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## A qualitative crossroads of rhythm and race: Black patients' experiences living with atrial fibrillation\*

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### Abstract

**Importance:** Race-based disparities in atrial fibrillation (AF) outcomes are well-documented, but few studies have investigated individuals' experiences of living with the condition, particularly among Black individuals.

**Objective:** We aimed to identify common themes and challenges experienced by individuals of Black race with AF.

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CRediT authorship contribution statement

**Harnoor Mann:** Formal Analysis, Writing-Original draft preparation, Visualization **Amber E. Johnson:** Conceptualization, Methodology, Formal Analysis, Writing-Original draft preparation, Writing-Reviewing and Editing **Danielle Ferry:** Resources, Project Administration, Writing – Review & Editing **Flor de Abril Cameron:** Investigation, Formal Analysis, Writing – Review & Editing **Julia Wasilewski:** Investigation, Writing – Review & Editing **Megan Hamm:** Investigation, Formal Analysis, Writing – Review & Editing **Jared W. Magnani:** Writing – Review & Editing, Supervision.

Ethical statement for American Heart Journal Plus

I, Harnoor Mann, affirm that for the manuscript "A Qualitative Crossroads of Rhythm and Race: Black Patients' Experiences Living with Atrial Fibrillation" the following is true:

1. This paper is the authors' own original work, which has not been previously published elsewhere.
2. This paper is not currently being considered for publication elsewhere.
3. This paper reflects the authors' own research and analysis in an honest and comprehensive manner.
4. All sources referenced in this paper are appropriately cited.
5. This study was performed in accordance with the ethical standards as stated in the 1964 Declaration of Helsinki and its amendments.

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**Design:** A tailored, qualitative script was developed to assess the perspectives of participants in focus groups.

**Setting:** Virtual focus groups.

**Participants:** Three focus groups of 4–6 participants (16 participants total) were recruited from the racial/ethnic minority participants in the Mobile Relational Agent to Enhance Atrial Fibrillation Self-care Trial.

**Main outcomes and measures:** Focus group transcripts were inductively coded to identify common themes.

**Results:** Nearly all participants self-identified as Black race ( $n = 15$ , 93.8 %). Participants were mostly male (62.5 %) with mean age of 67 (range 40–78) years. Three themes were identified. First, participants described physical and mental burdens associated with having AF. Second, participants described AF as being a condition that is difficult to manage. Lastly, participants identified key tenets to support self-management of AF (self-education, community support, and patient-provider relationships).

**Conclusions and relevance:** Participants reported AF is unpredictable and challenging to manage, and that social and community supports are essential. The social and behavioral themes identified in this qualitative research highlight the need for tailored clinical strategies for AF self-management which incorporate individuals' social contexts.

**Trial registration:** National Clinical Trial number 04075994.

## Keywords

Atrial fibrillation; Race; Racial inequities; Qualitative; Patient experience

## 1. Introduction

Atrial Fibrillation (AF) is a challenging condition which has had foremost study in individuals of non-Hispanic white race [1]. Black individuals made up only 5 % of AF-related randomized clinical trial participants in the U.S. in the last decade [1,2]. Yet, even the limited data from Black individuals has repeatedly demonstrated significant race-related differences in quality of life and clinical outcomes [3-5]. Specifically, individuals of Black race diagnosed with AF have disproportionately higher rates of stroke, heart failure, and hospital readmission than their counterparts of white race [3,4]. Black individuals with AF also report higher symptom burden and worse quality of life than white patients with the diagnosis [5]. AF management requires access to care, physician-patient communication to discuss symptoms, and shared decision-making. However, due to the social construct of race, individual-level racism and structural racism impede communication and care delivery [6,7]. Furthermore, the limited inclusion of Black individuals in clinical trials and studies of AF has been insufficient to elucidate how individuals of Black race experience the condition [8]. Patients' lived experiences of their chronic conditions alter their self-management, which in turn affects patients' health habits, risk factors, and health outcomes. Few studies have qualitatively investigated the individual experience of AF, and none have done so in Black individuals [9-12]. The sparse qualitative data that has been collected from individuals with

AF suggests themes of physical limitations, emotional stress, and lack of health education that affect patients' self-management [9-11]. Such themes are likely compounded in Black individuals with AF by micro and macro-level biases and discrimination [6].

