Effect of reinforced, targeted in-person education using the Jessa Atrial fibrillation Knowledge Questionnaire in patients with atrial fibrillation : a randomized controlled trial

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Abstract

Background: The knowledge level of atrial fibrillation (AF) patients about their arrhythmia, its consequences and treatment is poor. The best strategy to provide education is unknown.

Aim: To investigate the effect of reinforced targeted in-person education using the Jessa Atrial fibrillation Knowledge Questionnaire (JAKQ).

Methods: Sixty-seven AF patients were randomized to standard care (including brochures) or targeted education. Follow-up visits were scheduled after 1, 3, 6 and 12 months. Targeted education during each visit focused on the knowledge gaps revealed by the JAKQ. Patients completed two questionnaires to assess their quality of life (QOL) and symptom profile. Adherence to non-vitamin K antagonist oral anticoagulants was measured using electronic monitoring.

Results: Sixty-two patients (31 education; 31 standard care) completed follow-up. Median baseline score on the JAKQ was similar in education (62.5%) and standard care group (56.3%; P=0.815). The intervention group scored significantly better over time (1 month: 75.0%, 12 months: 87.5%; P<0.001) whereas there was no significant improvement in the control group (1 month: 62.5%, 12 months: 62.5%; P=0.085). Providing targeted education after completion of the JAKQ required on average 6.9±4.6 min. Some improvements on QOL, symptom burden and adherence were shown, without significant differences between both groups (P-values between 0.282 and 0.677).

Conclusion: The JAKQ is an effective tool for providing individualized education. A first targeted educational session significantly improved patients' knowledge level. Additional educational sessions maintained and strengthened this effect. A larger scale study is warranted to evaluate the impact on adherence and outcome measures.

Keywords: Atrial fibrillation – knowledge – education – self-management

Introduction

Atrial fibrillation (AF) is putting a large burden on the healthcare system and its prevalence is further increasing.[1] Optimal care of AF patients includes a proper understanding by the patient about the arrhythmia, its treatment and its management.[2,3] The 2016 European Guidelines on the management of AF indicate that a more integrated patient education is warranted.[2] Better patient knowledge can contribute to enhanced self-management and shared decision making.[2] Nevertheless, education is not systematically provided during the current care of AF patients and is likely suboptimal to achieve proper patient knowledge.[4,5] Different studies showed that the knowledge and insight of AF patients about their arrhythmia and its management are poor even after receiving verbal and/or written information.[5-14] Various educational interventions that were previously tested only led to mixed results and a feasible and effective manner of providing education is difficult to establish.[8-10,15-18] A consensus paper of the European Heart Rhythm Association stated that education should be provided in a standardized, structured and tailored way.[3] Validated questionnaires can be helpful in this respect as a way to map knowledge deficits and to target education specifically to the needs of every patient but such strategy has never been evaluated in daily practice.[3] Therefore, the main aim of this study was to investigate the effect of reinforced, targeted, in-person education of AF patients on their knowledge level. Enhancing disease-related knowledge is an important part of an integrated approach to optimize overall care and to improve other clinical outcome parameters in patients with chronic conditions, such as AF.[15,16,19-21] This has previously been demonstrated in for example heart failure patients.[22,23] Therefore, a possible influence on quality of life (QOL), symptom burden, and medication adherence was additionally explored in this study.

Methods

Design and study population

A prospective randomized controlled study was performed at a large Belgian tertiary care hospital between January 2016 and April 2017. Patients with AF hospitalized at the cardiology ward or seen at the out-patient clinic were recruited for this study. Patients were excluded if they were younger than 18 years, not capable to sign the informed consent, unable to speak Dutch or when they were cognitive-

impaired. A chart review was performed to evaluate demographic variables and the medical history of every patient. The study complied with the Declaration of Helsinki. Ethical approval was obtained from the local ethical committee and all patients provided written informed consent.

