Patient Knowledge about Atrial Fibrillation: Construction of a New Questionnaire and First Results

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Abstract

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1. BACKGROUND

Atrial fibrillation (AF) is a common heart arrhythmia in our society with a lifetime risk of 25\% to develop it above the age of 40. AF is associated with a high mortality and morbidity. The fact that patients understand the arrhythmia, its consequences, its treatment and what they have to do in specific situations is essential in the management of these patients. It is essential for shared decision making, improves adherence, self-care and quality-of-life. Currently, few instruments exist to easily assess the knowledge of patients with AF and that cover all these important aspects. Additionally, a lot of existing questionnaires are not practical to evaluate the knowledge concerning AF, i.e. they consist of open questions which are difficult to evaluate. We developed and validated a new AF questionnaire to address these needs, and evaluated it in a pilot study.

2. MATERIALS AND METHODS

A new AF knowledge questionnaire was developed by our research group after review of existing instruments \textsuperscript{(1-6)}. The Jessa AF knowledge questionnaire (JAKQ) was subjected to a content and face validation and was used to get a first insight in the knowledge levels of 40 AF patients at Jessa hospital Hasselt. Both AF patients hospitalised at the cardiology ward and patients with known AF who came for an outpatient visit at the cardiology department were asked to complete the questionnaire. Patients not able to speak Dutch were excluded. Ethics approval (B243201423036) was granted by the local ethics committee of Jessa Hospital Hasselt. A written informed consent was obtained.

The questionnaire has been implemented on an iPad, allowing for immediate transfer of the data to Excel. The questionnaire was filled out by the patient independently, or together with the investigator. SPSS 22.0 software (SPSS Inc, Chicago, IL, USA) was used to perform the statistical analyses of the data. Normal distribution was tested by means of the Shapiro-Wilk test. Student’s t-tests were applied to compare normally distributed variables and Mann-Whitney U tests were used to compare independent continuous variables, when appropriate.

3. RESULTS

3.1 Development of the questionnaire

The new JAKQ was developed based on: 1) other existing questionnaires \textsuperscript{(1, 2, 6)}, 2) patient information on support websites concerning AF (EHRA, The AF association in the UK, Anticoagulation Europe) and 3) an educational checklist for healthcare professionals for use in educating patients starting on non-vitamin K oral anticoagulation therapy \textsuperscript{(7)}. 
The questionnaire starts with five general questions asking for the patient’s name, gender, age, degree and whether the patient is known with AF. This is followed by 12 questions about AF with items about the arrhythmia, the possible consequences, the symptoms and how they should handle it. Finally there are 12 questions about oral anticoagulation (OAC) therapy, its potential benefits/side effects and self-management when taking OAC. These last 12 questions consist of seven general OAC questions and five questions concerning the specific OAC therapy of the patient (vitamin K antagonists or non-vitamin K oral anticoagulants). In case the AF patient does not take any OAC, only the first 12 questions have to be completed. The questionnaire consists of multiple choice questions with three possible answers and one ‘I do not know’ option. There is only one correct answer, which counts as one point. An incorrect or ‘I do not know’ answer counts for zero points.

3.2 Validation of the questionnaire
The questionnaire has been validated by means of a content validity and face validity study. In a first phase to evaluate for content, the questionnaire was presented to a panel of five cardiologists-electrophysiologists and 12 nurses with knowledge about the management of AF patients. They were asked if all facets concerning AF management were present in the questionnaire. They had only minor comments on the different questions and no items had to be added or removed. Changes were implemented before the questionnaire was given to patients.

For the face validity, AF patients who completed the questionnaire were asked to validate for question clarity, readability and time required for completion. No major complaints were received about the complexity or length of the questionnaire. Minor complaints about individual questions were noted and corrected by the investigators. There were no questions to which all patients gave the correct answer or to which none of the initial 40 patients gave the correct answer.

3.3 First results with the questionnaire: a pilot study
In a pilot phase, the JAKQ was completed by 40 patients (69 ± 10 years; 19 men), of which 19 patients came for an outpatient cardiology visit and 21 patients who were hospitalised at the cardiology ward for various reasons. Almost half of the patients had a secondary school degree or more, while about a quarter of the patients only had finished primary school and the final quarter had completed higher education (Figure 1). The mean score on the AF questionnaire of the entire group was 52.1 ± 20.6%, with a minimum score of 1 (4.2%) and a maximum score of 21 out of 24 (87.5%). No difference was noted between outpatients and hospitalised patients (p = 0.327). Intriguingly, one out of four patients was unaware that he/she did have AF (Figure 2). These were all patients with a lower education degree (70% primary school and 30% secondary school degree).

![Figure 1: Educational degree](image1.png)

![Figure 2: Awareness about AF](image2.png)
Only 32.5% of the patients knew that AF is an age-related disorder. Almost six out of ten patients (57.5%) did not know that AF can be asymptomatic. One in three patients (32.5%) did not know that AF can lead to stroke.

As expected, older patients (≥70 years; n=19) scored significantly less than younger ones: 43.4 ± 22.8% vs. 59.9 ± 15.0% (p = 0.01, Figure 3). This was true for both sections of the questionnaire (p = 0.022 respectively 0.031 for the general and for the OAC parts).

![Figure 3: Difference in AF knowledge scores between younger (age < 70 years) and older patients (age ≥ 70 years). AF knowledge scores are represented as % correct answers. Blue bars represent the mean score on the total questionnaire. Red bars represent the mean score on the 12 questions about atrial fibrillation in general. Mean scores on the 12 questions specifically related to oral anticoagulation are represented by the green bars. All bars are displayed as mean ± standard deviation. AF: atrial fibrillation, OAC: oral anticoagulation.* p < 0.05.](image)

4. DISCUSSION
Optimal care of AF requires patients with a proper understanding about their arrhythmia, its treatment and its management. Adequate patient knowledge allows shared decision making, improves treatment adherence, reduces anxiety and improves self-management capabilities and quality-of-life. Nevertheless, patient knowledge is hardly systematically evaluated, partly because there are no specific tools. We developed and validated a new questionnaire that clearly shows knowledge gaps, in most AF patients and even more so in the elderly population. Such information may allow directed and tailored education to optimise knowledge. Older patients are also often those with more comorbidities who have to take a variety of medications and who will have more difficulties to stick to the management plan. This in turn can result in non-adherence to medication and inadequate self-care. After our pilot phase, the questionnaire will be subjected to a more extensive sensitivity testing, needed to assess whether the questionnaire can accurately discriminate knowledge levels, and especially whether tailored patient education can improve those.

5. CONCLUSION
We report the construction and first validation of a new AF knowledge questionnaire. Preliminary results already show important knowledge gaps in patients with AF, both concerning their condition itself as concerning its treatment. The aim of the questionnaire is to efficiently assist in tailored patient education, hence contributing to improved care and outcomes.
6. REFERENCES