Brazil Patient Knowledge Questionnaire (PKQ)
and evaluation of disease-specific knowledge in patients
with rheumatoid arthritis

F. Jennings, S. Toffolo, M.R. de Assis, J. Natour

Division of Rheumatology, Federal University of São Paulo (UNIFESP), São Paulo, SP, Brazil.

Abstract

Objective

To create a Brazilian version of the Patient Knowledge Questionnaire – PKQ, an instrument for measuring the
knowledge of patients with rheumatoid arthritis (RA) as regards their disease, and through the use of this instru-
ment, also measure the knowledge of RA patients from reference hospitals in the city of São Paulo.

Methods

Two teachers of English translated the PKQ into Portuguese in order to obtain a single version, which was then
translated back into English to evaluate its equivalence to the original version (back translation). The final version
in Portuguese was applied to 20 patients with RA for adaptation to cultural issues, and questions not understood by
20% or more patients were subsequently modified. Inter- and intraobserver reliability and the constructive validity
of the PKQ were tested. The questionnaire was then applied to 100 RA patients, selected in four outpatient clinics at
reference hospitals in the city of São Paulo.

Results

Three of the PKQ questions were modified to adapt to cultural issues. Intraclass correlation coefficients used for the
reliability and validity of the PKQ were between were between 0.62 and 0.94, therefore, statistically significant
(p< 0.05). The mean PKQ score was 12.96 and the mean test application time was 10.3 minutes, for the 100
patients assessed. The lowest scores were observed in the domains of medications and joint protection/energy
conservation. PKQ scores showed a positive correlation with the level of education (r=0.40) and a negative
correlation with the patients’ age (r= -0.32) and with HAQ (r= -0.28).

Conclusions

The Brazilian version of the PKQ that was created and proved to be a reliable and valid instrument. Patients’
knowledge of RA is poor, particularly in the domains regarding medications and joint protection/energy
conservation.

Key words

Rheumatoid arthritis, patient’s knowledge, questionnaire, education.
Introduction
Patient education comprises any series of educational activities planned and designed to improve patients’ health behaviours, and thus improve their health status with long-term results. It is an adjuvant to standard treatment and consists in persuading the patient to increase compliance and to adopt attitudes that will benefit their condition. Educational groups represent the most common and least expensive means of providing patient education. (1).

Rheumatoid arthritis is a chronic disease characterized by its uncertain evolution and unpredictable course of exacerbation and remission. Clinical interventions may alleviate but do not eliminate its effects, and for many patients, the pain, disability, deformity, and poor quality of life persist despite treatment. (2).

The treatment of rheumatoid arthritis is usually a combination of drugs, with rest and exercises. Patients must learn to adjust their daily routines to the phases of the disease. Patient education may help them to organize the treatment regimens and to acquire the abilities necessary for self-management of the consequences of the disease (3).

Adopting consistent instruments to measure how much they know about arthritis can enhance patient education. These instruments can, for instance, help educators to identify subjects who are particularly in need of educational intervention. They also contribute because they are valid and reliable methods to evaluate the efficacy of educational programs. Health educators understand the need for such tests and have started developing instruments for measuring the arthritis-related knowledge(4).

Currently available instruments for the assessment of specific knowledge about rheumatoid arthritis were developed by Vignos et al. (5), Lorish et al. (6), Hill et al. (7), Edworthy et al. (4), Lineker et al. (8). Of these, the one most often used by other authors (9-11) was the questionnaire created by Hill et al. (7), the Patient Knowledge Questionnaire (PKQ).

The PKQ is a consistent and reliable instrument to evaluate the knowledge patients with RA have about their disease. It is a self-administered questionnaire with 16 multiple-choice questions covering the following topics: a) general knowledge, including etiology, symptoms, and laboratory tests; b) medications and their use; c) exercises; d) joint protection and energy conservation. Each question may have one, two, or three correct options and all questions include the alternative “don’t know”, to minimize the effect of a patient’s wish to deny the lack of knowledge. The total score is 30 correct responses, out of a maximum of 80 possible responses, and the questionnaire can be applied easily and quickly (7).

