



## PERCEPTION, KNOWLEDGE AND THE AWARENESS AMONG SAUDI ATRIAL FIBRILLATION PATIENTS ABOUT THEIR DISEASE AND ITS STROKE RISK

<b>Mostafa Q. Alshamiri</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Daneiah M. Arafah</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Nouf A. Althabit</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Alaa M. AlAhmari</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Haneen F. Amlih</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Bedoor H. Al Qadrah</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Afnan A. Almughaiseeb</b>	MD., College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia
<b>Fakhr Z Alayoubi</b>	Msc, R Pharma, College of Medicine King Saudi University, King fahad Cardiac Center, Riyadh, Saudi Arabia

### ABSTRACT

**Objective:** To examine the level of awareness about Atrial Fibrillation (AF) and its associated Risk of stroke among Saudi patients with AF.

**Method:** This cross-sectional study included 229 patients with AF, visiting arrhythmias clinic in a university hospital from December 2011 to April 2014. Questionnaires were prepared to measure the level of understanding of patients about their disease and its stroke complication.

**Results:** Out of 300 AF patients' records that were obtained from the medical record; 241 (80.3%) responded to the phone call, 12 (5%) of the patients who answered, refused participation in this survey. The remaining 239 participants in the study group, (46.3%) males and (53.7%) females, and the age of majority of AF for both genders was between 56-75 years, 31.9 % of patients don't know the meaning of their disease. The symptoms of AF is only known to 42% of the patients, which includes; palpitations, shortness of breath, dizziness, and chest pain. 71.1% don't recognize that they are at high risk of stroke, 14.8% of the study group had a previous transient ischemic attack, and 11.8% had stroke. 27.9% of AF patients knows that they have risk factors for development of AF, with no difference between male and female. The most common risk factors for development of AF known to the patients include hypertension, hypercholesterolemia, diabetes mellitus and ischemic heart disease. The most common cause of AF was hypertension with coexistent of other disease. 95.6% of the patients were on oral anticoagulation, however 35.3% do not know the advantages of the anticoagulation. 86.9% requested to have education about their disease and its complication. 84.7% of them preferred to receive education from their physicians.

**Conclusion:** Patient's awareness of their disease (AF) and stroke as a complication is very low, which indicate the greater need to develop health education programs to improve the knowledge of patient with AF and its complication.

**KEYWORDS :** Atrial Fibrillation, Stroke, awareness, patient's knowledge.

### INTRODUCTION

Atrial fibrillation (AF) is the most common serious cardiac arrhythmia, and the number of patients with AF is anticipated to increase in the next few decades.

The prevalence of 1% to 2% in the general population in North America and Europe (1-3). Prevalence of AF in the community outside the Europe and states ranges between 0.1% in India to 4% in Australia. *Prevalence of AF in Hospital-Based Studies* was higher among the hospital based cohorts than in community studies, ranging widely from 2.8% in Malaysia to 14% in Japan, the prevalence of stroke in patients with AF (2.8%-24.2%),(4). The prevalence of AF increases with age, from 0.5% at age 50 to 59 years to almost 9% at age 80 to 89 years (5). The prevalence of AF in the gulf countries is lacking, however it was 4.24%, among acute hospital admission in Kuwait,(6). Atrial fibrillation has been shown to increase the risk of ischemic stroke up to five-fold, associated with increased mortality (7,8). Such strokes tend to be more severe than strokes linked with other causes (9,10). Recent study reported Stroke caused death in 11 (10%) of 113 patients in the Middle East (11). There are concerns that AF is not perceived as a serious health threat. Patients also have limited awareness and poor perception of the broader risks associated with a diagnosis of AF. Like stroke and death (12,13). Only half (49%) of the patients were aware that their cardiac condition was known as AF (14). One in four patients

felt unable to explain AF and .33% were worried or fearful about their disease (15). Knowledge regarding stroke was poor among the groups that belonged to the highest risk bracket for stroke(16).

