

Cardiovascular Health

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



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ABSTRACT

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/m²; 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

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).

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.

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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 (Friberg, 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, Nieuwlaat, 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 selfefficacy, 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, enewsletters, 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 onehalf 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 significantly associated with body mass index (BMI), compliance with prescribed medications, fruit/vegetable consumption, physical activity, alcohol consumption, support group attendance, race/ ethnicity, marital status, and education, employment, and income levels. Two data analysts created categories to label recurring themes distilled from the open-ended survey comments.

Composite Score Scales

We created four composite score scales to capture the following AF-related concepts: self-efficacy, knowledge, activities of daily living, and social support. Scale reliability tests demonstrated that all four scales were reliable (See Appendix for the survey items used in the four scores). Although we created our own survey and scales for this study, we reviewed RAND Corporation's Medical Outcomes Study questions to inform our study's survey items (RAND Corporation, 2015).

Self-efficacy

We used seven survey items to create the composite AF selfefficacy score. Endpoints of the 4-point scale were "strongly disagree" and "strongly agree" (Cronbach's alpha for these items, .788; inter-item correlations range, r = 0.220-0.509). A higher 'self-efficacy score' corresponded with higher quality of life.

Knowledge

We used four survey items to create the composite AF knowledge score. Endpoints of the 4-point scale were "strongly disagree" and "Strongly agree" (Cronbach's alpha for these items, 0.753; inter-item correlations range, r = 0.304-0.567). A higher 'knowledge score' corresponded with higher quality of life.

For both the self-efficacy and knowledge composite scores, we successively assigned 1 point for "strongly disagree" and ended with 4 points for "strongly agree."

Activities of daily living

We used three survey items to create the composite activities of daily living score. Endpoints of the 3-point scale included, "yes, limited a lot," and, "no, not limited at all" (Cronbach's alpha for these items, 0.824; inter-item correlations range, r = 0.565– 0.688). We successively assigned positive figures to scale responses, starting with 1 point for "yes, limited a lot" and ending with 3 points for "no, not limited at all." A higher 'activities of daily living score' corresponded with fewer limitations in activities of daily living and thus a higher quality of life.

Social support

We used six survey items to create the composite social support score. Endpoints of the 4-point scale included "none of the time" and "all of the time" (Cronbach's alpha for these items, 0.895; inter-item correlations range, r = 0.336-0.830). We successively assigned 1 point for "none of the time" and ended with 4 points for "all of the time." A higher 'social support score' corresponded with more social support and thus a higher quality of life.

We added all the points to calculate the composite scores and means.

Informed Consent

Ethical & Independent Review Services, an independent institutional review board, reviewed and approved all aspects of this study. We kept all data confidential and on a passwordprotected computer. Only researchers involved with the study had access to the data. We did not collect personally identifiable information. Respondents participated voluntarily and did not receive a financial incentive to participate.

Results

Table 1 shows the demographic characteristics of the 332survey respondents.

Self-estimation of Health

Thirty-six percent of the survey respondents reported that their health was "fair" (29%) or "poor" (7%). Nineteen percent rated their health as "excellent" (3%) or "very good" (16%). Forty-five percent felt their health was "good" (Table 2).

Fall Injuries and Risk of Falling

Twenty-seven percent of the survey respondents reported experiencing an injury as a result of a fall. Of the 73% who reported never experiencing an injury as a result of a fall, 46% reported feeling they had little to no risk of falling (Table 2).

Health Behaviors

Although only 5% of the survey respondents reported currently smoking cigarettes, 42% were former smokers; 53% never smoked. Survey respondents reported consuming an average of 3.35 fruits/vegetables per day; 76.0% consumed 4 or fewer and only 24.0% consumed the recommended 5 or more servings per day. Respondents reported engaging in an average of 3.88 days of moderate physical activity for at least 10 minutes at a time in a typical week, with an average of 26.95 minutes spent doing moderate activity on exercise days (Table 2).

