

A focus group study to inform design of a symptom management intervention for adults with atrial fibrillation



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BACKGROUND Current symptom management approaches for patients with atrial fibrillation (AF) focus on addressing heart rhythm and do not include management of behavioral or emotional contributors to symptom manifestation or severity.

OBJECTIVE To inform content development of a digitally delivered AF symptom self-management program by exploring patients' experiences of the impact of AF symptoms and their perspectives on behavioral approaches to symptom management.

METHODS This was a qualitative study of 3 focus groups composed of adults living with symptomatic AF. Group transcripts underwent thematic content analysis to identify themes and subthemes. Themes were matched to available self-management strategies that could be adapted for use in a digitally delivered AF symptom self-management program.

RESULTS Six major themes (with subthemes) were identified: symptoms (anxiety, fatigue, stress/other negative emotions, AF-specific symptoms, heart rhythm); social aspects (social impact, social support); AF treatments (medication, procedures); health

behaviors (sleep, physical activity, hydration, breathing/mindfulness/relaxation); positive emotions; and AF education and information gathering. Symptom self-management strategies were identified that could be used to address these symptom-related themes.

CONCLUSION Patients with AF reported a wide range of emotional, physical, and social impacts of the condition. They endorsed attempts to self-manage symptoms and an interest in learning more about how to effectively self-manage. Findings indicate the potential for a digital self-management program to address existing gaps in AF symptom-related care.

KEYWORDS Atrial fibrillation; Digital health; Focus groups; Qualitative research; Symptom self-management

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Introduction

Atrial fibrillation (AF) is the most prevalent arrhythmia leading to hospital admissions.¹ Its incidence is associated with increased risk of stroke, congestive heart failure, and overall mortality.^{2–4} The majority of patients with AF report symptoms believed to be associated with the arrhythmia, including dyspnea, chest pain, dizziness, fatigue, and palpitations.⁵ These symptoms can lead to a decrease in functional status and are targets of many therapeutic interventions.^{6,7}

Despite interventions, many patients with AF remain symptomatic.⁸ Symptoms related to AF are likely to be multifactorial, resulting from both direct and indirect effects of the arrhythmia. There is growing evidence that affect, emotions,

and mood are important determinants of symptom severity in patients with cardiovascular disease.⁹ In a recent study of patients with AF, we found that negative affect was more strongly associated with symptom severity than heart rhythm.¹⁰ Data on behavioral aspects of AF management are extremely sparse and focus on treatment regime adherence.¹¹ Although affect and behavior may play important roles in determining AF symptom severity, current treatments are focused on addressing arrhythmia and no interventions aim to specifically address emotional and behavioral contributors to symptoms.

Evidence shows that patients can have a significant and positive impact on their symptoms and quality of life by taking an active role in self-management of their condition.^{12–15} Self-management is defined as “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition.”¹² Self-management interventions customarily

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include educational components and training in self-management skills, including self-monitoring, goal setting, coping skills, and problem solving. Despite the potential benefits of self-management, a high percentage of people with AF lack access to behavioral healthcare that promotes symptom self-management. Typically, AF is treated with pharmacological or electrophysiological interventions that address issues with heart rhythm/rate.¹⁶ Unlike other cardiac conditions such as cardiovascular disease and heart failure, where bodies of research on symptom self-management programs are large enough to support meta-analyses and reviews, there is a paucity of evidence for AF symptom self-management.^{17,18} Even in the best-case scenario where behavioral health services aimed at improving AF symptom self-management may be available, there are often logistical barriers to receiving this care; self-management interventions are inaccessible to those living in rural regions or far from an academic medical center, and fatigue, driving restrictions, or transportation/financial limitations may present barriers to frequent in-person appointments. Digital health interventions hold potential to improve the reach of behavioral health interventions via remote delivery and scalability to essentially “meet patients where they are.”^{19,20} Notably, there are currently no digital self-management tools tailored specifically for patients with AF.