We are not aware of any studies identifying the awareness of the Saudi AF patients about their condition. It is of paramount importance to better understand physicians' and patients' knowledge, perceptions, and attitudes to AF and its contribution to CV morbidity and mortality, a survey incorporating patients questionnaires was conducted in patients attending arrhythmia clinic in university center. This article reports the findings of this survey, with the aim of identifying potential gaps between the realities of AF and the perception of AF as a public health concern that may be addressed through improved educational intervention.

### Methodology

A paper form questionnaire was constructed to capture details of patient demographics and current understanding of the AF, risk factors, etiology and development of stroke and if the patients with AF will like to have the information about his/her disease, these questions given to participants in 7 categories, each question supplemented with a list of choices to be answered by YES or NO.

Q1: About demography of patients with Atrial Fibrillation (AF),

participating in the study, including gender, gender level of education, place of residence and occupation.

Q2: Do you have any of the following illness? (Include disease like Hypertension (HTN), Diabetes Miletus (DM), and Dyslipidemia, Ischemic heart disease (IHD), Stroke, Heart Failure or Transient Ischemic Attack (TIA).

Q3: Do you know what your disease diagnosis is?

Q4: If the patient knows that the disease is AF, what are the symptoms? (Include chest pain, palpitation, dyspnea, and dizziness etc.

Q5: Are you on Anticoagulation treatment? Do you know what the advantage of the treatment is?

Q6: Do you know what is Stroke? And do you know that AF is a risk factor for stroke or TIA?

Q7: Do you need education about your case? And who do you prefer to educate you, is it the Physician, relatives, paramedics, or media?

The study conducted at a single university center for treatment of arrhythmia in Riyadh Saudi Arabia. The institutional review board (I.R.B) approved to conduct this cross-sectional observational study of confirmed atrial fibrillation (AF) patients regardless of etiology. Patients should have no educational brochures before the interview. The medical record number (MRN) obtained from the file of the patients treated or under follow-up of arrhythmia clinic, the contact numbers obtained and used for communications with the patients or Patients' relatives, or patients visiting the clinic or admitted to hospital, the study explained to each patient or patient relatives and get the consent to be included in the survey before the study, the questionnaire was filled by one of the research group.

The initials of each patient and the MRN were used for patient identifications, obtaining additional information related to diagnosis and anticoagulation therapy, the anticoagulation decision was left to the discretion of treating physicians. The inclusion criteria were any patients with confirmed diagnosis of AF, older than 15 years, consented to be interviewed and should be Saudi nationality. The exclusion criteria are patients who cannot communicate by Himself or by his relatives did not consent, younger than 15 years or non-Saudi.

**Statistical Analysis**

The analysis of data done by utilizing Statistical Package for Social Sciences (S.P.S.S), version nineteen software for Windows. Chi-square tests were utilized for analyzing statistically important changes of categorical variables. Two-tailed P values < 0.05 were considered statistically significant. Also, contingency tables, charts, graphs, frequencies, percent, counts and averages (means and median) were used in the process.

**RESULTS**

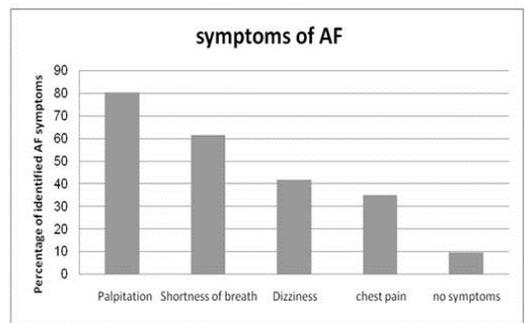
A 300 AF patients were obtained from the medical record; 241 (80.3%) responded to the phone call and 59 (19.7%) didn't respond. 12 (5%) of the patients who answered, refused participation in this study may be due to either old age or they don't want to disclose that they are sick, or they were too busy to answer the questionnaire. Both genders have approximately the same rate of no response. The study group was 229 AF, (46.3%) males and (53.7%) females. More than half of participants (58.5%) were in the age group between 56 to 75 years [Table 1]. 31.9% of AF patients do not know the meaning of AF, 59% are educated at least they can read & write) and 41% are illiterates, the awareness was higher among educated patients than illiterate (p < 0.05).

