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Association between subjective risk perception and objective risk estimation in patients with atrial fibrillation: a cross-sectional study

David Zweiker,[1] Robert Zweiker,[1] Elisabeth Winkler,[1] Konstantina Roesch,[1] Martin Schumacher,[2] Vinzenz Stepan,[3] Peter Krippl,[4] Norbert Bauer,[5] Martin Heine,[6] Gerhard Reicht,[7] Gudrun Zweiker,[8] Martin Sprenger,[9] Norbert Watzinger[10]

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For numbered affiliations see end of article.

Correspondence to
Dr Norbert Watzinger;
norbert.watzinger@lkh-feldbach.at

ABSTRACT

Objective Oral anticoagulation (OAC) is state-of-the-art therapy for atrial fibrillation (AF), the most common arrhythmia worldwide. However, little is known about the perception of patients with AF and how it correlates with risk scores used by their physicians. Therefore, we correlated patients' estimates of their own stroke and bleeding risk with the objectively predicted individual risk using CHA_2DS_2-VASc and HAS-BLED scores.

Design Cross-sectional prevalence study using convenience sampling and telephone follow-up.

Settings Eight hospital departments and one general practitioner in Austria. Patients' perception of stroke and bleeding risk was opposed to commonly used risk scoring.

Participants Patients with newly diagnosed AF and indication for anticoagulation.

Main outcome measures Comparison of subjective risk perception with CHA_2DS_2-VASc and HAS-BLED scores showing possible discrepancies between subjective and objective risk estimation. Patients' judgement of their own knowledge on AF and education were also correlated with accuracy of subjective risk appraisal.

Results Ninety-one patients (age 73±11 years, 45% female) were included in this study. Subjective stroke and bleeding risk estimation did not correlate with risk scores ($\rho=0.08$ and $\rho=0.17$). The majority of patients (57%) underestimated the individual stroke risk. Patients feared stroke more than bleeding (67% vs 10%). There was no relationship between accurate perception of stroke and bleeding risks and education level. However, we found a correlation between the patients' judgement of their own knowledge of AF and correct assessment of individual stroke risk ($\rho=0.24$, $p=0.02$). During follow-up, patients experienced the following events: death (n=5), stroke (n=2), bleeding (n=1). OAC discontinuation rate despite indication was 3%.

Conclusions In this cross-sectional analysis of OAC-naive patients with AF, we found major differences between patients' perceptions and physicians' assessments of risks and benefits of OAC. To ensure shared decision-making and informed consent, more attention should be given to evidence-based and useful communication strategies.

Trial registration number NCT03061123.

Strengths and limitations of this study

► The design of this cross-sectional study allowed the objective assessment of the patients' risk perception immediately after initiation of anticoagulation for atrial fibrillation.
► For generalisability, primary, secondary and tertiary healthcare centres were included in this study.
► To evaluate long-time outcome, follow-up was obtained via telephone.
► The study is statistically powered for the cross-sectional comparison, but the number of patients included does not allow association between baseline characteristics and events during follow-up.

INTRODUCTION

Atrial fibrillation (AF) is the most common significant arrhythmia worldwide, associated with a fivefold increase in risk for stroke[1] and almost doubles the risk of mortality.[2] In an ageing population, the number of individuals affected is projected to increase exponentially over the next decades.[3] Since the early 1990s, oral anticoagulation (OAC) is the state-of-the-art therapy for reducing stroke and embolic events.[2] OAC is considered a long-term, often lifelong medical intervention. Therefore, clinicians and particularly patients need to have a clear understanding of the related benefits and imminent harms.[4] It serves as a reasonable background for shared decision-making of patients and their doctors, one of the most important principles for patients' reliance, compliance and adherence to recommended medical strategies.[5 6]

Adequate information of patients[7] and increased health literacy[8] are of major importance for compliance and adherence to therapy. Patients' knowledge also affects the perception of risk for stroke, embolic

events and bleeding. It has been shown that the extent of information perceived influenced patients' preferences towards or against OAC treatment the most.[9]