Study procedure and targeted education

After inclusion at baseline, all AF patients were requested to come to the hospital for a study visit (i.e. data collection for the control group and additional education for the intervention group) during fixed time points: after 1, 3, 6 and 12 months (Figure 1). In the event that a patient was too ill or not able to come to the hospital for a follow-up visit, this in-person visit was replaced by a telephone follow-up. Patients had to complete three questionnaires during each visit to assess their QOL, symptom burden, and knowledge level about AF and oral anticoagulation (OAC) therapy. From the first till the third month, patients' adherence to their non-vitamin K antagonist oral anticoagulant (NOAC) was measured, if possible (i.e. only adherence to apixaban and rivaroxaban could be monitored). Details about the questionnaires and adherence measurements are described below.

Patients were randomly assigned in a 1:1 allocation to an education group (intervention group) or a standard care group (control group). Patients were allocated based on a computer-generated number randomization list with block sizes of four, six and eight prepared by a researcher who was not clinically involved. Stratification occurred based on age, highest educational degree and time since the diagnosis of AF. In the intervention group, on top of standard care, the study team consisting of two allied health professionals (L.D., L.E.), reinforced education based on the incorrectly answered questions of the Jessa Atrial fibrillation Knowledge Questionnaire (JAKQ; Supplementary Table 1).[12] More specifically, after completion of the JAKQ, the study team went through the questionnaire together with the patient and indicated for each question if the answer was correct or not. If the answer was correct, the study team immediately moved on to the next question. If the answer was wrong, the correct answer was indicated and shortly motivated. No additional educational materials were used. To assure consistency between the two allied health professionals in delivering the intervention, the following training was provided by the electrophysiology team before the start of the trial: i) literature study, ii) attending out-patient visits (on a regular basis for 4 weeks) at which an experienced electrophysiologist provided general AF education, iii) during the following 4 weeks the study members regularly provided patient education themselves (by means of the JAKQ) under supervision of an electrophysiologist. In the control group,

patients received standard care with no extra focused reinforcements and knowledge evolution was only monitored. Standard care in our hospital includes information from the cardiologist during outpatient visits or hospitalizations, and an information booklet about AF and OAC therapy (Supplementary appendix 1) which was provided at the first visit.

Measured parameters

Together with the AF knowledge assessment (using the JAKQ), other parameters such as symptom burden (using the Leuven ARrhythmia Questionnaire (LARQ)), QOL (using the SF-12 questionnaire) and adherence to NOACs were evaluated. Time to complete the JAKQ and to provide targeted in-person education were measured. The JAKQ and the LARQ were implemented electronically and patients could complete these questionnaires using a tablet. The SF-12 was in paper format. Patients had to complete the questionnaires individually without any help from family members or healthcare professionals. Assistance by the study team was only provided to mark their answers on the tablet if needed.

Knowledge level about atrial fibrillation

The 16-item JAKQ underwent a thorough validation process which was previously published[12], i.e. content validation, face validation, response process, construct validity, internal consistency (Cronbach's α 0.674-0.792[12,24]), test-retest reliability, sensitivity testing and discriminatory potential. The JAKQ consists of 16 questions: 8 about AF in general, 5 about OAC therapy and 3 about vitamin K antagonists (VKA) or NOACs depending on the medication use of the patient.[12] Patients without OAC indication only had to complete the first 8 questions of the JAKQ. In patients who completed both 8 and 16 questions during the trial - because they had to start or stop OAC - only the first 8 questions were taken into account for data analyses. The JAKQ contains only multiple choice questions with one correct answer, two distracters and one 'I do not know' option. A correct answer was scored as 1 point; incorrect and 'I do not know' answers as 0 points. The total score on the JAKQ was divided by the number of completed questions, resulting in a percentage.

Quality of life

The SF-12v2 consists of 12 questions to evaluate eight health and well-being concepts including physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health.[25,26] Additionally, the physical

component summary (PCS) and mental component summary (MCS) score were calculated. For each item, the weighted sum of the questions was calculated and transformed in a 0-100 scale. The higher the score, the better the QOL. The recall period was four weeks. The SF-12v2 was previously evaluated in the US National Health and Wellness Survey in AF patients[27], and the questionnaire was able to show an impact of AF-related interventions such as a pulmonary vein isolation[28] and a percutaneous closure of the left atrial appendage[29].