Activities of Daily Living

The majority of survey respondents reported being "limited a little" or "limited a lot" with climbing several flights of stairs (78% of respondents), walking several blocks (61% of respondents), and lifting or carrying groceries (52% of respondents; 20%, 38%, and 47%, respectively, reported "not being limited at all" with these activities). Within the past 4 weeks, the typical respondent also reported having "a little bit of difficulty" to "some difficulty" doing their work or other regular activities as a result of their physical health. And in the past 4 weeks, the typical respondent reported "a little bit of difficulty" doing their work or other regular activities as a result of their publical respondent reported "a little bit of difficulty" doing their work or other regular activities as a result of their bit of difficulty.

Body Mass Index

Survey respondents had an average BMI of 29.76, with 41% of the respondents having a BMI of 30 or greater (range, 14.09–60.92 kg/m²; Table 2).

Implantable Devices

Twenty percent of the survey respondents (n = 68) reported having an implantable device. Through an open-ended survey question, respondents most commonly described these devices as a "pacemaker" (n = 14) or an "implantable cardioverter defibrillator" (ICD; n = 11; Table 2).

E. Macario et al.	/ Women's Hea	lth Issues 26-3	(2016) 288-297
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Demographic Characteristics of Survey Sample (N = 332)

Demographic Characteristic	Results
Date diagnosed with atrial fibrillation Country of residence	Average: 7.75 years ago (range, 4 months-54 years; mode: 1 year, 38) United States (84.6%: 281): 48 other countries
, , , , , , , , , , , , , , , , , , ,	(22 United Kingdom, 15 Canada, 5 Australia, 2 New Zealand, 1 France, 1 India, 1 Ireland, 1 Netherlands)
Age (y)	Average (SD): 61.71 (11.93) (range, 26–93) 18-34: 2.1% (7)
	35-49: 14.8% (49) 50-64: 37.7% (125) 65-74: 34.9% (116%)
	75 or older: 10 5% (35)
Ethnicity	Hispanic or Latino: 2% (7)
Race (respondents	Not Hispanic or Latino: 98% (321)
could check >1	White/Caucasian: 94% (309)
racial/ethnic category)	Black/African American: 4% (14)
	Asian/Asian American: 1% (3) American Indian: 2% (5)
	Native Hawaiian: 0% (0)
	Other Pacific Islander: 0% (1)
	Other: 1% (2)
Education	9th, 10th or 11th grade: 2% (5)
	12th grade but no nigh school diploma: 1% (2) High school graduate (includes GFD): 13% (43)
	Some college credit or technical school, but
	<1 year: 9% (30)
	\geq 1 years of college or technical school, no
	degree: 16% (54)
	Bachelor's degree: 22% (72)
	Master's degree: 20% (67)
Household income (\$)	<20,000: 9% (30)
	20,000–39,999: 11% (36)
	40,000–69,999: 18% (58) 70,000–89,999: 9% (29)
	90,000–129,000: 10% (34)
	130,000–149,999: 8% (25)
	>150,000: 8% (25)
Employment status	Employed full time (\geq 32 hours a week):
	Employed part time (<32 hours a week): 11% (36)
	Out of work and looking for work: 2% (5)
	Out of work but not currently looking for work: 1% (2)
	1% (3) Homemaker: 6% (20)
	Student: 0% (1)
	Retired (not employed/not looking for work): 41% (133)
	Temporarily on medical leave: 2% (5)
Marital status	Unable to work: 10% (32) Single pover married: 9% (30)
Widi itdi Status	Now married: 60% (196)
	Living with partner: 6% (20)
	Separated: 2% (5)
	Divorced: 11% (37) Widowed: 11% (35)
Blood type	Blood type O: 31% (103)
JI	Blood type A: 24% (80)
	Blood type B: 8% (25)
	Blood type AB: 7% (22)
	1 don t Know, 50% (101)

Hormone Replacement Therapy

Ninety-five percent of the survey respondents reported not being on hormone replacement therapy (HRT). For the 5% of the respondents on HRT, they reported being on HRT an average of 11 years (Table 2).