We conducted focus groups to explore the perspectives of Black individuals living with AF. We leveraged an ongoing randomized control trial that provides and instructs individuals with smartphone-based mobile health technology among individuals with AF. We aimed to identify themes regarding Black participants' experiences and challenges in managing AF. Using a qualitative approach, we focused on individual perceptions of AF among Black individuals, specifically regarding self-management, interactions with healthcare professionals, and community resources.

## 2. Methods

### 2.1. Participant cohort

The Mobile Relational Agent to Enhance Atrial Fibrillation Self-care Trial is a randomized controlled trial ([NCT 04075994](#)) that randomized participants in a 1:1 fashion to receive either a detailed mobile health self-management intervention for AF or a control condition. The intervention combined a smartphone-based virtual health coach with the AliveCor Kardia<sup>®</sup> smartphone heart rate and rhythm monitor. The control arm received a smartphone with WebMD installed and the AliveCor Kardia for self-guided heart rate and electrocardiogram monitoring. Both arms of the trial received extensive teaching on smartphone use. The trial was designed to examine the efficacy of the intervention to improve the outcomes of anticoagulation adherence, health-related quality of life, and healthcare utilization. The trial duration was 12 months, with 4-month duration of the intervention. Further details of the trial may be accessed in the published protocol [13]. At the time of recruitment for the qualitative study, the randomized control trial was recruiting and collecting data concurrently. Study staff contacted all self-identified non-White participants who had consented for the parent trial and asked for their interest in participating in focus groups about living with AF, which totaled to 32 participants. Interested trial participants were separately consented for their participation in the qualitative study. Focus group participants were compensated with \$40 for their participation. The study received approval from the University of Pittsburgh Institutional Review Board.

### 2.2. Focus groups

Due to directives in place for the Coronavirus pandemic and physical distancing requirements occurring during 2021, the focus groups were conducted virtually via Zoom (Zoom Video Communications, Inc. San Jose, California). In this study, we used the qualitative description approach, in which qualitative data is analyzed for themes, patterns, and descriptive findings [14,15]. Because 3–5 focus groups are typically needed for thematic saturation, or the point at which no new themes emerge with continued data collection, we planned to conduct a minimum of 3 focus groups [16]. An experienced qualitative research specialist (FC) moderated each of the separate 45 to 60-minute groups. Using a semi-structured focus group guide, we collected data exploring participants' experiences of living with AF. Our focus group guide was developed to center on patient experiences

with self-management activities and mobile health technology use and is listed in Table 1. The focus group guide was initially developed de novo by a content expert (AJ), and iteratively reviewed with another content expert (JM). After reviewing, questions were further vetted by a qualitative research expert (FC) to ensure sufficient breadth and depth of participant perspectives. Questions were asked of the group, and stimulated discussion between the participants; the focus group moderator asked additional probes to clarify and further stimulate discussion as necessary. Two co-authors also observed the focus groups in real-time (HM and AJ).

### 2.3. Analysis

Audio recorded focus groups were transcribed verbatim and confirmed for accuracy, after which they were deidentified and uploaded into MaxQDA for the purposes of coding. Analysis began after the completion of the three focus groups. In the first phase, qualitative research expert (JW) reviewed all three transcripts and used inductive coding to develop the preliminary codebook [17]. Second, as two independent coders (FC and JW), they applied the codebook to all three transcripts, using descriptive line-by-line coding [17]. Both coders identified additional codes as needed, and differences in coding were discussed and adjudicated by the coders to full agreement. We have included the codebook in Supplement 1. In the second phase of analysis, qualitative research experts (MH, FG, and JW) implemented focused coding, during which they synthesized the descriptive codes into final recurrent themes and subthemes [18,19]. In the third phase of analysis, the themes were presented to the co-authors (AJ and HM) for further evaluation and discussion among coders and co-authors. Each analytic phase utilized the process of investigator triangulation, which supports confirmation of and strengthens the reliability of study findings [20,21]. The focus group moderator's (FC) initial review was that thematic saturation had been reached after 3 groups, in that no new insights were emerging, and thus data collection was halted. Thematic saturation was confirmed with the coding process outlined above.