Clinicians use algorithms like CHA_2DS_2-VASc (congestive heart failure, hypertension, age ≥75 years, diabetes mellitus, stroke, vascular disease, age 65–74 years, sex category) and HAS-BLED (hypertension, abnormal renal and liver function, stroke, bleeding, labile INR, elderly, drugs or alcohol) scores[10–12] to predict the balance of future risk for stroke and embolic events versus bleeding in an individual patient. A recent survey of the European Heart Rhythm Association proved that a considerable amount of time and resources are needed in daily clinical practice to communicate risk/benefit ratios to patients suffering from AF: several centres have established special OAC clinics and initial visits mostly lasted 21–30 min.[13] However, decades after the introduction of OAC therapy, standardised and validated risk communication tools[14–16] are still missing and adherence follow-up programmes are rare.[13] Those programmes have an important impact on effectiveness of OAC: adherence to OAC is considered a key factor for preventing events,[17] but it is still as low as 43%.[18]

Little is known about the perception of patients with AF and how it correlates with risk scores used by their physicians.[19] A potential gap between subjective and objective assessments may increase the likelihood of non-compliance to OAC in patients with AF.[20] Therefore, the study was designed to correlate the subjective stroke and bleeding risk with the objectively predicted individual risks calculated by CHA_2DS_2-VASc and HAS-BLED scores.

METHODS

This work is a cross-sectional prevalence study, using convenience sampling by trained doctors at nine centres (representing primary, secondary and tertiary healthcare) in the province of Styria, Austria. Responsible institutional review boards approved the study (1376/2015 (BHB Graz, Austria), 28-004 ex 15/16 (Medical University of Graz, Austria)). Furthermore, the study was registered under the ClinicalTrials.gov number NCT03061123. Patients with first diagnosed and ECG-documented non-valvular AF and indication for OAC were included in the study. Exclusion criteria were pre-existing OAC therapy, valvular heart disease, history of valve surgery, denial or inability of informed consent.

This study was designed to comply with standard operating procedures of individual centres for initiation of OAC therapy. Responsible physicians were asked to include all eligible patients. Immediately after the pretreatment interviews, which included the discussion of benefits, harms and side effects of OAC, patients were asked to participate in the study. After informed consent was signed, a standardised questionnaire was handed out to all patients (see table S1 in the online supplemental file 1)

Questionnaire

The survey was conducted using a standardised questionnaire with two parts (see table S1 in the online supplementary file 1) . The patient-oriented part consisted of seven questions covering subjective perception of patients with regard to general individual risk/benefit ratios of OAC in AF, the willingness of therapy continuation even in the possible case of minor adverse effects (haematoma, minor bleeding) and the individually discerned level of information. We used three-point and four-point verbal rating scales to comply with the patients' categorical perception of checks and balances.[21]

Physicians in charge of patients filled the second part, which included patient demographics, CHA_2DS_2-VASc and HAS-BLED scores, as well as the intended OAC therapy.

CHA_2DS_2-VASc and HAS-BLED scores were stratified into four risk categories each corresponding to the four different risk levels for stroke/embolic events and bleeding interrogated by the patient questionnaire. Risk estimations were based on published data from large population studies. Regarding CHA_2DS_2-VASc score, patients with zero points (stroke rate 0%–1%/year) were considered *low risk*, one point (stroke rate 1%–2%/year) *intermediate risk*, 2–4 points (stroke rate 2%–7%/year) *high risk* and ≥5 points (stroke rate >7%/year) *very high risk* cohort.[10 22 23] The corresponding categories concerning HAS-BLED score were as follows: no or one risk factor (*low risk* group, bleeding rate 0%–4%/year), two risk factors (*intermediate risk* group, bleeding rate 4%–6%/year), three or four risk factors (*high risk* group, bleeding rate 6%–10%/year) and five or more risk factors (*very high risk* group, bleeding rate >10%/year).[11 22]

