



## Cardiovascular Health

## Quality of Life Experiences among Women with Atrial Fibrillation: Findings from an Online Survey



Everly Macario, ScD, MS, EdM<sup>a,\*</sup>, Yukari T. Schneider, PhD, MPH<sup>a</sup>,  
Susan M. Campbell, MPH<sup>b</sup>, Annabelle Santos Volgman, MD, FACC, FAHA<sup>c</sup>

<sup>a</sup>IQ Solutions, Inc., Rockville, Maryland

<sup>b</sup>WomenHeart: The National Coalition for Women with Heart Disease, Washington, DC

<sup>c</sup>Rush College of Medicine, Chicago, Illinois

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### A B S T R A C T

**Background:** Although atrial fibrillation (AF) is the most common abnormal heart rhythm in men and women, there are gender differences. Mortality for women with AF can be 2.5 times greater than for men. AF risk among women is also greater than in men when patients have additional conditions. Women are more likely to experience longer symptomatic episodes, more recurrences, and higher ventricular rates during AF. We sought to explore presentation, comorbidities, treatment, and quality-of-life issues among women with AF.

**Methods:** A convenience sample of 332 women with AF completed a 58-item online survey fielded for 2 weeks in April 2015.

**Results:** Of the respondents, 94% were Caucasian; 76% consumed four or fewer servings of fruits or vegetables per day; 43% engaged in moderate physical activity for 10 minutes 3 or fewer days per week; 41% had a body mass index (BMI) of greater than 30 kg/m<sup>2</sup>; and 85% had never attended an AF support group. Women with AF often juggle many health conditions. Almost none had participated in an AF clinical trial. The ability to complete activities of daily living was associated significantly and positively with fruit/vegetable consumption and physical activity and significantly and negatively associated with BMI. Self-efficacy was associated significantly with physical activity and support group attendance. Open-ended comments showed many women patients have outstanding questions about their AF.

**Conclusions:** AF education resources should underscore the positive physical and mental health effects of increasing fruit/vegetable consumption and physical activity. Caregivers, clinicians, and women with AF need to be made aware of the benefits of support groups, whether in-person or online, and clinical trials. Future research should engage in effective recruitment of non-White women with AF.

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Atrial fibrillation (AF) is the most common abnormal heart rhythm. During AF, the heart's two upper chambers (the atria) beat chaotically and irregularly—out of coordination with the two lower chambers (the ventricles) of the heart. AF may occur in episodes lasting from minutes to days or may be permanent. AF frequently causes poor blood flow to the body. It may lead to

blood clots forming in the heart that may circulate to other organs and lead to blocked blood flow (ischemia) and thus markedly increases the risk of stroke. Treatments for AF may include medications and other interventions that try to alter the heart's electrical system as well as prevent strokes (Lloyd-Jones et al., 2010; Mayo Clinic staff, 2015; Shea & Sears, 2008).

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online survey respondents, deciding to submit the article for publication, and writing this manuscript. All authors maintained rigorous scientific objectivity and participants' confidentiality throughout the study.

Data Access and Responsibility: Mona Bosch, IRB Administrator at Ethical and Independent Review Services, has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

\* Correspondence to: Everly Macario, ScD, MS, EdM, IQ Solutions, Inc., 5719 S. Harper Avenue, Chicago, Illinois. Phone: 224-244-3965; fax: 301-984-4416.

E-mail address: [EMacario@IQSolutions.com](mailto:EMacario@IQSolutions.com) (E. Macario).

AF affects approximately 8 million United States adults (Naccarelli, Johnston, Dalal, Lin, & Patel, 2009). More than 150,000 new cases of AF are diagnosed each year. Approximately 4% of those over 65 years, and approximately 11% of those over 80 years, are affected (Shea & Sears, 2008). The prevalence of AF in the United States is projected to increase to 12 million by 2050 (Lloyd-Jones et al., 2010; Naccarelli et al., 2012). AF may cause no symptoms, but it is often associated with palpitations, fainting, chest pain, and congestive heart failure (Lloyd-Jones, et al., 2010; Shea & Sears, 2008).

Although AF is the most common sustained abnormal heart rhythm encountered in both men and women (Michelena, Powell, Brady, Friedman, & Ezekowitz, 2010; Perez et al., 2013), there are gender differences. Mortality for women with AF is up to 2.5 times greater than for men (Michelena et al., 2010). Among participants from the original Framingham Heart Study cohort, AF was associated with a 1.5-fold and 1.9-fold death rate among men and women, respectively (Benjamin et al., 1998).