Support Group Participation

Of the 15% of the survey respondents who had ever attended an AF-related support group, 53% had participated in a WomenHeart-specific support group (Table 2).

Clinical Trial Participation

Of the 98% of the survey respondents who reported never having participated in an AF-related clinical trial, 75% reported they had never been asked or told about a clinical trial opportunity. Only approximately one in five of these respondents reported being concerned about treatment effects (19%) or practical/logistical issues related to clinical trial participation (18%; Table 2).

AF Symptoms

Eighty-three percent of the survey respondents reported palpitations, 55% reported shortness of breath, and 46% reported weakness, fatigue, and/or difficulty engaging in physical activity as well as dizziness, light-headedness, and/or fainting (46%) before receiving treatment for AF (including medications; Table 3).

AF Comorbidities

Through a closed-ended survey question, survey respondents reported most commonly managing hypertension (47%), obesity (32%), anxiety (27%), a thyroid disorder (24%), sleep apnea (21%), and heart failure (19%) in addition to AF. Nine percent of the survey respondents reported having had a thromboembolic event (Table 4).

Of the 65 respondents (21%) with sleep apnea, 44 (68%) reported using a continuous positive airway pressure (CPAP) device. Nine of the 21 non–CPAP-using respondents with sleep apnea had been advised to use a CPAP but were not using a CPAP. Of the 13% of the respondents who reported having valve disease, 81% had mitral regurgitation, 24% mitral stenosis, and 40% a history of valve repair and/or valve replacement (Table 4).

Blood Type

Of the survey respondents who knew their blood type (70%), 31% had blood type O, 24% blood type A, 8% blood type B, and 7% blood type AB (Table 1).

AF Medications

Eighty-percent of the survey respondents reported using a prescribed medication for their AF, with 91% reporting taking their medication as prescribed "all of the time." The most commonly prescribed medications were the heart rate controlling beta-blockers (75%), followed by the heart rhythm controlling sodium channel blockers (58%) and potassium channel blockers (43%). For stroke prevention, the blood thinning warfarin use was higher at 43%, novel oral anticoagulants at 36%, and the antiplatelet aspirin at 33% (Tables 2, 5).

AF Medical Procedures

Of four possible AF medical procedure options, most survey respondents (39%) had undergone electrical cardioversion,

Health-Related Results of Survey Sample (N = 332)

Health-Related Measure	Results
Self-estimation of health	Excellent: 3% (11) Very good: 16% (52) Good: 45% (148) Fair: 29% (97) Poor: 7% (24)
Experienced an injury as a result of a fall	Yes: 27% (91) No: 73% (241)
Degree of risk respondent feels they have for experiencing a fall	Very high risk for falling: 2% (5) Moderate risk for falling: 17% (40) Low risk for falling: 29% (70) Little to no risk for falling: 46% (110) I don't know: 6% (14)
Body mass index (kg/m ²)	Average (SD): 29.76 (8.04) (range, 14.09– 60.92)
Cigarette smoking	Currently smoke: 5% (17) Quit smoking: 42% (138) Never smoked: 53% (175)
Fruit and vegetable consumption	Average (SD): 3.35 (1.75) ≤4 servings per day: 77.4% (257) >5 servings per day: 22.6% (75)
Moderate physical activity	Average (SD): 3.88 (2.20) days in a typical week engage in moderate activity for \geq 10 minutes at a time (18.1% engage in activity every day of the week; 9.9% do not engage in any activity) Average 26.95 minutes spent doing moderate activity on exercise days (73.2% engage in activity \leq 39 minutes on these days)
Alcohol consumption in the past 12 months	3-6 times per week: 8% (25) 3-4 times per week: 5% (18) 2 times per week: 5% (17) 1 time per week: 5% (20) 2-3 times per month: 13% (43) 1 time per month: 6% (20) 3-11 times in the past year: 12% (40) 1-2 times in the past year: 17% (56) Did not drink alcohol in past year, but drank in the past: 21% (70) Neuror dreads alcohol in life: 7% (22)
Activities of daily living Climbing several flights of stairs	Limited a lot: 39% (128) Limited a little: 39% (130) Not limited at all: 20% (68)
Lifting or carrying groceries	Limited a lot: 17% (56) Limited a little: 35% (116) Not limited at all: 47% (157)
Walking several blocks	Limited a lot: 28% (92) Limited a little: 33% (108) Not limited at all: 38% (127)
Difficulty doing work/other regular daily activities as a result of your physical health in past 4 weeks? Difficulty doing work/other regular daily activities as a result of any emotional problems in past 4 weeks (e.g., feeling depressed or anxious)?	 2.43, mean 1 = None at all; 2 = A little bit; 3 = Some; 4 = Quite a bit; 5 = Could not do daily work 2.18, mean 1 = None at all; 2 = A little bit; 3 = Some; 4 = Quite a bit; 5 = Could not do daily work
Use prescribed medication for atrial fibrillation Adherence to medication	Yes: 80% (267) No: 19% (64) All of the time: 91% (243) Most of the time: 8% (22)
Use implantable device	Rarely: 1% (n = 3) Yes: 20% (66) No: 80% (265)

