# Translation, cultural adaptation and aplication of a pain questionnaire for patients with polycystic kidney disease

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Submitted: 4/19/2010
Accepted: 9/21/2010

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**Financial support:**
CAPES - Coordenação de Aperfeiçoamento de Pessoal de Nível Superior.

This study was carried out at the Federal University of São Paulo.

We declare no conflict of interest.

## Abstract

**Introduction:** Pain is a common symptom in patients with autosomal dominant polycystic kidney disease (ADPKD), affecting around 60% of cases. **Objective:** Translate a pain questionnaire developed and validated for ADPKD in USA into Portuguese and to perform its cultural adaptation and apply it. **Method:** The cultural adaptation performed by a panel of experts resulted in small changes consisting of words substitution by synonyms or deletion of terms not commonly used in our culture in 12 out of the 46 questions posed, to solve patients difficulties in understanding the questionnaire. **Results:** There has been equivalence between the adapted form of the instrument with the back-translation. The final form of the questionnaire applied in 97 patients with ADPKD (64F/33M, 35 ± 12 years) showed that 65 (67%) had isolated or associated pain in multiple locations , more often at lumbar region (77%), followed by abdominal (66%), headache (15%) and chest (4%). The questionnaire revealed that after family history, pain was the second factor contributing to the diagnosis of ADPKD in this population (55% and 22% of cases, respectively). **Discussion:** Clinical and laboratory data from medical records showed that patients referring pain had renal volume and size of the largest cyst significantly higher than those without pain. **Conclusion:** We conclude that the use of a specific pain questionnaire for ADPKD population provided a better characterization of this symptom, as well as its relationship with the associated complications that commonly occur in this setting.

**Keywords:** polycystic kidney diseases, pain measurement, low back pain.

[J Bras Nefrol 2010;32(4): 386-399]

## Introduction

Autosomal dominant polycystic kidney disease (ADPKD), characterized by the progressive development of bilateral renal cysts, has an incidence ranging from 1:400 to 1:1000 live births. It accounts for up to 10% of the patients with end-stage renal disease (ESRD) undergoing renal replacement therapy (dialysis or transplantation).[1,2] In ADPKD, cysts may be found in other organs, such as the spleen, pancreas, and, most commonly, the liver.[2,3] In addition, other extra-renal manifestations, such as abdominal wall hernias, diverticulitis, valvular abnormalities, and cerebral aneurysms, can be found.[4,5] Among the renal manifestations of ADPKD, the following are the most common: arterial hypertension; urinary infection; nephrolithiasis; low back pain; hematuria; increased kidney volume; and progressive loss of renal function.[6] Arterial hypertension is an early and frequent complication of ADPKD. It affects 60% of the patients, even before renal function impairment, probably due to stimulation of the renin-angiotensin-aldosterone system caused by the growth of the cysts.[7] Hematuria can result from the rupture of cysts[8] or from the presence of kidney stones that are very frequent in ADPKD due to anatomical and/or metabolic abnormalities.[9,10,11] Urinary tract infection (UTI) and infection of the cysts are also frequent in ADPKD.[12] End-stage renal disease, which occurs in almost 50% of the patients with ADPKD until the sixth decade of life,[5] results from the reduction in the renal parenchyma replaced by the cysts, and from vascular sclerosis and interstitial fibrosis.[1,2] The diagnosis of ADCKD can be suspected from the investigation of the family history or of the

innumerous conditions associated. Ultrasonography is the most used imaging test for the diagnosis of ADPKD, and has a sensitivity close to 100% for individuals over the age of 30 years suspected of having ADPKD;[13] for younger individuals, nuclear magnetic resonance is the method of choice.[14]

Although ADPKD usually remains asymptomatic for many years, pain is a common symptom, and can even affect 60% of the adult population with that disease.[15] Bajwa *et al*[16] have reported the following most frequent locations of pain in that population: low back; abdomen; chest; lower limbs; and head. The low back and/or abdominal pain in patients with ADPKD is multifactorial. It can occur acutely due to cyst rupture or infection, kidney stone elimination, and UTI, or can be chronic resulting from increased kidney or liver volume, due to cyst expansion,[6] or even from diverticulitis. As the cysts are associated with excessive angiogenesis, polycystic kidneys are specially susceptible to traumas, which can lead to hemorrhage or bleeding in the retroperitoneal space, usually accompanied by intense pain.[17] Intracystic hemorrhages occur usually in 90% of ADPKD patients and are characterized by the presence of hyperdense cysts on imaging tests.[18] Some patients do not associate the pain with the cysts, and, thus, the episodes of cystic hemorrhage can pass undiagnosed when gross hematuria is absent.[18] The headache of ADPKD patients can be related to the presence of cerebral aneurysms, but the frequency of headache does not differ from that of the general population.[19] Thus, that diversity of factors turns pain into a challenging diagnosis in such patients. The pain reported by ADPKD patients is usually treated with analgesics, but, when the pain is severe, special therapies, such as transcutaneous stimulation, use of local anesthetics, or even open or laparoscopic surgery, may be required.[20,21]

The high percentage of ADPKD patients reporting pain emphasizes the importance of a specific pain questionnaire that better characterizes that symptomatology, providing better assessment to determine more adequate therapeutic measures for each patient. The cost and complexity involved in the elaboration of a questionnaire can be minimized by the use of a translated questionnaire already validated in other countries.[22] However, transcultural adaptation of such questionnaires is required for their use in each country.[23,24] The present study aimed at performing the Portuguese translation and transcultural adaptation of a pain questionnaire specific for ADPKD patients, developed and validated by Bajwa *et al*[16] in 2004, and at its application in a sample of ADPKD patients.

