


# Comparing Patient and Provider Experiences with Atrial Fibrillation to Highlight Gaps and Opportunities for Improving Care



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**BACKGROUND:** Atrial fibrillation (AF), the most common abnormal heart rhythm, places a considerable burden on patients, providers, and the US healthcare system.

**OBJECTIVE:** The purpose of this qualitative study was to compare patients' and providers' interpretations and responses to AF symptoms and to identify where treatment can be improved to better address patient needs and well-being.

**DESIGN:** Qualitative design using focus groups with patients (3 groups) and providers (3 groups).

**PARTICIPANTS:** Patients with physician-confirmed AF ( $n=29$ ) and cardiologists, primary care physicians, and cardiac nurses ( $n=24$ ).

**APPROACH:** Focus groups elicited patient and provider perspectives regarding the symptom experience of AF, treatment goals, and gaps in care. Patient and provider transcripts were analyzed separately, using a thematic content analysis approach, and then compared.

**KEY RESULTS:** While patients and providers described similar AF symptoms, patients' illness experiences included a wider range of symptoms that elicited anxiety and impacted quality of life (QOL) across many biopsychosocial domains. Patients and providers prioritized different treatment goals. Providers tended to focus on controlling symptoms congruent with objective findings, minimizing stroke risk, and restoring sinus rhythm. Patients focused on improving QOL by reducing medication use or procedures. Both patients and providers struggled with patients' cardiac-related anxiety. Patients expressed an unmet need for education and support.

**CONCLUSION:** Patients with AF experience a range of symptoms and QOL issues. While guidelines recommend shared-decision making, discordance between patient and provider perspectives on the importance, priority, and impact of patients' perceived AF symptoms and consequent cardiac anxiety may result in differing treatment priorities. Starting from a perspective that contextualizes AF in the broader context of patients' lives, prioritizes QOL, and addresses symptom-specific anxiety as a prime concern may better address patients' unmet needs.

**KEY WORDS:** atrial fibrillation; qualitative research; quality of life; cardiac anxiety; disease management.

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## INTRODUCTION

Atrial fibrillation (AF), the most common arrhythmia, affects approximately 3–5 million Americans and places a considerable burden on patients and the US healthcare system.<sup>1–3</sup> This burden manifests in patients' impaired mental and physical health and quality of life (QOL) and also increases healthcare costs.<sup>4–6</sup> The life-threatening consequences of untreated AF (e.g., stroke) often obscure patients' day-to-day illness burden. Even when rate or rhythm control treatments are effective in normalizing heart rhythm, they may not reliably resolve subjective symptoms<sup>7–9</sup> that compromise patients' QOL, physical functioning, and emotional well-being.<sup>10–13</sup>

The unpleasantness and unpredictability of AF symptoms may elicit anxiety,<sup>14–17</sup> having both physiological (e.g., sympathetic arousal) and psychological (e.g., health worries, hypervigilance, treatment compliance, and avoidance behaviors<sup>13, 17</sup>) impacts. To implement effective disease management programs, it is important to understand the precise nature and impact of anxiety and other biobehavioral factors from both patients' and providers' perspectives. Clinical guidelines<sup>18</sup> and prior research<sup>13, 16, 19, 20</sup> have emphasized general anxiety as it relates to the emotional unpleasantness of AF as a chronic illness, but they have not specifically focused on the anxiety cardiac symptoms elicit (e.g., attention to cardiac sensations driven by fear of symptoms' serious physical health consequences<sup>21</sup>). A recent systematic review identified multiple studies examining this heightened cardiac anxiety, but none of these studies explored this anxiety in patients with AF.<sup>22</sup>

For multifaceted chronic diseases such as AF, qualitative research methods are useful for understanding the range and complexity of individual experiences,<sup>23</sup> patients' complex

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biopsychosocial needs, actionable strategies to improve quality of care, and health behaviors that influence symptom perception and health care utilization.<sup>24</sup> Previous qualitative studies have briefly examined various aspects of the AF experience, including the distress patients experience because of the unpredictable and uncertain nature of AF symptoms, and subsequent QOL impairment,<sup>19, 20, 25, 26</sup> and the importance of a patient-physician partnership in the treatment of AF.<sup>26, 27</sup> However, qualitative researchers have not conducted a detailed examination of patients' symptom perceptions and experiences or the specific nature of patients' cardiac anxiety and how this compares with providers' understanding and treatment approaches.

Therefore, there is a significant gap in knowledge around how patients and providers perceive the illness experience of AF, and how these perspectives compare. The goal of this study was to identify areas of convergence and divergence in how patients and providers interpret and respond to AF symptoms and related anxiety to identify opportunities for improving AF management and the patient-physician relationship around shared treatment goals.

## METHODS

### Design

Focus groups were conducted to explore the AF illness experience from the patient and provider perspectives. Study procedures were approved by the University at Buffalo Institutional Review Board. All participants were provided with a study sheet containing detailed informed consent information and granted verbal consent to participate.

