

RESEARCH ARTICLE

Can nurses help improve self-care of patients living with atrial fibrillation? A focus group study exploring patients' disease knowledge gaps

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Abstract

Aims: To identify knowledge gaps and preferences for educational material to improve nurse–patient communication and self-care.

Design: Using a mixed-methods design, we conducted focus groups and quantitative surveys.

Methods: We conducted three focus groups with atrial fibrillation (AF) patients and support persons ($N = 17$ participants; 66 ± 16 years) at critical treatment junctures (recent diagnosis or medication switch). Patients and support persons were also surveyed on patient activation (self-management skills and knowledge), medication adherence, AF knowledge and health literacy. Iterative thematic analysis was performed using focus group transcripts.

Results: Although most participants had adequate health literacy, most reported gaps in AF knowledge. Participants lacked disease-related knowledge and were unsure how to manage health behaviours (e.g. diet and exercise). Few felt they received adequate education from their healthcare provider. Results emphasize the need for consistent information from nursing staff, in lay language, via both electronic and printed means.

KEYWORDS

adult nursing, anticoagulants, atrial fibrillation, focus groups, health information technology, medication adherence, patient engagement, qualitative research

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1 | INTRODUCTION

Atrial fibrillation (AF) is the most common sustained arrhythmia in the United States, affecting over three million Americans in 2010 and up to 12 million by 2030 (Benjamin et al., 2019). The increased incidence of AF represents an epidemic that was noted as a major public health problem in the early 2000s, when longitudinal studies began to confirm its strong link to stroke (Stewart, 2004). Chronic AF decreases quality of life both physically and mentally (Akintade, Chapa, Friedmann, & Thomas, 2015; McCabe, 2010; Stewart, 2004), causing feelings of depression and anxiety both directly related to symptoms, as well as the continual, progressive nature of the disease (Ekblad, Rönning, Fridlund, & Malm, 2013; McCabe & Barnason, 2012). Nurses are key to the treatment of AF patients, providing both clinical care and education that will help with disease management (Cutugno, 2015). However, disease management may be impeded by patients' significant knowledge gaps related to the disease and/or maintaining a healthy lifestyle (Desteghe et al., 2016; Frankel, Parker, Rosenfeld, & Gorelick, 2015; Koponen et al., 2008; McCabe, Schad, Hampton, & Holland, 2008; Mohamed, Abdul Razak, Hashim, & Mohd, 2017). In this study, we conducted focus groups with AF patients and their support persons to further explicate AF disease-related knowledge gaps among AF patients and their support persons and examine participants' preferences for educational material from healthcare providers.

1.1 | Background

Given the economic and personal impact of AF, self-care is a topic which merits further research (McCabe, 2018). Medication adherence, education and engagement in care are interrelated focal points for addressing non-adherence to oral anticoagulants (OACs), which can lead to devastating health outcomes. Clinical support for patients with AF is multifaceted and typically includes medication education, as well as self-care recommendations. Self-care, the collection of strategies employed by an individual to maintain their well-being, is an important aspect of chronic disease management that has been widely studied in heart failure (HF) patients (Harkness, Spaling, Currie, Strachan, & Clark, 2015), of which at least 10%–30% have AF (Offutt, 2004). Accordingly, McCabe (2005, 2008) called for self-care strategies to be implemented in AF treatment. Effective self-care requires both perception- and action-based strategies, where patients are able to accept and modify their sense of self in relation to their diagnosis, as well as adjust their daily activities (Harkness et al., 2015). There is some evidence that patient activation (i.e. the skills, knowledge and motivation patients bring to their own care management; Hibbard, Greene, & Tusler, 2009) is related to self-care in those with chronic disease (Zimbudzi et al., 2017). However, a recent study with HF patients showed that while patient activation was significantly related to self-care, disease knowledge and health literacy were not (Jacobson et al., 2018). Thus, direct self-care education that affects activation may be more important than simple disease- or health-related information.

Notably, in AF treatment settings, there is great diversity among providers in how much self-care education they give, which topics they cover and whether that education is effective. As an example, many physicians indicate they give brief medication education during appointments; however, adherence remains substandard (Brown et al., 2012). This non-adherence may be attributed to patients not following recommended self-care practices but could also be due to oversights in clinicians' education practices. Notably, researchers cite major AF knowledge gaps among patients and their caregivers (Desteghe et al., 2016; Frankel et al., 2015; Koponen et al., 2008; McCabe et al., 2008; Mohamed et al., 2017), such as unawareness that AF can cause stroke and what to do if the patient misses an OAC dose (Desteghe et al., 2016). In fact, a decade after her original call for implementation, McCabe (2018) noted that although much progress has been made about medical interventions for AF (i.e. more effective anticoagulants), patient education and engagement are still notably lacking overall.