The purpose of this study is to translate the PKQ into Portuguese, adapt it to the culture and test its reliability and validity for use with Brazilian populations. It also intends to evaluate the level of disease-specific knowledge of patients with rheumatoid arthritis by using the Brazilian version of the PKQ.

Patients and methods
The study was conducted in two stages. The first included the translation into Portuguese, the cultural adaptation, and testing the reliability and validity of the PKQ for use with the Brazilian population. Patients classified as having rheumatoid arthritis in accordance with American College of Rheumatology criteria (12), with ages between 18 and 60 years were interviewed and selected consecutively at the outpatient clinic of the Division of Rheumatology of the Federal University of São Paulo (UNIFESP). During the second step, the Brazilian version of the questionnaire was applied to RA patients under follow-up in the outpatient clinic of four reference hospitals in the city of São Paulo, in order to assess the knowledge these patients had about their disease.

Before applying the questionnaires, the clinical and demographic data were collected and the Brazilian-portuguese version of Health Assessment Questionnaire (HAQ) was interviewer-administered (13). Also, the Steinbrocher functional class was defined. In all stages, the questionnaires were
administered by interviewers because the level of education of our patients is not sufficient to enable them to answer self-administered questionnaires. The subjects’ written consent was obtained according to the Declaration of Helsinki and the design of the study was approved by The Ethical Committee of the Federal University of Sao Paulo.

**Translation and cultural adaptation**
This stage followed the systematization proposed by Guillemin et al. (14, 15) . Two teachers of English working independently from one another performed the translation, resulting in two versions of the questionnaire in Portuguese. In order to obtain the final version (V1), a comparison of the two translations was made by a group composed by two rheumatologists and one physiatrist proficient in the English language. The consensual Portuguese translation (V1) was again translated into English (back translation) by two different teachers of English who had not seen the original version in this language. A single English version (V2) was constructed based on these two new versions, which was then compared to the original version in English for equivalence. The same two rheumatologists and one physiatrist who evaluated the previous phase of the version, in addition to one teacher of English, performed the evaluation of V2. When compared to the original version, this new version in English proved to be semantically and grammatically equivalent, and thus, V1 was accepted as the final version in Portuguese.

The final Portuguese version of the questionnaire was applied to 20 patients with diagnosis of RA. The questionnaire was applied 3 times, the first two, by 2 different observers (interobserver evaluation) on the same day, and the third after a period of 7 to 14 days by one of the observers already mentioned (intraobserver evaluation). The construct validity of the PKQ was assessed interviewing 30 patients 20 of whom belonged to the same group evaluated for reproducibility, plus 10 other patients. During this step, in addition to the PKQ, another questionnaire on the knowledge of the disease was applied. This questionnaire consisted of 10 objective questions (with “right” or “wrong” answers) formulated by two rheumatologists, and covering the same topics included in the PKQ and with scores from 0 to 10.

**Applying the questionnaire (PKQ) to evaluate the knowledge about the disease**
After translation and validation, the questionnaire was applied to RA patients in specialized outpatient clinics from another three reference hospitals in the city of Sao Paulo: Hospital das Clínicas de São Paulo, Hospital Heliópolis and Hospital do Servidor Público Estadual. One hundred patients were interviewed, 25 from each hospital.

### Results
Questions 4 (options “d” and “e”), 7 (options “a” and “e”), and 9 (option “d”), which refer to laboratory exams, disease-modifying drugs, and exercises, respectively, were considered “not applicable” by more than 20% of the patients. After the modifications, the questions were applied to another group of 20 patients with rheumatoid arthritis, and were then considered applicable by 90% of the patients.