For assessing the awareness of general benefit of OAC, we asked patients to estimate their appraisal of relative risk reduction (RRR) for stroke and embolic events. We defined *high* (RRR 50%–74%) as an accurate answer,[24] others were *low* (RRR 0%–24%), *intermediate* (RRR 25%–49%) and *very high* (RRR 75%–100%). We extrapolated predicted HRs of bleeding due to OAC from meta-analyses[24–27] and defined the general risk of OAC as *intermediate* (HR 1.25–1.49). Other options were *low* (HR 1.00–1.24), *high* (HR 1.50–2.00) and *very high* (HR >2.00). Subjective scales were interpreted as 'correct' if they corresponded correctly to individual objective risk groups.

Follow-up

Follow-up was obtained by phone calls. Patients were asked about their current status of OAC therapy and the occurrence of cardiovascular or bleeding events.

Statistical analysis

Sample size calculation was performed using the freeware tool G*Power by Heinrich Heine University Düsseldorf (http://www.gpower.hhu.de). We sought to oppose the self-reported benefits and risks of OAC with an actual assessment using validated data (including CHA_2DS_2-VASc score and HAS-BLED score). To prove correlation

$(|\rho|<0.3)$ with type I error (α) of 0.05 and power $(1-\beta)$ of 80%, at least 84 patients had to be included into the study.

Two-sided significance level was 0.05. Data are presented as mean±SD deviation, median (IQR) or count (proportion), where appropriate. Pearson's test and Spearman's rank correlation coefficient were used to correlate ordinal variables (eg, subjective perceptions and risk scores). Correlation coefficients (ie, $|r|$, $|\rho|$) were interpreted as follows: negligible correlation (0.0–0.3), low correlation (0.3–0.5), moderate correlation (0.5–0.8) and strong correlation (0.8–1.0).[28]

Data were analysed with IBM SPSS Statistics V.23 (IBM Corporation, Armonk, New York, USA). All raw data can be found in the online supplementary file 1.
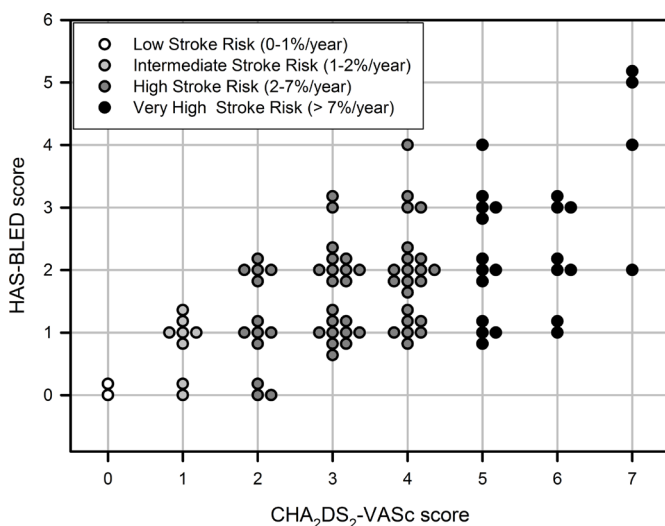
RESULTS
Patient population
From September 2015 to March 2016, 91 patients (age 73±11 years, 45% female) from nine centres were included in this study (see table S2 in the online supplementary file 1). As highest educational attainment, lower secondary education (International Standard Classification of Education (ISCED) level 2, n=32, 35%) and higher secondary vocational education (ISCED level 3B, n=25, 28%) were most prevalent. New oral anticoagulants were used most frequently (n=75, 82%). Vitamin K antagonists (n=14, 15%) and low-molecular weight heparin (n=2, 2%) were given to remaining patients.