There is a growing body of evidence to support qualitative exploratory methods to understand the underlying causes and motivations leading patients to experience the variety of behavioral factors that affect their AF symptoms. These qualitative approaches may provide guidance for development of behavioral-focused interventions.^{21–24} With the ultimate aim of developing a digital symptom self-management program for people with AF, the primary objective of this study was to develop a framework that characterizes patients’ experiences of AF symptoms and co-occurring symptoms, health behaviors, and naturally occurring symptom self-management behaviors. This exploration was undertaken with particular interest in patients’ perceptions of how behaviors and non-AF-specific symptoms intersect with and impact on AF symptoms. The second objective of the study was to identify candidate digital self-management program components, by mapping symptoms and behaviors that patients identified as being consequential to their AF symptoms to existing symptom self-management components.

Methods

The study protocol was submitted to the University of Michigan (UM) Medical Institutional Review Board and met federal and institutional criteria for exempt human subjects research. To be eligible, participants had to be aged ≥ 18 with physician-diagnosed AF, documented adequate heart rate control < 110 beats per minute at resting electrocardiogram, and at least 1 of the self-reported symptoms of chest pain, dyspnea, palpitations, fatigue, and lightheadedness/syncope. Participants were excluded if any of the following criteria applied: unable to participate in a virtual focus group owing to visual, hearing, or cognitive dysfunction; malignancy; pregnancy; or

life expectancy < 1 year. We identified 370 potential participants at the UM Cardiovascular Center through electronic medical record review, of which we approached 345 over the telephone to screen for eligibility. There were several reasons potential participants were unable to enroll, including not answering our phone calls, inability to endorse any of the aforementioned symptoms, inability to join the sessions virtually, and scheduling conflicts. If eligible, a research team member read a script detailing the exact nature of the study and any risks involved in taking part. It was clearly stated that the participant was free to withdraw from the study at any time for any reason without prejudice to their future care and with no obligation to give the reason. Participants were given as much time as they needed to consider the information and were given the opportunity to question the Principal Investigator, their healthcare provider, or other independent parties to decide whether they wanted to participate. Participants provided verbal consent over the telephone and returned a signed electronic consent form via e-mail. Participants attended 1 of 3 2-hour, virtual focus groups conducted using Zoom conferencing technology. Participants were compensated \$40. Focus groups were facilitated by a clinical psychologist (A.L.K.) with extensive experience facilitating focus groups and conducting qualitative data analyses; a medical student (H.J.H.) served as co-facilitator for all groups. Neither A.L.K. nor H.J.H. were involved in the participants’ treatment. After introducing the aim of the groups and providing rules for participation, the facilitator asked attendees open-ended questions regarding AF symptom experiences, impacts of AF symptoms, emotional aspects of AF symptoms, and strategies used to self-manage symptoms. Focus groups took place in July and August 2020 and were conducted until data saturation was achieved (ie, the point at which no new information was identified in subsequent groups).

All sessions were recorded and transcribed verbatim and anonymized using a third-party transcription service, subsequently checked for accuracy by H.J.H. Data were analyzed using thematic content analysis by 3 coders (a health psychologist [A.L.K.], a medical student [H.J.H.], and a cardiologist [H.G.]), who listened to recordings and read transcripts multiple times, identifying meaningful sections. The authors discussed themes and subthemes in video and telephone meetings until intersubjective consensus about the qualitative themes was reached. The transcripts were analyzed using the Dedoose qualitative analysis tool (Dedoose Version 8.0.35. Los Angeles, CA) with the aim of identifying themes related to symptoms, symptom impact, and symptom management. A codebook (ie, coding scheme listing code names [representing developing themes and subthemes] and code definitions) was created after a first round of coding by the coding team and edited iteratively following additional rounds of coding (Supplemental Appendix A). After a final consensus codebook was agreed upon, 1 coder (H.J.H.) conducted a final round of coding to ensure that finalized codes were applied to transcripts. Final coding was verified by the other coding team members to ensure consensus and appropriate application of the codebook to the transcripts. For all

themes and subthemes, exemplary quotes were selected to illustrate the concepts.

Results

Of the 20 participants enrolled in the study, 17 were able to attend 1 of 3 virtual focus groups (7, 6, and 4 attendees at each of the respective groups). Three participants agreed to participate but did not attend the scheduled visit. We did not inquire about specific reasons for nonattendance. Data saturation was determined to be achieved after the third focus group. Participant characteristics are summarized in [Table 1](#).