**Table 1: Age and Gender Distribution of AF Participants**

Age * Gender Crosstabulation					
			Gender		Total
			male	female	
Age	15-35 years old	Count	3	2	5
		% within Gender	2.8%	1.6%	2.2%
	36-55 years old	Count	15	26	41
		% within Gender	14.2%	21.1%	17.9%
56-75 years old	Count	64	70	134	
	% within Gender	60.4%	56.9%	58.5%	

	76 years old and more	Count	24	25	49
		% within Gender	22.6%	20.3%	21.4%
Total	Count	106	123	229	
	% within Gender	100.0%	100.0%	100.0%	

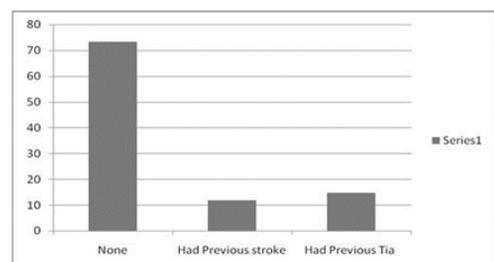
The source of their awareness was (65.2%) from physicians, 55.8% of these patients' physicians volunteered to pass the information to them but 44.2% of the patients requested the information. The symptoms of AF is only known to 42% of patients, it is in the form of palpitations, shortness of breath, dizziness and chest pain (Figure 1). 27.9% of AF patients knows that they have high risk factors for the development of AF, hypertension was the most common risk factors known to patients followed by other risk like hypercholesterolemia, diabetes mellitus and ischemic heart disease, with no difference between male and female. The most common cause of AF was hypertension with coexistent of other etiological associated diseases, [table 2]. Stroke awareness; 71.1% didn't know that they are at higher risk of stroke. Only 28.9% were aware of being at a higher risk of stroke. 30.5% of patients living in the city knew that AF causes stroke while only 6.7% of patients living in villages knew that. 14.8% of the study group had a previous transient ischemic attack (TIA), and 11.8% had stroke. The most identified symptoms of stroke or TIA were sudden numbness and unilateral weakness of the body 72.7%. (Figure 2). Only 42% of AF patients who had stroke or TIA knows the etiology is AF. 95.6% of the patients were on oral anticoagulation, however 35.3% don't know the advantages of the anticoagulation. 66.8% their doctor didn't inform them about the adverse effect of this drug. 86% of AF patients needs education by any means and 84.7% need to be educated by physicians (figure 3).



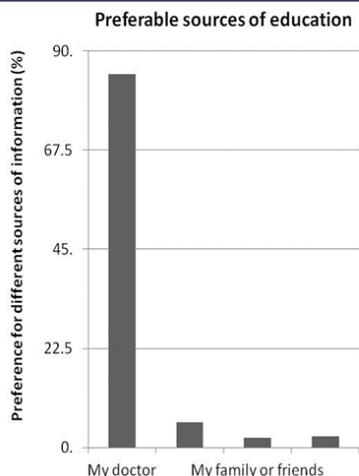
**Figure 1: Percentage of identified AF Symptoms**

**Table 2: Etiology and Associated Disease of AF Participants**

Risk factors	No.	%
Hypertension	163	71.2
Hypercholesterolemia	139	60.7
Diabetes	125	54.6
Ischemic heart disease	73	31.9
Family history of heart disease	60	26
Valvular heart disease	49	21.4
Heart failure	37	16.2
Thyroid Disease	35	15.3
Transient Ischemic Attack	34	14.8
Previous Stroke	27	11.8
Congenital heart disease	3	1.3