Objective risk estimation
Median CHA_2DS_2-VASc score was 4 (IQR 2–5). Therefore, we summarised most patients on high risk for stroke or embolic events (CHA_2DS_2-VASc score 2–4, stroke risk 2%–7%/year, figure 1). Most common risk factors were arterial hypertension and age>75 years (table 1). In terms

Table 1 CHA2DS2-VASc and HAS-BLED scores and individual risk factors

$CHADS_2$ score	2 (1–3)
CHA_2DS_2-VASc score	4 (2–5)
CHA_2DS_2-VASc score≥2	81 (89%)
Congestive heart failure	14 (15%)
Hypertension (diagnosis of arterial hypertension)	75 (82%)
Age>75 years	48 (53%)
Diabetes mellitus	18 (20%)
Stroke or TIA	15 (17%)
Vascular disease	27 (30%)
Age 65–75 years	25 (28%)
Female sex	41 (45%)
HAS-BLED score	2 (1–2)
HAS-BLED score≥3	17 (19%)
Hypertension (systolic blood pressure>160 mm Hg)	42 (46%)
Abnormal kidney/liver function	8 (9%)
Stroke	14 (15%)
Bleeding	1 (1%)
Labile INR values	1 (1%)
Elderly (age>65 years)	72 (79%)
Drugs or alcohol (one point)	16 (18%)
Drugs and alcohol (two points)	2 (2%)

INR, international normalised ratio; TIA, transient ischaemic attack.
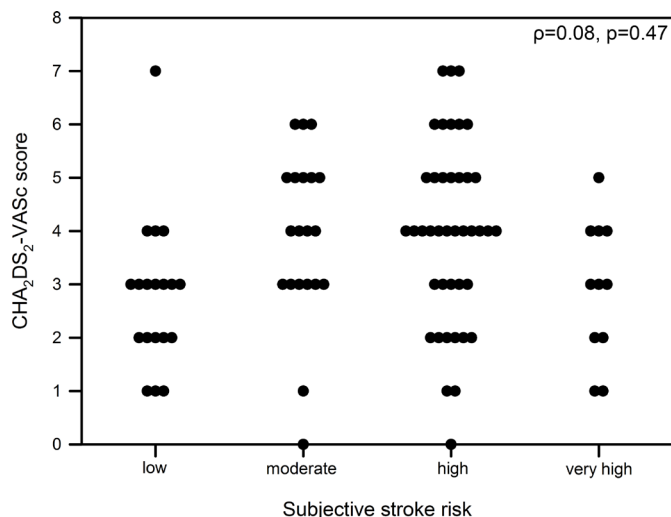
of HAS-BLED score, most of the patients were in low (0–1 points, bleeding risk 0%–4%) and intermediate risk groups (two points, bleeding risk 4%–6%; figure 1).

Perception of individual risk
Many patients (n=41, 45%) interpreted risk for stroke and embolic events in atrial fibrillation as *high* (corresponding stroke risk 2%–7% per year). Bleeding risk was estimated mainly as *intermediate* (corresponding bleeding risk 4%–6% per year, n=40, 44%). Patients feared stroke more than bleeding (67% vs 10%) and only 9% would discontinue OAC therapy if minor bleeding complications (eg, epistaxis) would occur. Patients estimated their personal level of information as *good* or *adequate* in 41% and 34%, respectively.

Correlations
Patients estimated their risk for stroke or embolic events in concordance to the individual CHA_2DS_2-VASc score in 28% (n=25) of cases, but by the majority (n=52, 57%) risk was under-rated. Bleeding risk was assumed accurately in 41% (n=37), but overestimated in 31 cases (34%). There were no significant correlations neither between objectively assessed and subjectively expected risk for stroke nor for bleeding ($\rho=0.08$, $p=0.47$, figure 2 and $\rho<0.01$, $p=0.98$, figure 3).


Figure 1 CHA_2DS_2-VASc and HAS-BLED scores of individual patients, including our classification into low, intermediate, high and very high stroke risk groups (stratified by CHA_2DS_2-VASc score).

Figure 2 Correlation of CHA$_2$DS$_2$-VASc score and subjective assessed stroke risk.

