Annals of Physical and Rehabilitation Medicine 59 (2016) 255–262

Available online at
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Elsevier Masson France
EM|consulte
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Original article

Patient-preference disability assessment for disabling knee osteoarthritis: Validity and responsiveness of the McMaster-Toronto Arthritis Patient Preference Disability Questionnaire

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ARTICLE INFO

Article history:
Received 18 February 2016
Accepted 31 May 2016

Keywords:
Knee
Osteoarthritis
Handicap
Disability assessment
Validity
Responsiveness
McMaster Toronto Arthritis Patient Preference Disability Questionnaire

ABSTRACT

Background: The McMaster-Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR) measurement of function may be more comprehensive and add useful information about disability than traditional fixed-item questionnaires, especially about issues that really matter to the patient, for developing personalized medicine.
Objectives: We aimed to assess priorities in disability and restriction in participation in patients with disabling knee osteoarthritis (OA) by the MACTAR and evaluate its validity and responsiveness.
Methods: We evaluated 127 in- and outpatients with knee OA in two tertiary care teaching hospitals between August 2010 and July 2012 by using the MACTAR, the Western Ontario and McMaster Universities Osteoarthritis Index, Lequesne scale, Fear Avoidance Beliefs Questionnaire, a life satisfaction score and pain, global assessment of disease activity and functional impairment scores on a numerical rating scale. Validity was assessed by Pearson correlation and responsiveness by the standardized response mean (SRM) and effect size (ES).
Results: Patients ranked 35 different activities by the MACTAR; the 3 domains of the International Classification of Functioning, Disability and Health most often identified were mobility (cited 233 times, 52.3%); community, social and civic life (cited 122 times, 27.4%); and domestic life (cited 64 times, 14.4%). The MACTAR score was best correlated with functional impairment ($r = 0.5$). Convergent and divergent validity was as expected. In all, 108 patients completed a 6-month follow-up evaluation: 27 patients shifted their priorities at 6 months, for a decrease in SRM and ES. The SRM (0.64) and ES (0.92) for the MACTAR without shifts in priorities were the highest among the outcome measures tested; for patients considering their condition improved, the values were 0.85 and 1.17, respectively.
Conclusions: For assessing priorities in disability and restriction in participation among patients with knee OA, the MACTAR has acceptable validity and responsiveness.

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http://dx.doi.org/10.1016/j.rehab.2016.05.003
1877-0657/

1. Introduction

Rheumatic and musculoskeletal disorders are a major cause of disability worldwide. The number of years lived with disability due to knee and hip OA increased by 64% between 1990 and 2010, and OA is ranked 11th in the list of leading causes of years lived with disability [1]. In France, OA ranks first, followed by low back pain (LBP) for patient-perceived disability [2].

Accurately evaluating outcomes of treatments in patients with OA is a key issue in daily practice and clinical research. The Outcome measures in rheumatology clinical trials (OMERACT) group proposed a core set of outcome dimensions for phase 3 trials of knee and hip OA; 3 domains should be systematically included: pain, physical function and patient global assessment [3].

Disability and participation restriction, also called handicap, are negative aspects of functioning and are widely assessed in knee OA by many validated outcomes. The instruments most commonly used are the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) [4,5], the Lequesne index [6,7] and more recently, the Intermittent and Constant Osteoarthritis Pain (ICOAP) [8] and the Knee disability and Osteoarthritis Outcome Score – Physical Function Short form (KOOS-PS) [9].

However, these tools do not take into account patient priorities. Previous research found that patients with rheumatoid arthritis (RA), healthy professionals, and healthy controls do not agree on the importance of disabilities [10]. Using a needs-based approach and accounting for patient priorities may help better understand what is important for patients and increase the content validity of scales assessing disability [11].

One functional scale that investigates patient priorities is the McMaster-Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR) [12]. Its developers noted good responsiveness for patients with RA in a controlled trial that revealed a clinically important change, and the scale was found to have validity in a multicenter randomised trial of RA [13]. The MACTAR concept of function may be more comprehensive than that of traditional fixed-item questionnaires and may reveal issues that really matter to the patient. Thus, the MACTAR seems to be a better appropriate tool to develop a real personalized medicine. Some recent studies evaluating patient priorities in disability in knee and hip OA, chronic LBP and systemic sclerosis (SSc) suggested that the MACTAR adds useful information about disability [14–16]. In addition, the MACTAR seems to be a quick tool to complete.