Atrial fibrillation patients do not always receive the necessary education and reassurance from their own provider to take appropriate self-management action (Harkness et al., 2015; McCabe, Schumacher, & Barnason, 2011; Siouta et al., 2016) they express desire for educational information that can be accessed outside the doctor's office (Clarkesmith, Lip, & Lane, 2017; Franke et al., 2015). If patients feel that they have a lack of knowledge about their disease, this can lead to negative illness perception (Mas Dalmau et al., 2017), which has been identified as the highest contributor to psychological distress among the AF population (McCabe & Barnason, 2012). However, patient-provider communication about AF can positively influence patients' attitude towards treatment (Altiok, Yilmaz, & Rencüsoğullari, 2015; Clarkesmith et al., 2017; Crivera, Nelson, Schein, & Witt, 2016; Neubeck et al., 2018) and mitigate associated negative mental health outcomes (Borg Xuereb, Shaw, & Lane, 2012; Garkina, Vavilova, Lebedev, & Mikhaylov, 2016; Heidbuchel et al., 2017; Lip, Lane, & Sarwar, 2017; McCabe & Barnason, 2012; McCabe et al., 2011). Caregivers, who are often isolated and overwhelmed, indicate they, too, wish they would have been more informed in the early stages of their partner or family member's care (Frankel et al., 2015). Thus, both patients and their caregivers acknowledge that they have significant knowledge gaps related to AF disease management, and this can have a negative effect on self-care, mental health outcomes the coordination of care.

Several previous studies have demonstrated that follow-up educational interventions, often nurse-led, can increase event-free survival among AF patients (Conti et al., 2012; Fuenzalida et al., 2017; Hendriks, Crijns, & Vrijhoef, 2015; Inglis et al., 2004), but such interventions have not become part of the standard of care. Beyond verbal instruction or scheduled refill reminders, there is potential for technology interventions to give a means for education outside of office visits. For example, our prior work illustrated the potential of personalized education for AF patients on OAC knowledge and self-reported adherence among those who received tailored education via personal health records (PHRs; Chen, Roebuck, Sami, Erison, & Mirro, 2017). One of the advantages of electronic messaging is that it can be automated or personalized, allowing for "quick" education and clinic responses without the necessity of an office visit

or scheduled phone call. Additionally, electronic resources could be stored in a searchable database, so that patients could have access to relevant disease- or lifestyle-related information in an on-demand fashion. That said, there may be scepticism surrounding the integration of technological interventions for a population of AF patients, composed primarily of people over 70. However, in our own work, we found older patients, who rated their computer literacy lower than that of a younger cohort, were more likely to actively use their PHR once introduced and trained (ToscOS et al., 2016). This suggests that even elderly patients, who may not have experience with technology or electronic health records, might actively engage with electronic health technology if trained to do so for disease management.

Facilitating lifestyle change in individuals with AF requires a deep and complex investigation (Borg Xuereb et al., 2012; Clarkesmith et al., 2017)—results of which might help to shape provider–patient communication. Therefore, through focus group discussions, our aims were:

1. Identify persistent disease-related knowledge gaps among the AF patient population and support persons
2. Assess AF patients' and support persons' preferences for messages from healthcare providers, including content, presentation style timing.

1.2 | Design

This was a mixed-methods study consisting of qualitative feedback from focus groups and quantitative data from surveys. Focus groups were conducted with patients and their caregivers, partners, or other friends/family members ("support persons") to generate discussion of perceptions, opinions beliefs about preferred content, timing delivery mechanism of tailored health education about AF and OAC therapy during key transitions in the treatment process. Focus groups encourage open discussion among peers and foster exploration of individuals' knowledge and experiences of disease and treatment (Kitzinger, 1995). Three focus groups were held, each lasting 3 hours: two for patients newly diagnosed with AF (≤ 6 months) treated with any OAC one for patients diagnosed with AF at any time but who recently (≤ 6 months) switched from a vitamin K antagonist (VKA) to a direct OAC (DOAC) or vice versa. Each group also included respective support persons. Additionally, all participants completed a quantitative survey to characterize the sample demographically and by the level of health activation.

1.3 | Method

The sample included adult ambulatory patients in a single cardiology practice in a large Midwestern health system who were diagnosed with AF and prescribed OAC medication. Participants were identified by clinic staff and researchers via the hospital's electronic record system. A research coordinator recruited patients by telephone. During this telephone conversation, patients' support persons were also invited to participate, either with or without the patient.