Symptom burden

The LARQ is based on the six most important AF-related symptoms: palpitations, shortness of breath, chest pain, syncope, dizziness and fatigue.[30] The LARQ was previously validated based on content, face, construct (known-groups and convergent) validity, and internal consistency reliability (Cronbach's α 0.909-0.952).[30] For each of these symptoms (except syncope), symptom prevalence, occurrence (frequency, duration, severity), distress, circumstances triggering the symptom, and effect on daily activities were requested. Questions were based on a recall period of four weeks. By means of specific algorithms, subscale scores on five domains (symptom frequency, duration, effect on daily activities, severity and distress) were calculated by summing the raw scores and transforming them to a 0-100 scale. Higher scores represent a more pronounced symptom burden.

Adherence

Adherence to NOACs was measured in AF patients taking apixaban (twice daily NOAC) and rivaroxaban (once daily NOAC) by means of electronic monitoring. Adherence to apixaban was measured with the "Helping Hand" device (WestRock, Switzerland). This device in the form of a blister sleeve measures the exact date and time whenever a patient removes the blister from the device to take his/her medication. Adherence to rivaroxaban was measured with the medication event monitoring system (WestRock, Switzerland), which is a special cap that fits on a medication bottle recording the exact date and time of bottle openings. Devices without a display were used. Dabigatran adherence could not be measured with the monitoring devices, as this drug should be stored in the original package to protect it from moisture and the blister does not fit into the Helping Hand. Edoxaban was not yet approved for use at the time of study initiation. Taking adherence (proportion of prescribed doses taken), regimen adherence (proportion of days with the correct number of doses taken) and number of unprotected

days (≥3 or ≥1 consecutively missed doses for apixaban or rivaroxaban, respectively, or excess doses during the prior 24 hours) were calculated based on the retrieved data assuming that every bottle opening or blister removal represents a medication intake.[31] Pill counts were performed during the three month follow-up visit.

Statistical analysis

According to the power calculation (power of 80%; alpha of 5%), at least 56 AF patients (28 in each study group) had to be included to achieve a 25% increase in the primary outcome of knowledge level after one year compared to baseline.[12] This estimated effect size was based on previous pilot data showing a 29.4% increase after a few days and a 24.9% increase after 1 month.[12] An additional drop-out margin of 15% was taken into account, resulting in a minimal inclusion rate of 66 patients. The study was not powered for the secondary outcome measures. Statistical analyses were performed using SPSS 25.0 (IBM, Armonk, USA). Continuous variables were reported as means ±standard deviation (SD) or median and interquartile range (IQR), as appropriate. Categorical variables were reported as numbers and percentages. Normal distribution was assessed using the Shapiro-Wilk test and Q-Q plots. Independent t-tests and Chi-squared tests were used to evaluate possible demographic differences between the two study groups. To investigate the effect of targeted education or standard care over time on the knowledge level, QOL and symptom burden, Friedman tests or repeated measures analyses of variance (ANOVAs) were used, when appropriate. Bonferroni correction was used to counteract the problem of multiple testing. Comparisons between groups were performed with Mann-Whitney U tests, independent t-tests, Chi-squared tests, mixed model or mixed ANOVAs, as appropriate. A P-value <0.05 was considered statistically significant.

Results

Patient characteristics

Of the 129 AF patients asked to participate, 62 patients (36 hospitalized and 26 outpatients) were excluded as they did not want to participate (37%) or were too ill (29%) (Figure 2). Of the 67 included patients (26 hospitalized and 41 outpatients), 33 were randomized to the intervention group and 34 to the control group. There was a dropout rate of 7.5% and 31 patients in each group completed all follow-

up visits. Eventually, 94.4% of the follow-up visits occurred in-person and 5.6% (4.0% in the control and 1.6% in the intervention group) by telephone follow-up. The included AF population was 72.1±8.6 years old and most patients (73.1%) received the AF diagnosis more than 1 year before study initiation. Patients randomized to the control group and the education group were well matched on different demographic characteristics (Table 1).