### Recruitment

Patients ( $N=29$ ) were recruited using a combination of: flyers in cardiology offices ( $n=6$ ), provider referral ( $n=9$ ), ads in local publications ( $n=12$ ), and word of mouth ( $n=2$ ). Each passed a detailed phone screen consisting of the following: a self-reported positive physician diagnosis of AF, supported by detailed questioning about type of AF and treatment(s) received, recent symptomatic episode(s) of AF, and at least moderate impact of symptoms (Text Box 1). Patients who passed screening participated in one of three focus groups.

#### Text Box 1. Participant eligibility criteria

Providers	Patients
<ul style="list-style-type: none"> <li>Actively practicing medicine</li> <li>Currently treating patients with AF</li> <li>Willing and able to attend a group in person and be recorded</li> </ul>	<ul style="list-style-type: none"> <li>18 years or older</li> <li>Self-reported receiving an AF diagnosis from a physician (detailed information collected included: date of diagnosis, type of physician, and type of AF (paroxysmal, persistent, permanent))</li> <li>Reported experiencing AF symptoms "sometimes, often, or always" in the past three months (as opposed to never/rarely)</li> <li>Reported that AF symptoms affected their daily lives to a</li> </ul>

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moderate, severe or extreme extent (as opposed to no effect/mild)

- Reported no suicidal intentions or severe substance use
- Willing and able to attend a group in person and be recorded

Providers ( $N=24$ ) were recruited via word of mouth through professional networks and email outreach to local primary care and cardiology practices. Three groups were held: cardiologists ( $n=7$ ), primary care physicians ( $n=7$ ), and cardiology nurses/nurse practitioners/physician assistant ( $n=10$ ).

### Data Collection

Two parallel sets of questions were developed to guide discussion, informed by existing literature and other qualitative studies of patient AF experiences (see [supplemental material](#)).<sup>10, 11, 17, 19, 28–35</sup> Provider questions asked about: perceptions of AF symptoms and their impact on patients; perspectives on AF treatment approaches, including goals and challenges; and how well treatments address symptoms. Patient questions similarly asked about: AF symptoms and their impact on their lives; treatment experiences, lifestyle changes, treatment goals; and how well treatments addressed symptoms. Before the focus groups, both patients and providers completed a demographics survey and patients completed additional survey questions about their experiences with AF.

All groups were led by an experienced, PhD-level facilitator (BV). Patient groups lasted approximately 90 min and provider groups lasted approximately 45 min. Discussions were audio-recorded and professionally transcribed verbatim. Participants were compensated for their time (\$200 for providers/\$100 for patients).

### Data Analysis

Qualitative data were analyzed using a thematic content analysis approach,<sup>36–39</sup> overseen by Dr. Vest. Provider and patient groups were analyzed separately. Three members of the research team (DL, CHM, KR) served as primary analysts, responsible for independently reading and reviewing all transcripts to identify preliminary themes. All team members read the transcripts and then met to discuss the identified themes, resolve discrepancies, and agree upon the final categorization. Themes, sub-themes, and supporting details were compiled in Microsoft Excel and reviewed by the three primary analysts and the lead qualitative investigator. The transcripts were reviewed again to extract quotations that supported each theme and sub-theme. As questions arose, the analysts and lead conferred and adjusted the organization and theme definitions as needed. The identified themes, their organization, categorization, details, and the selected quotations were all checked by multiple members of the team throughout the analysis process to ensure agreement. All team members met

to discuss key findings and interpretations, and compare provider and patient results.

**RESULTS**

Participant demographics are provided in Table I. We compare patient and provider findings across four broad areas: (1) AF symptoms, (2) the impact of AF symptoms and diagnosis on patients' lives, (3) experiences with treatment, and (4) gaps and unmet needs. (See the [supplemental online table](#) for additional supporting data.)

**AF Symptoms**

**Provider Perspective: Symptoms.** Providers listed fatigue, palpitations, and shortness of breath as AF symptoms that were most problematic for their patients. While providers discussed other symptoms, such as lightheadedness, their conversations generally focused on symptoms directly attributable to AF. They did note, however, that the non-specificity of AF symptoms is problematic for patients:

“Sometimes because the symptoms are so vague, they don't know if they're having Afib or not ... They don't know if they should be calling the doctor or going to the emergency room or changing medications.” [Cardiology Group]

Primary care providers also mentioned that a large proportion of their patients with AF are asymptomatic, having no idea they are in AF until it is identified during a routine exam.

**Patient Perspective: Symptoms.** Patients also recognized fatigue, palpitations, and shortness of breath as common symptoms caused by AF. According to one patient, “My Afib feels like my heart is doing a summersault in my chest. That's probably the best way I can describe it,” [Patient group #3].