## Patients and methods

The pain questionnaire developed and validated by the group of Steinman for the North-American population with ADPKD[16] has 46 questions. It included since how and when the diagnosis of ADPKD was made to pain characteristics, such as location, frequency, intensity, and associated pathologies. The initial translation of the pain questionnaire into Portuguese was performed by a nephrologist and revised by a multidisciplinary team (two physicians, one nurse, two biologists, and two nutritionists), aiming at assessing the clarity and understanding of the questions. The differences found or expressions considered difficult to be understood by the lay population were replaced with a more simple language, in such a way not to change the conceptual translation of the question. Eventually, the version considered definitive underwent backtranslation by an independent translator, aiming at comparing the Portuguese translated and the English original versions.

### Selection of patients

One hundred adult patients, followed up at the Polycystic Kidney Outpatient Clinics of the Discipline of Nephrology of the Federal University of São Paulo (UNIFESP) were selected. The diagnosis of ADPKD was made based on the presence of a family history of the disease (an affected parent) and data obtained with kidney ultrasonography, meeting the criteria proposed by Pei[13] for each age bracket. Data regarding kidney volume, number of cysts, and size of the largest cyst were obtained from the ultrasound reports on the medical records. Kidney volume was determined by use of the formula of the modified ellipsoid = $4/3\ \varpi$ x (anteroposterior diameter/4 + width/4)$^2$ x length/2,[25] and, in the present study, it was considered as the sum of the volumes of both kidneys.[26]

The initial contact with patients occurred during the pre-consultation at the Polycystic Kidney Outpatient Clinics, which consisted in measuring weight, height, and blood pressure (BP), and was followed by an informal approach for questioning about the volunteer participation in the study. Patients with the pre-established diagnosis of arterial hypertension, or those undergoing medicamentous treatment and having a normal BP on the day of measurement have also been considered as hypertensives. Other clinical findings, such as presence of lithiasis, UTI, or hematuria, were obtained from the medical records. The renal function level was defined by determining creatinine clearance (CrCl) in blood and 24-h urine, which was also extracted from the medical

records. Chronic kidney disease (CKD) stage 1 was defined as kidney damage caused by the presence of cysts on imaging tests, and CrCl ≥ 90 mL/min/1.73m$^2$. Stage 2 was defined as the presence of kidney damage and CrCl between 60 and 89 mL/min/1.73m$^2$; and stage 3 was defined as CrCl below 60 mL/min/1.73m$^2$.[27]

### Application of the questionnaire

The questionnaire was applied to 97 patients out of the 100 previously selected, considered as having a good capacity of understanding. They had no pain at the time of questionnaire application to reduce the possibility of influencing their responses. Three patients refused to or could not participate in the study because they could not understand the questions proposed. The questionnaire was individually applied at a private room, with no interference of a third party, for a mean time of 15 minutes. All patients included in the study were informed about the research and provided written informed consent. The study was approved by the Committee on Ethics of the UNIFESP.

Pain intensity was measured by use of the visual analogue scale (VAS),[28] present in the original questionnaire[16] and used in clinical practice and other studies. That scale comprises a score ranging from zero to ten, where zero corresponds to lack of pain and ten corresponds to maximum pain intensity.[16]

### Statistical analysis

The numerical variables were expressed as medians (minimum value – maximum value), and the Mann-Whitney test was used to compare the groups. The categorical variables were expressed as numbers and percentages, and the Chi-square test and Fisher exact test, when indicated, were used for comparisons. Non-parametric tests were used due to lack of normal distribution of the numerical variables between both groups. The significance level adopted for the statistical tests was 5% (p value < 0.05), and the software used for the analyses was the SAS System for Windows (Statistical Analysis system), version 8.02.

## Results

### Translation and transcultural adaptation of the questionnaire

The initial translation from English to Portuguese was assessed by the multidisciplinary team. Some expressions originally used required changes to be better understood by the patients. The first change was in the title of the questionnaire adopted in the English original version: from "The questionnaire employed in the PKD population – headache and pain in polycystic kidney disease project" to "Questionnaire for patients with polycystic kidney disease". As shown in Table 1, only some words present in 12 of the 46 questions required changes for adaptation to local culture. Those changes consisted basically in replacing some words or expressions by synonyms, or in including between parentheses terms to which no equivalent was found in Portuguese, aiming at enhancing understanding by the patients. For example, as shown in Table 1, in item D3, in the description of the type of chest pain, the term "undefined" was added between parentheses to the expression "aching", to exclude all other adjectives for defining that pain (stabbing, dull pressure, cramping, intermittent, and continuous). That change