Women with AF in one study had an 18% higher risk of stroke than men, even after adjusting for other factors (Friebert, Benson, Rosenqvist, & Lip, 2012). A study of 83,000 patients admitted to the hospital with recently diagnosed AF found women had a 14% greater risk of stroke than men. The difference was particularly pronounced among those older than 75 years. The risk remained high even when women were taking the anticoagulant warfarin (Avgil Tsadok et al., 2012). This was further investigated in a meta-analysis evaluating gender differences in residual risk of strokes and major bleeding in patients treated with warfarin or a novel anticoagulant. Compared with men, women with AF taking warfarin had a significantly greater residual risk of stroke and systemic embolism. This gender difference was not seen in patients with nonvalvular AF receiving novel anticoagulants. Major bleeding was seen less frequently in women with AF treated with a novel anticoagulant. The researchers concluded that the clinical disadvantage of women with AF compared with men disappeared with the use of novel anticoagulants (Pancholy et al., 2014). Furthermore, women overall are more likely to live with stroke-related disability and as a consequence, experience a significantly lower quality of life (related to physical, social, and emotional functioning) (Volgman, Manankil, Mookherjee, & Trohman, 2009).

Compared with men, women have been found to have different symptoms with heart disease, including heart attacks, angina, and arrhythmias. Women have been reported to experience symptomatic attacks, a higher frequency of recurrences, and significantly higher heart rates during AF (Canto et al., 2012; McSweeney, et al., 2003; Volgman et al., 2009). Women may also perceive pain differently and report symptoms differently than men (Petrini, Matthieson, & Arendt-Nielsen, 2015). There may also be cultural differences in pain perception (Vigil et al., 2015).

In addition, differences between genders in awareness and response to symptoms of stroke exist. Despite women being more aware than men of stroke symptoms, they delay longer getting to the hospital. Women at high risk for cardiovascular disease and stroke are more likely to perceive their risk as the same as lower risk peers. Because they underestimate their risk overall, women are less likely to adopt healthy lifestyles to reduce their risk for stroke (Dearborn & McCullough, 2009).

When patients with AF have comorbidities there is a higher risk of AF among women than men (Volgman et al., 2009). Women with comorbidities are more likely to experience longer symptomatic episodes, more recurrences, and significantly higher ventricular rates during AF (Roy et al., 2000). Women with

AF have more than double the thromboembolism risk than men with AF (Lip, Nieuwlaet, Pisters, Lane, & Crinjs, 2010). Elevated blood pressure is strongly associated with AF in women. The systolic blood pressure reading is a better predictor in women than diastolic blood pressure (Conen et al., 2009). Because women live longer than men on average, they are vulnerable for AF for longer (Mason et al., 2010). In a recent study, physical activity offset some, but not all, of the AF risk incurred with excess body weight for men, but not women (Huxley et al., 2014). On the other hand, the Women's Health Initiative study examining 93,676 postmenopausal women found that higher levels of physical activity were significantly protective against the development of incident AF (Azarbal et al., 2014).

We expect men with AF to have some similarities in symptoms such as fatigue, shortness of breath, and palpitations, but because women tend to have higher heart rates, they may experience more AF symptoms. We were therefore interested in exploring this research question: What does quality of life among women with AF look like? We measured "quality of life" among women with AF by principally examining their AF self-efficacy, AF knowledge, AF activities of daily living, and AF social support and assessing how those four constructs may be associated with a range of health behaviors.

WomenHeart: The National Coalition of Women with Heart Disease ("WomenHeart"), a national patient-centered organization on women's heart disease, will use the findings from this study to 1) inform the development of research-based AF patient resources, 2) provide current statistics for research-based AF advocacy, and 3) offer AF research-based assistance to patient support groups.

## Methods

WomenHeart maintains a database of approximately 35,000 members who voluntarily registered through WomenHeart's website. In April 2015, from this pool of members and other WomenHeart online platforms (National Hospital Alliance, Support Network Coordinators, Scientific Advisory Council, e-newsletters, Facebook, Twitter, LinkedIn, online patient community), WomenHeart invited women with AF to participate in an online survey. The survey included 57 closed-ended questions and 1 open-ended question. The survey link was live from April 9, 2015, through April 23, 2015. WomenHeart sent three reminder emails. Inclusion criteria included female gender, diagnosis of AF by a health care professional, 18 years or older, access to the Internet, and ability to read English. Only one completed survey per computer was allowed.

Before survey implementation, we agreed that a survey would be considered "complete" if a respondent answered at least one-half of the questions. Of the 37 closed-ended questions pertinent to every respondent (other questions were posed to respondents as applied to them through skip logic), 64.9% (24 questions) were completed by the entire 332 respondent sample. Three questions were completed by 329 respondents, seven questions were completed by 328 respondents, one question was completed by 326 respondents, one question was completed by 321 respondents, and one question was completed by 283 respondents.

## Data Analysis

We programmed the survey and generated descriptive statistics using Qualtrics (note: we did not aim to validate this study's survey). We used analyses of variance and regression analyses to assess whether any of four composite scores (see below) were

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