<table>
<thead>
<tr>
<th>PKQ Components</th>
<th>Mean (SD)</th>
<th>Coefficients</th>
<th>ICC</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Obs1</td>
<td>Obs2</td>
<td>ICC</td>
<td></td>
</tr>
<tr>
<td>Ethiology, symptoms, and laboratory exams</td>
<td>4.15 (1.95)</td>
<td>4.05 (1.99)</td>
<td>0.80**</td>
<td>(0.50-0.92)</td>
</tr>
<tr>
<td>Medications</td>
<td>2.85 (1.14)</td>
<td>2.8 (0.95)</td>
<td>0.62*</td>
<td>(0.04-0.85)</td>
</tr>
<tr>
<td>Exercises</td>
<td>3.5 (1.0)</td>
<td>3.55 (0.99)</td>
<td>0.90**</td>
<td>(0.74-0.96)</td>
</tr>
<tr>
<td>Joint protection and energy conservation</td>
<td>2.7 (1.3)</td>
<td>2.5 (1.32)</td>
<td>0.92**</td>
<td>(0.81-0.97)</td>
</tr>
<tr>
<td>Total PKQ score</td>
<td>13.15 (4.07)</td>
<td>12.95 (3.77)</td>
<td>0.94**</td>
<td>(0.85-0.98)</td>
</tr>
</tbody>
</table>

SD: Standard deviation; ICC: Intraclass correlation coefficient; 95% CI: 95% confidence interval; *Obs 1: initial observation; †Obs 2: observation conducted on the same day of the initial observation by a different interviewer.

\( p < 0.05 \)

\[ p < 0.01 \]
Knowledge Questionnaire” (PKQ), after verification of its cultural equivalence, is in the appendix.

**Evaluation of the measuring properties of the PKQ**

Twenty patients with rheumatoid arthritis were included in the assessment of reliability of the Brazilian version of the PKQ. This group had a mean age of 48.45 years and was comprised mainly of female patients. The mean level of education was 5.15 complete years of school and the mean PKQ score in the initial evaluation was 13.15. As regards functional class, the majority (65%) belonged to class 1.

The intraclass correlation coefficients for interobserver reliability, 0.62 to 0.94, were considered statistically significant (p < 0.05). These results can be found in Table I, which also shows the means (standard deviations) of the two observers for each component and for the total PKQ score.

Table II shows the evaluation of intraobserver reliability using the means (standard deviations) for each component and the total PKQ score. The intraclass correlation coefficients ranged from 0.76 to 0.90. In addition to such coefficients of correlation, the intraclass coefficients of correlation ranged from 0.76 to 0.90. Therefore, statistically significant (p < 0.01) and highly reliable.

**Construct validation was evaluated through the correlation of scores between PKQ and the 10-question “right” or “wrong” response questionnaire. The intraclass correlation coefficient was 0.66, therefore, statistically significant (p < 0.01).**

**Evaluation of the knowledge of RA patients from reference hospitals in the city of São Paulo**

The clinical and demographical characteristics of the 100 RA patients interviewed at the outpatient clinic of 4 different hospitals in the city of São Paulo are shown in Table III.

The mean PKQ score was 12.96 from a possible maximum of 30, scores ranging from 2 a 22. The mean time for applying the questionnaire was 10.31 minutes (7 to 17 minutes).

For the initial part of the questionnaire related to general aspects of RA, including etiology, symptoms, and laboratory tests, the mean score was 4.2 (maximum score = 9). The second component of the questionnaire covers conditions related to the disease. Out of a maximum score of 7, the mean score achieved by the patients was 2.8. The third component refers to exercises and the mean score was 3.5 (maximum score = 7).

The last component covers joint protection and energy conservation, with a maximum score of 7. The mean for the population studied was 2.5.

As regards general knowledge of RA, 38% of patients answered that the cause of the disease was unknown and only 17% believed bacteria or virus could trigger it. Forty-six patients (46%) believed cold or damp weather could cause the disease. Seventy-two subjects (72%) knew RA could be a long-term disease and only 4% believed the disease could be curable.

The patients correctly identified fatigue (59%), anemia (49%) and nodules (28%), as common symptoms of RA. As regards laboratory testing, patients knew that complete blood cell count (69%) and erythrocyte sedimentation rate - ESR (56%) are associated with activity of the disease. Thirty-one (31%) did not know that laboratory testing is used to evaluate their disease. In the section regarding medications, the majority (67%) was aware that non-steroidal anti-inflammatory drugs (NSAIDs) are used to relieve the pain, swelling and stiffness. Erroneously, 19% believed NSAIDs could stop disease progression.

