAH protocol is still not accessible to the Brazilian population since it is neither translated nor validated to Brazilian Portuguese. Thus, this study aimed to translate and culturally adapt the SARAH exercises protocol into Brazilian Portuguese and perform content validation.

Methods

After obtaining formal authorization from the SARAH authors, the documents 'Patient Exercise Booklet' and 'Personal Exercise Guide' were translated and culturally adapted to Brazilian Portuguese. Finally, we obtained the content validity by calculating the content validity index (CVI).

The study protocol was approved by the Federal University of Juiz de Fora ethics committee (CAAE: 07,888,819.4.0000.5147), and all procedures followed the principles of the Declaration of Helsinki. The participants received information about the study objectives and agreed to participate by signing an informed consent form voluntarily.

Translation and cross-cultural adaptation

The research team performed the translation and cross-cultural adaptation of the guidance documents according to procedures recommended by Beaton et al. [25]. Although this guideline is for self-report measures it was used to guarantee a comprehensible version of SARAH exercise program for the Brazilian population.

Initial translation of the SARAH documents into Brazilian Portuguese was performed by two independent Brazilian native speakers: an experienced physiotherapist familiar with the concepts assessed by the protocol and an English teacher with no medical background. Each of the translators produced a written report of the translation.

The translators synthesized the two versions, discussing the choice of some terms and solving out the discrepancies. Then, a written report was produced, documenting the synthesis process.

Two other translators performed the back-translation independently. The translators are savvy language professionals with proficiency in the Brazilian Portuguese and English language, without any knowledge of the concepts assessed by the protocol. Once again, the back-translators each produced a written report of the back-translation.

All the documents produced (i.e., reports, translations, synthesis of translations, and back-translations) were sent to a committee composed of five professionals (four physical therapists and one physical educator) experts in translation and cross-cultural adaptation and experienced in rheumatoid arthritis management and treatment. The committee gathered to qualitatively assess the semantic (vocabulary and grammar), idiomatic (expressions' meanings), cultural (capability to adapt to the context and culture of the target population), and conceptual (maintenance of the original instrument's concept) equivalences among documents. After discussion, the researchers consolidated a preliminary version of the SARAH protocol.

A pre-test was performed on 30 women with RA diagnosis recruited on social networks by posts on groups to assess verbal comprehension by the target population. The eligibility criteria were: women or men; age between 18 and 75 years; with RA diagnosis. RA was defined by a self-reported diagnosis and by the American College of Rheumatology criteria, as recommended by the Brazilian Society of Rheumatology [26]. The people who had Minimal Mental State Examination score under than 24 points were not eligible for this study.

All assessments were performed by videoconference, using a multiplatform instant messaging and voice calling app for smartphones. There were registered the socio-demographic and hands' function data (using the Disabilities of the Arm, Shoulder and Hand questionnaire) of each participant. The Disabilities of the Arm, Shoulder and Hand questionnaire comprises 30 items (two items assess physical function, six items assess symptoms and three the social function) that were idealized to measure upper limbs' physical disability and symptoms [27]. The participants rated their ability to perform the activities described in each item using a 5-point Likert scale in the last week. The total Disabilities of the Arm, Shoulder and Hand questionnaire score was calculated by summing the scores of the 30 items, subtracting 30 from the total, and dividing it by 1.2. Total scores range from 0 (no dysfunction) to 100 (severe dysfunction) [28]. After reading the exercises and items by the evaluator, all participants rated their understanding and awareness of each exercise. An ordinal score ranging from 0 ("I did not understand") to 5 ("I understood perfectly, and I have no doubts") was used to assess the verbal comprehension of the SARAH protocol. Values below three were considered insufficient for

oral understanding. Participants were also asked to identify words, items, or sentences they considered unusual in their language.

Content validity

The content validity was performed using a scale scored from 1 to 4, in which 1 corresponds to "It is not clear" and 4 to "It is clear, and I do not have doubts". The content validity index (CVI) was used to assess concordance proportions between the five experts. The CVI is calculated by dividing the number of items marked "3" or "4" by the total items. Those that received a score of "1" or "2" must be reviewed or eliminated. Values above 0.80 were considered acceptable [29].

We shared all the documents produced during the translation and cross-cultural adaptation processes with the SARAH protocol authors. SARAH creators approved the Brazilian Portuguese version and made it available on the website (<https://www.ndorms.ox.ac.uk/research/research-groups/centre-for-rehabilitation-research-in-oxford/resources/translations-of-sarah-programme-materials#brazilian-portugese>).

