Patient knowledge and misconceptions of osteoarthritis assessed by a validated self-completed knowledge questionnaire (PKQ-OA)

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Objectives. To design and validate an osteoarthritis (OA) patient knowledge questionnaire (PKQ-OA) and to use it to assess the patients' level of knowledge of their disease, treatments and appropriate management techniques.

Methods. The PKQ-OA comprises 16 multiple choice questions with 30 correct answers. It was developed in two phases and tested for face validity, readability (Flesch Reading Index) and understanding, reliability (Kuder–Richardson Formula 20) and reproducibility (test/retest). The questionnaire was then used to assess knowledge of disease and management of OA in a cohort of 83 patients with established disease.

Results. The PKQ was found to be fairly easy to read, reliable (r = 0.75) and reproducible (r = 0.81; P < 0.01). The overall median score for the PKQ-OA was 19 ranging from 8 to 26. There was a highly significant association between the scores obtained and the number of years patients had spent in formal education, higher scores equating with greater length of education (P < 0.005). The majority of patients was knowledgeable about the symptoms of OA and exercise, but confused joint protection and energy conservation. The most worrying finding was the lack of knowledge regarding analgesics and some aspects of non-steroidal anti-inflammatory drug (NSAID) therapy. Less than a third of patients knew that analgesics could be taken prophylactically and 70% did not know that they should be taken when pain starts to build.

Among the patients 34% did not know that NSAIDs should be taken with or following food.

Conclusions. The PKQ-OA is a readable, reliable and reproducible questionnaire. It is quick to complete and score and could be used in outpatient clinics or GP surgeries to assess knowledge of patients with OA.

Key words: Patient knowledge, Questionnaire, Osteoarthritis.

Osteoarthritis (OA) is a globally common joint disorder with symptoms of pain, joint stiffness and reduced function [1]. It is estimated that 8.5 million people are affected in the UK [2] and amongst the elderly it accounts for more disability than any other disease [3]. Nearly one in five women over the age of 60 yrs are affected [4] and 60% of people over the age of 64 yrs have moderate to severe OA in at least one joint. The prevalence of OA rises with age, and with increasing longevity, the incidence is certain to rise. A paper published in 1995 in the United States suggested that by the year 2020 there will be a 66% increase in the number of people with OA-related disability [5]. The management of the disease has particular consequences in primary care in UK, as over 2 million adults consult their GPs with OA attributed symptoms each year [6]. At present there is no cure for OA and the enormity of the problem places a burden on the patient and society in terms of morbidity and cost.

The objectives of management are to control pain, optimize function, modify the OA process and to educate the patient about their disease and its treatments. The latter is the foundation of the treatment programme. Education is particularly important when the patient has a chronic disease such as OA, as effective long-term management relies on the patient’s willingness to co-operate and their ability to adhere with treatments such as exercise. Many patients also require drug therapy in the form of analgesics and non-steroidal anti-inflammatory drugs (NSAIDs), both of which can have unwanted side effects, particularly in the elderly. Indeed education has been highlighted as one of the ‘essential’ elements of treatment, based on evidence-based guidelines for OA management [7], and it is one of the EULAR recommendations for evidence-based management of knee OA [8]. Not only is education and the provision of information an essential element of management, it is one of the practitioner’s responsibilities and considered to be one of our fundamental ethical, legal and professional obligations [9]. However, providing education can be time-consuming and therefore expensive, and it is important to assess its efficacy. One way to do this is to measure patient knowledge pre- and post-education/information provision, and the quickest and easiest way to do this is by completion of knowledge questionnaires. At present there are validated questionnaires available for rheumatoid arthritis (RA) [10–12], psoriatic arthritis [13] and ankylosing spondylitis [14] and a general questionnaire based on the Stanford Arthritis Self-Management Program [15]. A literature search found no specific tool for patients with OA.

The aims of this study were to design a valid and reliable OA patient knowledge questionnaire (PKQ-OA) and to use it to assess the level of the patient’s knowledge of their OA, its treatments and appropriate self-management techniques.

Patients and methods

The study was undertaken in three phases. In phases 1 and 2 the PKQ-OA was developed and tested. The final phase used the PKQ-OA to assess patient knowledge.