Another patient described the fatigue caused by AF as:

“I'm sort of in that fog a lot of the time...Which isn't helpful. So I've cut, my work down, like in half over the last six years. And the other day I was exhausted. I

**Table I Participant Characteristics**

Patients	Providers
<u>Demographics</u>	<u>Demographics</u>
Gender:	Gender:
Male	Male
Female	Female
Age:	Ethnicity:
Age range:	Asian
Ethnicity:	Black/AA
Non-Hispanic	White
Hispanic	Other
Race:	<u>Medical background</u>
Black/AA	Yrs in practice:
White	Yrs in practice range:
Education:	Training:
High school/ GED	MD
Some college	PA
College degree	NP
Post-Grad degree	RN
Income:	Physiologist
< \$50k	Specialty:
\$50k to 100k	Family medicine
> \$100k	Cardiology
Refused to answer	Internal medicine
Insurance:	AF patients per Wk:
Medicare	5 or less
Medicaid	6 to 10
Private	> 10
No answer	
<u>AF characteristics</u>	
Age of 1 <sup>st</sup> AF episode:	
Range age of 1 <sup>st</sup> AF:	
Age of AF diagnosis:	
Range age of AF Dx:	
AF treatments:	
Cardioversion	
Ablation	
Anticoagulant	
Antiarrhythmic	
Rate control	
All three classes	

put the CPAP on, slept for 14 hours, and wasted a whole day.” [Patient group #1]

While providers and patients generally agreed on the top AF symptoms, patients reported a much broader range of perceived AF symptoms, including chest pain, muscle fatigue, and decreased stamina, which they uncertainly connected to their AF. While providers saw chest pain as symptomatic of a more serious cardiac problem, patients reported it as a common AF symptom:

“Yeah. It’s a pounding pain...mine is in my upper back. It’s like somebody took a sledgehammer and slammed you in the back when you least expected it.” [Patient group #3]

Patients also reported symptoms related to muscle cramping, fatigue, and reduced strength: “When you’re exhausted going up the stairs or hiking, when I do too much, I can just tell my muscles aren’t getting enough blood flow. It’s like running a marathon and all of a sudden, I get cramps up and down my back... I can’t lift everything...” [Patient group #1].

Patients mentioned other symptoms they attributed to AF, which may have been a result of AF sequelae, medication side effects, or unrelated physical sensations, including nausea and vomiting, trouble sleeping, general feelings of mental “fuzziness” or “brain fog,” sweating, swelling in their legs, fluctuations in blood pressure, and headaches. Patients acknowledged that it was sometimes difficult for them to tell if their symptoms were from AF or a result of other comorbid conditions.

### Impact of Living with AF

**Provider Perspective: Impact.** Providers acknowledged that AF affects patients’ QOL, emotional well-being, and physical activity levels:

“I think people who are really symptomatic, it just really interrupts or reduces their QOL. Because they think about it, they can’t do what they’re planning to do, they can’t exercise and it is just very interruptive and disruptive for them.” [Advanced Practice Provider/Nurse Group]

Providers also discussed that frequent doctors’ visits and medication regimens made it difficult for patients to work or travel.

Providers highlighted AF’s emotional toll, recognizing that patients often experienced anxiety, and their role in offering reassurance:

“I think most of the people with acute atrial fib, they’re scared... They’re worried they’re having a heart attack. They’re worried they’re dying. So, I think a lot of

reassurance is necessary. ‘This happens a lot. We can take care of it. No big deal.’” [Primary Care Group]

**Patient Perspective: Impact.** Patients discussed the broad-ranging mental, physical, social, and emotional impacts that their symptoms have on their lives and took a broader view than the providers. One patient summarized the impact as follows: “It affects your life. You allow it to affect your life, and then that whole thing controls you.” [Patient group #2]

Physically, patients described feeling weak and lacking the energy to exercise, complete household chores, or participate in previously enjoyable activities. They reported adaptations, such as avoiding stairs or getting up earlier to pace themselves. Physical limitations also affect patients’ social lives, including feeling embarrassment about work limitations, forgoing social gatherings or playing with grandchildren, and having a partner that does not understand:

“I think the hardest thing with Afib is that...when we’re fatigued, we mean we’re fatigued. And people look at you, what’s the matter with you?...And people on the outside world, because they don’t see the disability, and they don’t see the physical, they don’t get it. And that can be very hurtful at times.” [Patient group #2]

Symptom unpredictability was a major challenge for patients, described as disruptive and inhibiting. Patients discussed experiencing constant worry and fear over when symptoms would occur:

“It concerns me where I’m going to be when it happens. And in September I took a riverboat cruise in Europe and I planned it a year ago. And I don’t think it was off my mind one day in that year. What if? ... Where am I gonna be, how bad is it gonna be?” [Patient group #3]

Importantly, some patients indicated that AF had either a minimal impact on their lives, or that they were able to cope and adapt:

“I was afraid at first to do anything physically after I was diagnosed because you’re afraid that you’re going to die of a heart attack or something. But my doctor said ... ‘Just live your life normally.’ And ever since then, I’ve tried to do that. I work out three times a week in the gym. I do the ellipticals, I walk backwards on the treadmill, I play golf... You have to fight this a little bit and not be so afraid of it.” [Patient group #3]

Some patients indicated protective factors that helped them cope with their diagnosis, such as being a caregiver for others, overall resiliency, being able to let go, religion, and surrounding themselves with positive people.