We aimed to assess priorities in disability and restriction in participation for patients with disabling knee OA by the MACTAR and evaluate the instrument's validity and responsiveness in such patients.

2. Methods

2.1. Study design

We asked 200 in- and outpatients admitted to the physical medicine and rehabilitation and rheumatology departments at Cochin and Lariboisière university hospitals in Paris for intensification of treatments of their knee OA between August 2010 and July 2012. The inclusion criteria were knee pain due to OA with pain duration of at least 3 months. The exclusion criteria were age < 35 years, etiology other than OA, inability to understand French or complete a self-administered written questionnaire, and uncontrolled mental disease. Patients had to complete self-administered questionnaires, undergo a 15-min interview with a physician to check for unanswered questions and gather clinical data. Six months later, they received the same questionnaire by mail for completion. This delay corresponds to the time used in daily practice and studies evaluating the effect of pharmacological and non-pharmacological treatment in knee OA.

2.2. Demographic and clinical variables

Variables recorded at baseline were age, sex, knee pain duration, body mass index, Kellgren and Laurence (KL) radiologic score, educational level (baccalaureate degree or lower, higher than university degree), professional status, previous meniscectomy, pharmacological and non-pharmacological treatment.

2.3. Patient-reported outcome measures

Patient priorities in disability were assessed by the MACTAR, developed to evaluate functional priorities in patients with RA [12]. We used the French version [15] and questions were adapted for knee pain (File S1). Patients were first asked about activities affected by chronic knee pain, then asked to rank these activities in order of importance by answering "Which of these activities would you consider most important to be able to do with minimal pain and difficulty?" We used a 3-item priority function. Each item is scored on an 11-point semiquantitative Likert scale (0–10), the global score ranging from 0 (no disability) to 30 (maximal disability) [13].

At follow-up, patients were reminded of the 3 baseline priorities they had identified and were asked to score them (0–10). To assess possible shifts in priorities, participants were asked to define and score on a scale from 1 to 3 other activities that may have become more important to them since the baseline visit. So at 6 months, patients had 2 MACTAR scores, one maintaining baseline activities and another considering shifts in activity priorities.

We classified the activities by the domains of the International Classification of Functioning, Disability, and Health (ICF) [17], considering the linking rules given by the World Health Assembly, in May 2001 [18].

The WOMAC is a 3-D measure. It contains 5 items related to pain, 2 to stiffness, and 17 to physical function [4]. The function subscale is widely used in clinical trials of hip and knee OA [5,19]. We used the short form of the function subscale, containing 8 questions, with scores ranging from 0 to 100 (worse status) and validated in knee and hip OA in French [20].

The Lequesne index is a composite French scale used to assess the concept of algofunctional disability induced by knee OA [6,7]. It includes 11 questions about pain, discomfort and function. The scores range from 0 to 24 (maximum pain and disability) [21]. Its responsiveness and construct validity have been assessed in French [22,23].

A numerical rating scale (NRS) was used to evaluate pain [24,25], global assessment of disease activity and function [20]. The NRS contained 11 points, with scores ranging from 0 to 10 (high level of symptoms).

The Fear-Avoidance Beliefs Questionnaire for physical activity (FABQ-PA) was originally developed for LBP [26], and van Baar et al. [27] used it for patients with knee abnormalities. It consists of 4 items; each scored from 0 to 6. Higher scores represent greater fear-avoidance beliefs. The scale has adequate internal consistency in patients with knee OA [28].

Anxiety and depression were assessed by the Hospital Anxiety and Depression scale (HADa, for anxiety, and HADd, for depression) [29]. This scale has 7 questions for anxiety and 7 for depression. Each question is answered on a scale from 0 to 3. The total score ranges from 0 to 21 (maximal depression, maximal anxiety).