Qualitative themes

The final codebook contained 6 themes and 13 subthemes ([Supplemental Appendix B](#)). The results below, with illustrative quotes, highlight a range of physical, emotional, and social experiences related to living with AF.

Theme: Symptoms

Participants reported cardinal symptoms of AF, captured in subthemes *AF-specific symptoms* and *Heart rhythm*, as well as other somatic and emotional symptoms that they associated with their AF, captured by subthemes *Anxiety*, *Fatigue*, and *Stress/other negative emotions*. Collectively, these findings point to the often substantial symptom burden that, for many patients, extends beyond classical AF symptoms that are the focus of clinical care. Some participants remarked on the differing experiences of symptoms that were being described during the focus group:

“This is a small group, but I didn’t realize the variety of symptoms that AFib gave and how it exhibits in different people”

Symptoms subtheme: Anxiety

Descriptions of *Anxiety* ranged from mild worry to feelings of terror. Participants reported that they had many sources of anxiety related to their AF treatments, their future, the cause of their AF, the effects of their AF on others, and fear about experiencing serious secondary medical events (eg, stroke) or death owing to AF. Anxiety was often described as having a serious impact on quality of life.

“And it’s that fear factor. Am I going to have a stroke if my heart rate goes up that much? Or I’m afraid I’m going to pass out...”

“I think about it every day. I watch what I’m doing. So it kind of takes away from your life, when you kind of worry about that.”

“When I see that I am in AFib, I think oh, why am I in AFib? And it just makes me more anxious, and I feel like it makes it more difficult to get out of it.”

Symptoms subtheme: Fatigue

Although mentioned as a common symptom in AF across focus groups, for some fatigue was described as the most extreme symptom; yet others mentioned fatigue as their only AF symptom. In most cases, fatigue was described as having a significant impact on individuals’ lives.

“I’ve never had like heart palpitations or some of the more dramatic symptoms that some folks, I think, have had. For me, it’s just been extreme fatigue.”

“In the evening, I will just be so tired that I’m sitting on a couch, I’m thinking: ‘all right, I just have to get upstairs, take my medications and go to bed. Can I do it?’ I can’t even explain that fatigue.”

Symptoms subtheme: Stress/other negative emotions

Anxiety, worry, and fear were the most prominent negative emotions mentioned in the focus groups and were coded separately (subtheme *Anxiety*). However, stress, depression, frustration, anger, and other negative emotions were also discussed in relation to participants’ AF, though with less frequency than anxious feelings.

“I’m frustrated. Like, I’m taking my medications. I’m drinking my water and I’m taking my walks, and why is it still happening? So it doesn’t make me angry, but it makes me kind of frustrated slash sad – why is this still happening?”

“For me, stress management is a large part of preventing it from happening or at least controlling it. So maybe not in the ‘it is happening and I need to manage my stress,’ but in the other way. If I get too stressed, it [AF] is likely to happen to me. So managing it is proactive.”

“So for me, atrial fibrillation, it’s been a significant emotional, psychological event for me because things I used to be able to do; run a marathon, swim a mile, bike 100 miles... I can’t do that anymore. The emotional effect of that, the depression. It’s like it takes a lot of mental strength to just say, you know what? I can’t do this anymore. You got to shift gears... to manage that psychologically for me has been very difficult.”

Symptoms subtheme: AF-specific symptoms

AF-specific symptoms (palpitations, chest pain, dyspnea, lightheadedness) were identified as important.

“I knew immediately with the symptoms, uh-oh, the palpitations, the shortness of breath, the dizzy spells that I bet I was in AFib again...”

“Because again, if I get up, with the shortness of breath, I don’t get chest pains. But shortness of breath is one of my big deals.”

“I get really short of breath when I’m in AFib. Sometimes a little lightheaded.”

Symptoms subtheme: Heart rhythm

Perception of irregular heart rhythms was not universally reported in the focus groups, though participants generally described feeling other symptoms or having an emotional reaction (eg, stress, frustration, anxiety) when noticing irregular heart rhythms.