After completing an informed consent form, participants completed a survey, which included: demographic questions; the 10-question patient activation measure—PAM (Hibbard et al., 2009; $\alpha = 0.91$); the 12-question Altarum Consumer Engagement scale—ACE (Duke, Lynch, Smith, & Winstanley, 2015; subscales $\alpha = 0.85, 0.82, 0.72, 0.66$); the eight-item Morisky Medication Adherence Survey—MMAS-8 (Morisky, Ang, Krousel-Wood, & Ward, 2008; $\alpha = 0.83$); the 11-question AF Knowledge Scale (Hendriks, Crijns, Tieleman, & Vrijhoef, 2013; $\alpha = 0.58$); and the newest vital sign (Weiss et al., 2005; $\alpha = 0.76$), a six-question health literacy scale. Validated scoring measures were available for all measures except AF knowledge, for which our research team created a simple scale by evenly dividing the number of possible correct answers into low, medium and high scoring brackets.

After completing the surveys, participants engaged in a structured focus group discussions in a private room in a dedicated research centre for a large regional hospital in northeast Indiana. There were three focus groups held. Focus group A had nine participants (five patients, four support persons), focus group B had three participants (two patients, one support person), and focus group C had five participants (three patients, two support persons). Additionally, each focus group included two subject experts (a cardiac electrophysiologist and an anticoagulation therapy unit clinic pharmacist), one observer, two notetakers and one moderator. For approximately the first half hour of each session, the subject experts presented information about AF, OAC therapy stroke risk. After the presentation, the moderator presented a fictitious scenario modelled after patients' own experiences (i.e. a patient who was recently diagnosed with AF or recently switched medication types), followed by a series of prompts (i.e. developing an effective care plan for this patient; see Table 1 for a full list of the scenarios and prompts). The focus groups were video and audio recorded and transcribed to text. Observers recorded field notes during the focus groups and added additional information during debrief sessions among the research team. All personally identifiable information and protected health information collected for the purposes of the study, including audio-visual recordings of participants, are securely stored on the health system's enterprise data storage drive, with no external access outside the organization and access rights assigned exclusively to the research team.

1.4 | Analysis

Descriptive analyses were used on the survey results to characterize the sample. For the focus group data, a team of seven researchers with both clinical and human–computer interaction backgrounds, including those who were present at the focus groups, held three meetings to develop an initial codebook for the transcripts using field notes, which was later refined through thematic, iterative analysis of the transcripts using QSR International's NVivo 11 qualitative data analysis software. Following the initial codebook development, the team reviewed transcripts and met seven times to compare

TABLE 1 Full list of scenarios and prompts

Scenario	Prompts
<p>Patients newly diagnosed with NVAf:</p> <p>1. Mr. Johnson is seeing his cardiologist today for a routine yearly follow-up appointment. He mentions to his cardiologist that he has been experiencing some heart palpitations recently and an EKG is completed during his office appointment. Mr. Johnson's EKG shows that he is in Atrial Fibrillation. After reviewing Mr. Johnson's health history, his cardiologist determines that he should be prescribed an anticoagulant to reduce the risk of a stroke caused by a blood clot in the future</p> <p>2. If you could design the ideal plan for Mr. Johnson's healthcare team to best give him with follow-up education and support for the next 6 months about his new NVAf diagnosis and his new anticoagulation medication, what would that plan look like?</p> <p>3. How can the healthcare team help Mr. Johnson take his medication as prescribed by his doctor?</p>	<ul style="list-style-type: none"> • What information would be most helpful for Mr. Johnson to receive initially at this office appointment? • Looking back on your own personal experience when you were newly diagnosed with NVAf, what things would you change regarding the type of information you received and how it was presented to you? Were you included as much as you wanted or needed to be? • How often should Mr. Johnson be contacted? • What form(s) of communication would be most ideal? • What would be the best way for Mr. Johnson to communicate his questions and concerns to his healthcare providers? • What questions should they ask Mr. Johnson to find out whether he is taking the medicine the way he should? • What form of communication and what information do you think would be helpful to Mr. Johnson?
<p>Patients switching medication:</p> <p>1. During a routine follow-up visit today, Mrs. Robert's cardiologist discussed with her that she would have the option to choose to switch from Coumadin to one of the newer anticoagulant medications if she would like to do so. Mrs. Robert's cardiologist tells her about the risks and benefits related to switching medications. Keeping in mind the time constraints of a routine office visit, what would your recommendations be regarding how Mrs. Robert's healthcare team can best assist her with this transition?</p> <p>2. If you could design the ideal way for the healthcare team to assist patients with a significant change in their medical therapy such as this, what would it look like?</p>	<ul style="list-style-type: none"> • What type of information should Mrs. Roberts walk out of the office with today? • Should there be follow-up communication with Mrs. Roberts regarding this change of therapy? If so, how often should she be contacted and what type of information would be helpful? • Looking back at your personal experience, what would you change about the way your situation was handled? Were you included as much as you wanted or needed to be? • How can the healthcare team help Mrs. Roberts take her medications as prescribed by her doctor? • What questions should they ask Mrs. Roberts to find out whether she is taking the medicine the way she should? • What form of communication do you think would be helpful to Mrs. Roberts?

concepts, resolve discrepancies and ambiguities and discuss emergent themes until consensus was achieved and potential biases were reconciled (Corbin & Strauss, 2007).