Phase 1—development of the PKQ-OA

The tool was developed in consultation with patients, nurses, a rheumatologist, a physiotherapist and an occupational therapist. The patient cohort comprised a convenience sample of 12 consecutive patients attending a rheumatology outpatient clinic of a large teaching hospital. They had a diagnosis of symptomatic OA of any joint and their demographic data is shown in Table 1. The patients were interviewed face-to-face by an independent researcher who asked each patient ‘If you had the opportunity for someone to teach you more about your condition, what would you like to know about?’ They were also asked to share any information that they thought would be useful to a newly diagnosed patient. The interviews lasted on average 30 min and each was taped and transcribed verbatim. The ensuing transcripts were then subjected to content analysis. The emerging topics fell into a number of categories (Table 2) and these were then scrutinized for inclusion in the questionnaire. The PKQ-OA

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Submitted 8 September 2006; accepted 31 October 2006.

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Knowledge assessed by a validated OA questionnaire

Phase 1—development of the knowledge questionnaire

A validated OA questionnaire was developed and tested on a cohort of patients. The questionnaire was designed to assess patients' knowledge of OA and its management. It included questions on disease process, drug therapy, exercise, rest, and complementary therapies. The questionnaire was tested using the Flesch Reading Index which provides a summary of readability statistics including reading ease. Reading ease scores range from 0 (very difficult) to 100 (very easy) and minor changes were made until an acceptable index was achieved [19].

Phase 2—testing the PKQ-OA

The pilot study was carried out in a single rheumatology outpatient department. Patients were forewarned by post that they may be approached to complete a questionnaire prior to the clinic visit. Thirty consecutive patients from five consecutive clinics were approached and all consented and completed the PKQ-OA unaided prior to their clinic consultation. Their details are displayed on Table 1. Following completion, patients were asked about the ease of completion, the length of the questionnaire, wording, readability and understanding. None had experienced problems.

The completed questionnaires were then tested for readability and reproducibility. To assess reliability, the completed questionnaire was tested using the Kuder–Richardson Formula 20 which tests internal consistency [20]. Reproducibility was measured using test/retest technique [21]. A second copy of the questionnaire was posted to the patients 4 weeks after initial completion and results from this were compared with those of the initial questionnaire. This resulted in 20 questionnaires for test/retest.

Phase 3—patient knowledge of OA

This study was undertaken to ascertain patients level of knowledge of OA and self-management techniques. The cohort comprised 83 patients who were taking part in a random controlled trial of outcome of patients with established OA. The PKQ-OA was given to patients and collected on completion by an independent assessor. It was completed by the patients unaided, whilst they waited for their rheumatology outpatient consultation with a nurse or rheumatologist. The demographic details of the cohort are shown in Table 3 and their concomitant diseases and drug therapies are shown in Table 4.

Statistical analysis was undertaken using the statistical package SPSS for Windows version 12. Non-parametric tests were used for data analysis. Questionnaire scores were compared using Mann–Whitney U test (for two groups). Univariate correlations were made using Spearman correlation coefficient. A two tailed significance level of 0.01 was used throughout.

Results

Questionnaire testing

A Flesch reading ease ≥70 (fairly easy to read) was set for the PKQ-OA and this was attained by version 3 of the questionnaire (Flesch Index 72.9). The reliability of the questionnaire was tested by the Kuder–Richardson method. In homogeneous groups such as medical students coefficient values (r) are expected to reach between 0.8 and 0.9. However, in non-homogeneous groups such as this sample, coefficient values (r) ≥0.7 are acceptable. In this study, r = 0.75. Reproducibility was assessed by the test/retest method. This demonstrated that the PKQ-OA was reproducible, r = 0.81; P < 0.01. The final version of the PKQ-OA was completed by patients in 5–10 min, and physically easy for patients to complete and quick for practitioners to score.

Patient knowledge of OA

The majority of patients in this study was older females. Seventy-one (86%) patients had a concomitant disease (Table 4) of which hypertension was the most common (n = 19; 27%). Two patients had experienced gastric ulcers and one a duodenal ulcer prior to the start of the study. Of these, one was taking analgesics alone and the other two were on NSAIDs, analgesics and...
gastro-protective drugs. The majority of patients was taking some form of drug therapy for their OA \((n=76; 92\%)\), either as a combination or as a lone drug (Table 4). A large number of patients had a concomitant disease \((n=71; 86\%)\) and 68 (80\%) of them were taking at least one concomitant drug and 29 (35\%) of the cohort were taking three or more concomitant drugs (Table 4).