“I kept a journal the one time between my ablations, and it was all over the place. It could be for minutes, and then I could go back into sinus rhythm.”

“My heart rate would just jump into the 200s, and then back down to the nineties, and just back and forth all the time. I know that’s all part of AFib. But when I can’t catch my breath, I know I’m in AFib.”

Theme: Social aspects

Participants discussed the complex social aspects of AF, including the impact AF has on their social identities, activities, and roles and the role of others, via social support, in dealing with the AF diagnosis and treatments. Participants also described encountering a general lack of understanding of AF within their social network, which was perceived as a barrier to receiving adequate support, eliciting feelings of frustration and helplessness in some cases.

Social aspects subtheme: Social impact

“When I’m close to a bad episode, I pull myself back. I’m afraid to do anything, I’m afraid to socialize too much.”

“I don’t want to think that it [AF] defines me. It’s not as far as socially, I think it’s something that I keep to myself. I’m almost like embarrassed about it.”

“Being in AFib, I can no longer compete in endurance athletics. So I had to totally revamp my social structure because all of my athletic friends, I don’t hang out anymore because I can’t keep up...So the bigger effect for me was I had to recycle all of my friends, throw out the old existing and get new ones. That was probably the biggest effect for me was social structure.”

Social aspects subtheme: Social support

Social support, particularly emotional support regarding AF issues, was identified as an important subtheme. This

indicates the potential importance of social networks in supporting adoption and reinforcement/maintenance of self-management behaviors.

“I guess you know, my husband is really attuned to what goes on with me, and understands as much as he can. But you know, he feels kind of at a loss when I’m going through an episode. I mean, he doesn’t know what to do.”

“It is helpful, having a spouse that can see when I’m in it and you know, take some of the load off. Or, just offer a helping hand, or a kind word. That makes it easier.”

“I call them the 2:00 in the morning friends. If I need to call somebody at 2:00 in the morning, I would call them. So I think plugging into people that really love and care for you, that will support you in multiple ways. That is key for emotional support. And continue to seek out those type of – make that part of your tribe. Make that part of the group of people that you lean into.”

Theme: AF treatments

Two subthemes related to AF treatments: *Medications* and *Procedures*. Participants expressed the need for good communication, empathy, support, and feedback from clinicians. Participants cited lack of information about the treatment strategy, concerns about long-term side effects, and uncertainty regarding efficacy as major factors contributing to AF treatment-related anxiety. Satisfaction with treatment was mixed, with some describing complete, lasting success after ablation procedures and others reporting frustration and disappointment with failed attempts to treat their AF.

AF treatments subtheme: Medications

“I think about it every day. I worry about it. I carry my pills, my little pill in pocket around with me. Because you just never know.”

“Mine has been relatively well controlled on medication, and we’ve had to change it oh, a few times over the years.”

AF treatments subtheme: Procedures

“So what do you do with that? I still don’t know the answer. And I’ve had 3 catheter ablations, and I still have it. Now, what?”

“I don’t want anyone who’s looking forward to their ablation to think that I’m still having AFib. But after my

ablations, it's clear to me that sometimes you still have your symptoms until your heart heals."

Theme: Health behaviors

Sleep, physical activity, hydration, and breathing/mindfulness activities were described by participants as health-related behaviors that they noticed had been affected by their AF diagnosis and/or believed were important for the overall symptom management.

Health behaviors subtheme: Sleep

Several participants relayed that AF negatively affects their sleep. Often participants described that their symptoms (eg, racing heart, dyspnea, anxiety) interfered with sleep initiation and/or maintenance. Good sleep hygiene and use of relaxation strategies were described as important factors for sleep improvement.

"Sometimes I'm going to bed, I'll be thinking about things and that will be one of the triggers. And it will get my AFib... And sometimes it would continue on for most of the night and be kind of disruptive to getting to sleep... And one of the things I've found is trying to make sure that my time I go to bed is the same, and also try to limit the things that I'm – you know, don't watch TV for half an hour before you go to bed. Try to calm down a little bit before it's time to hit the hay."