## Treatment Experiences and Goals

**Provider Approach to AF Treatment.** Providers discussed their general AF treatment approaches, including providing patient education, managing stroke risk through anticoagulation, eliminating symptoms, and recommending lifestyle changes. Providers perceived one of the primary goals of treatment to be the elimination of symptoms, framed as restoring sinus rhythm. Comments revealed providers' belief that once patients were in sinus rhythm, the daily impact of AF would be minimal:

“They’re so symptomatic. I want to make their QOL the best. They have so many years to enjoy. The earlier we achieve the sinus, the better it is.” [Cardiology Group]

Providers expressed several AF treatment challenges, including the trial-and-error process necessary to find efficacious and tolerable medications, determining when more invasive procedures are necessary, and assessing responses to treatment:

“Each patient is really an individual case. It’s not like a clear cut algorithm that we follow with everyone because of the varying symptoms, the different etiologies.” [Cardiology Group]

Providers were also challenged by the ambiguity of AF symptoms, which could be misattributed, or related to other comorbidities:

“With Afib you can have fatigue and it can be the problem, but there’s a million other diagnoses that can also contribute to fatigue that are not cardiac related. So sometimes we do our darndest and it’s just, it’s their thyroid, or it was all their psych meds, or x, y, z. Those things also contribute. Maybe it’s just depression, but everybody is tired. And [Afib’s] always the reason why you’re tired because it’s this tangible thing, ‘Well, I have Afib, so I must be tired from my Afib.’” [Advanced Practice Provider/Nurse Group]

Finally, providers discussed challenges related to patient willingness to engage in treatment, especially regarding anticoagulation therapy, but also adherence to diet restrictions, avoidance of high-risk activities, and testing requirements.

**Patient Experiences with and Goals for Treatment.** Patients discussed experiencing multiple treatments to control heart rate/rhythm including: multiple medications, cardioversions, and ablations with mixed effectiveness. Patients were frustrated that even more invasive procedures often did not resolve their AF, or helped only for a short period of time. Reflecting provider comments on the trial and error nature of AF treatment, patients described feeling like a guinea pig:

“I find that number one, I don’t like being tired all the time. And I also have the breathing machine, the CPAP machine, and I’m in Afib constantly and I’ve had...two ablations, been cardioverted three times. It lasts a day, if that. And going over the list of what drugs, I’m going well, I’ve had that one, I’ve had that one, had that one...I feel like I’m their guinea pig...” [Patient group #1]

There were some discrepancies between providers' and patients' primary goals for treatment. While both patients and providers identified being symptom-free as a goal, patients also expressed much broader views, reflecting a focus on overall QOL, and concerns about medication side effects sometimes seen as bothersome as the symptoms. In contrast to providers—for whom restoring sinus rhythm was the primary treatment goal—patients often indicated their primary goals were taking less medication or using more natural treatments, and restoring energy and strength they perceived as lost due to AF.

## Gaps in AF Treatment and Management

Patient and provider groups revealed important gaps regarding AF treatment and management. Treatment rarely addressed patients' cardiac anxiety and seldom provided sufficient access to AF-specific knowledge and support.

### **Cardiac Anxiety Challenging to Manage.**

**Provider Perspective on Cardiac Anxiety.** Providers discussed the challenge of addressing patients' cardiac anxiety. Some mentioned that an AF diagnosis itself can cause anxiety in patients and that it can be difficult to distinguish AF symptoms from anxiety symptoms (e.g., heart palpitations):

“[P]art of having the diagnosis of Afib is the anxiety that it provokes for some of the people. And I don’t know if it’s just our particular population, but they’re very anxious, right? ...that alone induces palpitations. So, having them be able to differentiate between, “Okay, that’s Afib palpitations and you’re just a little worried today.” [Primary Care Provider Group]

Providers also reported that differentiating between AF and anxiety symptoms can make it difficult to determine a management plan, and acknowledged that they were unable to successfully address patients' cardiac anxiety. Providers were sometimes uncertain whether and how to address patient anxiety and need for reassurance.

**Patient Experiences with Cardiac Anxiety.** Across all groups, patients also described how the onset of symptoms caused them to feel anxious. Patients acknowledged that they are unable to identify which symptoms are a result of AF or which are somatic manifestations of anxiety. One patient described the experience as, “It’s almost like an anxiety but then it will become a flutter. I don’t know which came first: the

flutter or the anxiety but it's scary" [Patient group 2]. The anxiety around cardiac symptoms, their onset, potential duration, and whether they signal something more serious, significantly impacts patients' emotional and mental well-being, as well as their QOL.

### **Patients Need More Knowledge and Support Around AF.**

**Knowledge of AF.** Patients discussed knowing little about AF prior to diagnosis, "I wasn't given a lot of info about it either. Here, take this med, try that. You know? They told me the mechanics behind it but not a ton. I don't know." [Patient group #1]. Patients felt they needed more information about how AF would affect their lives, in some cases learning things from each other during the group, which they said their doctors never mentioned:

"What bugs me is why the doctors don't tell you that – nobody ever said that with Afib you're going to be out of breath. I just disconnected the two. I figured, oh, that's because you're overweight, you don't exercise, you're sedentary, or you don't work a full-time job so you're not as active." [Patient group #3].

