Patient Education and Counseling 77 (2009) 136–143

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Assessment

Development and initial validation of a heart disease knowledge questionnaire for people with rheumatoid arthritis

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ARTICLE INFO

Article history:
Received 23 October 2008
Received in revised form 19 February 2009
Accepted 16 March 2009

Keywords:
Rheumatoid arthritis
Cardiovascular disease
Questionnaire
Psychometric validation
Patient education

ABSTRACT

Objective: To develop and validate two parallel versions of the Heart Disease Fact Questionnaire-Rheumatoid Arthritis (HDFQ-RA), a modified and RA-specific version of the HDFQ.
Methods: The questionnaire was composed of generic questions from the original HDFQ with additional RA-specific questions added. Cognitive interviewing was performed and the questionnaire piloted to generate two parallel questionnaires. For psychometric validation, 130 patients with RA completed the questionnaires at baseline and 2 weeks later.
Results: Parallel form reliability of both questionnaires was established; the median score for both questionnaires was 9/13 with no statistical difference in scores. Kuder–Richardson-20 formula was 0.65 and 0.67 for both questionnaires. Test–retest stability showed constant median scores of 9/13 and no statistical difference in scores between baseline and follow-up. Known groups comparison revealed that patients who had self-educated themselves about heart disease, or who were taking CVD medications, had significantly higher scores on the questionnaires.
Conclusion: The two parallel forms of the HDFQ-RA have been shown to be equivalent measures of CVD knowledge and evidence supporting their reliability and validity is presented.
Practice implications: The HDFQ-RA is an appropriate tool for application in clinical and research settings, e.g., assessing novel educational interventions or tracking participants' progress on an education course.

1. Introduction

The most common cause of mortality in the western world is cardiovascular disease (CVD), and its prevention and management is a national health priority [1,2]. Identification and intensive management of risk factors for CVD is important, particularly in high-risk groups of people such as those with diabetes mellitus. People with rheumatoid arthritis (RA) are also at increased risk of CVD [3], thought to be due to both clustering of traditional risk factors as well as novel risk factors such as inflammation [4,5]. Traditional risk factors may be affected by both the disease itself and/or its treatments, for example, dyslipidaemia may relate to uncontrolled systemic inflammation [5], or hypertension may relate to ongoing use of non-steroidal anti-inflammatory drugs [6] or coxibs [7]. The screening for CVD and its management (both relevant lifestyle changes and necessary pharmacological treatment) is therefore an important component of long term care of all patients with RA [5,8,9]. Underpinning such a CVD screening programme must be patient education; improving patients' knowledge is fundamental to all treatment programmes [10] and is often a pre-requisite for initiating desired behaviour changes [11].

Before implementing patient education programmes it is prudent to show their efficacy [12]; the availability of a relevant valid knowledge questionnaire is an essential tool to evaluate a novel educational intervention. In addition, such a questionnaire would also be useful in clinical practice to identify both patients who know little about CVD in general as well as to help tailor educational opportunities to meet a patient's specific needs within this vast field of knowledge [13].

Validated knowledge questionnaires exist for use among patients with RA, but these are concerned with general knowledge

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0738-3991/$ – see front matter © 2009 Published by Elsevier Ireland Ltd.
doi:10.1016/j.pec.2009.03.014

about RA, signs and symptoms, as well as pharmacological management of joint pain and self-management techniques [14–17]. Use of these questionnaires has revealed a lack of knowledge among patients with RA, particularly about the aetiology of RA and its drug treatment [14], and that patient knowledge increases following a group educational intervention [15,17]. Currently available questionnaires, however, do not include questions about the CVD co-morbidity associated with RA. There is therefore a pressing need to construct a psychometrically sound questionnaire to measure heart disease knowledge in patients with RA, both to evaluate necessary cardiovascular patient education programmes and to identify patients' particularly requiring education.