"I suddenly just woke up the middle of the night and felt just like heart palpitations."

"I've had AFib episodes like suddenly happening in the middle of the night. I just wake up, can't breathe. Feel like my heart is racing."

Health behaviors subtheme: Physical activity

Discussion around physical activity focused on both the impact that AF has on ability to be physically active (both lifestyle activities and exercise) and use of physical activity to maintain health and manage their condition. Features of activity pacing, including taking rest breaks and breaking tasks into smaller segments, were mentioned as ways of managing symptoms, particularly fatigue. Participants expressed desire for personalized guidance about physical activity that was safe and could improve their functional status and help alleviate the consequences of AF on their daily lives.

"I still have some of the symptoms, and one is being a little fatigued and a little short of breath. So I have to take little bites out of my projects [pace myself] to just make sure I feel well."

"I am a retired competitive athlete, endurance athlete, and getting AFib killed my athletic career, started to

drop ice hockey, triathlon, marathoning, cycling, long distance swimming, and many other athletic activities."

"So I think keeping active is good for me. It's mentally good for me, I know that. And hopefully physically good. So as long as I can do that, I'm going to keep doing it. So from that standpoint, I think it's been positive to me, to be active."

"I can't do athletic activities like I used to. So I can't go to the rink and sprint up and down the ice. I have to just stop. When my heart rate maxes out, I have to slow down. ...on hot days, I used to be able to go and ride my bicycle and go hard. Can't do that anymore. I have to watch how hard I work and how hot I get. I can't get overheated. And I have to be careful – if I'm walking upstairs or hiking and going up a steep incline, my heart maxes out and I have to stop or slow down so that my level of activity matches my – the heart rate."

Health behaviors subtheme: Hydration

A prominent subtheme that was identified was that lack of hydration was a trigger for AF and regular hydration would help in preventing future AF episodes and alleviating symptoms associated with AF episodes when they occurred.

I also agree with the dehydration. That's another kind of, I think, trigger that I think can happen for me. But it's really hard to, you know, to drink all day long, you know, but it [staying hydrated] definitely makes a difference."

But the house that I've been building is down in Arizona, and it's pretty hot... So I'll find quite often that you really have to drink a lot of water. If you don't, your electrolytes do get messed up and I'll find – I have found that I was kicking into more AFib there than I have in Michigan."

Health behaviors subtheme: Breathing/meditation/relaxation

Many participants reported using relaxation strategies (eg, breathing exercises, meditation) to manage stress, anxiety, and other AF-related symptoms. The use of practices to cultivate positive emotions was also described as potentially helpful for managing symptoms and the use of existing digital tools to aid relaxation was repeatedly mentioned.

"I've done Headspace before. And I just remember having that direction and calming voice to just get your minds off something would help me not focus as much on the terror and the fear, and just kind of distract me."

"When I used the Calm app it just clears your mind from all that fear/anxiety... all that "chatter," the second voice

in your mind. Yeah, so, I guess, that's a form of meditation, and I did find it helpful."

"I think that's a great way just to ease your mind. If you can get into that meditative state a little bit, anything positive to calm your mind down. Because our mind is what's going to dictate so much of our feelings and everything else. When you're in AFib, it's going to be there no matter what you do until it decides to go away... So if you can just get mentally into that state"

Theme: Positive emotions

Focus group discussions revealed positive emotional experiences, including gratitude (ie, benefit finding), hope for the future, feelings of relief at positive treatment outcomes, determination and hope to return to "normal," trust and confidence in healthcare providers and social support networks, and acceptance of their current situation. Many talked about feeling that they were "getting on with life" despite the challenges of AF.

I'm one of those people whose balloon doesn't land. This [AF] has never really affected me.

We want to be as active as possible. And I'm very grateful, I mean other than this AFib, I believe that I'm in good shape, if that's ironic or not.

I think I was always a perfectionist. I always wanted to do everything, I always could do everything. So now I'm trying to slow myself down and relax and enjoy. You know, in the morning, try to get outside, listen to the birds and see, you know, I need that in my life.