Table 2	(continued)
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Health-Related Measure	Results
On HRT now	Yes: 5% (17) Average number of years on HRT: 11 No: 95% (314)
Participate in support group	Yes: 15% (50) (53% reported participating in a WomenHeart group) No: 85% (282)
Participated in clinical trial related to atrial fibrillation	Yes: 2% (8) *No, thinking about it but did not: 19% (61) *No, never considered it: 75% (247) Never been asked/told about opportunity: 75% (240) Concerned about treatment effects: 19% (60) Concerned about practical/logistical issues: 18% (57) Not enough risk/benefit information: 7% (22) Not comfortable with trial process: 6% (19) Eligibility requirements too narrow: 3% (9)

Abbreviation: HRT, hormone replacement therapy. * Reasons for not participating in clinical trial.

followed by catheter ablation (29%), atrioventricular node ablation (8%), and surgical maze procedure (5%). Almost one-half the respondents (46%) had not undergone any of these procedures (Table 6).

Analyses of Variance

The social support composite score was significantly associated with marital status and income (p < .05). "Now married" and "living with a partner" respondents had the highest levels of social support. "Single, never married" women had higher levels of social support than "separated" women but not higher than "divorced" or "widowed" women (Figure 1A).

The activities of daily living composite score was significantly associated with marital status, education level, employment level, and income. Ability to complete activities of daily living was significantly and negatively associated with BMI and significantly and positively associated with physical activity and fruit/vegetable consumption (Figure 1B). Moreover, respondents of our survey who consumed alcohol twice a week in the past year were the most limited in activities of daily living. Respondents who never consumed alcohol were the least limited in activities of daily living.

The AF self-efficacy composite score was significantly associated with physical activity and support group attendance. Of the seven self-efficacy score survey items, the following received the highest mean ranking: "Taking an active role in my own health care is the most important factor in determining my health and ability to function." This indicates that women with AF reported greatest agreement in their belief that being proactive about their own health is important to how they feel.

Open-Ended Comments

The open-ended survey question asking respondents to share what WomenHeart should consider when it develops patient resources, lobbies in Congress, and offers support to heart health advocates received 137 responses (41.3% of the respondent sample). The research team identified the following themes from the comments, supported by respondent quotes.