Effect on knowledge level

Patients needed 6.9±3.0 min to complete the JAKQ. Eight patients completed the 8-item JAKQ and 54 patients the 16-item JAKQ with OAC questions. Providing targeted in-person education required an extra 8.5±4.9 min at baseline, 8.5±6.0 min at 1 month, 6.2±3.0 min at 3 months, 6.7±4.1 min at 6 months and 4.5±3.1 min at 12 months. The score on the JAKQ at baseline was similar for the education [median (IQR): 62.5% (50.0-68.8); mean±SD: 58.5±15.9%] and the control group (median (IQR): 56.3% (50.0-75.0); mean±SD: 58.5±18.6%; P=0.815) (Figure 3). It was significantly higher in the education group after 1 [75.0% (68.8-87.5) vs. 62.5% (43.8-75.0); P=0.002], 3 [81.3% (75.0-93.8) vs. 62.5% (50.0-81.3); P<0.001], 6 [87.5% (68.8-100.0) vs. 62.5% (43.8-75.0); P<0.001] and 12 months [87.5% (75.0-100.0) vs. 62.5% (43.8-75.0); P<0.001] compared to the standard care group. The intervention group scored significantly better over time (P<0.001) whereas there was no significant improvement in the control group (P=0.085). One targeted education session significantly improved the knowledge level (P=0.001 between baseline and 1 month). Additional education sessions further increased and maintained this knowledge level (P=0.080 between 1 and 12 months). The knowledge score over time was significantly different between both groups (P=0.0006).

Targeted education improved the knowledge level for all different AF aspects. At the end of the study, significantly more patients in the education group knew that AF can be asymptomatic compared to baseline (74.2% vs. 25.8%; P<0.001). At the start, only 41.9% of all patients indicated that one can detect AF by regularly taking his pulse; this was 74.2% after reinforced education (P=0.010). At the start, only one in four patients (25.8%) knew that AF will increasingly recur with ageing, despite medication; this was 64.5% after 12 months (P=0.002). Furthermore, at 12 months 96.3% of the patients on OAC vs. only 63.0% at baseline were aware of the possible bleeding complications associated with the therapy (P=0.002). Finally, 77.8% of the patients taking VKA or NOAC knew what to do when missing a dose; this was only 25.9% at the start of the study (P<0.001).

Impact on quality of life

At baseline, none of the eight items of the SF-12 questionnaire were significantly different between both study groups (P-values between 0.276 and 0.908), with both the PCS and MCS showing comparable results (control vs. education: 45.3±7.4 vs. 45.0±9.6, P=0.909 respectively 47.5±8.0 vs. 47.7±11.0, P=0.927) (Supplementary Figure 1). The PCS did not change significantly over time in either group (control: P=0.873; education: P=0.077). The MCS did not change significantly over time in the control group (P=0.094), but there was a significant increase in the MCS score between baseline and three months (P=0.008) and one month and three months (P=0.026) in the in-person education group. The PCS and MCS score over time were however not significantly different between both groups (P=0.462 and P=0.677 respectively).

Effect on symptom burden

The overall symptom burden on the LARQ was the highest at baseline and decreased over time (standard care: P=0.007, education: P=0.239; Supplementary Figure 2). However, the overall symptom burden score over time was not significantly different between both groups (P=0.669). A detailed representation of the symptom experience per symptom and per burden domain during the different follow-up visits is shown in Supplementary Figure 3.

Impact on adherence

Adherence to NOACs was measured in 29 patients, 14 in the control group (10 rivaroxaban, 4 apixaban) and 15 in the education group (10 rivaroxaban, 5 apixaban). Taking adherence (P=0.464), regimen adherence (P=0.619) and pill count (P=0.282) were numerically higher in the education group, but not significantly so due to the small groups and large variability in adherence measures (Supplementary Figure 4). The number of unprotected days was also not statistically lower in the intervention group (P=0.417).

Discussion

Patients' knowledge about AF and OAC therapy is of pivotal importance for their overall management. However, this aspect is often overlooked and not systematically addressed due to time constraints of physicians and the lack of proven efficient educational interventions.[3,5]

Patient knowledge regarding atrial fibrillation

The score on the JAKQ (58.5%) at baseline in both study groups was comparable with two previous large population surveys with the JAKQ (55.8%-61.6%).[12,14] This indicates that a representative subset of patients was included in this study, despite the fact that almost half of the patients was not willing or not able to participate. Although standard care consisted of an information brochure on top of information from the cardiologist, very important knowledge gaps were still present. The standard care in our study was probably better than the average daily care in most centers since a European survey showed that only 22.7% of cardiology centers make use of a patient information brochure.[32] Notwithstanding, 43.4% of the centers indicated they had a structured program for patient education.[32] The lack of knowledge by patients concerned various aspects of AF care and OAC therapy, as previously also shown by other studies making use of (validated) questionnaires.[5-14]