Theme: AF education and information gathering

Participants discussed a desire for information and guidance about all aspects of AF, including causes, contributors to AF symptoms, and treatments. They highlighted the need for up-to-date information from credible sources that covered the full biopsychosocial experience of AF (ie, not solely focused on heart rhythm).

"Nobody has enough time to really talk you down or explain these things to you when you're in my circumstance. So maybe other people's feelings aren't that, but I haven't really felt like I've ever gotten a good explanation of some of these things. But being able to self-guide through a wealth of information tailored for an AF person would have really helped me."

"I have a lot of questions. It's my job, I ask questions. And he [doctor] answered them all. And, but I never got him to the emotional, they [doctors] don't want to discuss the

emotional aspect. That would be something, yeah. And that's my one burning question. Is there data, is there proof that shows that AFib is purely random in a heart irregularity, or is it emotional?"

"Because, right now, to read stuff on the Web, it's very limited. Where I would love to talk to other patients and say, you know, what's it like for you? What do you do? How do you manage it? What drug regimen are you on? How does it affect your physical ability, your athletic ability, etcetera? You can't get that off the Web."

"Data is always good. Data is beautiful. I love looking at my traces on my Fitbit for the last few months just to see if I'm trending up or trending down, and, you know, what are the things that triggered it."

Candidate components for a digital AF symptom self-management program: Development of MiAfib Navigator

Based on the themes and subthemes identified from analysis of focus group discussions, it is evident that there is an appetite and need for a self-management intervention aimed at improving symptoms, health behaviors, emotional well-being, and greater access to information for patients with AF. Such an intervention could address physical and emotional health through provision of AF-tailored education and skills training that includes a personalized physical activity program, cognitive-behavioral therapy-informed relaxation and cognitive restructuring modules, and behavioral strategies to improve sleep. We consulted with researchers (including members of our research team) who have developed existing digital symptom self-management programs²⁵ that used a comparable approach to map patient needs/preferences to intervention content. We refer to our program as *MiAfib Navigator*, and an outline of program content is presented in [Table 2](#). MiAfib Navigator will be designed to be a patient-driven online self-management program with users encouraged to explore all aspects of the website/app, following built-in prompts and guides, with no additional contact from professionals needed during an anticipated 12-week program duration. Users will be encouraged to practice and apply the behavioral skills on a regular basis and to revisit the MiAfib Navigator site on at least a weekly basis, and more frequently when new issues arise.

Discussion

This focus group study explored AF patients' experiences of symptoms and symptom management and identified areas that may benefit from more attention and support. Findings informed the selection of content domains for a digital therapeutic program for patients with AF. This is the first study to use thematic content analysis to identify themes related to the impact and management of AF symptoms beyond those

Table 1 Baseline patient characteristics

Patient characteristics	Result (N = 17 patients)
Age (years)	60.8 ± 10.8
Female sex, n (%)	7 (41.2%)
Hypertension	9 (52.9%)
Diabetes mellitus	2 (11.8%)
Obstructive sleep apnea	7 (41.2%)
CHADVASCS score	1.76 ± 1.1
Atrial fibrillation designation	
Paroxysmal AF	10 (58.8%)
Persistent AF	7 (41.2%)
History of radiofrequency ablation	10 (58.8%)
Antiarrhythmic drug therapy	17 (100%)
Ejection fraction	58.4 ± 11.9
Left atrium size (mm)	44.5 ± 8.7
History of depression	0 (0)

Age, CHADVASCS score, ejection fraction, and left atrium size represented by mean + SD. Categorical variables are represented by absolute number (%) of participants.

AF = atrial fibrillation.

directly associated with arrhythmia. This approach facilitated an understanding of the heterogeneity and nuance in the experience of living with AF and will ensure that the digital program we develop is fit for use for a range of different people with varying symptom profiles. Our study highlights the importance of undertaking qualitative research as a critical step in developing digital interventions, as it can help identify important aspects of symptom management from a patient perspective and increase the likelihood that the end digital product is accessible, acceptable, and effective in the target population.