Results

Translation and cross-cultural adaptation

The cross-cultural adaptation involved modifications to the exercise protocol descriptions to achieve clarity and ensure participants' understanding. These modifications included the translation of technical terms into literal forms and removing ambiguous expressions.

(a) Patient exercise booklet

On the first exercise of the Patient Exercise Booklet, the expression "knuckle bends" was first translated into "flexão dos 'nós' dos dedos", but the specialists agreed on changing it to "flexão das articulações dos dedos das mãos".

On the fourth exercise, the expression "move your hand in a circle", initially translated as "mova sua mão em um círculo", was altered to "gire suas mãos em círculos" after experts' consensus.

On the sixth exercise, the expression "wrist backward bends", translated as "flexão invertida (para trás) de punho", was replaced for "flexões para trás de punhos" after experts' analyses.

Furthermore, the experts adopted the verbal expression 'as much as comfortably possible' into "o máximo possível, de modo confortável" throughout the document.

Lastly, despite the translation into Brazilian Portuguese, the acronym "SARAH" was maintained in the title to facilitate protocol recognition.

(b) Personal exercise guide

The expression ‘My specific exercise goal’, initially translated into “Meu objetivo de exercício específico”, was changed to “Meu objetivo específico com o exercício”.

The sentence ‘Review: If none of the above has changed since the last session, review the form again along with the Exercise Diary, re-check their goals and confidence level, and go through their action plans for the programme and Exercise Diary completion. Re-read through the Patient and Practitioner statements above and then re-sign below. If any part changes OR NEEDS TO CHANGE, you must fill out a new sheet.’ translated into “Revisão: Se nada acima tiver se modificado desde a última sessão, revise o formulário novamente juntamente com o Diário de Exercício verifique novamente os objetivos e nível de confiança dos pacientes e repasse seus planos de ação para o programa e o preenchimento do Diário de Exercício. Releia os compromissos do Paciente e do Profissional acima e então assine abaixo. Se qualquer parte acima se modificar OU NECESSITAR SER MODIFICADA, você deverá preencher um novo formulário.” was changed to “Se nenhum dos itens acima foi alterado desde a última sessão, revise o formulário novamente junto com o Diário de Exercício. Verifique novamente os objetivos e o nível de confiança e repasse seus planos de ação para o programa e preencha o Diário de Exercício. Releia os compromissos do Paciente e do Profissional acima e então assine abaixo. Se qualquer parte acima

Table 1 Demographic and clinical characteristics of patients that participated in the pre-test

Variable	Value
Age (y)	47 ± 11
Female (%)	100
Time of diagnosis (m)	109 ± 117
Scholarship level (%)	
Incomplete elementary school level	10
Incomplete high school level	3.3
Complete high school level	20
Incomplete undergraduate level	6.7
Complete undergraduate level	60
Self-related health status (%)	
Very good	6.7
Good	16.7
Regular	43.3
Poor	6.7
Very poor	26.7
DASH score	49.1 ± 19.3

DASH = Disabilities of the arm, shoulder and hand

Table 2 Verbal comprehension assessment of the patient exercise booklet and personal exercise guide by women with RA

	Patient exercise booklet		Personal exercise guide	
	Verbal comprehension (n = 30)*		Verbal comprehension (n = 30)*	
Exercise 1	4.9 ± 0.4	Item 1	4.9 ± 0.4	
Exercise 2	5 ± 0	Item 2	4.9 ± 0.4	
Exercise 3	4.8 ± 0.7	Item 3	5 ± 0	
Exercise 4	4.8 ± 0.6	Item 4	5 ± 0	
Exercise 5	5 ± 0.2	Item 5	5 ± 0	
Exercise 6	4.6 ± 0.8	Item 6	5 ± 0	
Exercise 7	5 ± 0	Item 7	5 ± 0	
Exercise 8	4.9 ± 0.4	Item 8	5 ± 0	
Exercise 9	5 ± 0	Item 9	5 ± 0	
Exercise 10	5 ± 0	–	–	
Exercise 11	5 ± 0	–	–	
Total	4.9 ± 0.1	Total	4.9 ± 0.2	

*Assessment scale ranging from 0 to 5; Variables are presented in mean ± standard deviation.

se modificar OU NECESSITAR MODIFICAÇÃO, você deverá preencher um novo formulário.”

Finally, the term ‘meeting’, initially translated into ‘consulta’, was changed by the specialists to “encontro” throughout the document since the term “consulta” is the Brazilian Portuguese form for ‘appointment’.