Although 42% answered NSAIDs should be taken with food to reduce dyspeptic symptoms, the most commonly reported side effect was dry mouth (35%) and not indigestion (28%).

The majority (68%) of patients answered methotrexate was a disease-modifying drug that could cause remission of the disease. Yet, diclofenac and indomethacin were also mentioned by 32% and 17%, respectively, as being disease-modifying drugs. As regards analgesics, 58% of the individuals thought they should be taken only for severe pain.

Seventy per cent of patients believed that exercise could reduce the chance of a joint deforming. However, 36% answered that exercises were not necessary if they led a normally active life. Walking was the most frequent exercise (87%) mentioned by the patients as beneficial for RA, followed by muscle tightening exercises (35%).

Again regarding exercises, the majority (54%) of patients replied that they should perform their exercises according to their usual flexibility if their joints were painful or stiff. Twenty-five per cent (25%) said they would stay in bed most of the day and 10 (10%) said they preferred not to do any exercises at all.

---

**Table II. Intraobserver reliability using intraclass correlation coefficient (ICC) showing the means (standard deviation) of both observations for each PKQ component, in 20 patients with RA.**

<table>
<thead>
<tr>
<th>PKQ Components</th>
<th>Mean (SD)</th>
<th>Coefficients</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Obs1a§</td>
<td>Obs 1b§</td>
<td>ICC</td>
</tr>
<tr>
<td>Etiology, symptoms, and laboratory exams</td>
<td>4.15 (1.93)</td>
<td>4.85 (1.75)</td>
<td>0.77</td>
</tr>
<tr>
<td>Medications</td>
<td>2.85 (1.14)</td>
<td>3.1 (1.17)</td>
<td>0.76</td>
</tr>
<tr>
<td>Exercises</td>
<td>3.5 (1.0)</td>
<td>3.66 (0.87)</td>
<td>0.81*</td>
</tr>
<tr>
<td>Joint protection and energy conservation</td>
<td>2.7 (1.3)</td>
<td>3.29 (1.06)</td>
<td>0.88*</td>
</tr>
<tr>
<td>Total PKQ score</td>
<td>13.15 (4.07)</td>
<td>14.8 (3.52)</td>
<td>0.90*</td>
</tr>
</tbody>
</table>

SD: standard deviation; ICC: Intraclass coefficient of correlation; 95% CI: 95% confidence interval; *Obs 1a: Initial observation; Obs 1b: observation conducted by the same interviewer, who conducted the observation 7 to 14 days after the initial observation; p < 0.01.
As regards joint protection, 55 patients said that when they had an inflamed wrist, they exercised the wrist several times a day to preserve flexibility. Thirty-two (32%) said they would wear splints on their wrist. Yet, 46% erroneously said they would avoid any movement by keeping their wrist in the same position most of the time. Sliding objects rather than lifting them and using larger joints rather than smaller joints were options correctly identified by 58% and 18% of patients, respectively, as methods of joint protection. Patients also correctly replied that they would use the palm of their hands rather than their fingers to open jars (47%) and having power assisted steering on their car (13%), as ways of protecting their joints. However, patients erroneously reported as methods of joint protection: acting as if their arthritis was non-existent (33%); grip objects tightly (51%); and applying heat or ice to the joints (34%). Forty-eight patients said they conserved their energy by doing only what was necessary if they felt tired but 32% said they would take a short rest and then do all things they had planned. Fifty-two (52%) individuals correctly identified balancing periods of work and rest, and 20%, sitting while ironing, as energy conservation strategies. However, 84% said carrying objects with both hands would be a method of conserving energy. Spearman's correlation coefficient was used to determine the correlation of PKQ scores with the other clinical-demographical variables. PKQ showed statistically significant correlation with the following variables: age of patients, negative correlation (r = -0.32); education, positive correlation (r= 0.40); and HAQ, negative correlation (r = -0.28).