To ensure rigour, focus group transcripts were sectioned and divided among the team, who validated the initial codebook with the first transcript, making minor adjustments, before using the validated codebook for the final two transcripts. Researchers coded the first transcript individually, based on the entire codebook, due to distinct emerging themes with dense subthemes, coded the latter two in teams of two or three, with each team applying a specific subset of codes. The smaller teams compared coding for approximately 80%–90% agreement and brought discrepancies back to the research team, employing the constant comparison method to resolve ambiguities and reach consensus on the codebook (Bradley, Curry, & Devers, 2007).

2 | ETHICS

All study activities were approved by the health system's Institutional Review Board. Debrief sessions were held among the research team after each focus group. All notes from the focus groups were deidentified, and all electronic files were kept on a password-protected server.

3 | RESULTS

Seventeen individuals participated across three focus groups: 10 patients with AF and seven support persons, predominantly white (94.1%, 16), female (59%, 10) and over age 65 (76.5%, 13; see Table 2). Most rated their ability to use a computer and the Internet as at least average. Half of the participating patients were taking the anticoagulant apixaban, with others taking warfarin and rivaroxaban.

The AF Knowledge Scale revealed that most participants had a "medium" level of AF knowledge (20% low, 60% medium, 20% high). Among patients specifically, there were seven questions missed by 50%–100% (see Table 3 for the AF Knowledge questions and participant results).

Patients' PAM and ACE scores characterized the sample as representing a full range of activation. Notably, most patients evaluated themselves as having low levels of both "informed choice" (60%) and "commitment to health" (90%), while scoring more evenly across "navigation" levels on the ACE. Patients were fairly evenly distributed between low (30%), medium (30%) and high (40%) medication adherence. Most of both patients and support persons demonstrated a likelihood of adequate health literacy (90% and 71.4%, respectively; see Table 4 for the full quantitative survey results).

TABLE 2 Participant demographics

Characteristic (N = 17)	N (%)
Age (years)	
26–35	0 (0.0)
36–45	0 (0.0)
46–55	2 (11.8)
56–65	2 (11.8)
66–75	7 (41.2)
>76	6 (35.3)
Gender	
Male	7 (41.2)
Female	10 (58.8)
Race	
White	16 (94.1)
Black or African American	0 (0.0)
American Indian, Alaska Native	0 (0.0)
Native Hawaiian, Pacific Islander	0 (0.0)
Asian	0 (0.0)
Do not wish to answer	1 (5.9)
Education	
<High school	0 (0.0)
High school/GED	6 (35.3)
Trade/some college	6 (35.3)
College graduate	1 (5.9)
Postgraduate	4 (23.5)
No answer	0 (0.0)
Current employment status	
Employed full time	3 (17.6)
Employed part time	0 (0.0)
Unemployed	1 (5.9)
Disabled/unable to work	0 (0.0)
Retired	13 (76.5)
Student	0 (0.0)
Yearly income	
\$0–\$19,999	1 (5.9)
\$20,000–\$39,999	5 (29.4)
\$40,000–\$59,999	3 (17.6)
\$60,000–\$79,999	4 (23.5)
\$80,000–\$99,999	0 (0.0)
>\$100,000	3 (17.6)
No answer	1 (5.9)
Household occupants	
I live by myself	1 (5.9)
I live with my spouse or partner	15 (88.2)
I live with a family member	1 (5.9)
Self-reported ability to use computer	
Very poor	0 (0.0)

(Continues)

TABLE 2 (Continued)

Characteristic (N = 17)	N (%)
Poor	2 (11.8)
Average	9 (52.9)
Good	4 (23.5)
Very good	1 (5.9)
No answer	1 (5.9)
Self-reported ability to use internet	
Very poor	0 (0.0)
Poor	4 (23.5)
Average	7 (41.2)
Good	4 (23.5)
Very good	1 (5.9)
No answer	1 (5.9)
Anticoagulant ^a (N = 10)	
Coumadin [®] (warfarin)	1 (10.0)
Xarelto [®] (rivaroxaban)	3 (30.0)
Eliquis [®] (apixaban)	5 (50.0)
Pradaxa [®] (dabigatran)	0 (0.0)
Savaysa [®] (edoxaban)	0 (0.0)
No answer	1 (10.0)

^aPatients only, N = 10.

Abbreviation: GED, general educational development.

With regard to the composition of the focus groups, groups A and B consisted of patients who had been both diagnosed with AF and prescribed any OAC in the 6 months prior, along with their support persons: N = 7 patients (noted in quotes as p1–p7) and five support persons (s1–s5). Group C consisted of patients diagnosed with AF at any time who had switched from a VKA to a DOAC, or vice versa, within the last 6 months: N = 3 patients (p8–p10) and two support persons (s6–s7).