(c) Pre-test

Thirty women aged 30 to 74 years old with RA diagnosis participated in the pre-test. Disease duration ranged

Table 3 Individual and total content validity indexes for the patient exercise booklet and the personal exercise guide

	Patient exercise booklet		Personal exercise guide	
	Individual CVI		Individual CVI	
Exercise 1	0.6	Item 1	1.0	
Exercise 2	1.0	Item 2	0.8	
Exercise 3	1.0	Item 3	0.8	
Exercise 4	0.6	Item 4	1.0	
Exercise 5	1.0	Item 5	1.0	
Exercise 6	0.6	Item 6	1.0	
Exercise 7	0.8	Item 7	1.0	
Exercise 8	0.8	Item 8	1.0	
Exercise 9	0.8	Item 9	1.0	
Exercise 10	1.0	–	–	
Exercise 11	1.0	–	–	
Total CVI	0.8	Total CVI	1.0	

CVI: content validity index.

from 3 months to 37 years. Most women (60%) reported an undergraduate level and 43% self-related their health status as regular (Table 1).

Both Patient Exercise Booklet and Personal Exercise Guide showed good verbal comprehension by women with RA, with an average score of 4.9 (maximum of 5) (Table 2).

Content Validity

(a) Patient exercise booklet

The individual content validity index (CVI) and the total CVI were used to rate each exercise or item and the protocol's content validity. Exercises 2, 3, 5, 7, 8, 9, 10, and 11 reached sufficient clarity, with a CVI above 0.8 [16] (Table 3). The experts discussed exercises 1, 4, and 6 until total agreement was reached (CVI = 1.0) (Table 3).

(b) Patient exercise guide

All items reached sufficient clarity (Table 3).

Discussion

Concerning the review by an expert committee stage, the specialists made modifications during the meetings to reach clarity, semantic, idiomatic, cultural and conceptual equivalences between the original and the target instruments. Beaton et al. (2020) highlighted that achieving good content validity increases confidence that the impact of a protocol is described similarly in multinational trials or outcome evaluations. [25]

The CVI showed an adequate level of concordance between experts, which means content validity. Moreover, the documents showed an appropriate verbal comprehension by the women with RA, suggesting that the translation and cultural adaptation reached semantic equivalence and made the Patient Exercise Booklet and the Personal Exercise Guide accessible to people with RA of different ages and education levels.

During the cross-cultural adaptation, the authors choose not to change the acronym SARAH to facilitate the recognition of the protocol by all the academic community, the clinical physical therapists, and people with RA.

Hand impairments and activity limitations remain a significant problem for people with RA, even if they are using disease-modifying anti-rheumatic drugs (DMARDs) and biological treatments [30]. Besides, hand problems exacerbate progressively even in patients in remission or with low disease activity [31]. In addition to

the disease activity and pain, grip strength is one of the modifiable factors that most influence hand function in people with RA [7], which can be increased with hand exercises. [12–14]

Although RA patients demonstrate awareness of the advantages of exercise for their joints, they also perceive that health professionals lack certainty and clarity regarding specific exercise recommendations and the occurrence of joint damage [32]. However, interviewees of the qualitative study did not express these concerns regarding the SARAH exercise program [18]. In addition to the SARAH protocol being effective and safe [18–21], the program is well structured, providing sufficient guidance to patients to perform the exercises independently and daily at home.

Future randomized controlled trials in the Brazilian population with RA presenting involvement in the hands should be carried out to test the effectiveness of the SARAH program and the adherence of patients to this type of exercise program.

Conclusion

The Brazilian Portuguese version of the SARAH protocol reached semantic, idiomatic, conceptual, and cultural equivalences, a suitable content validity, and high verbal comprehension by the target population. In this sense, it is ready to be used by rehabilitation professionals and people with compromised hands due to RA.

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Author contributions

RQC, PHBC, GLRM, and LF conceived the article. Data acquisition, analysis and/or interpretation: RQC, LVB, PHBC, CMC, DSF and LF. Draft and revision of the work: RQC, LVB, PHBC, DSF, STM, CMC, GLRM, and LF. All authors approved the final version of the manuscript.

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Availability of data and materials

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethical approval and consent to participate

The study protocol was approved by the Federal University of Juiz de Fora ethics committee (CAAE: 07888819.4.0000.5147), and all procedures followed the principles of the Declaration of Helsinki. The participants received information about the study objectives and agreed to participate by signing an informed consent form voluntarily.

Consent for publication

Not applicable.

Conflict of interests

The authors declare that there is no conflict of interest.

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