**Table 1** Modifications of the descriptors of the original questionnaire suggested by the multidisciplinary team

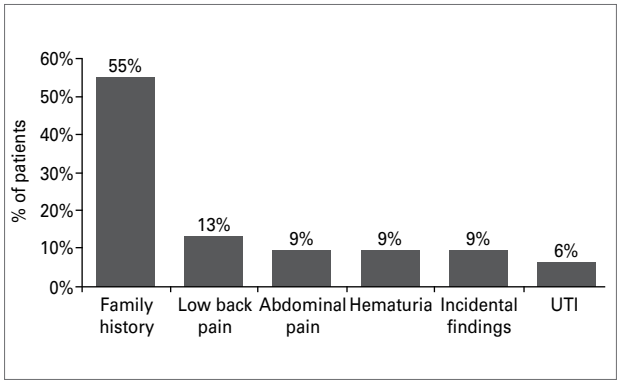
| Item of the questionnaire/ words | Initial translation (Version 1) | Modification (Version 2) |
|---|---|---|
| 10/ Has your pain ever been associated with blood in your urine? | Alguma vez esta dor "associou-se" com sangue na urina? | Alguma vez esta dor foi acompanhada de sangue na urina? |
| A4/... Ice massage | ... "Massagem fria" | ... "Gelo" |
| A5/... Abdominal fullness? | ... "Sensação de plenitude abdominal"? | ... "sensação de estômago cheio"? |
| D3/ Dull press | Pressão "incômoda" | Pressão "desagradável" |
| D3/Type of pain ...Aching | Tipo de dor ... "dolorida" | Tipo de dor: ... "dolorida" (indefinida) |
| D3/Type of pain…Intermittent | "Intermitente" | "Intermitente" (que vai e volta) |
| E3/ Front of the head | Região "frontal" | "Frente da cabeça" |
| E3/ Back of the head | Região "occipital" | "Atrás da cabeça" |
| E4/ …Throbbing | ... "Pulsátil" | ... "Latejante" |
| 6 a/... "Aura" | ... "Aura" | ... "Sensação diferente" |
| 6 a/... Nausea | ... "Náusea" | ... "Enjoo" |
| F/... Antihistamine medications | ... "Medicamentos anti-histamínicos" | ... "Antialérgicos" |

was performed to not jeopardize that item in the backtranslation, and also to better express missing terms or those that made no sense in Portuguese. In the same question, we added the expression "that comes and goes" to the term "intermittent", and replaced the adjective in the expression "dull pressure" by "unpleasant" to improve understanding. Backtranslation performed by an independent translator showed no conceptual difference when compared to the text of the English original questionnaire. When assessing the equivalence between the backtranslation and the English original version of the questionnaire, it was evident that only a few items had been altered, because the translation suppressed and/or modified certain words. Those changes were aimed at providing semantic equivalence (equivalence between words) and idiomatic equivalence (items that needed to be replaced). For example, expressions of the English original questionnaire, such as "do you experience abdominal pain?" translated and adapted to Portuguese as "*você tem dor abdominal?*" were backtranslated as "do you have abdominal pain?". In other words, the term "experience" disappeared from the backtranslation because it is not part of an usual expression in Portuguese, being suppressed already in the phase of translation and adaptation. The final version of the questionnaire later applied to patients is found in the Appendix.

## Application of the questionnaire

Ninety-seven adult patients with ADPKD (64 F/33 M; 35 ± 12 years) were assessed by use of a pain questionnaire, 57% being Caucasians, 18% afro descendents, 21% mixed heritage, and 2% Asians. Figure 1 shows the percentage of patients with a family history of ADPKD and signs and/or symptoms contributing to the diagnosis of ADPKD. The presence of a family history of ADPKD was the most contributing factor for the diagnosis, and was observed in 55% of the patients. Other elements leading to the diagnosis of ADPKD were: pain (22%); assessment of hypertension or hematuria (18%); UTI (6%); and incidental findings on periodic tests or medical consultations not related to nephrology (9%). The sum of all factors reported by patients exceeds 100% (110%), because some patients looked for medical assessment due to the presence of some symptoms and/or because they also had a family history of ADPKD, although they did not relate the symptom reported to ADPKD prior to the diagnosis.

**Figure 1**. Family history, symptoms and/or signs leading to the diagnosis of ADPKD.




According to the answers to the pain questionnaire, pain at any location was present in 67% (65/97) of the patients. Low back pain was more frequent when considered in isolation (26%), followed by headache (8%), and abdominal (4%) or chest pains (4%). However, patients most commonly reported pain in its associated form, as shown in Figure 2, which highlights the greater frequency of the association between low back and/or abdominal pains (52% of the reports of pain) and the additional association with headache (36% of the reports). Based on the patients' report in the present series, the following percentage distribution of pain was observed: low back pain, 77%; abdominal pain, 66%; headache, 15%; and chest pain, 4%.