## 3. Results

### 3.1. Participant characteristics

After initial recruitment and screening, 24 participants agreed to take part in the focus groups. Sixteen participants completed one of three groups (4, 6, and 6 participants each). We list participant demographic characteristics and clinical information among focus group participants and from those in the greater trial cohort in Table 2. Nearly all focus group participants self-identified as Black race ( $n = 15$ , 93.8 %), with one participant self-identifying as Asian, as we had initially recruited any non-white trial participant. Participants were mostly male (62.5 %) with mean age of 67 (range 40–78) years. Most participants had annual household income less than \$50,000 per year per family. Participants at various levels of educational attainment were included in the focus groups. Atrial Fibrillation Quality of Life (AFEQT) Scores were generally high [22]. The AFEQT instrument is a 20-item AF-specific validated measure of patients' perceptions of symptom burden, functional abilities, and treatment satisfaction, with higher scores indicating positive patient perceptions and thus increased quality of life [22]. Nine of the sixteen participants were randomized to the intervention arm of the prior mentioned trial; the other seven

participants were randomized to the control arm. Demographic data were collected via telephone with self-report and survey assessments at baseline enrollment in the original study.

### 3.2. Themes

We identified themes in the coded data, summarized in Table 3 along with direction quotations. The Fig. 1 shows our emergent conceptual framework for AF self-management based upon focus group discussions.

**3.2.1. Theme 1. Participants reported substantial physical and mental burdens associated with living with AF**—Participants described a spectrum of symptom severity, ranging from none to prominent. Some participants reported discernible symptoms, such as fatigue, dizziness, palpitations, and shortness of breath. In particular, symptomatic participants made significant lifestyle changes to try to manage their heart condition, as they perceived increased physical stress in association with their diagnosis of AF. Thus, symptomatic participants referred to the disease as a “game changer” and a “whole new ballgame.” They described limiting their physical activity out of concern for inciting their AF, including decreasing physical chores, exercise, and even decreasing sexual activity with their partner.

Multiple participants noted the psychological toll with the unpredictability of their symptoms. “It gets scary when your heart just out of nowhere gets crazy...It just rips everything from up underneath you.” The concern that mental stress could trigger their AF also prompted some participants to make changes in their interpersonal relationships to avoid additional stress. Furthermore, some participants mentioned their faith beliefs as a source of comfort when discussing the mental toll of having AF.

The physical and mental burdens of AF prompted most participants to make lifestyle changes. All respondents reported taking daily medications to manage their heart conditions and some had undergone cardioversion to restore normal rhythm. Some respondents remarked on diet changes such as increased vegetable intake, decreased salt intake, and decreased meat intake. Some participants stated they used prayer, rest, and mindfulness techniques such as meditation to manage their disease.

**3.2.2. Theme 2. Participants sometimes described AF as “unmanageable,” or were uncertain of self-management effectiveness**—The presence or absence of symptoms affected the way participants manage their disease burden. Symptomatic participants made great efforts to engage in healthy lifestyle behaviors. However, the paroxysmal nature of the disease created an additional challenge in self-management. Participants noted that the intermittent nature of the disease led to uncertainty whether lifestyle changes affected their disease burden. For this reason, multiple participants described AF as “unmanageable”. Reflecting the importance of the doctor-patient relationship in chronic disease management, some participants described feeling inadequately counseled. One participant noted that when they were diagnosed, they were not “told anything specifically, to do [for their AF]. So that was frightening.” Overall, participants who reported a lack of AF symptoms also reported less physical or mental stress

from AF. One asymptomatic participant commented, “I never really thought of it in the [sense] of trying to manage.”

**3.2.3. Theme 3. Participants identified 3 key factors to facilitating successful AF self-management self-education, community support, and patient-provider relationships**—In pointed discussion regarding what factors would be most supportive in participants' self-management of disease, 3 key factors were identified: education, interpersonal support, and community understanding. Each of these is discussed below.