Analogies in patients' answers and CHA$_2$DS$_2$-VASc and HAS-BLED scores did not correlate to the levels of highest education (ρ=−0.06, p=0.64 and ρ=0.17, p=0.15). However, we observed a significant correlation between patients' judgement of their knowledge of AF with regard to concordant assumptions of stroke risk and CHA$_2$DS$_2$-VASc score (ρ=0.24, p=0.02, figure 4). No correlation was observed between patients' judgement of AF knowledge and concordance with subjectively assumed and objectively predicted risk for bleeding events (ρ=0.08, p=0.45).

Perception of general risk

Most patients (n=51, 56%) assumed score-predicted effectiveness of OAC in AF as *high* (corresponding stroke risk reduction 50%–74%). Other answers were *very high* (RRR 75%–100%; n=23, 25%), *intermediate* (RRR 25%–49%; n=15, 17%) or *low* (RRR 0%–24%; n=1, 1%). The estimated general risk of bleeding caused by OAC was considered by patients as *intermediate* (HR for bleeding
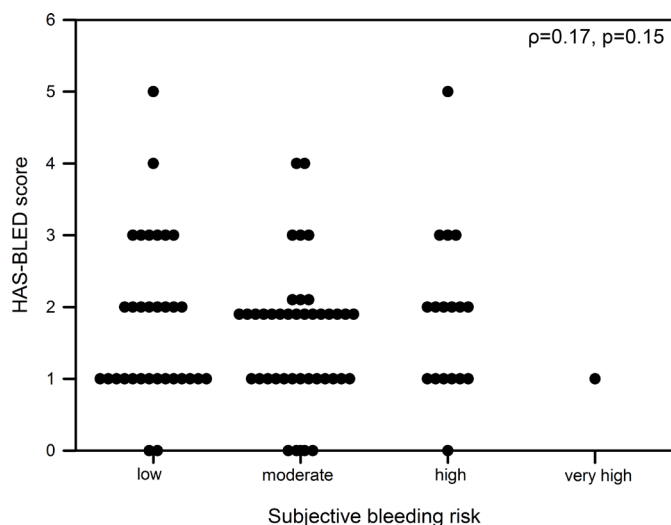
Figure 3 Correlation of HAS-BLED score and subjective assessed bleeding risk.
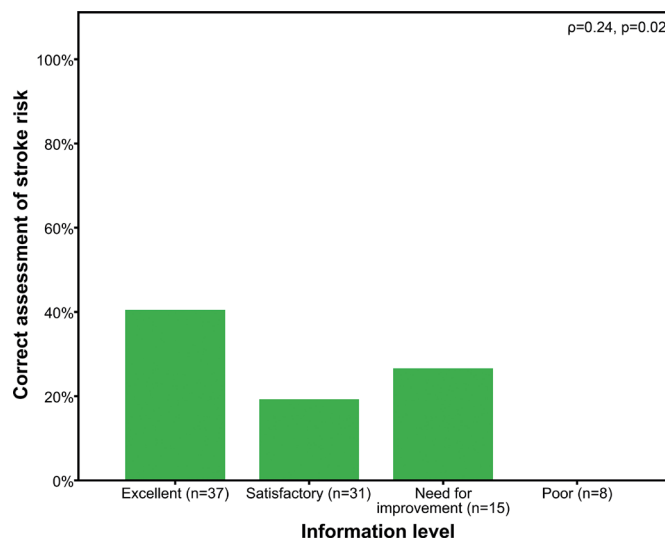
Figure 4 Amount of correct answered assessment of stroke risk in patients with different self-assessed levels of information.

1.25–1.49; n=37, 41%) and *low* (HR 1.00–1.24; n=30, 33%). Only three patients (3%) estimated the bleeding risk associated with OAC as *very high* (HR>2.00).

Follow-up

Follow-up via telephone was obtained 18±2 months after enrolment from 84 patients (92%). The remaining seven patients were lost to follow-up because of missing contact details (n=6, 7%) or denial to participate (n=1, 1%). The following events were reported during follow-up: death of unknown cause (n=5, 5%), ischaemic stroke (n=2, 2%) and epistaxis requiring hospitalisation (n=1, 1%). All patients with ischaemic or bleeding events were under OAC therapy and had continued it until follow-up.