**Figure 2**. Location of the pain (% of patients).

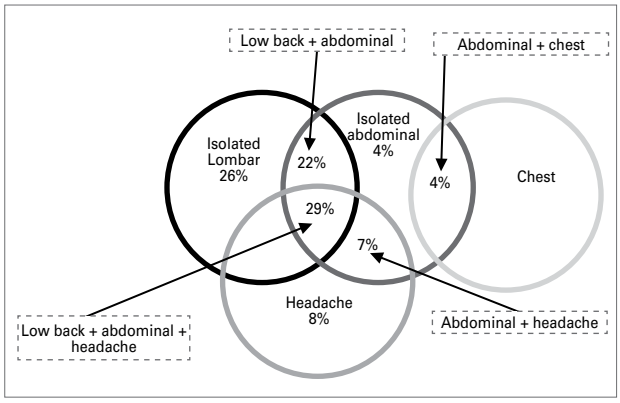



Table 2 shows the clinical and ultrasonographic characteristics of the patients who reported isolated low back pain, the association of low back and abdominal pains, and the association of low back and abdominal pains with headache. Patients with isolated low back pain had a longer history as compared with the group with no pain. The kidney volume of patients with isolated low back pain, or with the association of abdominal pain and/or headache was significantly greater than that of patients with no pain. A higher percentage of patients with

**Table 2** Clinical and ultrasonographic characteristics

| | No pain (n = 32) | Isolated low back pain (n = 25) | Low back + Abdominal pain (n = 21) | Headache + Abdominal + Low back pain (n = 28) |
|---|---|---|---|---|
| Age (years) | 33 (19 – 63) [a] | 34 (23 – 62) | 40 (21 – 61) | 38 (20 – 58) |
| Sex (M/F) | 15/17 | 09/16 | 03/18 | 05/23 |
| Age at diagnosis (years) | 24 (5 – 58) | 28 (6 – 56) | 30 (13 – 56) | 31 (7 – 45)* |
| Time of history (years) | 3 (0 – 21) | 6 (1 – 34)* | 5 (1 – 19) | 8 (0 – 18) |
| BMI (kg/m$^2$) | 25 (18 – 35) | 26 (19 – 36) | 25 (19 – 35) | 25 (19 – 35) |
| Hypertension | 12 (37%) [b] | 16 (64%)* | 16 (76%)* | 18 (64%)* |
| Lithiasis | 5(16%) | 9 (36%)* | 14 (67%)* | 0 |
| UTI | 1(3%) | 2 ((8%) | 3 (14%)* | 0 |
| Hematuria | 22(69%) | 2 (8%) | 6 (29%) | 0 |
| CKD 1 / 2 | 26 (81%) | 22 (88%) | 15 (71%) | 25 (89%) |
| CKD 3 | 6 (19%) | 3 (12%) | 6 (29%) | 03 (11%) |
| Kidney volume (mL) | 361 (180 - 2482) | 646 (251-2150)* | 657 (216 – 2394)* | 600 (263 – 2870)* |
| Number of cysts | 15 (4 – 15) | 15 (4 – 15) | 15 (4 – 15) | 15 (4 – 15) |
| Largest cyst size (cm) | 3 (2 – 6) | 5 (2 – 8)* | 4 (2 – 7)* | 4 (2 – 11)* |

[a] Median (minimum – maximum); [b] number (percentage) of patients; *p < 0.05 vs no pain.

hypertension and lithiasis was observed in all groups with pain. However, even excluding hypertensive patients from the analysis, the kidney volume of normotensive patients with pain (n = 26) was also significantly greater than that of normotensive patients with no pain (n = 20), 430 mL *vs* 315 mL, respectively (p < 0.036) (data not shown in table). When patients with lithiasis are excluded, the kidney volume of ADPKD patients without lithiasis but with pain (n = 41) is significantly greater than that of patients without pain (n = 27), 591 mL *vs* 335 mL, respectively (p < 0.001). As the total number of patients reporting isolated abdominal pain (n = 4) or isolated headache (n = 8) was small, those patients were not included in the statistical analysis. A greater number of patients with UTI was observed in the group of low back pain associated with abdominal pain, and a BMI significantly greater was observed in patients with isolated abdominal pain. No statistically significant difference was observed in age, number of cysts, and loss of renal function between the groups. The female sex predominated in the total group of pain, especially in that of low back pain.

Figure 3 shows that 46% of the patients with low back pain reported its intensity as moderate (scores 4 - 6). The frequency of low back pain was once a week in 39% of the patients (Figure 4). Among patients with abdominal pain, 42% reported its intensity as moderate (scores 4 - 6) (Figure 5), and 37% as less frequently than once a month (Figure 6).

Patients complaining of headache described their pain as throbbing (44%), pressure (28%), pounding (8%), exploding (5%), and stabbing (3%), occurring once a week in 36% of the cases.