Table III. Clinical and demographical characteristics of 100 patients with rheumatoid arthritis included in the evaluation of disease-specific knowledge in 4 reference hospitals in the city of São Paulo.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years)</td>
<td>47.53</td>
</tr>
<tr>
<td>Sex: females and males</td>
<td>87.13</td>
</tr>
<tr>
<td>Race: caucasoids and non-caucasoids</td>
<td>32.68</td>
</tr>
<tr>
<td>Duration of disease in years mean (SD)</td>
<td>11.78 (7.04)</td>
</tr>
<tr>
<td>Time since diagnosis in years mean (SD)</td>
<td>10.03 (6.14)</td>
</tr>
<tr>
<td>Education - complete years of formal education mean (SD)</td>
<td>6.4 (4.35)</td>
</tr>
<tr>
<td>HAQ score mean (SD)</td>
<td>1.09 (0.07)</td>
</tr>
</tbody>
</table>

Function class:
- class 1: 64 (64%)
- class 2: 31 (31%)
- class 3: 4 (4%)
- class 4: 1 (1%)

PKQ score mean (SD): 12.96 (4.37)

Time (minutes) to apply the PKQ mean (SD): 10.31 (1.9)

SD = standard deviation.

Table IV. Clinical and demographical variables of 100 patients with RA from 4 reference hospitals in the city of São Paulo.

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex: males and females</td>
<td>5.20</td>
<td>3.22</td>
<td>1.24</td>
<td>4.21</td>
<td>0.38</td>
</tr>
<tr>
<td>Race: caucasoid and non-caucasoid</td>
<td>8.17</td>
<td>3.22</td>
<td>11.14</td>
<td>10.15</td>
<td>0.07</td>
</tr>
<tr>
<td>Age in years mean (SD)</td>
<td>48.56 (7.69)</td>
<td>47.16 (8.72)</td>
<td>45.44 (7.12)</td>
<td>48.96 (8.48)</td>
<td>0.26</td>
</tr>
<tr>
<td>Education - complete years of formal education mean (SD)</td>
<td>5.12 (2.76)</td>
<td>4.64 (3.59)</td>
<td>10.88 (3.85)</td>
<td>4.96 (3.85)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Duration of disease in years mean (SD)</td>
<td>12.04 (7.77)</td>
<td>13.84 (4.44)</td>
<td>10.8 (8.48)</td>
<td>10.44 (6.6)</td>
<td>0.09</td>
</tr>
<tr>
<td>Time since diagnosis in years mean (SD)</td>
<td>10.52 (6.75)</td>
<td>12.24 (4.85)</td>
<td>8.16 (6.24)</td>
<td>9.2 (6.2)</td>
<td>0.05</td>
</tr>
<tr>
<td>HAQ mean (SD)</td>
<td>1.2 (0.6)</td>
<td>1.04 (0.73)</td>
<td>1.22 (0.86)</td>
<td>0.88 (0.72)</td>
<td>0.28</td>
</tr>
<tr>
<td>PKQ score mean (SD)</td>
<td>13.04 (4.07)</td>
<td>13.92 (4.17)</td>
<td>13.76 (4.75)</td>
<td>11.12 (4.15)</td>
<td>0.09</td>
</tr>
</tbody>
</table>

Functional class:
- class 1: 15 (60%)
- class 2: 8 (32%)
- class 3: 1 (4%)
- class 4: 1 (4%)

SD = standard deviation.
Discussion

Any instrument designed to evaluate the knowledge RA patients have about their disease must be both valid and reliable. The results of this study allow us to use the PKQ to test patients’ knowledge about RA, after cultural adaptation. As mentioned above, two interviewers applied the questionnaire. In our environment, in addition to not being used to these types of questionnaires, the level of education of our patients is not sufficient to enable them to answer self-administered questionnaires. Thus, the purpose of having an interviewer apply the PKQ was to increase patient compliance to the survey and also to compensate for the low level of education commonly seen in our patients.