### 3.3. Self-education

Multiple participants stated that self-management requires education, that they are eager to receive more knowledge, and identified several different educational resources. As one participant stated, “the more we know... the more we can do to minimize [AF] and live longer.” Participants sought to equip themselves with as much knowledge as possible, turning to online information sources, such as WebMD and YouTube. Participants expressed a variety of preferences for methods of receiving educational information, including materials for reading, videos to watch, in-person counseling, technological devices, or a combination of these modalities.

### 3.4. Community support

Participants described a range of approaches towards enlisting social support to assist them with the condition. Most participants emphasized the importance of interpersonal support from family, friends, and the community. Participants reported notable barriers to interpersonal support as well. When asked about how participants' relationships supported their management of AF, some participants described the alienating and isolating experience of living with an invisible chronic condition: “you have to be strong for yourself, you know what I'm sayin'? ... You have to be your own support group.” One participant explained that the invisibility of her illness is even more reason to conceal her condition from others. Regarding her friends and family, she noted, “They have enough problems of their own.” Some participants de-emphasized the importance of social support and emphasized the importance of personal responsibility and self-sufficiency. One participant proudly declared, “I don't rely on anybody to help me with anything.”

In general, participants observed a lack of public awareness surrounding AF in their communities that made interpersonal support more difficult to obtain. Some participants noted that AF is less relatable than other cardiovascular problems, such as high blood pressure, a common condition in the Black community. Some participants took it upon themselves to educate others about AF, as detailed in the following quote: “I try to educate my kids and, you know, sometimes their friends... give them a little bit of information that might help them... especially in the Black community.” When asked about community resources to support them with their self-management, almost all participants were unaware of any such entities. Only one participant stated that she knew of local health classes and a dietician that focused on heart-healthy diets. One participant even identified being a focus group participant in this study as a helpful source of knowledge and support, to which other participants offered affirmative responses in agreement to the benefit of support groups.



### 3.5. Patient-provider relationships

Interpersonal interactions between patients and provider were considerably nuanced and variable among participants. Some participants reported healthy, therapeutic relationships with medical personnel and used their self-management techniques to compliment the advice from their medical providers. One participant noted that coordination of care between her primary care doctor and cardiologist was extremely helpful in her management of AF and comorbid conditions, stating “I guess, one of the biggest hurdles that I had to get over was duplication, but, like I said, my PCP is wonderful. She keeps in touch with my cardiologist so they don't duplicate my blood work anymore.”

However, many participants expressed skepticism towards members in the medical field. Multiple participants expressed concern over safety and efficacy of medications. For example, one participant noted, “I've learned that you have to watch... these doctors... They can still give you medication that is not compatible to your system”. Many participants also expressed hesitation and concerns with procedures, including ablations and cardiac device implantation. Some participants, particularly women, emphasized that dismissive doctors posed a significant barrier to their medical care. Several participants cited not feeling listened to at their appointments as a barrier to their self-management.

## 4. Discussion

We found that among focus groups of predominantly Black individuals, group members noted barriers to AF self-management including physical and mental stressors, the unpredictable and invisible nature of the condition, a lack of awareness in their communities, and dismissal from providers. Focus group participants even expressed being unaware that one could successfully self-manage one's AF. Facilitators of AF self-management reported by participants included being open to receiving more education about AF, interpersonal support, as well as considerate patient-provider relationships. Along with the quotations and summary of themes in Table 3, we list potential clinical implications and actionable items based on these findings, as identified in discussion by the co-authors (HM, JM, & AJ).

Our findings are consistent with prior data which identified the unpredictability of the disease and increased stress/anxiety with higher symptom burdens [9,23]. We identified that AF is a stressful condition in two distinct ways: 1) stress is a trigger for AF as well as 2) AF leads to distress within patients' lives. Our focus groups' discussion of stress-reduction techniques as part of atrial fibrillation-self management is novel. The overlap of patients' lived experience with pathophysiology underscores the importance of understanding the mechanism of how stress affects patients' lives and methods for stress mitigation. Similarly, how distress from AF management affects the daily lives of patients deserves further investigation. Our study adds additional context to the AF self-management literature with emphasis on the known physiologic stressors within the Black community [24]. A better understanding of the AF-stress relationship may yield development of clinical lifestyle interventions to address the biologic manifestations of stress occurring in disenfranchised communities [25,26]. In prior studies, patients' level of stress and fear associated with their diagnosis of AF was mitigated by supportive care from their clinicians, demonstrating patient-focused care as integral to stress management itself [10].