Reported Symptoms by Survey Sample before Atrial Fibrillation Treatment or Atrial Fibrillation Medications (N = 332)

Symptom	Response
Palpitations (being aware of your heart muscle	83% (277)
contracting in the chest; you may feel hard	
beats, fast beats, irregular beats, and/or pauses)	
Shortness of breath	55% (182)
Weakness/fatigue/difficulty engaging in physical activity	46% (154)
Dizziness/light headedness/fainting	46% (153)
Chest pain (angina)/chest discomfort	26% (86)
Sweating	18% (60)
Shortness of breath when lying flat	14% (47)
Swelling of the lower extremities (legs and feet)	14% (47)
Sudden onset of shortness of breath during the night	9% (29)
Confusion	6% (21)
Diarrhea	4% (12)
Weight loss	2% (7)
None of the above	4% (13)

Women with AF desire more AF knowledge

Many survey respondents reported wanting more information on their individual AF. They asked about the causes of AF, how AF progresses, the role of heredity in AF, why AF does not resolve itself after a pacemaker, how menopause and other hormonal issues affect AF, side effects and long-term risks of AF medications, the connection between AF and hearing problems, the normal heart rate for AF at resting after surgery, and alternative therapies for AF that do not include surgery or medications. One respondent commented on "the perception that breast cancer is the biggest killer of women when in fact it is heart disease" and said an awareness campaign to communicate this message to the public is needed. Another respondent noted that before her AF diagnosis she "knew nothing about atrial fibrillation." A third wanted to learn more about AF clinical trials.

- "I know that AF can cause stroke but I need a better understanding of it and the issues associated with it."
- "Almost all the materials or discussion on heart disease are about cardiovascular, not heart rhythm disorders."

Women with AF desire more engagement from the health care system

Survey respondents reported that their doctors often do not know answers to their AF-related questions. They felt there is a need for more education on AF in women, as well as training in sensitivity around this topic, during medical school, residency, and clinical practice. Many respondents also commented on frustrations toward doctors for "not taking them seriously" with respect to AF symptoms, questions, and treatments, including not appropriately referring them to knowledgeable cardiologists.

- "My internist blew me off when I complained of terrible tiredness, saying menopausal women don't sleep well and that it's my age."
- "Having symptoms discounted because of being female and having mild anxiety."
- "Cardiologists limit conversation to sharing results of diagnostic studies and medications prescribed. They fail to inform the client of how the medication might affect the body as a whole."

Table 4

Health Conditions in Addition to Atrial Fibrillation Reported by Survey Sample (N = 332)

Health Condition	Response
	Kesponse
High blood pressure (hypertension)	47% (157)
Obesity	32% (107)
Thuroid disorder (such as hyperthyroidicm)	27% (91)
Sleen appea/sleen disorder	24% (80)
Use a CPAP device	21% (05)
Yes	68% (44)
No	32% (21)
Yes	43% (9)
No*	57% (12)
Heart failure/congestive heart failure	19% (64)
Chronic fatigue	14% (48)
Diabetes	14% (47)
Valve disease (when the flaps of the mitral	13% (42)
valve do not close tightly)	
Mitral regurgitation	
Yes	81% (34)
No	19% (8)
Mitral stenosis	
Yes	24% (10)
NO	76% (32)
History of valve repair and/or had valve replacement	40% (17)
No	40% (17) 60% (25)
No of times had valve repaired or replaced	00% (23)
	59% (10)
2	29% (5)
3	6% (1)
4	6% (1)
Osteoporosis	11% (37)
Heart surgery (previous heart surgery)	11% (37)
Coronary artery disease (hardening of your arteries)	10% (34)
Atherosclerosis (buildup of fats, cholesterol, and	10% (33)
other substances in and on your artery walls)	
Heart attack (previous heart attack)	9% (29)
Stroke (previous stroke)/ministroke/transient	9% (29)
ischemic attack/thromboembolism/blood clots	50((00))
Congenital heart disease (a problem with your heart's	7% (23)
Obstructure and function present at Dirtin)	E% (17)
pulmonary disease	5%(17)
Rheumatic fever (a disease that can result from	4% (14)
inadequately treated strep throat or scarlet fever)	100 (11)
Hypertrophic cardiomyopathy (when your heart	3% (10)
becomes abnormally thick)	
Cognitive dysfunction (mental health disorders that	3% (9)
affect learning, memory, perception, and	
problem solving)	
Hypokalemia	3% (9)
Lung disease (such as pneumonia, lung cancer,	3% (10)
pulmonary embolism, sarcoidosis)	
Renal failure/chronic renal failure/kidney failure	3% (9)
Pericarditis (inflammation of the lining around the heart)	2% (6)
Peripheral arterial disease (when your limbs do not	2% (6)
receive enough blood flow)	

Abbreviation: CPAP, continuous positive airway pressure.