The analysis of the PKQ-OA showed the median questionnaire score to be 19 (range 8–26) out of a maximum of 30. No statistical associations were found between the mean score and age (Spearman’s \(\rho = 0.16, P = 0.16\)), disease duration (Spearman’s \(\rho = 0.01, P = 0.91\)) or gender (Mann–Whitney U = 668, \(P = 0.98\)). There was, however, a highly significant association between the mean scores obtained and the number of years that patients had spent in formal education (Spearman’s \(\rho = 0.314, P = 0.004\)); the longer the time spent in education, the higher their mean score.

To assess knowledge in the four subgroups of the PKQ-OA, each was analysed separately and the mean percentage achieved in each of these areas is shown in Fig. 2.

Disease process: aetiology, symptoms and diagnostic tests. The maximum score for this section of the questionnaire is 9. The median score was 6 and this ranged from 2 to a maximum of 9, each achieved by one patient. A total of 68 patients (82\%) knew that OA can affect joints that are already damaged and 43 (52\%) correctly stated that OA usually affects older people and 17 (20\%) thought that the condition was caused by cold, damp weather. There was some confusion about the effects of OA. About a quarter \((n=23; 28\%)\) of the patients knew that OA can cause mild swelling of the synovium and 49\% \((n=41)\) knew that OA was a chronic problem. Well over half of the cohort \((n=56; 67\%)\) thought that OA only affected the bones of the body and 16\% \((n=13)\) thought it was caused by too much acid in the joints. No one thought that OA was curable. As expected, the majority of patients knew that the symptoms of OA were loss of joint movement \((n=79; 95\%)\) and joint stiffness \((n=79; 95\%)\). However, 74 (89\%) patients also correctly identified that aches and pains are a symptom. There were some misconceptions about methods of diagnosing OA. Although 78 (94\%) patients knew that X-rays and examining the joints \((n=31; 37\%)\) were used to make a diagnosis, 44 (53\%) patients believed that blood tests were also used. No patient chose the ‘don’t know’ response to this section.

Drug therapy: the effects of commonly used medications and their side effects and how to take them. The maximum score for this section is 7. The median score achieved was 4, ranging from 0 (4 patients) to 7, achieved by one patient. A total of 63 patients (76\%) knew that NSAIDs reduce pain and swelling and that they should be taken with or following food ingestion \((n=55; 66\%)\). However, 11 (13\%) thought that NSAIDs should only be taken when their pain was severe. Although 56 (67\%) patients knew that NSAIDs can cause stomach upsets, 21 (25\%) patients answered ‘don’t know’ about side effects, and 64 (77\%) knew that steroid injected into a joint could lessen pain, and 16 (19\%) correctly identified capsaicin as another form of pain relief. However, 58\% \((n=48)\) of the cohort did not know that ibuprofen was an NSAID. Knowledge of analgesics was erratic. Among the patients, 31\% \((n=26)\) knew that they could be used prophylactically and that they should be taken when the pain starts to build \((n=25; 30\%)\). However, almost half the cohort \((n=38; 46\%)\) thought analgesics should always be taken with food, 24 (29\%) patients chose the ‘don’t know’ option to this analgesic question.

Exercise and rest: suitable methods of exercise and ways to get a good night’s sleep. The maximum score for this section is 7. Patients were knowledgeable about exercise and the median score was 5, range 0 (one patient) to 7 (achieved by 19 patients). A total of 84\% \((n=70)\) of patients knew that exercise strengthens muscles and ligaments, and 69 (83\%) knew that it should be a regular activity. Swimming \((n=69; 83\%)\) and muscle tightening/strengthening \((n=60; 72\%)\) were known to be suitable forms of exercise, but 11 (13\%) patients thought wrongly that housework fell into this category. Among the cohort, 17\% \((n=14)\) did not know suitable forms of exercise, and responded accordingly. When asked to choose the most suitable method of reducing the chances of the progression of OA, 59 (71\%) rightly thought that keeping their weight down to the ideal for their height and age was the correct answer. However, 22 (27\%) patients thought that taking their drug therapy regularly would reduce disease progression. When asked to choose two suitable methods of getting a good night’s rest, 57\% \((n=47)\) knew that taking regular aerobic exercise and getting into a regular sleep pattern \((n=55; 66\%)\) helped and 27 (33\%) patients did not know the answers to this question.