Participants' lack of awareness that AF is a diagnosis that could be self-managed, and lack of education on how to do so, directly reflects a dearth of disease counseling [10,11,23,27]. Prior qualitative data have demonstrated that patients with AF have knowledge gaps and misconceptions that affect their care, even though patients are open to further education [10,11,23]. One study found that although patients would prefer to have discussions about their individualized risk, clinicians rarely communicate CHA2DS2-VASc scores due to preconceived notions of patient's lack of concern or inability to understand risk predictions [23]. Another qualitative study found that providers often used persuasive language when discussing treatment options, omit treatment options from discussion, and were less likely to discuss side effects and risk [27]. Limited therapeutic patient-provider relationships have been shown to contribute to disparities in arrhythmia treatment as well [28]. The dearth of disease counseling that exists in AF may be compounded by longstanding bias and discrimination against racial and ethnic minorities [6]. The American Heart Association advocates for self-management skills, such as symptom monitoring and maintenance of healthful behaviors [29]. As expressed by our study's participants, more counseling and dedicated shared decision-making for individuals in their self-management is a needed addition to routine patient care [30]. Further studies regarding the ideal methods of disease diagnosis and counseling using validated educational tools may improve patient-provider communication [31].

Interpersonal support played a varied role in patients' lives that was dependent on their symptom burden and functional status. Many participants remarked that their community support was limited by lack of AF awareness. One prior study explored family members' perceptions regarding a loved one's diagnosis of AF, and found many members felt ill-prepared and undereducated to support their loved one in managing the disease [32]. Public health awareness efforts could make the disease more visible to individuals in the Black community. Public education efforts may not only make individuals with AF feel more supported, but may also combat the AF racial paradox of minorities having lower rates of the disease due to likely underdiagnosis [8].

Our focus group guide included questions about community health awareness and efforts to employ technology for better disease management among Black individuals. Given the mobile health intervention deployed in the accompanying clinical trial, we were interested in qualitatively assessing how technology could influence self-management. Although no significant technology themes emerged in this cohort of participants from a mobile health trial, future studies may evaluate the mechanisms of mobile health for AF self-management among Black individuals.

Our study has notable strengths. We leveraged a diverse clinical trial to recruit focus group participants with minoritized backgrounds, thus learning about Black individuals' experiences of AF from patients with well-characterized AF. We employed an established qualitative research center to ensure robust methodology by use of experienced coders, validated coding methods, and practices of triangulation. In conducting focus groups instead of individual interviews, we were able to create a nurturing discussion space.



Nevertheless, our findings should be viewed in light of its limitations. Qualitative research, in an attempt to collect data of increased depth, is usually conducted with smaller sample sizes. We also acknowledge that our focus group participants were recruited from a single-center trial focused in one geographic region. We derived a focus group guide based upon clinically relevant participant perspectives, but we did not assess providers' perspectives. However, participants' perspectives reflect their interpersonal needs, as has been validated elsewhere [30]. Our participants represent a wide range of patients with AF who have experienced various pharmacologic and non-pharmacologic interventions for their AF diagnoses. While this variation potentially adds to the diversity of patient perspectives, it is possible that responses could have been varied depending upon treatment history. Notably, use of oral anticoagulant was an entry criterion. Therefore, this study is unable to address medication use as part of the known disparities among racially minoritized patients, as has been documented in other cohorts [33-35]. Participant perspectives may also be skewed from their participation in the randomized control trial, particularly the intervention arm. Nonetheless, participants identified barriers to AF management, even within the context of the intervention. Participant perspectives may also be confounded by comorbid conditions, which may increase their self-management burdens.

Due to the ongoing enrollment of participants in the randomized control trial at the time of focus group enrollment, we tried to maximize recruitment by initially recruiting any non-White participants. Thus, our participants included one Asian individual. As is the nature of qualitative research and focus group data, it was not possible to exclude the Asian individual from our analysis. We recognize that varying minorities have varying social experiences, but felt our results still identified important themes for Black individuals with AF. We also lack generalizability to other ethnicities and races, or the consideration of diversity within individuals of Black race.