At time of follow-up, four patients had discontinued OAC therapy intermittently (n=1, 1%) or permanently (n=3, 3%). One female patient with CHA$_2$DS$_2$-VASc score of 2 reported that OAC therapy was terminated due to successful pulmonary vein isolation without any recurrence of AF during 9 months of event recorder monitoring. Three patients (CHA$_2$DS$_2$-VASc score between 3 and 7) discontinued OAC therapy on their own; although one patient reinitiated OAC therapy after discussion with his general practitioner.

Patients, who stopped OAC therapy on their own, believed that their current condition 'had no indication' for OAC therapy. Two of them had underestimated their individual stroke risk at baseline interrogation, while one had overestimated it. Two stoppers feared the risk of bleeding more than the risk for ischaemic events.

DISCUSSION

This cross-sectional questionnaire study in 91 OAC-naive patients with non-valvular AF shows that (1) patients generally underestimated their risk of stroke, (2) they perceived their individual stroke risk

to higher extent than bleeding risk and (3) there was a significant correlation between accuracy in answers and patients' judgement of their knowledge of AF. During follow-up, we observed OAC discontinuation despite clear indication in 3% of patients.

Due to the high prevalence of AF in the western world, non-adherence to OAC in patients with AF has a tremendous impact on our society. Despite the availability of adequate therapy, AF-related strokes are still estimated to cost US$ 8 billion annually in the USA[29][30] or over 9000 GBP per stroke in the UK.[31] The increased severity of AF-related strokes compared with other aetiologies[32] may even increase the negative effect of general embolic events on quality of life.[33] As a consequence, it is urgently necessary to ameliorate adherence to OAC therapy for AF. We proved under-judgement of stroke risk and, therefore, postulate better patient education as a possibility to overcome this problem.

No correlation between subjective assessment and objective risk

To our knowledge, this is the first study that compares the subjective risk perception of patients with AF with evidence-based risk scores used in daily clinical practice. We found no significant correlation between subjective and objective assessment of stroke or bleeding risk. Therefore, our study provides evidence that a perception gap remains after informed consent discussion before OAC initiation. Although not powered for it, we provide preliminary data on the OAC discontinuation rate 1 year after OAC initiation. Two of three patients, who stopped OAC on their own, had underestimated their stroke risk at baseline.

If this finding remains constant in larger trials, it has a direct impact on clinical practice. A perception gap between subjective and objective assessment of stroke or bleeding risk is considered a major obstacle at the start of a lifelong medical intervention. It hinders not only shared decision-making, but may also worsen treatment compliance and adherence.[34]

Previous studies already evaluated the levels of information in patients after initiation of OAC treatment.[19][35–39] In a survey of 711 patients with AF that were on OAC for at least 1 year, only 7% knew the purpose of anticoagulation in AF.[38] Lane et al[35] observed that 51% of patients with AF with OAC therapy for ≥3 months could not name their cardiac condition. Furthermore, the knowledge could not be increased by a brief educational intervention. McCabe et al[40] showed considerable knowledge deficits already 2 weeks after initial diagnosis of AF. A recent qualitative systematic review postulated the lack of patient information as one of the most important reasons for vitamin K antagonists underuse.[41]

Although Dantas et al[37] demonstrated that only minimal knowledge of patients is needed to allow acceptance of OAC, doctors should seek shared decisions. This is even more important, when evidence for drug treatment is marginal,[42] which is definitely not the case in patients with

high risk scores for AF.[2] However, the physician's perspective of shared decision-making may not be congruent to the patient's perceptions.[43] LaHaye et al[44] demonstrated high interpatient variability regarding individual treatment thresholds. Consequently, we propose that health literacy of patients should be enhanced before OAC initiation, especially regarding the individual risk/benefit ratio. Thus, patients may be able to participate in decision-making of therapy initiation. Patients also seem to have difficulties regarding verbal descriptions of risk.[45] Therefore, graphical information might help overcome this problem.[7][14] One promising example is an electronic prototype for the translation of Grading of Recommendations Assessment, Development and Evaluation summaries[46] into decision aids using interactive formats to present evidence summaries at varying levels of detail.[16] Another possibility is the establishment of a Fact Box, which describes evidence of benefits and harms without making recommendations.[15] Further theory-driven educational interventions have been shown to increase OAC control[47] or knowledge of international normalised ratio targets.[35]