Although nondigital delivery of the proposed solution is possible, the digital program may increase accessibility and

affordability. Indeed, web-based self-management interventions have the potential to improve the reach of behavioral health interventions into more of the population via remote delivery and scalability. Further, they hold potential for personalized delivery of intervention content in the patient's natural environment. Therefore, we believe that digital delivery of the proposed intervention is preferable to analog delivery of a comparable program and is likely to result in significant cost savings.²⁶

Symptoms related to AF emerged as an important theme perceived to influence patients' quality of life. AF symptoms are associated with a higher risk of hospitalization.²⁷ Therefore, interventions targeting improvement in symptoms and quality of life may be important for reducing healthcare utilization in this population.²⁷ However, despite interventional and pharmacological approaches, a significant number of patients continue to experience symptoms.²⁸ Furthermore, negative emotions have been shown to be more significantly associated with severity of symptoms in patients with AF when compared to heart rhythm.¹⁰ This quantitative finding is mirrored in the current qualitative study, where perception of heart rhythm was not consistently described as being associated with AF-specific symptoms. Within a *Symptoms* theme we identified *Anxiety* as a key subtheme and *Stress/other negative emotions* as important subthemes, distinct from *AF-specific symptoms* (eg, palpitations, chest pain, dyspnea, lightheadedness) and *Heart rhythm*. This distinction indicates a need for alternative therapies that target the *holistic* experience of AF beyond heart rate and rhythm control strategies.

Social support, defined as social relationships and resources an individual has in their network, has been shown to lead to reduced depressive symptoms,^{29–31} lower risk for

Table 2 Outline of candidate components for a digital symptom self-management program: MiAfib Navigator

Program modules	Module content (presented in text, figures, animations, videos, audio recordings, worksheets, etc)	Problems addressed (related to focus group themes/subthemes)
1. Introduction	Education about common AF symptoms, ongoing medical management, the role of self-management, self-monitoring, identifying personal strengths and social supports	AF education and information gathering, AF medication
2. Personalized physical activity plan	Goal setting (graded activity plan), avoiding boom or bust cycles (activity pacing), lifestyle activity	Fatigue, Stress/other negative emotions, Physical activity
3. Working with emotions	Understanding control, living in the present, building positive emotions, identifying and challenging unhelpful thoughts, generating alternative thoughts	Stress/other negative emotions, Anxiety, Positive emotions
4. Relaxation	Stress response, diaphragmatic breathing, progressive muscle relaxation, meditation, preparing for stressful experiences	Stress/other negative emotions, Anxiety
5. Communication	Communicating about AF, communicating with providers, partnering with friends and family to build new habits	Social impact, Social support
6. Sleep	The sleep/symptom connection, prioritizing sleep, healthy sleep behaviors	Sleep, Fatigue

AF = atrial fibrillation.

anxiety,^{32–34} and higher quality of life in other chronic medical conditions.^{35–38} However, the role of specific aspects of social support such as sources of support (family, friends, significant others), overall size of the social network, and types of support (emotional, informational, and instrumental or tangible support) has not been explored in patients with AF. Furthermore, the impacts of social factors on the perception of disease and on AF burden and severity have not yet been evaluated in large studies. The complex social aspects of AF, including the impact on social identity, activities, and roles, and the role of others, via social support, in dealing with an AF diagnosis and treatments were described as important factors influencing patients' experience of AF in our study. Participants also mentioned often encountering a general lack of understanding of AF within their social network, presenting a barrier to receiving adequate support and leading to feelings of frustration and helplessness in some cases. These findings indicate that there is a need for interventions focused on improving all aspects of support in patients with AF.³⁹

Sleep is an important aspect of overall health,^{40,41} and there is evidence that sleep apnea and sleep-disordered breathing are associated with an increase in AF incidence.^{42,43} Several mechanisms have been proposed to explain the association between sleep-disordered breathing and development/maintenance of AF. Hyperarousal by activation of central and peripheral autonomic nervous systems can lead to hyperexcitability of atrial tissue.^{44,45} Increased inflammation and impaired glucose tolerance in patients with sleep-disordered breathing may also contribute to AF development.^{46–51} There is a lack of tailored therapeutic strategies for treatment of insomnia or improvement of sleep quality for patients with AF. Digital sleep improvement interventions have been shown to improve sleep quality in other conditions^{52,53} and hold tremendous potential for improving quality of life of patients with AF.⁵⁴