## 5. Conclusions

In this qualitative study, we found that Black individuals with AF generally feel unsupported in their self-management and face important interpersonal challenges in their care. We expect that by addressing education and treatment strategies, providing educational resources, and empowering community support we can develop future interventions for better AF self-management in racially diverse patient populations [36,37].

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

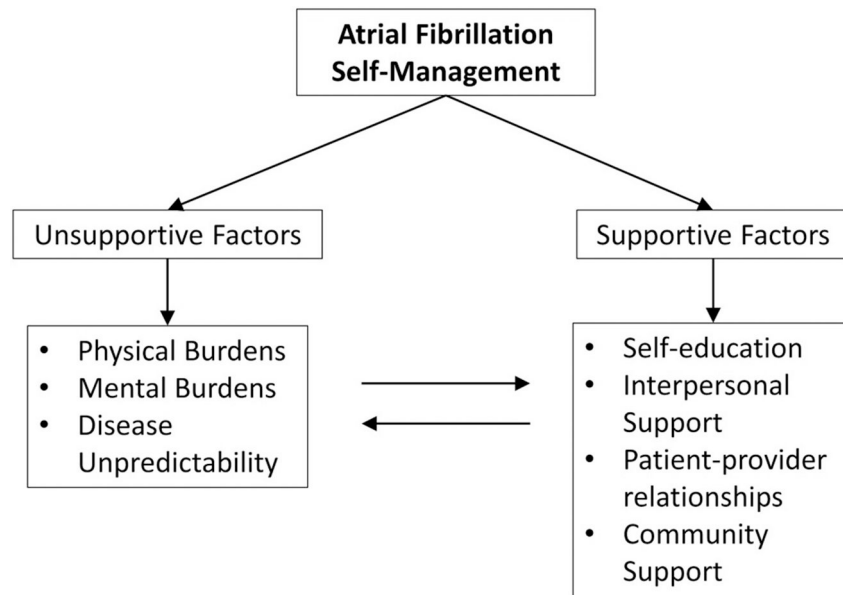
## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. This work was supported by Funder: National Institutes of Health Grant Number. R33HL144669 (PI: Magnani).

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**Fig. 1.** Conceptual framework for atrial fibrillation self-management among Black participants in a clinical trial.

**Table 1**

## Semi-structured, patient-centered interview guide.

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What are the most important things you do to care for your heart?

What personal skills do you use to help manage atrial fibrillation?

What tools or resources do you use to manage your cardiovascular disease?

Do you rely on anyone to help you manage your atrial fibrillation? If so, who? If not, why not?

How important is your community in your atrial fibrillation self-care?

What barriers or adversities prevent you from managing your atrial fibrillation? Are there any other barriers you can identify in managing any other cardiovascular conditions that you may have?

Are there resources in your community that contribute to heart health improvement?

Have you faced setbacks to your mental and physical health? If so how did you overcome them? How would you overcome them in the future?

Are there aspects of cardiovascular self-care that you find particularly difficult or troublesome?

Are any of these aspects related to your disease (e.g., atrial fibrillation, hypertension, heart failure, coronary artery disease, peripheral artery disease)? Please explain.

Are there aspects that are particularly easy to manage? Please explain.

Prior to this study, did you have a smart phone? How do you use a smart phone?

Do you have wireless internet in your home? Has lack of internet access ever been a problem for you or your community?

What kinds of technologies, if any, do you use to help with atrial fibrillation care?

How familiar are you with wearable devices to monitor your heart rate, blood pressure, and other health aspects?

If you could, would you use smart devices more? Please explain.

How important is education in managing your heart disease? Do you think videos, teaching, or other lessons about atrial fibrillation, heart failure, or other heart conditions are useful? Why or why not?

How do you learn best (video, reading, having a live person demonstrate, etc.)?

Would you use a smart phone to understand more about how heart disease affects your life? Why or why not?

Would you use a smart phone or device to help you with taking your medications? Why or why not?

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**Table 2**

Participant demographic data.