Table 5 outlines emergent themes and subthemes of focus group discussions, along with exemplar quotes and associated recommendations for practice. As shown in Table 5, patients and their support persons had many questions about AF, including basics about the disease as well as self-care questions, such as compatible lifestyle activities and medication adherence. They also expressed that they would have liked more follow-up information from their provider:

M1: So would you have liked some follow up education from your doctor's office?

P16: I would like to have a person with that information.

M1: From your doctor's team? It doesn't necessarily have to be the doctor.

P16: Right and like I said with the nurse practitioner she reviewed everything and told me what to expect, she told me that this was common – so to speak, that there were lots of people have this, she told me the 12 hours.

M1: Is it similar or different that the education you received from the doctor?

P16: I knew a lot of it, but not from the doctor.

TABLE 3 AF knowledge questions and percentage of patients who answered correctly

AF knowledge scale questions	% correct (patients)
<i>What are the trigger factors for atrial fibrillation?</i>	50
Allergy to grass, animals or house dust	
Alcohol, coffee or spicy food ^a	
Noise or loud sounds	
<i>Why is it important to take my medication for atrial fibrillation properly?</i>	40
Because the doctor wants me to	
To prevent severe consequences of the arrhythmia ^a	
To prevent the possibility of a heart attack or sudden death	
<i>If atrial fibrillation is identified without the patient experiencing any complaints, the patients should immediately visit the hospital.</i>	0
True	
False ^a	
Do not know	
<i>What is atrial fibrillation?</i>	90
A heart disease in which the heart is not able to pump a sufficient amount of blood through the body	
A blood disorder causing blood clots in the heart	
An electric disorder in the atrial of the heart which results in the heart contracting too fast and irregularly ^a	
<i>Why is oral anticoagulation medication prescribed in certain patients with atrial fibrillation?</i>	90
To prevent the risk of blood clots which can cause a stroke ^a	
To make the blood flow more easily through the body	
To prevent fluid retention in the body	
<i>Why should a person using anticoagulation medication be careful with the use of alcohol?</i>	50
Alcohol increases the retention of fluid in the body resulting in the blood becoming too thin	
Alcohol causes a blockage of the blood vessels which, in turn, slows blood flow to the heart	
Alcohol influences the effect of the medication and this effects the clotting ability of the blood ^a	
<i>Atrial fibrillation is a rare condition</i>	60
True	
False ^a	
Do not know	
<i>It is particularly risky if a person does not feel his/her atrial fibrillation</i>	0
True	
False ^a	
Do not know	
<i>Which statement with regard to physical exercise is true of patients with atrial fibrillation?</i>	90
It is important for patients to rest in order to maintain normal heart activity	
Patients with chronic atrial fibrillation cannot work full time	
It is important to exercise normally within personal limitations ^a	
<i>Which statement is true?</i>	50
Atrial fibrillation is life endangering because it can result in a heart attack	
Atrial fibrillation is completely harmless	
Atrial fibrillation is harmless if the right medication is taken ^a	
<i>What is the function of the anticoagulation therapy unit (ATU) clinic?</i>	50
To monitor blood clotting and the number of tablets taken each day ^a	
To determine whether the arrhythmia is presented	
To determine whether the patient needs to continue taking oral anticoagulation	

Abbreviation: AF, atrial fibrillation.

^aCorrect answer.

Additionally, participants commented on their preferred mode of delivery for AF-related information, with many suggesting that nurses and doctors were valuable and trusted sources with preferences for clearly presented material, whatever the delivery format (e.g. paper or via their electronic health record). Participants also indicated that the timing of the material was critical, with some citing the importance of detailed information given at the time of diagnosis and others emphasizing the need for follow-up information after the patient had time to adjust to the initial diagnosis.

Alongside these main themes, patients also expressed feelings of anxiety, fear, depression and stress related to their lack of AF knowledge, information overload uncertainty with how to recognize and respond to symptoms:

You know...every once in a while there's some instruction that we don't understand...and I think that's the scary part.

(s3)

TABLE 4 Quantitative survey results

Measure	Patients (N = 10; %)	Support persons (N = 7; %)
Patient activation measure		
Level 1: Disengaged and overwhelmed	1 (10)	0 (0)
Level 2: Becoming aware but still struggling	4 (40)	0 (0)
Level 3: Taking action	4 (40)	7 (100)
Level 4: Maintaining behaviours and pushing further	1 (10)	0 (0)
Altarum consumer engagement		
Navigation		
Low	4 (40)	2 (28.6)
Medium	3 (30)	4 (57.1)
High	3 (30)	1 (14.3)
Commitment to health		
Low	9 (90)	5 (71.4)
Medium	0 (0)	1 (14.3)
High	1 (10)	1 (14.3)
Informed choice		
Low	6 (60)	3 (42.9)
Medium	2 (20)	4 (57.1)
High	2 (20)	0 (0)
Morisky Medication Adherence Scale		
Self-reported medication adherence		
Low	3 (30)	2 (28.6)
Medium	3 (30)	1 (14.3)
High	4 (40)	4 (57.1)
Newest vital sign		
High likelihood of limited literacy	1 (10)	1 (14.3)
Possibility of limited literacy	0 (0)	1 (14.3)
Adequate literacy	9 (90)	5 (71.4)