Joint protection and complementary therapies: the most suitable methods of joint protection and energy conservation, pain relief and knowledge of proven complementary therapies. The maximum score for this section is 7 and this was the lowest scoring section of the questionnaire. The median score was 3, range 0 (one patient) to 7 (one patient). There were some misconceptions about joint protection. Although 54 (65\%) patients knew that using a walking aid would reduce stress on the lower limbs, and 48 (58\%) knew that trainers would help to reduce the impact on the joints, 32 (39\%) patients thought that they should not alter their lifestyle at all and simply continue as though they did not have OA. The question on proven

<table>
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<th>Variable</th>
<th>(n)</th>
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<tr>
<td>Number of patients taking analgesics</td>
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<tr>
<td>Number of patients taking NSAIDs</td>
<td>47</td>
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<tr>
<td>Number of patients taking an NSAID alone</td>
<td>15</td>
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<tr>
<td>Number of patients taking an analgesic alone</td>
<td>29</td>
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<tr>
<td>Number of patients taking no drug therapy</td>
<td>7</td>
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<td>Number of patients with a concomitant disease</td>
<td>71</td>
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<td>Number of patients taking one concomitant drug</td>
<td>20</td>
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<tr>
<td>Number of patients taking two concomitant drugs</td>
<td>17</td>
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<tr>
<td>Number of patients taking three or more concomitant drugs</td>
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complimentary therapies proved difficult for patients to answer. In the cohort, 14 (17%) patients knew that acupuncture could be used successfully, and 10 (12%) thought wrongly that acid-free diets were a proven treatment and 52 (63%) patients used the ‘don’t know’ option to this question. Knowledge of energy conservation was also patchy. Patients were asked to choose two suitable methods of energy conservation and 58 (70%) knew that sitting rather than standing to undertake daily tasks was energy saving and 36% (30) also knew that alternating heavy and light tasks throughout the day would help. However, 54 (65%) of the cohort thought that using both hands to carry heavy objects was a way of conserving energy, thereby confusing joint protection with energy conservation. In the cohort, 37 (45%) patients knew that a joint replacement would help relieve the pain of severe OA of the hip or knee, and 48 (58%) knew that aids such as tap turners, raised toilet seats and easy reach helpers could be used to protect a joint could be protected by applying heat and ice. However, 21 (25%) patients thought that if their OA was bad they should just take a short rest and then continue to do all the tasks they had planned regardlessly.

Discussion

The purpose of this study was 2-fold; firstly to design and validate a questionnaire for use with patients who have OA, and secondly to use it to assess their level of knowledge of their disease. To ensure that the PKQ-OA is an acceptable, self-complete patient questionnaire and a suitable quick to complete and score and so could be used in clinics or GP surgeries as a clinical tool to assess knowledge. If used in the latter setting it would be wise to re-pilot the tool to ensure its validity in primary or secondary care settings. Perhaps one of the cheapest but effective ways of giving information about drug therapy is a simple question such as ‘how and when are you going to take it?’ when the patient is given a prescription for a new NSAID. Asking for a simple question such as ‘how and when are you going to take it?’ will highlight any problems and the skilled practitioner can easily direct the conversation to include possible side effects and interactions with other drugs.

Although the results of this study are encouraging there are a number of limitations to the research. As in the study by Hennell et al. [12], it was not possible to demonstrate criterion validity as at present there is no accepted gold standard comparator. The sensitivity to change of the PKQ-OA has yet to be established. However, unpublished results from a study in which the PKQ-OA was given to patients prior to and following a patient education programme, show very promising results for its use in this context.

Even given these caveats, we conclude that the PKQ-OA is an acceptable, self-complete patient questionnaire and a suitable tool with which to assess patient knowledge, or lack of it. It is quick to complete and score and so could be used in clinics or GP surgeries as a clinical tool to assess knowledge. If used in the latter setting it would be wise to re-pilot the tool to ensure its validity in the primary care population.

Rheumatology key messages

- A new self-complete knowledge questionnaire has been developed and validated
- Patients are well-versed in their knowledge of exercise
- Poor knowledge of prophylactic analgesia and side effects of NSAIDs

Acknowledgement

The authors would like to thank Ms Ruth Thorpe who acted as the independent assessor in this study.

The authors have declared no conflicts of interest.
References