* Advised to use a CPAP device but you are not currently using one.

Women with AF experience unique side effects

Many survey respondents described side effects specific to their AF and AF treatments and medications such as "severe tinnitus," "significant hearing loss," and "ringing in ears." Another described her concern "touring a high altitude environment." A third mentioned, "jaw pain" as a result of AF. Of note, several respondents commented that because of differences in symptoms and treatments for paroxysmal AF (AF that occurs sometimes and then stops), persistent AF (AF that does not stop by itself), and

Prescription Medications Used by Survey Sample (N = 332)

Medication	Response
Blood thinners	
Antiplatelets (e.g., aspirin [acetylsalicylic acid or ASA], clopidogrel [plavix])	33% (75)
Anticoagulants (e.g., warfarin [Coumadin])	43% (98)
Novel oral anticoagulant (e.g., apixaban [Eliquis],	36% (81)
dabigatran [Pradaxa], rivaroxaban [Xarelto], edoxaban	
[Syvasa])	
Heart rate controllers	
Beta blockers (e.g., atenolol [Tenormin], bisoprolol	75% (165)
[Zebeta], carvedilol [Coreg], metoprolol [Lopressor,	
Toprol XL], nadolol [Corgard], propranolol [Inderal],	
timolol [Blocardren])	
Calcium channel blockers (e.g., dilitiazem [Cardizem,	31% (69)
Tiazac], verapamil [Calan, Isoptin Verelan])	
Digoxin (Lanoxin)	15% (33)
Heart rhythm controllers	
Sodium channel blockers (e.g., flecainide [Tambocor],	58% (59)
propafenone [Rythmol], quinidine)	
Potassium channel blockers (e.g., amiodarone [Cordarone,	43% (44)
Pacerone], sotalol [Betapace], dofetilide [Tikosyn])	

permanent AF (AF that is chronic and no further attempts at converting the rhythm is planned), a one-size-fits-all approach to AF management is imprudent.

- "I have side effects from two different medications. I am dizzy and lightheaded 100% of the time."
- "The side effects of medications used to treat AF are very frustrating."

Women with AF need emotional support

Many survey respondents shared feeling anxious, fearful, and isolated as a result of AF and wished there were support groups in their communities. Younger respondents, especially, said they could not find support groups or other resources tailored to their age cohort.

- "I moved to a city of 45,000 people but there are no support groups in my immediate area. It is very isolating."
- "The complications from the procedures to resolve my AF have a direct effect on my mental health."

Discussion

Survey Sample Profile

This descriptive survey study's findings reflect the experiences of a convenience sample of 332 mostly Caucasian women with AF. For those respondents who reported the country in which they live, 281 said they lived in the United States and 48 said they lived in other countries (22 United Kingdom, 15 Canada, 5 Australia, 2 New Zealand, 1 France, 1 India, 1 Ireland, 1 Netherlands).

Social Support, Self-efficacy, and Facebook

The most common ways that survey respondents learned about our survey were from a WomenHeart email (46%) and/or Facebook (41%). The popularity of Facebook as a medium for connecting women with AF is noteworthy. Our study showed attendance in a support group was significantly related to AF

Table 6

Rer	orted	Medical	Procedures	for	Atrial	Fibrillation	bv	/ Surve	v Sam	ple (ίN	= 332	2)
									,	1			- /