Stroke risk is topping bleeding risk

In our study, most of the patients assumed their personal stroke risk to be the most frequent and serious complication of untreated atrial fibrillation in their setting. However, the majority (57%) underestimated their stroke risk while 41% interpreted their bleeding risk accurately. In other studies, patients were keen on avoiding stroke more than bleeding[48] and placed even more importance on stroke prevention than doctors[49] with higher tolerance of adverse bleeding events.[50] Nevertheless, with increased duration of OAC therapy, knowledge about OAC in the indication of AF seems to deteriorate.[38]

Factors influencing correct risk estimation

We found out that the highest level of educational attainment did not correlate with analogies in risk estimation in our analysis. Our results therefore indicate that understanding of individuals' risk is not correlated with formal education levels. However, the preservation of knowledge might be correlated with better education.[40] Lip et al[39] showed differences of AF perceptions in different ethnical groups. We could not add evidence to this factor as we included only Caucasian patients.

Patients that felt better informed had an improved understanding of their individual risks in this study. Consequently, we encourage to evaluate patients' information level repeatedly by asking how informed they felt and to take appropriate measures to enhance the patient's level of information if required.

Limitations

Our study has several limitations. First, due to the absence of a screening log, consecutive patient enrolment cannot be guaranteed. Second, the study was powered for cross-sectional analysis, but not for associations between

baseline parameters and OAC adherence or events at follow-up. Therefore, we can only speculate that higher levels of information might be associated with better adherence and outcomes as results of previous studies suggested. Third, we did not evaluate other bleeding risk scores, such as AnTicoagulation and Risk Factors in Atrial Fibrillation (ATRIA)[51] or Outcomes Registry for Better Informed Treatment (ORBIT),[52] into the analysis. Lastly, we intended to concentrate on the risk perception of individual patients and did not evaluate the general knowledge of AF and stroke prevention per se in a standardised questionnaire.[53] Due to this fact, we kept the questionnaire short and tried to minimise bias due to selection of motivated patients that may not be representative of the general AF population.[19]

CONCLUSION

In this cross-sectional analysis of OAC-naive patients with AF, we found major differences between patients' perceptions and physicians' assessments of risks and benefits of OAC. To ensure shared decision-making and informed consent, more attention should be given to evidence-based and useful communication strategies.

Author affiliations

[1]Division of Cardiology, Department of Internal Medicine, Medizinische University Graz, Graz, Steiermark, Austria
[2]Department of Internal Medicine, Hospital Barmherzige Brueder Marschallgasse, Graz, Steiermark, Austria
[3]Department of Internal Medicine, Hospital Elisabethinen, Graz, Austria
[4]Department of Internal Medicine, LKH Fürstenfeld, Krankenhausverbund Feldbach, Fürstenfeld, Austria
[5]Department of Internal Medicine, LKH Hartberg, Steiermark, Austria
[6]Department of Neurology, LKH Feldbach, Krankenhausverbund Feldbach-Fürstenfeld, Feldbach, Steiermark, Austria
[7]Department of Internal Medicine, Krankenhaus Barmherzige Bruder Graz-Eggenberg, Graz, Steiermark, Austria
[8]General Practitioner Dr. Gudrun Zweiker, Straden, Austria
[9]Department of Social Medicine and Epidemiology, Medical University of Graz, Steiermark, Austria
[10]Department of Internal Medicine, Landeskrankenhaus Feldbach, Feldbach, Steiermark, Austria

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