**Figure 3.** Intensity of low back pain.

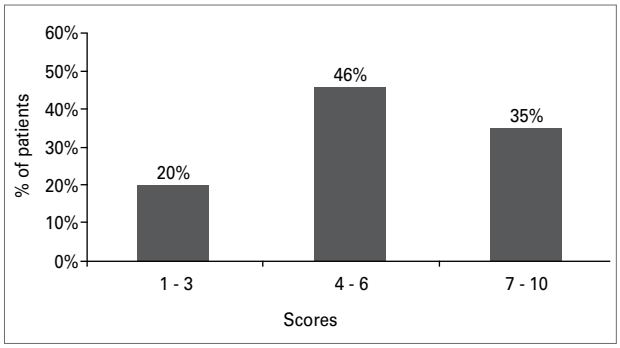



**Figure 4.** Frequency of low back pain.

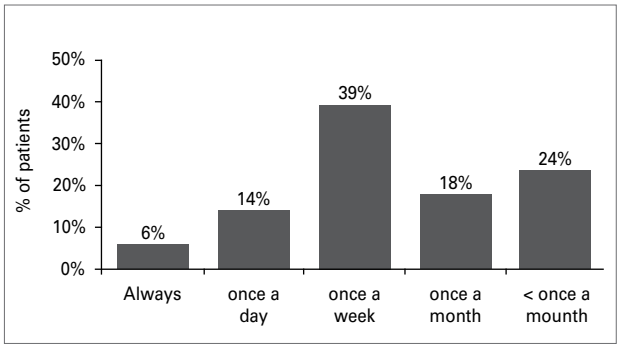


**Figure 5.** Intensity of abdominal pain.

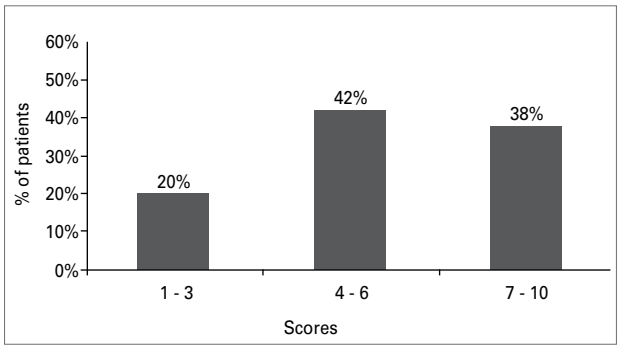
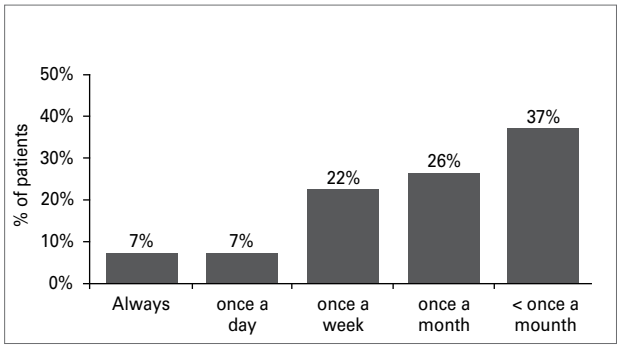



**Figure 6.** Frequency of abdominal pain.




## Discussion

Researchers interested in better assessing and characterizing specific conditions in the health area, but who do not have instruments built in their countries and languages, can choose to create a new instrument or adapt questionnaires already validated in another language. Factors such as time and cost for elaborating a questionnaire lead most researchers to choose translation and transcultural adaptation of questionnaires already existing in other languages.[22,24,29] Guillemin *et al*[30] have standardized the process of translation and transcultural adaptation into five steps: translation; review of the translation by a multidisciplinary committee; translation into the original language (backtranslation); pre-test to assess cultural equivalence; and assessment of the need to attribute weight to the scores. However, the simplification of that method has already been suggested by Da Mota-Falcão *et al*,[31] who have reported that even simplified questionnaires still satisfy the objectives proposed.

Pain has been reported as a very frequent symptom of ADPKD patients, affecting up to 60% of them[15,32] and jeopardizing their quality of life.[33] Because that symptom involves a series of sensorial qualities and subjective aspects,[22,32] it requires a careful investigation by a multiprofessional team. Duarte *et al*[23] have emphasized the importance of using proper instruments to assess the situations and experiences in the health area, so that reliable information is obtained. Despite the existence of some pain questionnaires translated and validated in Brazil,[22,34] none of them has the necessary and/or adequate specifications to assess pain in ADPKD. Thus, this study aimed at performing a translation and transcultural adaptation of an English pain questionnaire, already validated to be used in ADPKD patients.[16] That validated pain questionnaire is currently being used in the HALT PKD study.[35] A simplified version of the method developed by Guillemin[30] was adopted, since the questionnaire to be used in our study approached simple questions, which did not require weight attributions, using only scores of pain intensity of the visual analogue scale (VAS).[16,28]

The modification of the title of the pain questionnaire adopted in this study to "Questionnaire for patients with polycystic kidney disease", suppressing the subtitle of the English original version containing the terms "pain" and "headache", and the simplification of the terminology aimed at neither inducing patients to report non-existing pains nor overestimating the value of existing pains. In addition, in our opinion, our decision not to include patients with pain on the occasion of completing the questionnaire contributes to legitimate the results, a preoccupation not expressed by the authors of the English original version, but which we consider important.

The comparison of the initial translation and that suggested by the multidisciplinary team provided equivalence and reconciliation between most items. In the phase of transcultural adaptation, the use of more simple expressions or synonyms, in addition to the suppression of words in the backtranslation, has already occurred in other studies of translation and transcultural adaptation performed in Brazil,[22,24] without jeopardizing the final result of the study. Differently from the English original questionnaire that was self-applied,[16] in our study, the questionnaire was applied during the pre-consultation, so that the greatest amount of information could be obtained from the patient, in addition to preventing and minimizing the number of non-responders usually found with self-applied questionnaires. However, the questionnaire proved to be of rapid and easy application, and can be self-applied in the future.