Characteristic	Focus group participants	Main cohort
Age, mean (standard deviation)	64.1 (9.9)	70.73 (9.82)
Female sex, n (%)	6 (37.5)	156 (64.2)
Race		
Black	15 (93.8)	74 (30.5)
Asian	1 (6.3)	1 (0.4)
Multiple or unlisted race	0	5 (2.1)
Prefer not to respond	0	2 (0.8)
Total family income		
\$19,999	4 (25)	29 (11.9)
\$20,000 to \$34,999	3 (18.8)	35 (14.4)
\$35,000 to \$49,999	2 (12.5)	32 (13.2)
\$50,000 to \$74,999	1 (6.3)	39 (16.0)
\$75,000 to \$99,999	1 (6.3)	27 (11.1)
\$100,000	2 (12.5)	34 (14.0)
Don't know	1 (6.3)	22 (9.1)
Prefer not to respond	2 (12.5)	25 (10.3)
Education level		
Some high school, no diploma	0	7 (3.0)
High school graduate	4 (25)	47 (20.3)
Some vocational school	1 (6.3)	5 (2.2)
Completed vocational school	1 (6.3)	5 (2.2)
Some college, no degree	0	42 (18.2)
Associates degree	4 (25)	30 (13.0)
Bachelor's degree	2 (12.5)	37 (16.0)
Graduate degree	4 (25)	50 (21.6)
AFEQT [22] quality of life score, median (range)	63.4 (23.1–100)	74.1 (61.1, 89.8)
Pacemaker	2 (12.5)	36 (14.8)
Defibrillator	2 (12.5)	18 (7.4)
Prior cardioversion	6 (37.5)	71 (29.2)

AFEQT = Atrial Fibrillation Effect on QualiTy-of-life.



**Table 3**

Emergent themes with representative quotations and clinical implications.

Thematic concepts	Quotes	Implications
1) Physical and mental burdens of disease		
Physical shifts in amount of exertion are necessary	“I can't-I can't exercise or workout like I used to. I can't, uh, you know, I gotta pace myself. Can't work in the yard like I used to because of my AFib.”	<ul style="list-style-type: none"> <li>• Counseling regarding potential lifestyle limitations with diagnosis</li> </ul>
Mental stress is high and stress mitigation efforts were critical	“For me, the biggest thing is not letting myself get stressed out. When I get stressed out, everything [goes] crazy. As long as I ain't stressed out, my heart is good.”	<ul style="list-style-type: none"> <li>• Counseling regarding mental health maintenance in relation to AF</li> <li>• Further studies more concretely identifying relationships between stress mitigation strategies and AF symptoms/burden</li> </ul>
Lifestyle changes were universal	“I've cut a lot of sodium out of my diet. Along with the meats. There're only certain things that I'll eat. Also controlling my weight. Because it has a lot to do with your AFib.”	<ul style="list-style-type: none"> <li>• Advocating for insurance coverage of stress-mitigation resources/classes (i.e., yoga classes, meditation classes, therapy)</li> <li>• Regularly discussion of dietician referrals with patients</li> </ul>
2) “Un-manageable” nature of disease		
Asymptomatic and paroxysmal nature made AF difficult to manage	“No matter how much exercise you do, no matter how much stress free you try to do be, no matter what you do, it's still hard to manage because you don't know when it's gonna come. You can be having a great day on the beach, you can be layin' in bed, you can be asleep.”	<ul style="list-style-type: none"> <li>• Counseling regarding erratic nature of disease</li> <li>• Feedback of when AF is occurring, such as mobile electrocardiograms or heart monitors</li> <li>• AF patient support groups as discussed below</li> </ul>
Irrespective of health-management behaviors, AF would recur.	“All you can do is pray about it, takin your medication, and-and hope for the best. You really can't manage it.”	
3) Key tenets of self-management		
3.a) Self-education		
Patients universally felt knowledge of self-management was imperative	“Well, I think that the more you know about your condition, the better you can manage your condition. And the better decisions you can make about your condition.”	<ul style="list-style-type: none"> <li>• Minimizing provider bias that patients may not be interested in gaining medical health knowledge</li> <li>• Utilizing support staff in outpatient offices to screen patients for interest in further receiving medical health knowledge, prior education level, and type of preferred educational modality (article, video, audio, technology application, etc.)</li> </ul>
Effective patient education came in many modalities	“And I also have, um, a diabetes educator. And she is just a wealth of knowledge. She's helped me a lot with—and the diet that helps my diabetes is just as healthy for-for my heart. And she has all sorts of information and resources at her office. And, I mean, it's nothing that I get charged for either. She said a lot of people don't-don't utilize it as much as they should.”	<ul style="list-style-type: none"> <li>• Sharing educational information in various modalities (article, video, audio) at appropriate educational level with patients</li> <li>• Use of technology applications to provide accessible, trustworthy source of information to patients</li> </ul>
	“I'm one of those people that believe a picture's worth a thousand words. If I look at something and—that leaves an impression on my mind. Oh, I remember that.”	<ul style="list-style-type: none"> <li>• Regular referral to associated health professionals such as dietitians, weight management experts, pharmacists, etc.</li> </ul>
	“I use my smartphone to look up medicines. Like, I want to know the effects, the side effects.”	<ul style="list-style-type: none"> <li>• Increased efforts to integrate supportive health professionals into outpatient cardiology offices for more accessible &amp; holistic care</li> </ul>
3.b) Community support		
Invisibility of illness adds to disease burden	“Everyone always like, oh, he's so strong, you know, he don't need anything. With this, I notice that a lot of times they don't ask are you okay. Are you—you have to be strong for yourself, you know what I'm sayin'. Because they don't look at you like you've gotten weak, but you know you've gotten weak [...] You have to be your own support group.”	<ul style="list-style-type: none"> <li>• AF support groups for patients with diagnosis to discuss burden of disease and share mitigation efforts</li> <li>• Educational campaigns by medical associations in concert with governmental agencies to increase general public awareness</li> </ul>