Several studies have examined the benefits of exercise and cardiorespiratory fitness in the management of AF. The "Impact of the CARDIOrespiratory FITness on Arrhythmia Recurrence in Obese Individuals With Atrial Fibrillation (CARDIO-FIT)" study demonstrated that patients who achieved a cardiorespiratory fitness gain ≥ 2 metabolic equivalents (METs) significantly reduced AF burden and alleviated AF-specific symptoms, when compared with those with < 2 MET gain.⁵² Furthermore, gains of > 2 METs obtained over 48 months were associated with a 2-fold increased chance of AF recurrence.⁵⁵ A recent randomized trial also demonstrated reduced AF burden after aerobic interval training, alongside fewer hospital admissions and cardioversions, resulting in reduced AF symptoms, and improvement in quality of life and peak oxygen uptake.⁵⁶ Higher physical activity and cardiorespiratory fitness is also associated with lower long-term risk of cardiovascular disease and all-cause mortality in individuals with AF.⁵⁷ These studies support optimization of physical activity and exercise prescription in AF symptom management. Personalized exer-

cise programs such as the one proposed in our study have demonstrated effectiveness for those with other chronic conditions^{58–61} and offer a low-cost intervention with tremendous benefits.

There are limitations that need to be considered when evaluating the findings of this study. A small number of patients were recruited. However, the number of participants was appropriate for our study design (qualitative focus groups), as data saturation was determined to be reached after the third focus group. We acknowledge that there is potential overlap between the themes and subthemes that we identified and baseline characteristics, symptom severity, comorbidities, and medications used by participants. Although we collected information on AF subtype (ie, persistent or paroxysmal), our study was not designed to detect differences in experiences based on this categorization. Future qualitative work conducted with samples of people with more strictly defined AF characteristics (including restricting recruitment to those with persistent or paroxysmal AF, older adults, and/or those receiving care in a primary care setting) and different socioeconomic status will allow exploration of the possibility that some types of patients require an emphasis on different symptoms and/or intervention components. It is possible that the format of the focus groups biased participants to report perspectives to appease researchers. We attempted to minimize this by not involving clinicians or those directly involved in their care at the focus groups. It is also possible that the virtual nature of the focus groups altered the dynamic that may have been observed if focus groups were held in person.

Next steps

Intervention content will be developed within identified domains based on current evidence-based behavior change techniques for optimization of physical activity/exercise adherence and cognitive behavioral strategies for self-management of negative emotions and AF symptoms (eg, dyspnea, pain, and fatigue). All content will be formulated with an eye toward optimizing comprehensibility and accessibility within a web- or app-based platform context. Education and informational resources regarding medical management of AF patients will be available within the web- or app-based platform. The design of this digital intervention will be guided by the needs and preferences expressed by participants. End-user engagement will be central at each phase of development to ensure that the patient's voice is central in all decision-making. We will achieve this by creating a multidisciplinary advisory committee composed of patients guiding program development, discussions around privacy and security, and appropriate representation of different populations.⁶²

Conclusion

We have gathered and analyzed perspectives from people living with AF to identify important areas to consider in a new, holistic, digitally delivered symptom self-management

program. Insights from focus groups have informed the selection of intervention content domains, comprising educational, behavioral, and physical components. Once the feasibility and acceptability of the program has been established, effectiveness will be assessed in a large randomized trial vs standard of care in patients with AF.

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Disclosures

The authors have no conflicts of interest to disclose.

Authorship

All authors attest they meet the current ICMJE criteria for authorship.

Patient Consent

All patients provided written informed consent.

Ethics Statement

The authors designed the study and gathered and analyzed the data according to the Helsinki Declaration guidelines on human research.

Disclaimer

Given his role as Deputy Editor, Hamid Ghanbari had no involvement in the peer review of this article and has no access to information regarding its peer review. Full responsibility for the editorial process for this article was handled by Dr David Duncker.

Appendix Supplementary data

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.cvdhj.2021.09.001>.

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