Patient conversations also revealed a knowledge gap around how to respond to symptoms, i.e., when to seek medical assistance or wait to see if symptoms resolve.

In the absence of feeling their questions were addressed, patients discussed looking for information on their own:

"You need to educate yourself... You've got to be your own advocate. You've got to look things up. Go on the internet, look through the web... Don't strictly rely on that medical person to give you all the information." [Patient group #3]

**Support.** Patients indicated needing AF-specific support in addition to information. One participant mentioned asking her provider about this, "I ask her every time is there a support group or something?" [Patient group #3]. Another participant said that just being in the focus group was helpful "I feel good being here listening to the different stories because I'm learning" [Patient group #2].

While providers offered reassurance, patients described feeling that their providers do not fully understand or acknowledge their concerns. One patient indicated that they "got the brush off" because "it's not that big of a deal to her" [Patient group #1]. Another patient echoed, "It's difficult to hear 'don't worry about it' from the doctor" [Patient group #3].

Patients may also need support to implement lifestyle changes recommended as part of AF management. Some patients discussed feeling that their physicians' recommendations were not feasible or unrealistic due to financial and other limitations.

## DISCUSSION

This study compared how patients and providers understand and respond to AF, specifically experiences and perceptions of AF symptoms and their impact, and identified key gaps, challenges, and opportunities for AF care improvement. To our knowledge, only two other studies have directly compared patient and provider views from a qualitative perspective, but both focused specifically on oral anticoagulant therapy rather than the broader experience of AF.<sup>40, 41</sup> Our findings indicate that patients with AF experience a wide range of perceived symptoms, significant cardiac-related anxiety, and QOL concerns that providers struggle to address with existing medical and lifestyle treatments. This highlights important areas for improvement of AF treatment for the benefit of both patients and practitioners.

Patients' AF illness experiences are informed by a broad range of impacts including physical, mental, emotional, and social domains (Fig. 1), which affect overall well-being. Providers felt confident in their ability to address AF's medical aspects, focusing more on the objective presence of symptoms, rate and rhythm control, and management of stroke risk through anticoagulation. However, existing treatments fail to address patients' subjective symptom experiences, cardiac anxiety, and broader effects on QOL. Patients tended to focus on the ability to experience and engage in their lives fully, often discussed as reducing medications and interventions.<sup>19</sup> The unpredictable nature of AF, often requiring trying multiple treatment modalities to restore sinus rhythm, was frustrating for patients and often at odds with intervention reduction goals, an issue that did not resonate with the providers. Starting from a place of patient-provider agreement on treatment goals would enable better shared decision-making processes, as emphasized in clinical guidelines.<sup>18, 27, 42</sup>

Patients' cardiac-related anxiety, a psychological factor known to be related to AF diagnosis,<sup>11, 14, 16, 43</sup> was emphasized by both patients and providers as it relates to the experience of AF symptoms. Providers acknowledge the significant role of anxiety in patients' experiences of AF, but feel they have no way to address this, other than to respond to patients' worries with reassurance (e.g., "don't worry about it"). This approach at best provides temporary relief, but likely serves as negative reinforcement that may escalate the very anxiety that reassurance aims to relieve.<sup>44, 45</sup> Clinically, this suggests that physicians may need to move beyond dispensing reassurance or prescribing generic lifestyle modification changes (e.g., dietary recommendations, relaxation training, avoidance of stressful situations) for patients with AF whose perceived symptoms do not necessarily correspond with physical signs. Routine assessment of anxiety, particularly heart-focused anxiety, may identify patients prone to persistent cardiac symptoms even after medical therapy for the arrhythmia. Those with elevated cardiac anxiety may be triaged to behavioral treatment utilizing evidence-based strategies to gain control over illness beliefs and behaviors that fuel