Participants also noted that they used media as an external source of content. Specifically, over one-third of participants sought information about AF and OACs from external media sources, such as the Internet. However, they noted that sometimes media (such as television commercials for medications emphasizing potential side effects) created fears and concerns and/or exaggerated existing ones. They also noted that if their providers gave them clear and adequate information, they did not feel the need to go online:

M1: Did you look up anything online?

P15: Not in the beginning no because the doctor did a really good job of explaining to me what was happening.

To allay negative emotional reactions related to living with AF, participants felt it was important that their healthcare team give them

with the reassurance that they could still live a full life with the AF diagnosis. They also expressed the importance of feedback from trusted providers who provided quality care, reassurance and comfort.

I think trust with your doctor is very important because if you don't trust the doctor you're not going to trust the medication that you're on or the health advice that they give.

(p10)

4 | DISCUSSION

Patients and support persons in our study indicated a range of preferences on the content, timing and delivery of AF-related information. In this group of patients and support persons, who, on average, indicated a moderate level of AF knowledge, activation and engagement in care on our surveys, there were still substantial AF knowledge gaps. Consistent with the literature (Desteghe et al., 2016; Frankel et al., 2015; Koponen et al., 2008; McCabe et al., 2008; Mohamed et al., 2017), patients and their support persons indicated they lacked the necessary information about AF and desired more. Participants felt that they understood issues related to their AF when they received clear explanations from their healthcare providers the groups identified a range of participants about which they would have liked clearer self-care information, including aspects of the disease and treatment (e.g. symptoms, stroke risk, medication information, life expectancy), as well as how to manage their health and behaviours (i.e. activity, weight, diet). Patients revealed a range of knowledge levels, with some asking basic questions, such as “what is stroke?,” to others seeking more nuanced information, such as clarification on “normal” physical activity. Research suggests the level of information received about AF is closely tied to satisfaction with care (Neubeck et al., 2018) that continual education and communication between patient and provider are of high importance (Borg Xuereb et al., 2012; Garkina et al., 2016; Heidbuchel et al., 2017; Lip et al., 2017; McCabe & Barnason, 2012; McCabe et al., 2011), sentiments which our participants echoed. Based on feedback from participants on the value of provider-based information, it is clear that nurses at bedside and in outpatient settings are seen as primary sources of both information *about* the disease (i.e. disease-specific content), as well as information about *how to live* with the disease.

Participants also expressed feelings of fear, anxiety stress related to diagnosis and treatment, which echoed themes from prior research (Altiok et al., 2015; Clarkesmith et al., 2017; McCabe et al., 2011) and were perpetuated by a lack of knowledge about onset, symptoms and medication prognosis. Research with HF patients has suggested that these emotional reactions can both hinder and promote self-care—they can lead to maladaptive coping, but also to increased vigilance and adherence (Harkness et al., 2015). Notably, participants cited the media as a potential source of negative emotional reactions. As anxiety and depression symptoms have been

associated with lower quality of life in those with AF (Akintade et al., 2015), it is important that these fears and concerns be addressed. Here, input from cardiology nurses may be critical, as participants emphasized the importance of receiving accurate education and reassurance from trusted sources, such as a doctor or provider-mediated support group, as a way to mitigate these negative feelings (Altiok et al., 2015; Clarkesmith et al., 2017). Nurses at the bedside and in outpatient settings should be cued into patients' negative emotional reactions (including any stated symptoms of anxiety or depression) and develop referral protocols for patients who may need additional psychological support. Such referrals may be critical to effective coordination of care.

Participants expressed varying levels of satisfaction with their individual providers and the healthcare system expressed similar needs as patients in previous studies, such as the importance of receiving consistent care and information, getting quality time to establish trust with their provider being included in decision-making (Borg Xuereb et al., 2012; Neubeck et al., 2018). Patient attitudes towards treatment are greatly influenced by their provider (Altiok et al., 2015; Clarkesmith et al., 2017; Crivera et al., 2016), as reflected in our participant comments. While not all participants worked with their provider to discuss concerns or compare types of OACs, those who did appreciated having a role in the decision-making process. With newer anticoagulants that do not require frequent checkups, patient-provider communication and shared decision-making is even more crucial (Maikranz et al., 2017). Our participants voiced concerns about side effects, not having antidotes or knowing long-term outcomes for newer DOACs and being unsure how to take their medication correctly (i.e. how to store it, when to take it, whether to take it with food drug interactions). These uncertainties contributed to condition-related anxiety and would probably be mitigated by education and reassurance from a trusted, reliable source, such as outpatient nursing staff or cardiologists. Interestingly, participants had varying thoughts and opinions on medication adherence, but almost all believed it was ultimately their responsibility. However, participants also posited medication adherence could be improved by providers asking more direct questions about medication-taking behaviours, as well as fully explaining the purpose of the medication and detailing the regimen.