Existing patient knowledge questionnaires about CVD and its risk factors have been validated in male patients with diagnosed coronary heart disease [18] as well as in high-risk patients with diabetes [13]. This latter psychometrically validated questionnaire, the Heart Disease Fact Questionnaire (HDFQ), has 25 items; 15 questions concern the well-established risk factors of family history, age, gender, smoking, physical activity, lipids, blood pressure, weight and whether a person necessarily knows if heart disease is present; a further 10 questions address diabetes-related coronary heart disease risk factors. The HDFQ employs closed questions with a dichotomous response format, supplemented by an 'I don't know' option. Dichotomous answers are suitable for factual questions, whereas scaled response formats may be less so [15]. Questions are worded to try to minimize acquiescence, which is appropriate [19]. Validation studies of the HDFQ showed a spectrum of item difficulty scores; it is important to have a balance and broad range of item-difficulty scores [17]. The HDFQ demonstrated adequate internal consistency, good content and face validity and criterion related validity in a sample of people with diabetes, and has been recommended for both clinical and research applications [13]. Indeed, use of this questionnaire has not only highlighted groups of patients in greatest need of patient education but also identified timely opportunities where further education is required [20]. This excellent patient knowledge questionnaire is therefore a very valuable resource but it is specific to patients with diabetes. Patients with RA require disease-specific education to also address additional issues as exercise despite joint pain, (where they may have previously received conflicting advice [21]), the novel role of systemic inflammation as a risk factor for CVD, and the complex adverse effects on the vasculature of some medication used in RA such as non-steroidal anti-inflammatory drugs or steroid medication. It is therefore appropriate to modify the HDFQ to develop a RA-specific version, the Heart Disease Fact Questionnaire-Rheumatoid Arthritis (HDFQ-RA). This will require re-validation among patients with RA. Validation of the HDFQ did not include measuring test–retest reliability in a large sample and the authors propose this should be performed in the future [13]. To use a questionnaire as a tool to evaluate an educational intervention requires its stability over time (in the absence of intervention) to be shown [19]. Moreover, repeat administration of the same questionnaire may result in a respondent only 'learning' the answers to the questionnaire during the intervention in an artefactual nature. It would therefore be optimal to develop parallel forms of the questionnaire (HDFQ-RA-1 and HDFQ-RA-2) to be used in a pre- and post-intervention fashion [17,22]; these must show parallel form reliability and both must be validated and shown to be stable over time in the absence of intervention.

The purpose of this study was to develop and validate two parallel versions of the HDFQ-RA questionnaire which can be used clinically and in a research setting to measure knowledge of heart disease in patients with RA.

2. Methods

The present study used a multi-stage questionnaire development and validation process for which local research ethics committee approval was given.

2.1. Questionnaire design

The initial questions collected demographic data on the respondents, including sex, age, marital status, highest level of educational qualification, ethnicity and job/role. Self-reported diagnoses of CVD and CVD risk factors, medication and attendance at different health education opportunities were also requested.

Two domains of questions were generated; generic risk factors for CVD and risk factors for CVD specific to patients with RA. Questions in the first domain were the initial 15 questions from the original HDFQ, including the transfer of the question on diabetes as a risk factor for CVD, which was originally in the diabetes-specific subscale. Subsequent diabetes-specific questions in the HDFQ were not retained. Nine questions in the second domain addressing CVD risk factors for a person with RA were generated on the basis of face validity following group discussion amongst the authors (HJ, GJT, EDH). A focus group of five consultant rheumatologists was next convened to discuss the questionnaire for content validity. The panel felt the questions addressed the full spectrum of CVD risk factors for a patient with RA, both novel risk factors and traditional risk factors that may be adversely modified by systemic inflammation or the medications use to treat RA. The panel did, however, suggest amending the language of the generic CVD risk factor questions into more lay language by changing "...you are at risk for developing heart disease..." to "...you are more likely to develop heart disease..." Additionally, the language used in the questions collecting demographic data was simplified and any medical jargon minimized.

This version of the questionnaire was then used for individual cognitive interviewing ('think-aloud' interviewing). This technique allows the interviewer to gain an understanding of how a participant perceives and interprets the questions and so is a valuable method of pre-testing a questionnaire [23]. Four patients with RA (two men and two women) gave informed consent for an audio-recorded individual cognitive interview, all of which lasted around 1 hour. The participants both 'read aloud' the questions and 'thought aloud' their response. Appropriate probing by the interviewer (HJ) was used to clarify any hesitancies in answering a question as well as identifying any ambiguities or omissions with the wording or problems with the layout of the questionnaire. These interviews were used to identify questions that worked well [24] and a list of recommendations to improve the questionnaire was compiled and implemented (Table 1).

This modified 24-item questionnaire was then piloted on 50 consecutive patients with RA attending an outpatient clinic. Data analysis was performed using SPSS for windows version 13.0. Each response to each question was coded as correct or incorrect ('I don't know' was coded as incorrect in reflection of the individual not knowing the correct answer). The responses of one respondent gave an overall score more than three standard deviations away from the mean; this respondent was treated as an outlier and their answers removed from analyses. Two further questions were added after this initial pilot; one question on generic risk factors for CVD and one question on RA-specific risk factors for CVD (see Table 3). Within each of the two domains of questions, responses to items were compared (using percentage of respondents to score the correct answer) to identify concordant pairs of questions, with similar levels of difficulty for the parallel forms of the HDFQ-RA. Two parallel questionnaires were then developed by splitting the paired questions into two sets of questions, ensuring the question