The reason for deciding to evaluate 4 different hospitals was to test the knowledge of different populations to avoid possible bias, which could be the case if the situation of a single hospital was shown. In fact, it was found that specific populations had been involved, as statistically significant differences were observed in the variables of education and time since diagnosis. This study showed a wide degree of variability in the knowledge RA patients had as regards their disease, with PKQ scores ranging from 6 to 22 out of a maximum score of 30. This variation could be justified by the already mentioned heterogeneity in the population studied. This was also observed by Hill et al. (7), with PKQ scores ranging from 3 to 28 and by Hellwell et al. (10) with scores ranging from 5 to 26.

The mean PKQ score for the 100 evaluated patients was 12.96 (SD 4.37). This score is lower than the score of 16 reported by Hill et al. (7) when evaluating 70 patients with RA. However, it must be emphasized that in the population evaluated by that group the mean of complete years of formal education was 9.7 (ranging from 9 to 15) years while in this study the mean was 6.4 years, and some of the patients were illiterate (5%).

In the study by Hellwell et al. (10) the mean score for knowledge (measured by the PKQ) was 16, also higher than the mean score observed in our sample. However, the population studied by this author was of patients with recent disease (duration of less than 5 years) and the majority (over 80%) with at least secondary level of education. Considering the low level of education seen in the population studied, the knowledge obtained by the patient could be the result of the number of years the patient had been suffering from RA, yet the PKQ score did not show statistically significant correlation either with disease duration or with time since diagnosis. Other studies (5, 7, 8, 9) also failed to observe correlation between the level of knowledge and disease duration.

Although patients older than 60 years of age were excluded from our study, there was negative correlation between age and the level of disease-specific knowledge. In other words, with increasing age there is decreasing knowledge about the disease. Lineker et al. (8) also observed a decreased knowledge with increasing age when applying the ACREU questionnaire to patients with RA. Yet this group included individuals of up to 85 years of age in the sample. The study by Vignos et al. (5) did not include patients over 65 years of age, and in the study by Hill et al. (7), patients over 75 were excluded. These studies did not observe a correlation between age and the level of knowledge about RA.

In this study, there was a positive correlation between scores measuring knowledge and the number of complete years of formal education. Hill et al. (7), also observed this correlation despite having studied a population with a higher level of formal education (the mean for complete years of education was 9.7 years, ranging from 9 to 15). Likewise, Vignos et al. (5), also observed association between the level of education and the scores of knowledge. Patients showed less knowledge in PKQ components such as medications (mean score 2.8 out of 7), and joint protection and energy conservation (mean score 2.5 out of 7). Similar results were observed by Hill et al. (7) with a mean score of 3.3 for items regarding medications and 3.9 for joint protection and energy conservation.

In a study by Barlow et al. (9) comparing patients with RA in different stages of evolution, the lowest PKQ scores were achieved in the sections related to medications and exercises. As regards medications, the question most commonly answered erroneously was related to the side effects caused by NSAIDs. Patients said the most common side effect was dry mouth (35%) and not indigestion (28%). This was not observed by Hill et al. (7), in a study in which 62% of patients reported indigestion as the most common adverse effect. Nevertheless, in the study conducted by Kay & Punchak (17) side effects represented the topic most frequently reported when they were questioned about what they would like to be informed of in RA medication publicity fliers. In question 7, the term “sulphasalazine” was changed to “methotrexate”. That is because “methotrexate” is the most known medication in our country and most of the Brazilian patients do not know the other drug. Also, as the original questionnaire was developed in the 1980’s, the use of methotrexate was not so widespread. The poor performance of patients with regards to questions about joint protection and energy conservation was, to a certain extent, due to confusion regarding these two concepts. For instance, 84% of patients erroneously said that carrying objects with both hands would represent a means of conserving energy and that acting as though they did not have arthritis (33%), grip objects tightly (51%) and applying heat or ice to the joints (34%) could be ways to protect the joints. Despite Hill et al. (7) having reported a higher score in this topic of the PKQ, the same difficulty in distinguishing between the two concepts was also observed. Even the belief that applying ice or heat would be a way to protect the joint was reported by a larger portion of patients (43%) in the study by Hill et al. (7) compared to our study (34%).