Thematic concepts	Quotes	Implications
Variable reports of self-reliance versus communal management	<p>“Well, I will say that, um, I had shared with a couple people at church, um, the one thing that I missed the most is doing my own yard work. And my cardiologist had not given me the go ahead to continue that. So the young ones from my church come up and cut my grass and weed whack. And I guess that's the closest I get to, you know, asking for support with it.”</p> <p>“The people where I live... are watchful... Somebody is always asking me, ‘are you okay? Is everything okay?’ ... So yes, I guess the community, you know, in a way, plays a part that sometimes I really don't realize it myself.”</p> <p>“My community has nothing to do with my AFib. At all. Nothing. I don't go out and tell people, oh, I have AFib. It's something that I have that I deal with. Other people got their own problems. You know. And it's not like this-this AFib is so debilitating that I can't do anything. I do everything that a husband-and-wife team would do.”</p>	
Community's lack of awareness of disease	<p>“I don't know what percentage of people would be aware of what AFib is, you know, to really help the community.”</p> <p>“AFib is not like high blood pressure. Everybody knows your blood pressure is high. That's clear. But AFib is not the same. Family. Everybody. They know you have high blood pressure, they encourage you, make sure you take the medication. AFib is on a different level.”</p> <p>“I just like to say that I appreciate this call, conference, or what have you. And that you gave me some questions to ask my doctor. And also you made me a little more aware of the seriousness of my condition, and I do appreciate that. And I thank you guys for the questions and the questions that you left me with.”</p>	
3.c) Patient-provider relationships		
Dismissal of concerns	<p>“I ask a lot of questions when I go to the hospital. And when I ask the doctor a question, if they give me that feedback that I think is alright, I'll use that. But when I get them doctors that just want to get you out of office, I don't use that.”</p> <p>“There are no barriers. The only barrier that I have are the doctors who don't seem to pay attention when you tell them that you have this problem. And they tell, at least they tell me, that's something we don't deal with. It'll go away. That's baloney. But there are no barriers. The physicians are the barriers.”</p>	<ul style="list-style-type: none"> <li>• Minimizing provider bias that patients may not be interested in gaining medical health knowledge</li> <li>• Utilization of validated shared-decision making tools with patients during visits</li> <li>• Regular referral to associated health professionals such as dieticians, weight management experts, pharmacists, etc. to support provider with education.</li> <li>• More efficient resource utilization to increase patient accessibility (e.g. telehealth, physician extenders.)</li> </ul>