By applying the questionnaire in our ADPKD sample, 67% (65/97) of the patients assessed could be identified as having some type of pain, a prevalence similar to that reported in the literature, which is around 60%.[6,15,22,32] The use of that questionnaire has also evidenced that the presence of a family

history of ADPKD was the finding that most frequently led to the diagnosis of ADPKD (55% of the cases). However, low back pain was the symptom most frequently reported by the patients (13%), and, when added to abdominal pain, it reached 22% of the patients, confirming that pain can contribute to the diagnosis of ADPKD.[16] In addition, it is worth noting that of the patients who sought a specialist due to a positive family history, 21% reported pain before the diagnosis, but had not related it to polycystic kidney disease, in accordance with that reported by Bajwa *et al.*[16] Low back and abdominal pains were the most frequent ones, followed by headache and chest pain, as reported by Bajwa *et al.*[16] and, in Brazil, by Romão *et al.*[36] The present study evidenced that those pains (low back, abdominal, and headache) were reported in isolation or, more frequently, in association, which is also in accordance with the study by Bajwa *et al*,[16] in which 70% of the patients had more than one type of pain, and in only 18% the pain had a single location. The frequencies of low back (once a week) and abdominal (less than once a month) pains found in our study differed from those of the North-American population, which characterized those pains as continuous. The intensity of the low back/abdominal pains was similar to that in the literature.[16] The reasons why the patients reported a lower recurrence of the episodes of low back/abdominal pain in the present series are not clear, but that finding may be attributed to a shorter time interval between the diagnosis of ADPKD and the application of the questionnaire, which was six years, while in the study by Bajwa *et al*[16] that interval was around 16 years. In addition, as the English original questionnaire was self-applied, it may have caused an overestimation of the frequency of pains that can or cannot be related to polycystic kidney disease.

In the present study, the female sex predominated among patients reporting pain in general. In the study by Bajwa *et al*,[16] the number of women in the total sample was also greater. However, because of the characteristics of the present instrument, the greater report of pain in women could represent a bias of pains originating from the female genital tract not related to ADPKD.

Regarding the clinical manifestations and laboratory alterations and their associations with the presence of pain, the present sample showed a greater percentage of hypertensive patients with associated nephrolithiasis in the groups of patients with pain, especially low back and/or abdominal pain. Although UTI episodes were slightly more frequent in the total group with pain, the number of confirmations with urine cultures on medical records was small, thus, hindering the relevance of that finding. Surprisingly, microscopic hematuria did not differ between the groups with and without pain. As hematuria is usually related to the rupture of cysts,[1,37] the urine sediment exams reported on the medical records, required on a routine basis and not during an episode of pain, may explain the lack of a temporal relation between hematuria and the episodes of pain in our study. As low back pain could be related to excessive weight, we also assessed the relation between the presence of pain and BMI. That association, however, has not been detected.

Although the median age of patients with isolated or associated low back pain and that of patients with no pain did not differ, the median age at the diagnosis of ADPKD tended to be greater in the groups with low back and abdominal pains (associated or not with headache), despite the lack of statistical significance. The estimated time of history (from diagnosis to application of the questionnaire) was longer in patients with pain, but statistical significance was reached only by those with isolated low back pain. Still, in accordance with data reported by Bajwa *et al*,[16] the pain in the present sample appeared early in the course of ADPKD, when approximately 80% of the patients still had normal renal function. Thus, no association was observed between pain and alteration in renal function, emphasizing that pain is not a late manifestation in the course of ADPKD, as already reported by other authors.[16]

The progressive increase in kidney volume does not associate only with the deterioration of renal function in ADPKD,[26,38] but also with the presence of hypertension[39] and nephrolithiasis, as previously reported by Nishiura *et al*[10] at our service, and possibly with the appearance of pain. In our series, the patients with isolated low back and/or abdominal pain (or associated with headache) had a kidney volume significantly greater than that in the group with no pain. The size of the largest cyst was also significantly greater in patients with those types of pains. The fact that the number of patients with hypertension and lithiasis is greater in the groups with pain could represent a bias in the conclusions about kidney volume. However, as previously mentioned, when patients with hypertension and lithiasis were excluded from the analysis (see Results), the differences in kidney volume between the groups with and without pain persisted in normotensive patients with ADPKD and no lithiasis associated.

In conclusion, the results of this study emphasize the importance of the use of a specific instrument to assess pain in patients with ADPKD. The pain questionnaire revealed that pain, in addition to being a very frequent and early symptom in the course of ADPKD, can help in the early diagnosis of that disease. The use of that tool has allowed a better characterization of pain location, intensity, and frequency, in addition to the assessment of the association of pain with other clinical, laboratory, and imaging manifestations in ADPKD. A greater frequency of low back and/or abdominal pains and its significant association with the increase in kidney volume has been observed. Thus, we believe that the use of a specific pain questionnaire for assessing ADPKD patients will draw attention to the pain complaints of that population, contributing to the follow-up and control of their associated complications.