Educational strategies for atrial fibrillation

Our study shows that the JAKQ is a good instrument to guide education in a more individualized and targeted manner. After one targeted in-person education session, the knowledge level had significantly improved. Additional education sessions at 1 and 3 months further increased the knowledge level and this improved level was maintained during the following visits due to repeated reinforced education, stressing the importance of the repetitive character of such intervention. It was somewhat surprising to note that providing the JAKQ to the control group during each visit did not improve their scoring over time. Although we have not systematically evaluated this aspect, it seems that JAKQ taking by itself hardly triggered those patients to look up deficient knowledge in the brochures that were provided to them, by asking health care workers, or by active searching on online resources.

Various other educational methods, frequently focusing on OAC therapy, have been evaluated in AF patients, with mixed results: brochures[8-10,15], educational videos[9,10], group education sessions[9], general face-to-face education[15,16], a complex general practice driven program[17] and a mobile application[18]. An intervention in which an information booklet was given to and discussed with the patient had no significant impact on the awareness about AF and the potential side effects and benefits of OAC therapy.[8] McCabe et al. evaluated the effect of education by nurses in hospitalized patients with recently detected AF using AF and OAC brochures together with a video about OAC therapy: two weeks after the hospitalization, knowledge was not retained.[10] Hendriks et al. showed that a nurse-led

AF chronic care program including reinforced in-person education at regular time points, can lead to a significant increase (with 14.1%) in AF-related knowledge after one year.[16] This education was more comprehensive including general information about AF, treatment options, and lifestyle interventions combined with psychosocial support.[6,16] The educational visits in that study took 30 minutes of time, which of course impacts personnel costs. In Hendriks' study, the knowledge level of the control group also significantly improved with 10.8%, which was not the case in our study.

Feasibility of reinforced targeted education based on the JAKQ

The JAKQ has proven to be a fast and valid tool to assess existing knowledge of AF patients in about 6-7 minutes. Moreover, by targeting the education to only the knowledge deficits of the patient, limited time of an allied health professional (i.e. up to 8.5 min) was needed during each visit. Only a short training period of the health care providers is required to implement this way of education as the JAKQ provides guidance. Targeted education based on the JAKQ is therefore feasible to be used in daily care both from the perspective of the hospital and the patient. All patients will receive education in a uniform way without overwhelming them with too much or superfluous information and by only focusing on the important key aspects in their management. By implementing the JAKQ in a tablet application, as performed in this study, patients are able to complete it at home or in the waiting room before their visit. During the visit, a healthcare practitioner can then provide immediate targeted education. This way, providing targeted education was implemented as an integral piece of the entire care framework of a specialized AF clinic.[33,34]

Impact of education in atrial fibrillation patients

Only a few studies have investigated so far the effect of an educational strategy on clinical outcome parameters. Although our study was not powered for these secondary outcome parameters, some statistically significant differences were found in QOL and symptom burden. Emotional health was lowest and symptom burden highest at baseline in both groups. It is difficult, however, to draw definitive conclusions about the effect size of the education intervention itself on improvements in QOL and symptom burden. E.g., 38.8% of the participants were included during an (un)planned hospitalization, which is a state of high symptom burden, which tends to regress towards a more stable out-patient setting. The contribution of education to improved patient coping with AF-related symptoms remains to

be determined. In any case, education seems to be an important driver of improved QOL. The nurse-led integrated chronic care program by Hendriks et al. that included patient education as an important pillar, also showed that the QOL (measured with the SF-36 questionnaire) significantly improved over time in both the intervention group and the standard care group.[16] This also led to a decrease in anxiety over time in both study groups.[16]