With regard to specific ways self-care content could be delivered, patients noted that high-level medical terminology was a barrier to their understanding, demonstrating the importance of including patients in the design of such content. Additionally, patients emphasized that, just as too little information was problematic, receiving too much information at once was uncondusive to memory and only added to the stress of their diagnosis. The timing of this information also appeared to be critical. Participants suggested that follow-up education from their provider would be beneficial to allow more time to absorb and understand new concepts. This re-education approach is not new; a previous study demonstrated that a complex education intervention increased AF patients' knowledge of their condition at both 12 and 24 months (Taitel, Mu, Gooptu, & Lou, 2017). In our own pilot work, we found that both AF knowledge

and OAC adherence could be increased by the use of tailored digital education through the electronic health record (Chen et al., 2017). Though participants in this study suggested tailoring precise timing to the individual for maximum effectiveness, many agreed it would be helpful to initially receive more frequent follow-ups for a short period of time immediately after diagnosis (i.e. several months), especially when prescribed a medication they were unfamiliar with, highlighting the value in considering the individual's stage of AF management for continual health education follow-up (i.e. newly diagnosed, new medication, new comorbidity). Emergency room and outpatient clinic nurse managers may consider devising both automated and tailored messaging for AF patients, to be delivered through the patient health portal with regular frequency right after diagnosis and after critical changes to a patient's treatment plan. Then, outpatient nurses could establish a continued care protocol that includes answering patient questions through the portal, which may help to improve patient-provider communication during office visits.

Participant preferences for delivery of self-care education and reminders varied, demonstrating the need to not only tailor content to the individual but also tailor the way the content is presented. While some participants felt postal mail, phone calls paper handouts were most convenient, others preferred smartphone applications, electronic PHR portals the Internet many emphasized that different methods were appropriate for different types of content. They generally rated their computer literacy as adequate, but the age group most affected by AF (65+) contains a wide range of technological capabilities. However, prior research has demonstrated effectiveness in using a computerized PHR to deliver messaging to AF patients that increases knowledge and adherence (Chen et al., 2017), as well as that, although older patients rate their computer literacy lower, they may be more likely to actively use electronic methods of monitoring their health once they are introduced and trained on how to use them (ToscOS et al., 2016). Our participants' current device use (i.e. computers, smartphones) represents an opportunity to use technology to deliver education and alerts. Targeted refill reminder calls or text message reminders have increased refill rate and proportion of days covered in previous studies (Treskes, Van der Velde, Schoones, & Schallij, 2018) recent research has shown telemonitoring to be effective in maintaining high adherence to DOACs (Desteghe et al., 2018; Marquez-Contreras et al., 2018). Therefore, nurses in the outpatient setting may consider creating tailored reminders for patients, delivered via their preferred methods (i.e. paper or through the electronic health record).

Though our study both reaffirms findings from previous studies and provides a current look into an issue that was identified a decade ago and has yet to be sufficiently addressed, there are some limitations to consider. When coding, we did not calculate inter-rater reliability, although we did collaborate and compare coding to ensure that team members were in agreement. Additionally, although our focus groups were generally representative of the AF patient population of the hospital system, they were small, particularly Group 2 and limited in ethnic diversity compared with the US population

TABLE 5 Emergent themes of focus group discussion, information needs and practice recommendations