The relatively good performance of patients as regards questions about exercises and RA should be mentioned. The majority said exercises help to prevent joint deformity, that one of the
best ways to exercise was walking, and that in the active stage of disease, exercises should be made according to their flexibility instead of resting all day. These results are very similar to those obtained by Hill et al (7).

However, it is important to comment that the original PKQ was published in the 1980’s and the today the prescription of physical activities in RA patients has changed. Even if in early disease, the patients can be instructed regarding muscle strength and aerobic exercises once they are under correct drug treatment (18, 19). The poor knowledge patients have about their disease lies in a more ample and universal issue, and there is the fact that those who suffer rheumatic diseases are denied the benefits of an educational program. Possible reasons for this have been discussed by Lorig (20). The author mentions that maybe the foremost reason is that these educational programs are usually offered outside the limits of medical practice, in other words, rheumatologists are not prepared and do not have available time to develop and offer well-structured educational programs. The second reason may be that not all patients are treated by a rheumatologist, they are usually seen by a general practitioner providing primary care. And last, but not least, the lack of investment in patient education is also mentioned. Bötman et al (21), observed the low level of knowledge about the disease among rheumatologists and general practitioners and it can represent another reason to the poor knowledge among rheumatic patients.

In São Paulo, we have only our educational program specific to RA patients. Because of the lack of knowledge about the disease and low level of education reported in the patients in this study we will need to modify the contents and use alternative methods like visual instruments to reach satisfactory results. The present study supports the need for a multidisciplinary approach of patients with RA, to impart the information required for these individuals to understand their disease through appropriate educational programs. In addition, it offers an instrument to evaluate disease-specific knowledge of RA patients in our population, allowing the implementation, evaluation, and enhancement of educational programs.

Conclusions

At study completion, a Brazilian version of the Patient Knowledge Questionnaire (PKQ), was created, which proved to be a valid and reliable instrument to evaluate disease-specific knowledge in RA patients.

The lack of knowledge of Brazilian patients with rheumatoid arthritis about their disease was also confirmed. Patients showed less knowledge concerning topics related to medications and ways of joint protection and energy conservation. Additionally, as measured by the PKQ, the level of knowledge correlated positively with the level of formal education and negatively with patients’ age and the HAQ scores achieved by the patients.

Acknowledgements

We wish to thank Ieda Laurindo, William Chaude, Rina Gorgi, Cristiano Zerbini, and Luis Carlos Latowe, for allowing us to evaluate individuals at the outpatient clinics under their responsibility. Also, we wish to thank the PKQ’s author, Jackie Hill, for allowing us to use the questionnaire.

References

9. BARLOW JH, CULLEN LA, ROWE H: Comparison of knowledge and psychological well-being between patients with a short disease duration (≤ 1 year) and patients with more established rheumatoid arthritis (≥ 10 years duration). Patient Education and Counseling 1999; 38: 195-203.

527
Brazil Patient Knowledge Questionnaire

1. Escolha duas frases verdadeiras da lista abaixo.
   Artrite reumatóide:
   a) é herdada dos pais
   b) começa depois que uma junta é machucada
   c) é causada pela temperatura fria e úmida
   d) a causa é desconhecida
   e) poderia começar por causa de um vírus ou bactéria
   f) não sei

2. Escolha duas frases verdadeiras da lista abaixo.
   Artrite reumatóide:
   a) afeta somente os ossos do corpo
   b) às vezes afeta os pulmões, olhos e outros órgãos
   c) é mais comum em idade avançada
   d) é uma doença de longa duração
   e) é curável
   f) não sei

3. Escolha três alterações que podem ser causadas pela artrite reumatóide.
   a) anemia
   b) nódulos
   c) excesso de peso
   d) perda de cabelos
   e) pressão alta
   f) cansaço
g) não sei

4. Escolha dois exames de sangue que podem ser usados para avaliar sua artrite.
   a) nível de colesterol
   b) VHS (velocidade de hemossedimentação)
   c) tipo sanguíneo
   d) hemograma
   e) dosagem de açúcar no sangue
   f) não sei