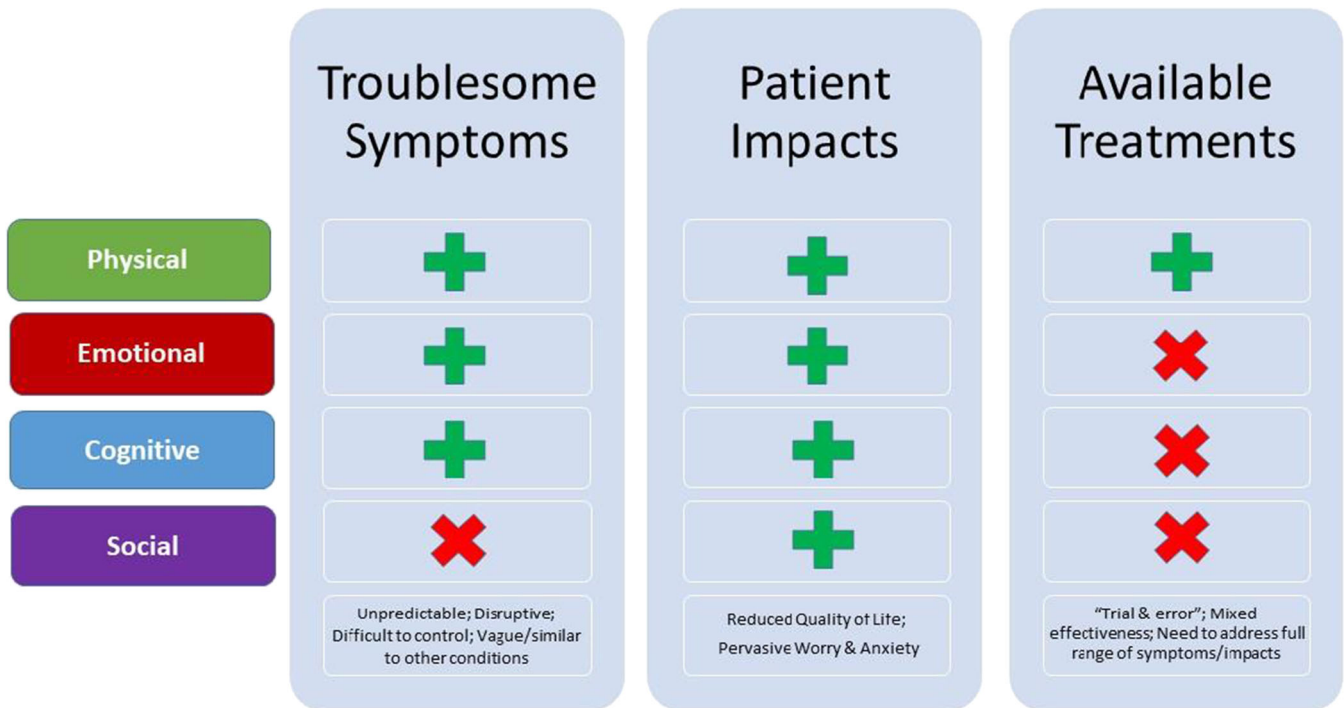


Figure 1 Symptoms, impacts, and identified gaps in AF treatment: results from patient and provider focus groups. Notes: + denotes concordance between provider and patient perspectives; X denotes discrepancy between provider and patient perspectives.

symptom fears. e.g.,<sup>25, 39, 46</sup> Because cardiac anxiety is not specific to AF and is seen in other cardiac diseases (e.g., non-cardiac chest pain, heart failure),<sup>47-49</sup> it may be efficiently targeted in routine settings with diverse cardiac patients.

**Limitations**

As a single study drawn from one metropolitan area, results may not be generalizable; nonetheless, they provide an improved understanding of the clinical experiences, symptoms, and perceptions important to patients and providers which may inform additional research and program development. We were unable to cross-verify patients’ self-reported AF diagnosis. However, detailed screening and questionnaires on AF symptoms and treatments provided additional points of verification, and the breadth of our recruitment approach reduced selection bias. Eligibility for the study requiring patients to have experienced recent symptoms may have biased our sample toward those with more severe disease, but these are the very patients who struggle with the day-to-day burden of AF and would benefit most from improvements in care. Finally, patients were primarily white and college-educated; whether our findings extend to other populations is unknown.

**Conclusions**

Patients with AF may benefit from treatment approaches that address the full range of its biopsychosocial impacts. Although providers acknowledge the emotional impact of AF,<sup>26</sup> they may not recognize or feel equipped to address the cumulative burden of physical and emotional experiences on patients’

lives, which patients described as all-encompassing. Generic lifestyle modifications have been structured around changing behaviors to *prevent* AF recurrences. Our data suggest that more robust approaches may need to target factors (e.g., illness beliefs) that drive patients’ *perception* of symptoms and their impact regardless of *whether those symptoms are connected to AF recurrence*. In other words, the behavioral factors that potentiate AF onset/recurrence may not necessarily be the factors that help patients manage the day-to-day illness burden that makes AF so challenging. The outpatient clinic setting where AF is primarily managed is an ideal place for these drivers to be identified and targeted. Brief behavioral self-management strategies delivered in a clinic setting has promise for reducing patients’ cardiac anxiety,<sup>50</sup> particularly intense worries about what bodily sensations mean and their impact on illness behaviors such as healthcare seeking. While patients often believe they lack sufficient information about their diagnoses and disease management, this study identifies a number of patient concerns that can be the focus of future collaboration for more effective care. Starting from a perspective that prioritizes QOL and the psychosocial aspects of patients’ AF experience, and addresses the cognitive and affective underpinnings of cardiac symptoms through evidence-based approaches to addressing patients’ anxiety, may improve care and patients’ overall well-being.