Medical Procedure*	Response
Electrical cardioversion (A procedure in which an electric current is used to reset the heart's rhythm back to its regular pattern, a normal sinus rhythm. An electric current enters the body through metal paddles or patches applied to the chest wall)	39% (129)
Catheter ablation (A procedure used to selectively destroy areas of the heart that are causing a heart rhythm problem.)	29% (97)
Atrioventricular (AV) node ablation (The AV node is ablated and thereafter a permanent pacemaker is implanted in the chest to regulate the lower chambers of the heart [ventricles].)	8% (25)
Maze procedure (A procedure that can be done by surgery or by catheter ablation in which a surgeon or cardiologist uses small incisions, radio waves, freezing, or microwave or ultrasound energy to create scar tissue. The scar tissue, which does not conduct electrical activity, blocks the abnormal electrical signals causing arrhythmia. The scar tissue directs electric signals through a controlled path, or maze, to the lower heart chambers [ventricles].)	5% (16)
None of the above	46% (154)

* Respondents Could Check More >1 category.

self-efficacy (a belief in one's capacity to execute behaviors necessary to manage one's AF condition as optimally as possible). Facebook is accessible by many people regardless of income or marital status—two variables associated with greater social support in our study. Facebook can serve as an important portal for providing support and information to women with AF. Other research has shown that perceived similarity, through characteristics such as shared illness, engender more positive evaluations of health messages, which in turn can influence changes in health behaviors (Hu & Sundar, 2010; Walther, DeAndrea, Kim, & Anthony, 2010).

Perceived Health Status and Symptoms before and after AF Treatment

In this study, we asked survey respondents to report their AF symptoms before beginning any treatment for AF, including AF medications. Although we did not ask respondents to report their AF symptoms after treatment, respondents in our study perceived their current health as poor (7%), fair (29%), good (45%), very good (16%), or excellent (3%). Respondents reported limitations in climbing stairs (39% limited a little; 39% limited a lot), walking several blocks (33% limited a little; 28% limited a lot), and lifting/carrying groceries (35% limited a little; 17% limited a lot). These self-estimations of health status can serve as a descriptive measure of the health of women with AF while on treatment. These results indicate that women with AF are faring well enough, on average, but could do better. Future research should specifically ask about AF symptoms both before and after AF treatment to assess the extent to which AF treatment help patients lead a higher quality life.

Comorbidities and Concomitant Challenges

Numerous women with AF who completed our survey suffer from multiple health conditions and face concomitant challenges alongside their AF management. Many respondents reported having health conditions in addition to AF, most commonly hypertension (47%), obesity (32%), anxiety (27%), a



Figure 1. (*A*) Relationship between marital status and social support. (*B*) Relationship between the activities of daily living composite score and fruit/vegetable consumption. Note: A higher 'activities of daily living score' corresponds with fewer limitations.

thyroid disorder (24%), sleep apnea (21%), and heart failure (19%). Fifty-three percent of the survey respondents had undergone some kind of medical AF procedure; 28% had experienced an injury as a result of a fall; 20% had an implantable device; and 41% previously smoked, with 6% currently smoking cigarettes. Nine respondents had been advised to use a CPAP but were not using one. Qualitative comments mirrored these quantitative findings.

Fruit and Vegetable Consumption, Physical Activity, and BMI

Seventy-six percent of women with AF who completed our survey consumed four or fewer servings of fruits/vegetables a day—a quantity that is below the recommended minimum five daily servings. Moreover, only 18% of the survey respondents engaged in daily moderate physical activity and 41% had a BMI of greater than 30 kg/m². Our results showed that respondents who consumed more fruits/vegetables, engaged in more physical activity, and had lower BMIs were statistically significantly better able to engage in activities of daily living. These findings indicate the need to raise awareness among women with AF of the benefits of modifiable behaviors including fruit/vegetable consumption and physical activity. We must continue to identify tactics that are successful in getting women to exercise. Although our small descriptive study showed a significant and positive association between fruit/vegetable consumption and the ability to engage in activities of daily living, the Physicians' Health Study with 21,054 male participants showed no significant association between nut consumption and incident AF among U.S. male physicians (Khawaja, Graziano, & Djousse, 2012). A future, larger study could investigate whether the fruit and vegetable/ activities of daily living association is a gender-specific benefit to women.