**Figure 2: Percentage of those AF patients who knows symptoms of stroke or TIA.**



**Figure 3:** Preferable sources of Education

## DISCUSSION

This survey is the first study to evaluate the knowledge and the awareness of Saudi AF patients, which most of the AF patients are in the older age groups and more than half of them are female, this is similar to previous two studies conducted in Kuwait (6,17). Two studies in United Kingdom(14,18), and one study in Japan(19). This is understandable as most of the older age group had multiple factors for the development of AF. Only 31.9% of our AF patients know the meaning of AF, compared to West Birmingham patients 49% knows that their cardiac conditions are AF (14), and to other European patients 25% were unable to explain the meaning of AF(15), the less awareness of our patients could be related to the common occurrence of illiteracy (41%). Previous studies reported that the paucity of patient's knowledge concerning AF could be attributed to the lack of information and explanations given by healthcare professionals due to the time constraints of outpatient clinics, the lack of appropriate educational literature, and the risk/benefit analogies employed by Physicians(20). 65.2% of our participants that are aware got the information from the physicians this will explain how important it is the time physicians spend to educate patients, particularly the illiterate patients who cannot write or read. 42 % of our patients knows the symptoms of AF and the commonest symptoms were palpitation in 80% of patients (figure1), similar to Japanese registry(19), if the symptoms exist then the palpitation is the commonest 34.4%, however previous Saudi studies revealed that the commonest symptoms were dyspnea 59.3 % followed by palpitation 24.5% (21) , which was similar to a British study, breathlessness is a common symptom found in 25% of the patients(18). However, the symptoms may vary as a result of clustering associated conditions.

The coexistent of underlined etiology or associated conditions summarized in (Table 2), where hypertension, hypercholesterolemia and diabetes mellitus were the top three associated conditions were hypertension present in 71.1 % of AF patients. Our study similar to other studies revealed that Hypertension was globally the most common risk factor for AF, ranging in prevalence from 41.6% in India to 80.7% in Eastern Europe(22). However the previous Saudi study of 720 AF patients in Riyadh (21), revealed that hypertension was 59.3 %, while Diabetes mellitus (DM) 68.8% and similar to Japanese registry(19). The variability of coexisting condition continues, in Kuwaiti study (6), hypertension was 65.8 %, DM, 53.3% and in Gulf SAVE study (23), HTN was 52%. This variability probably related to the general Cardiovascular Risk Factor Burden in Africa and the Middle East, reported by Dr. Alwai et al. (24), where hypertension prevalence was 43% and DM 25%. In relation to awareness about stroke majority of our AF patients 71.7 % don't know that they are at risk of stroke despite that 26.6 % had stroke previously or TIA, (figure 2), only 42% of them knows the cause of stroke was AF, and the most recognized symptoms of TIA or stroke was numbness and weakness 72.7%. The knowledge was worse in AF patients living outside the city 6.7%, this could be also explained by illiteracy and lack of health facility outside big cities.

In the general population of Gulf countries, weakness was the most identified symptoms of stroke, the majority of the patients had not even

heard the term stroke. Stroke knowledge was poorest among the groups that were at the highest risk for stroke (16). In UK study (14), 54% of the patients were aware that AF could predispose to blood clots or stroke. These findings clearly call for an urgent campaign of education for people at high stroke risk.

The anticoagulation is considered the most therapeutic strategy for prevention of stroke in AF patients. These Framingham Study data, indicates that AF exerts a significant impact on the risk of stroke, that is independent of the often-associated cardiovascular abnormalities (8), 95.6% of our patients were on oral anticoagulation. However, 35.3% do not know the advantages of the anticoagulation, 66.8% their doctor didn't inform them about the adverse effect of this drug, this clearly demonstrates the gap of knowledge for a very serious and dangerous drug used in chronic bases. 52% of the UK AF patients knows that anticoagulation prevents clot formations (14), the difference probably is that UK patients are less illiterate than our cohort. Our patients are well treated as most of them use oral anticoagulation, compared to Japanese registry(19), where Warfarin was prescribed in only 48.5% of patients, whereas anti-platelet drugs, mainly aspirin, were prescribed for more than 30% of the patients. The reason is that all our patients are under follow-up of arrhythmia specialized clinic in tertiary center. (Figure 3) demonstrated the need for education by any means as it was requested by 86% of patients, although 84.7% of them needs education by the physicians, this can be explained by the inability of our patients to read the educational materials that is probably the reason for requesting education by medical professionals. As per AWARENESS study (15), many physicians (51%) wanted more patients information, with 60% viewing available information as poor/difficult to find.