5. Escolha duas frases verdadeiras sobre antiinflamatórios.
   a) param o progresso da doença
   b) levam semanas para começar a funcionar
   c) diminuem a dor, o inchaço e a rigidez
   d) somente devem ser tomados quando a dor está muito forte
   e) devem ser tomados com a comida
   f) não sei

6. Escolha o efeito colateral mais comum que os antiinflamatórios podem causar.
   a) cocô na pele
   b) má digestão
   c) hematomas
   d) boca seca
   e) perda de paladar
   f) não sei

7. Escolha duas drogas de uso prolongado que podem acalmar a doença.
   a) metotrexate também conhecido como MTX
   b) diclofenaco também chamado Voltareem
   c) indometacina também chamada Indocid
   d) sulfasalazina também chamada Azulfin
   e) ácido acetil-salicílico também chamado AAS, Aspirina e Melhoral
   f) não sei

8. Escolha duas frases verdadeiras sobre remédios contra a dor.
   a) não causam dependência
   b) devem ser tomados apenas quando a dor é muito forte
   c) devem ser tomados antes de qualquer atividade que possa causar dor
   d) devem ser tomados quando a dor começa a piorar
   e) devem ser sempre tomados com a comida
   f) não sei

9. Escolha duas frases corretas sobre exercício e artrite reumatóide.
   a) não é necessário fazer exercício se você tem atividade normal
   b) o exercício vai curar a artrite reumatóide
   c) o exercício enfraquece as juntas danificadas
   d) movimento sua junta até sentir dor
   e) o exercício pode diminuir as chances da sua junta se deformar
   f) não sei

10. Escolha as duas melhores maneiras de uma pessoa com artrite reumatóide se exercitar.
    a) exercícios de fortalecimento muscular
    b) corrida leve
    c) caminhada
    d) yoga
    e) ir às compras
    f) não sei

11. Escolha uma atividade que você deve praticar quando todas as suas juntas estiverem doloridas e rígidas.
    a) não fazer nenhum exercício
    b) descansar na cama a maior parte do dia
    c) realizar seus exercícios de acordo com sua flexibilidade habitual
    d) fazer exercícios mais fortes
    e) não sei

12. Escolha dois tratamentos que podem ser feitos caso seus punhos fiquem mais doloridos, inchados e rígidos que o usual.
    a) descansar os punhos colocando talas nos mesmos
    b) diminuir a rigidez através de exercícios fortes
    c) usar os punhos o máximo possível
    d) evitar movimento colocando os punhos em uma mesma posição a maior parte do tempo
    e) fazer a movimentação máxima das juntas várias vezes ao dia
    f) não sei

13. Escolha duas frases desta lista. O modo mais prático de proteger suas juntas de distensão é:
    a) usar as juntas rapidamente
    b) usar as grandes juntas ao invés das pequenas
    c) arrastar os objetos ao invés de carregar
    d) fazer o mínimo possível
    e) fazer como se não tivesse artrite
    f) não sei

14. Escolha o melhor a fazer quando você tem um dia muito ocupado e percebe que está cansado.
    a) tirar folga e fazer mais amanhã
    b) fazer tudo o que você planejou
    c) descansar um pouco e depois fazer tudo o que você planejou
    d) fazer somente o necessário
    e) passar o dia na cama
    f) não sei

15. Escolha duas maneiras de economizar sua energia.
    a) passar roupa sentado
    b) planejar um equilíbrio entre trabalho e descanso
    c) usar talas
    d) usar os músculos maiores e mais fortes
    e) usar as duas mãos para carregar objetos como panelas
    f) não sei

16. Escolha duas maneiras para proteger as juntas.
    a) seguir firme os objetos
    b) usar um pano de prato ao invés de uma esponja
    c) usar as palmas das mãos e não os dedos para abrir um pote
    d) colocar calor ou gelo nas juntas
    e) ter direção hidráulica no carro
    f) não sei

OBRIGADO POR TER RESPONDIDO ESTE QUESTIONÁRIO.