Optimal adherence to OAC medication, especially with NOACs, is of great importance to achieve the prognostic benefit of anticoagulation. Therefore, half of the JAKQ questions are attributed to OAC. A systematic review from 2017, however, did not find any effect of educational and behavioral interventions on time in therapeutic range in AF patients taking VKA.[35] Three large trials investigated the effect of an educational intervention on NOAC adherence.[21,36,37] Although the AEGEAN trial did not show any impact of a structured educational program (i.e. booklet, reminder tools and follow-up telephone calls) on adherence to apixaban[36], the IMPACT-AF trial (majority of patients still on VKA) showed that an educational intervention for both patients and healthcare providers improved OAC use in AF patients.[21] The FACILITA study showed that a mixed intervention, consisting of patient education and a simple calendar reminder, led to a dabigatran regimen adherence of 89.2% compared to 63.2% in a control group after one year.[37] In our study the effect of targeted education was evaluated on NOAC adherence measured with electronic monitoring, showing lower values in the standard care group but not significantly different from the education group, possibly due to the small sample size and the short monitoring period. Electronic adherence monitoring can also be used as a tool to promote a good adherence by discussing the measured data together with the patient or even by providing direct feedback based on telemonitoring, as part of an educational program.[38]

Study limitations

This is a single center study with a small sample size, although it was correctly sized for the primary outcome. Almost half of the eligible patients did not participate. Beyond a study setting this probably would have been lower, i.e. the possibility to be randomized to a control group could have had an impact and in daily practice education sessions can be coupled to planned hospital visits. Generalizability of these results to other settings should be made with caution as the impact of this intervention can depend on the experience and enthusiasm of the healthcare workers providing education. In our hospital no standardized educational program for AF patients is implemented yet beyond regular physician contacts

and provision of information brochures. Although electronic monitoring is assumed as one of the most accurate ways to measure adherence, it is always possible that patients do not use the device correctly for a certain period or do not take their medication although a device registration occurred.[39] Moreover, using such devices can already lead to an increased patient awareness to take their medications better than usual.[38]

Future perspectives

A large randomized controlled multicenter trial could be set up to evaluate the impact of targeted in-person education as part of daily care on different clinical outcome data (e.g. complications, hospitalizations, emergency room visits) and on other secondary outcome measures for which this trial was not powered. Fuenzalida et al. recently showed that nurse-led education at discharge of the emergency department significantly decreased AF-related complications, treatment-related complications, and death.[15] Further, the cost-effectiveness of such interventions should be evaluated. We have currently started such a large-scale prospective trial, including integral targeted patient education, funded through the Flemish government. It demonstrates the interest of health authorities in finding ways to optimize implementation of guideline-based care through enhanced patient involvement.

Conclusion

The JAKQ is a suitable tool to provide individualized education for AF patients. A first targeted in-person educational session based on the JAKQ significantly improved patients' knowledge level. Additional educational sessions maintained and strengthened this effect. This study showed some improvements on QOL, symptom burden and likely medication adherence, although not significantly different between both groups. Integrated targeted education opens the perspective for improving clinical outcomes and prognosis of AF patients.

Implications for practice

- The best strategy to provide education for atrial fibrillation patients is unknown.
- The JAKQ proved to be an effective tool to provide individualized education.
- Reinforced targeted in-person education is feasible to implement in daily practice.

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The JAKQ with questions and full answers is not in the public domain, but can be obtained from Hasselt University through a user agreement. If interested, please send an e-mail to jakq.uhasselt@gmail.com. WestRock Switzerland Ltd. supported this study with devices, but they were not involved in study planning, conduct, analysis or reporting.

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Figure legends

Figure 1

Study design. The green striped vertical bars indicate the moments when each AF patient received targeted education based on specific knowledge gaps of that patient. The blue period represents the two months of adherence measurement (only adherence to apixaban and rivaroxaban could be monitored).

JAKQ: Jessa Atrial fibrillation Knowledge Questionnaire, LARQ: Leuven ARrhythmia Questionnaire

Figure 2

Patient inclusion flow chart.

AF: atrial fibrillation

Figure 3

Score on the Jessa Atrial fibrillation Knowledge Questionnaire over time in the standard care group (blue dots) and the group receiving targeted in-person education (green triangles). Data are represented as scatter dot plots with indicated median and interquartile range. Statistical analysis: Friedman tests for differences over time within each group and mixed model for comparison between groups.