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#### Declarations:

**Conflict of Interest:** The authors declare that they do not have a conflict of interest.

## REFERENCES

- Miyasaka Y, Barnes ME, Gersh BJ, et al. Secular trends in incidence of atrial fibrillation in Olmsted County, Minnesota, 1980 to 2000, and implications on the projections for future prevalence. *Circulation*. 2006;114(2):119-125.
- Pinter A, Dorian P. New approaches to atrial fibrillation management: treat the patient, not the ECG. *Cardiovasc Ther*. 2010;28(5):302-310.
- Zulkifly H, Lip GYH, Lane DA. Epidemiology of atrial fibrillation. *International Journal of Clinical Practice*. 2018;72(3):e13070.
- Coyne KS, Paramore C, Grandy S, Mercader M, Reynolds M, Zimetbaum P. Assessing the direct costs of treating nonvalvular atrial fibrillation in the United States. *Value Health*. 2006;9(5):348-356.
- Lee WC, Lamas GA, Balu S, Spalding J, Wang Q, Pashos CL. Direct treatment cost of atrial fibrillation in the elderly American population: a Medicare perspective. *J Med Econ*. 2008;11(2):281-298.
- Risom SS, Zwisler AD, Thygesen LC, Svendsen JH, Berg SK. High readmission rates and mental distress 1 yr after ablation for atrial fibrillation or atrial flutter: a nationwide survey. *J Cardiopulm Rehabil Prev*. 2019;39(1):33-38.
- Garimella RS, Chung EH, Mounsey JP, Schwartz JD, Pursell I, Gehi AK. Accuracy of patient perception of their prevailing rhythm: a comparative analysis of monitor data and questionnaire responses in patients with atrial fibrillation. *Heart Rhythm*. 2015;12(4):658-665.
- Mehall JR, Kohut RM, Jr., Schneeberger EW, Merrill WH, Wolf RK. Absence of correlation between symptoms and rhythm in "symptomatic" atrial fibrillation. *Ann Thorac Surg*. 2007;83(6):2118-2121.
- Page RL, Wilkinson WE, Clair WK, McCarthy EA, Pritchett EL. Asymptomatic arrhythmias in patients with symptomatic paroxysmal atrial fibrillation and paroxysmal supraventricular tachycardia. *Circulation*. 1994;89(1):224-227.
- Luderitz B, Jung W. Quality of life in patients with atrial fibrillation. *Arch Intern Med*. 2000;160(12):1749-1757.
- McCabe PJ. Psychological distress in patients diagnosed with atrial fibrillation: the state of the science. *J Cardiovasc Nurs*. 2010;25(1):40-51.
- Ong L, Cribbie R, Harris L, et al. Psychological correlates of quality of life in atrial fibrillation. *Qual Life Res*. 2006;15(8):1323-1333.
- Suzuki S, Kasanuki H. The influences of psychosocial aspects and anxiety symptoms on quality of life of patients with arrhythmia: investigation in paroxysmal atrial fibrillation. *Int J Behav Med*. 2004;11(2):104-109.
- Akintade BF, Chapa D, Friedmann E, Thomas SA. The influence of depression and anxiety symptoms on health-related quality of life in patients with atrial fibrillation and atrial flutter. *J Cardiovasc Nurs*. 2015;30(1):66-73.
- Baumgartner C, Fan D, Fang MC, et al. Anxiety, depression, and adverse clinical outcomes in patients with atrial fibrillation starting warfarin: Cardiovascular Research Network WAVE Study. *J Am Heart Assoc*. 2018;7(8):e007814.
- Thrall G, Lip GY, Carroll D, Lane D. Depression, anxiety, and quality of life in patients with atrial fibrillation. *Chest*. 2007;132(4):1259-1264.
- Lane DA, Langman CM, Lip GYH, Nouwen A. Illness perceptions, affective response, and health-related quality of life in patients with atrial fibrillation. *J Psychosom Res*. 2009;66(3):203-210.
- Hindricks G, Potpara T, Dagres N, et al. 2020 ESC Guidelines for the diagnosis and management of atrial fibrillation developed in collaboration with the European Association for Cardio-Thoracic Surgery (EACTS) The Task Force for the diagnosis and management of atrial fibrillation of the European Society of Cardiology (ESC) Developed with the special contribution of the European Heart Rhythm Association (EHRA) of the ESC. *Eur Heart J*. 2021;42(5):373-498.
- McCabe PJ, Rhudy LM, DeVon HA. Patients' experiences from symptom onset to initial treatment for atrial fibrillation. *J Clin Nurs*. 2015;24(5-6):786-796.
- McCabe PJ, Schumacher K, Barnason SA. Living with atrial fibrillation: a qualitative study. *J Cardiovasc Nurs*. 2011;26(4):336-344.
- Eifert GH. Cardiophobia: a paradigmatic behavioural model of heart-focused anxiety and non-anginal chest pain. *Behav Res Ther*. 1992;30(4):329-345.
- Lebel S, Mutsaers B, Tomei C, et al. Health anxiety and illness-related fears across diverse chronic illnesses: a systematic review on conceptualization, measurement, prevalence, course, and correlates. *PLoS ONE*. 2020;15(7):e0234124.
- Miles MB, Huberman AM. *Qualitative Data Analysis*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
- Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. *Patient Educ Couns*. 2005;57(3):300-307.
- Risom SS, Lind J, Dickson VV, Berg SK. Exploring the mechanism of effectiveness of a psychoeducational intervention in a rehabilitation program (CopenHeartRFA) for patients treated with ablation for atrial fibrillation: a mixed methods study. *J Cardiovasc Nurs*. 2019;34(4):336-343.
- Suutari A-M, Areskoug-Josefsson K, Kjellström S, Nordin AMM, Thor J. Promoting a sense of security in everyday life—a case study of patients and professionals moving towards co-production in an atrial fibrillation "learning café". *Health Expect*. 2019;22(6):1240-1250.
- Hellström Muhli U, Trost J, Siouta E. Patient involvement in consultation for atrial fibrillation - the cardiologists' perspective. *Int J Health Care Qual Assur*. 2019;32(4):765-776.
- Fu YH, He WF, Ma JY, Wei B. Relationship between psychological factors and atrial fibrillation A meta-analysis and systematic review. *Medicine*. 2020;99(16):e19615.
- Gehi AK, Sears S, Goli N, et al. Psychopathology and symptoms of atrial fibrillation: implications for therapy. *J Cardiovasc Electrophysiol*. 2012;23(5):473-478.
- McCabe PJ, Barnason SA. Illness perceptions, coping strategies, and symptoms contribute to psychological distress in patients with recurrent symptomatic atrial fibrillation. *J Cardiovasc Nurs*. 2012;27(5):431-444.
- McCabe PJ, Chamberlain AM, Rhudy L, DeVon HA. Symptom representation and treatment-seeking prior to diagnosis of atrial fibrillation. *West J Nurs Res*. 2016;38(2):200-215.
- Pavelkova Z, Bulava A. Nursing and quality of life in patients with atrial fibrillation before and after radiofrequency ablation. *Neuro Endocrinol Lett*. 2014;35 Suppl 1:49-53.
- Sang CH, Chen K, Pang XF, et al. Depression, anxiety, and quality of life after catheter ablation in patients with paroxysmal atrial fibrillation. *Clin Cardiol*. 2013;36(1):40-45.
- Yamamoto M, Watanabe E, Suzuki T, et al. Association between the quality of life and asymptomatic episodes of paroxysmal atrial fibrillation in the J-RHYTHM II study. *J Cardiol*. 2014;64(1):64-69.
- Yu SB, Hu W, Zhao QY, et al. Effect of anxiety and depression on the recurrence of persistent atrial fibrillation after circumferential pulmonary vein ablation. *Chin Med J (Engl)*. 2012;125(24):4368-4372.
- Bernard HR. *Research methods in anthropology: qualitative and quantitative approaches*. 3rd ed. Walnut Creek: Altamira Press; 2002.
- Burnard P, Gill P, Stewart K, Treasure E, Chadwick B. Analysing and presenting qualitative data. *Br Dent J*. 2008;204(8):429-432.
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
- Reavell J, Hopkinson M, Clarkesmith D, Lane DA. Effectiveness of cognitive behavioral therapy for depression and anxiety in patients with cardiovascular disease: a systematic review and meta-analysis. *Psychosom Med*. 2018;80(8):742-753.
- Bajorek BV, Ogle SJ, Duguid MJ, Shenfield GM, Krass I. Management of warfarin in atrial fibrillation: views of health professionals, older patients and their carers. *Med J Aust*. 2007;186(4):175-180.