In our study, physical activity was also associated significantly with greater confidence in being proactive about one's AF condition (self-efficacy). AF self-efficacy predicted attendance in a support group. Furthermore, respondents who drank more alcohol were more limited in their daily activities. Given that alcohol is a risk factor for AF (Larsson, Drca, & Wolk, 2014), this would indicate the need for further interventions to influence another modifiable behavior, alcohol consumption, among women with AF.

AF Support Groups and AF Clinical Trials

Only 15% of the survey respondents had ever attended an AF support group. Almost none had ever participated in an AF clinical trial and 75% had never been told about AF clinical trials. These are woefully low numbers given the recurring comments respondents made in the open-ended survey question about feeling isolated and needing emotional support as well as desiring more information and participation in research to advance knowledge in the AF field specific to women. Of interest, respondents with a live-in partner ("now married," "living with a partner") had the highest levels of social support and social support level was directly associated with income level-the higher the income, the stronger the social support a respondent enjoyed. Our study suggests that separated women especially could benefit from support groups, because this transitional period may have detrimental health effects.

Role of HRT

The role that HRT plays in AF is not well-understood (Bretler et al., 2012; Perez et al., 2012). A previous study found that HRT did not independently predict mortality, thromboembolism, or bleeding among women with AF (Apostolakis, Sullivan, Olshansky, & Lip, 2014). Another study concluded that HRT was associated with a decreased risk of new-onset AF in women with myocardial infarction first year after discharge (Bretler et al., 2012). A Women's Health Initiative trial analysis showed the risk of AF was modestly elevated in women taking postmenopausal HRT (Perez et al., 2012). Women (who had had a hysterectomy) taking estrogen alone had a higher rate of AF. This was not seen in women with an intact uterus taking estrogen plus medroxyprogesterone, but there was a significant effect when both groups were combined (Perez et al., 2012). Our study analyzed variance on HRT and the composite scores and found no significance for any of them (17 total respondents in our study were on HRT and only one of these respondents had ever experienced a stroke).

AF, Stroke, and Blood Type

Although research has shown that AF markedly increases the risk of stroke, only 9% of our survey respondents reported having had a thromboembolic event (i.e., stroke; Table 4) and this is likely owing to the high rate of anticoagulant use (i.e., warfarin; 43% of the respondent sample) or antiplatelet use (i.e., aspirin; 33% of the respondent sample). Another study suggested that women with type B blood had a 17% increase in stroke risk compared with men (MediLexicon, 2011). In our survey study, 29 respondents reported having had a stroke/stroke condition (Table 4). None of these 29 respondents who had a stroke reported having type B blood.

Limitations

This study's findings may not be generalizable to all women with AF because we did not select respondents randomly. Because most respondents were familiar with WomenHeart, they may be more knowledgeable and proactive about living with AF than other women with AF (self-selection bias).

To reduce respondent burden through fewer survey questions per composite score, we selectively adapted measures from other sources and thus did not use previously validated measures. The survey was only available electronically, so eligible women who did not have Internet access are not represented in the results. We administered all data collection methods in English, excluding women whose primary language is one other than English.

Respondent recruitment efforts included placing announcements on social media, making it impossible to know the total viewing audience. Because we do not know the total denominator of potential respondents, we are not able to calculate a survey response rate. More than 90% of our sample was composed of Caucasian women with AF. Future research must engage in more effective recruitment of non-White women with AF.

Implications for Practice and/or Policy

We would expect men with AF to report at least some different results than women with AF. A next study should administer the same survey with both men and women. This study on women with AF and their quality of life showed that women with AF may benefit from support groups in local communities, especially women recently separated from their partners and younger women likely not to have other women in their age cohort with whom they can identify. Patients would benefit if clinicians and health educators provided more information on AF and the different types of AF. AF resources must underscore the positive physical and mental health effects of fruit/vegetable consumption (specifying which fruits/vegetables are uniquely not beneficial to AF patients), physical activity, and attending support groups as well as of diminishing alcohol intake for women with AF.

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Supplementary data

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