## APPENDIX: QUESTIONNAIRE FOR PATIENTS WITH POLYCYSTIC KIDNEY DISEASE

DATE OF COMPLETION _____/_____/____

Name :

_____

Address:

_____

Age: _____ Sex: M [ ] F [ ] Birth date: __/__ /__

Race: Black [ ] Caucasian [ ] Asian [ ] Other [ ]

1. Year you were first aware that you had polycystic kidney disease (PKD): _____

2. Age at diagnosis: _____

3. What led to the diagnosis? (please explain)

- Finding during evaluation of another problem [ ]
- Routine evaluation done because of family history of polycystic kidneys [ ]
- Symptoms led to a physician ordering exams [ ]
- Abdominal pain [ ]
- Low back pain [ ]
- Blood in the urine [ ]
- Other [ ] Please, explain:

_____

4. Do you know of any blood relatives who have polycystic kidneys: Y [ ] N [ ]

5. If yes, please list with relationship and age of relative at the time of diagnosis of polycystic kidneys:

| Age | Relationship |
|---|---|
| | |
| | |
| | |
| | |

6. Which diagnostic tests have you had for polycystic kidneys? Please, list the results:

| | Age at time of test | Results reported to you |
|---|---|---|
| Abdominal ultrasound | | |
| Intravenous pyelogram | | |
| Abdominal CT scan | | |
| Cerebral CT scan | | |
| Abdominal MRI | | |
| Cerebral MRI | | |

7. Did you experience abdominal or low back pain before the diagnosis of polycystic kidneys? Y [ ] N [ ]

8. How was that pain treated before the diagnosis of polycystic kidneys?

9. Since the diagnosis of polycystic kidneys, have you experienced persistent or chronic pain in the following locations?
Mark with an X, Yes or No:

Head – Y [ ] N [ ] Chest - Y [ ] N [ ]

Back – Y [ ] N [ ] Abdomen Y [ ] N [ ]

Legs – Y [ ] N [ ]

10. Did you ever think that those pains were related to polycystic kidneys? Y [ ] N [ ]

11. Has that pain ever been associated with blood in your urine? Y [ ] No [ ]

**Section A – Abdominal pain**

1. Do you experience abdominal pain? Y [ ] N [ ]
If your answer is yes, please mark the location on Chart 1 (front and back) on the last page and complete this section. If your answer is no, please skip to Section B.

2. How often?
[ ] always
[ ] at least once a day
[ ] about once a week
[ ] about once a month
[ ] less than once a month

3. Can you rate this pain on average by placing an X on the following scale:

(no pain) 0 1 2 3 4 5 6 7 8 9 10 (worst pain possible)

4. Have you had any of the following treatments for this pain?
Mark with an X, Yes [ ] or No [ ]
a) surgery: Y [ ] N [ ]
b) analgesics Y [ ] N [ ]
If yes, please name:_____
c) ice Y [ ] N [ ]
d) heat Y [ ] No [ ]
e) others (please specify): _____

5. Do you experience stomach fullness? Y [ ] No [ ]

6. Do you feel full after eating a small amount of food? Y [ ] N [ ]
7. Is your appetite poor? Y [ ] No [ ]

8. Is your appetite poor because of stomach fullness? Y [ ] N [ ]

9. Is your appetite poor because of nausea? Y [ ] N [ ]

**Section B – Back pain**
1. Do you experience low back pain? Y [ ] N [ ]
If your answer is yes, please mark the location of pain on Chart 1 attached and complete this section.
If your answer is no, please skip to Section C.

2. How often?
[ ] always
[ ] at least once a day
[ ] about once a week
[ ] about once a month
[ ] less than once a month

**Section C – Back pain shooting to the hips or legs**
1. Do you experience back pain shooting down to your hips or legs? Y [ ] N [ ]
If yes, please mark the location on Chart 1 attached and complete this section. If no, skip to Section D.

2. How often?
[ ] always
[ ] at least once a day
[ ] about once a week
[ ] about once a month
[ ] less than once a month

3. Can you rate this pain on average by placing an X on the following scale:

(no pain) 0 1 2 3 4 5 6 7 8 9 10 (worst pain possible)

4. Have you had any of the following treatments for this pain?
a) surgery Y [ ] N [ ]
b) analgesics Y [ ] N [ ]
If yes, please name: _____
c) ice Y [ ] N [ ]
d) heat Y [ ] N [ ]
e) others (please specify): _____

**Section D – Chest pain**

1. Do you experience chest pain? Yes [ ] No [ ]
If your answer is yes, please mark the location of pain on Chart 1 attached and complete this section.
If your answer is no, skip to Section E.

2. How often?
[ ] always
[ ] at least once a day
[ ] about once a week
[ ] about once a month
[ ] less than once a month

3. Can you rate this pain on average by placing an X on the following scale:

(no pain) 0 1 2 3 4 5 6 7 8 9 10 (worst pain possible)
Type of pain:
[ ] stabbing
[ ] dull pressure
[ ] cramping
[ ] aching (undefined)
[ ] intermittent (that comes and goes)
[ ] continuous

4. Have you had any of the following treatments for this pain?
a) surgery Y [ ] N [ ]
b) analgesics Y [ ] N [ ] If yes, please name:_____
c) ice Y [ ] N [ ]
d) heat Y [ ] N [ ]
e) others (please specify):_____

**Section E - Headache**

1. Do you experience chronic headache? Y [ ] N [ ]

2. How often?
a) daily
b) once a week
c) 5 – 10 per month
d) once a month
e) rarely

3. My headache affects:
a) one side of the head
b) both sides of the head
c) front of the head
d) back of the head
e) the whole head