This study gives a good insight to the need of education for patients with AF to understand their disease and its risk factors and complications, what we do not know in this Saudi group of patients is their response to education. As previous educational interventions study (15), all patients with AF were given an information booklet which explained what AF was, associated symptoms, the possible causes and consequences of AF, treatment options and their benefits/risks, what the INR is and what factors may affect it. The educational intervention significantly improved patient's knowledge of the target INR range and factors that may affect INR levels with somewhat improvement in other aspect but not significant. However, this intervention was brief and it was a booklet not by medical professionals. The limitation of this study is a single tertiary care center, a short period of time for the inclusion.

## Conclusion

Patient's awareness of their disease (AF) and stroke as a complication is very low, which indicate the greater need to develop health education programs to improve the knowledge of patient with AF and its complications.

## Declaration of conflicting interest:

The authors declare that there is no conflict of interest.

## Funding

This research received no specific grant from any funding agency in the public, commercial, or not for-profit sectors.

## Acknowledgement

We thank our patients who agree to answer this survey and we thank, Prof. Ahmed HERSI and arrhythmia clinic staff in King Khalid university hospital.

## References

- Go AS, Hylek EM, Phillips KA, et al. Prevalence of diagnosed atrial fibrillation in adults: national implications for rhythm management and stroke prevention: the AnTicoagulation and Risk Factors in Atrial Fibrillation (ATRIA) Study. *JAMA*. 2001; 285 (18): 2370-2375.
- Camm AJ, Kirchhof P, Lip GY, et al; European Heart Rhythm Association; European Association for Cardio- Thoracic Surgery. Guidelines for the management of atrial fibrillation: the Task Force for the Management of Atrial Fibrillation of the European Society of Cardiology (ESC). *Eur Heart J*. 2010; 31 (19): 2369-2429.
- Stewart S, Hart CL, Hole DJ, McMurray JJ. Population prevalence, incidence, and predictors of atrial fibrillation in the Renfrew/Paisley study. *Heart*. 2001; 86 (5): 516-521
- Gregory Y. H. Lip, MD; Carolyn M. Brechin, Ph.D.; and Deirdre A. Lane, Ph.D. The Global Burden of Atrial Fibrillation and Stroke A Systematic Review of the Epidemiology of Atrial Fibrillation in Regions Outside North America and Europe, *CHEST* 2012; 142(6):1489-1498
- Kannel WB, Wolf PA, Benjamin EJ, Levy D. Prevalence, incidence, prognosis, and predisposing conditions for a trial fibrillation: population-based estimates. *Am J*