41. Xuereb CB, Shaw RL, Lane DA. Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a qualitative meta-synthesis. *Patient Educ Couns.* 2012;88(2):330-337.
42. Thomson RG, Eccles MP, Steen IN, et al. A patient decision aid to support shared decision-making on anti-thrombotic treatment of patients with atrial fibrillation: randomised controlled trial. *Qual Saf Health Care.* 2007;16(3):216-223.
43. Garg PK, O'Neal WT, Diez-Roux AV, Alonso A, Soliman EZ, Heckbert S. Negative affect and risk of atrial fibrillation: MESA. *J Am Heart Assoc.* 2019;8(1):e010603.
44. Neal RD, Morley S. Value of breast imaging in women with painful breasts: negative results are not reassuring. *BMJ: Brit Med J.* 1999;318(7189):1009.
45. Quigley BM, Sova CC, Brenner DM, et al. (Can't get no) Patient satisfaction: the predictive power of demographic, GI, and psychological factors in IBS patients. *J Clin Gastroenterol.* 2018;52(7):614.
46. Sarnholm J, Skuladottir H, Ruck C, Pedersen SS, Braunschweig F, Ljotsson B. Exposure-based therapy for symptom preoccupation in atrial fibrillation: an uncontrolled pilot study. *Behav Ther.* 2017;48(6):808-819.
47. Wedegärtner SM, Schwantke I, Kindermann I, Karbach J. Predictors of heart-focused anxiety in patients with stable heart failure. *J Affect Disord.* 2020;276:380-387.
48. White KS, Craft JM, Gervino EV. Anxiety and hypervigilance to cardiopulmonary sensations in non-cardiac chest pain patients with and without psychiatric disorders. *Behav Res Ther.* 2010;48(5):394-401.
49. Bunz M, Lenski D, Wedegartner S, et al. Heart-focused anxiety in patients with chronic heart failure before implantation of an implantable cardioverter defibrillator: baseline findings of the Anxiety-CHF Study. *Clin Res Cardiol.* 2016;105(3):216-224.
50. Cape J, Whittington C, Buszewicz M, Wallace P, Underwood L. Brief psychological therapies for anxiety and depression in primary care: meta-analysis and meta-regression. *BMC Med.* 2010;8(1):1-13.

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