4. My headache feels like:
a) throbbing
b) pounding
c) pressure
d) stabbing
e) exploding
f) other (please, specify):_____

5. Have you ever experienced a very strong headache? Y [ ] No [ ]
If the answer is yes, how was it treated? Please, describe:_____

6. Is your headache:
a) preceded by an "aura" (different sensation): Y [ ] N [ ]
b) associated with nausea: Y [ ] N [ ]
c) associated with vomiting: Y [ ] N [ ]

7. Have you ever had a CT or MRI of your head? Y [ ] N [ ]
If yes, result: _____

8. Do you suffer from migraine? Y [ ] N [ ]
Who diagnosed the migraine? _____

9. Timing – at what time of the day?
a) morning
b) afternoon
c) evening
d) night

10. Have you or a family member ever been diagnosed with a brain hemorrhage?
Y [ ] N [ ]
If yes, please explain: _____

**Section F – List antiallergic medications that you take:** _____

**Section G - List medications for high blood pressure that you take:** _____

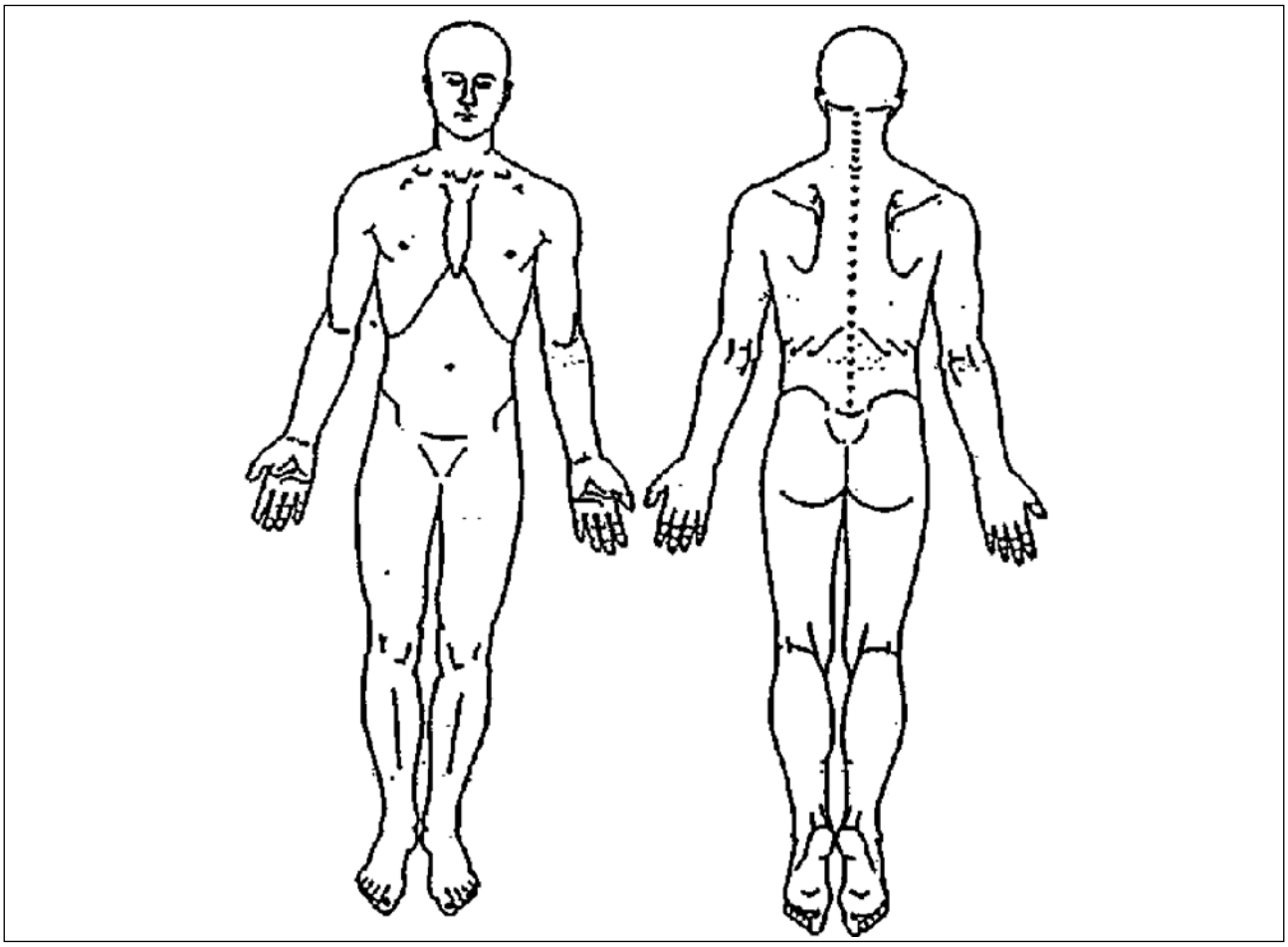
**Section H - List other current medications:** _____

**Section I – List any other treatment for polycystic kidneys:** _____

**Section J – Do you suffer from any other medical problem? If yes, please list:** _____

_____

**Figure 1.** Questionnaire for patients with polycystic kidneys.



Mark with an X the exact location of your pain

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