- Cardiol. 1998 ;82 ( 8A ):2N -9N.
6. Salhamoud A. Saleh, Boby Cherian ,Fawziah Al-Kandari, et al: The Prevalence of Atrial Fibrillation among Acute Medical Admissions in Kuwait, *Med Princ Pract* 2005;14:136–139.
  7. Benjamin EJ, Wolf PA, D'Agostino RB, Silbershatz H, Kannel WB, Levy D. Impact of atrial fibrillation on the risk of death: the Framingham Heart Study. *Circulation* 1998;98:946–52
  8. Wolf PA, Abbott RD, Kannel WB. Atrial fibrillation as an independent risk factor for stroke: the Framingham Study. *Stroke* 1991;22:983–8.
  9. Lin HJ, Wolf PA, Kelly-Hayes M, Beiser AS, Kase CS, Benjamin EJ. Stroke severity in atrial fibrillation. The Framingham Study. *Stroke* 1996;27:1760–4.
  10. Dulli DA, Stanko H, Levine RL. Atrial fibrillation is associated with severe acute ischemic stroke. *Neuroepidemiology* 2003;22:118–23.
  11. Healey JS, Oldgren J, Ezekowitz J, Zhu J, Pais P, Wang J, et al , Occurrence of death and stroke in patients in 47 countries 1 year after presenting with atrial fibrillation: a cohort study, *Lancet* 2016; 388: 1161–69.
  12. Dearborn JL, McCullough LD. Perception of risk and knowledge of risk factors in women at high risk for stroke. *Stroke* 2009;40:1181–6.
  13. Lip GY, Kamath S, Jafri M, Mohammed A, Bareford D. Ethnic differences in patient perceptions of atrial fibrillation and anticoagulation therapy: the West Birmingham Atrial Fibrillation Project. *Stroke* 2002;33:238–42.
  14. Deirdre A. Lane, Jennie Ponsford, Alison Shelley, Anu Sirpal, Gregory Y.H. Lip ,Patient knowledge and perceptions of atrial fibrillation and anticoagulant therapy: Effects of an educational intervention programme The West Birmingham Atrial Fibrillation Project, *International Journal of Cardiology* 110 (2006) 354–358.
  15. Etienne Aliot, Gu nterBreithardt , JosepBrugada, et al, An international survey of physician and patient understanding, perception, and attitudes to atrial fibrillation and its contribution to cardiovascular disease morbidity and mortality, *Europace* (2010) 12, 626–633.
  16. Kamran S, Bener AB, Deleu D, Khoja W, Jumma M, Al Shubali A, et al. The level of awareness of stroke risk factors and symptoms in the Gulf Cooperation Council countries: Gulf Cooperation Council stroke awareness study. *Neuroepidemiology*. 2007;29(3-4):235-42.
  17. Mohammad Zubaid, hisham saad and Mustafa Ridha et al.. Quality of Anticoagulation with Warfarin Across Kuwait, *Hellenic J Cardiol* 2013; 54: 102-106.
  18. John Soong, Anjali Balasanthiran, Donald C MacLeod, Derek Bell ,National survey of patients with AF in the acute medical unit: a day in the life survey, *The British Journal of Cardiology* 20(3):106 , July 2013.
  19. Masaharu Akao (MD, PhD), Yeong-Hwa Chun (MD, PhD) Hiromichi Wada (MD, PhD) et al.. Current status of clinical background of patients with atrial fibrillation in a community-based survey: The Fushimi AF Registry: *Journal of Cardiology* 61 (2013) 260–266.
  20. Fuller R, Dudley N, Blacktop J. Risk communication and older people—understanding of probability and risk information by medical inpatients aged 75 years and older. *Age Ageing* 2001;30:473–6.
  21. Salih A. Bin Salih, Mohammed S. Showlag, Mohammed A. Al-Qahtani, et al ... Clinical characteristics of patients with atrial fibrillation at a tertiary care hospital in the central region of Saudi Arabia, *Journal of Family and Community Medicine* ,August 2011 , Vol. 18 , Issue 2 ,80-84.
  22. Jonas Oldgren, MD, PhD Jeff S. Healey, MD, MS, Michael Ezekowitz, MD Variations in Etiology and Management of Atrial Fibrillation in a Prospective Registry of 15,400 Emergency Department Patients in 46 Countries: The RE-LY AF Registry , *Circulation*. 2014;129:1568-1576.
  23. Mohammad Zubaid, FRCPC; Wafa A. Rashed, FRCP (Lond); Alawi A. Alsheikh-Ali, MD, MS; (Gulf SAFE) Investigators, Gulf Survey of Atrial Fibrillation Events (Gulf SAFE) Design and Baseline Characteristics of Patients With Atrial Fibrillation in the Arab Middle East, *Circ Cardiovasc Qual Outcomes*. 2011;4:477-482.
  24. Alawi A. Alsheikh-Ali , Mohamed I. Omar, Frederick J. Raal tal. Cardiovascular Risk Factor Burden in Africa and the Middle East: The Africa Middle East Cardiovascular .Epidemiological (ACE) Study: *plos one* ,August 2014 , Volume 9 , Issue 8 .