Main theme	Subtheme	Exemplary quotes	Participant information needs	Practice recommendations
1. Content	a. Atrial fibrillation and stroke symptoms	<p>"I'm still not sure what the total condition [is]. It's very vague to me." (p7)</p> <p>"Still today I don't know what causes it." (p3)</p> <p>"How do you know if you're in Afib?" (s6)</p> <p>"What's a TIA?" (p1)</p> <p>"I don't know what a stroke is." (p4)</p>	<ul style="list-style-type: none"> • NVAf causes, symptoms, detection, treatment, risk factors and prevention • Stroke or transient ischaemic attack (TIAs) education 	<ul style="list-style-type: none"> • Give more detailed and more frequent (at each follow-up appointment) patient education on AF and strokes • Ask AF knowledge questions to patient at follow-up (e.g. "Could you explain AF to me? Or could you explain a TIA or stroke to me?"). Record if they answer correctly and give further explanations if they do not
	b. Dietary and activity restrictions	<p>"I thought it would be helpful to know if I should reduce activity. There was no indication, I was just sent home." (p7)</p> <p>"I have a son who swears that nutrition is key and nobody seems to talk about that." (p7)</p> <p>"You want to know what your limitations are. And if there are no limitations, you want to know that too." (p7)</p>	<ul style="list-style-type: none"> • Impact of NVAf on activity, weight, diet, nutrition • General information on diet, nutrition and vitamins/supplements • Alcohol and caffeine consumption • The meaning of "normal" exercise • Debilitating factors of NVAf (effect on day-to-day life), reassurance from providers 	<ul style="list-style-type: none"> • Give bedside or outpatient education (e.g. flyers, messaging portals, videos or conversations) on "dos and don'ts" of diet and activity
	c. Treatment plan/ medication	<p>"I found myself on Eliquis[®] without any information at all, and the nurse practitioner reinforced the fact that it had to be 12 hr apart." (p6)</p> <p>"On the blood thinners, does that make anybody tired, really tired or is that the effect of the medication to regulate your heart?" (p5)</p> <p>"...it's kind of scary to take a new medication and not know the long-term results." (p10)</p> <p>"There's some [medication] that you just don't want to take after listening to the commercials." (s3)</p>	<ul style="list-style-type: none"> • Instructions for use, interactions, side effects • Comparison of OACs • How medication works and its importance • Risks with non-adherence or abruptly stopping • Individual stroke risk • How to manage with comorbidities and other medications • Insurance/cost 	<ul style="list-style-type: none"> • Build inventory of resources for different drugs/treatment plans, including external web sources or common FAQs for all drugs and/or types of drugs
			Participant preferences	
2. Delivery	a. Source of information	<p>"I was really impressed when I was in the hospital. One of the nurses, he went and he printed me off all kinds of information and gave it to me to read." (p5)</p> <p>"I think trust with your doctor is very important because if you don't trust the doctor you're not going to trust the medication that you're on or the health advice that they give." (p10)</p> <p>"Some type of support group to help reassure [people] that they aren't the only ones that have it...you learn how common it is." (p7)</p>	<ul style="list-style-type: none"> • Physician, nurse (practitioner), caregiver, pharmacist—trusted source • Family, friends, peers • Internet, commercials • Insurance company 	<ul style="list-style-type: none"> • Create practice or health system-specific electronic resources, like videos or bulk emails to communicate (and reiterate) important treatment information

(Continues)

TABLE 5 (Continued)

		Participant preferences	
	b. Delivery mechanism	<p>“That [older] age bracket doesn't always go on the computer. They don't check email...that age group didn't grow up with computers and stuff...they're not used to computers.” (s3)</p> <p>“[MyChart] is a nice little tool but a lot of the doctors are not in it...like neurology group over here is huge [but] they're not a part of [Epic] so none of my stuff is on [MyChart].” (p9)</p> <p>“[My app] shows me my color of my pill, when to take it, if I have taken it, if I missed it.” (p5)</p>	<ul style="list-style-type: none"> • Phone call (<i>immediate response</i>) • Online health record portal message (<i>non-immediate</i>) • Smartphone apps and alarms • Tablet/computer apps • Internet • Email • Text message • Mail • Paper handout <ul style="list-style-type: none"> • Use electronic and non-electronic methods to deliver information so that patients who do not use technology will still receive regular information
	c. Presentation	<p>“The thing that I noticed was that one time I'll be getting some information but the next time I was getting different [information]. It seemed to be a little contradicting, which left me a little confused at times.” (p7)</p> <p>“... You can accept something better if you understand it.” (s3)</p> <p>“I guess I don't know how you can be the decision maker when you don't understand.” (s1)</p>	<ul style="list-style-type: none"> • Materials to reference outside of physician's office • Consistent information across sources • Lay terminology and explanations for medical terminology • Condensed volume of information <ul style="list-style-type: none"> • Use lay terminology and consistent information on all printed and word-of-mouth instructions and informational material
3. Timing	a. Follow-up	<p>“I don't want someone calling me all the time... ask [patients] if they want to be contacted and they [will] let you know.” (p7)</p>	<ul style="list-style-type: none"> • Preferences varied for timeline of follow-up contact from medical professional • One year between visits with no follow-up is too long • Monthly may be too frequent • Three-month postdiagnosis follow-up ideal for NVAF management <ul style="list-style-type: none"> • Follow-up with patients every 3 months and ask them if new questions arose. For non-emergency questions, advise them to keep a notebook with their questions for 3-month follow-ups
	b. Educational information	<p>“I think we've been able to absorb it better now [during the focus group]. Because when it first happens you're scared, your confrontation [guard] is up...so four or five months down the road it seems like this right here [today], you're absorbing more of it.” (s3)</p> <p>“Well you see when I first found out about [my AF diagnosis] I got a whole pamphlet that just told me about AF and what to expect, what to look for and that sort of thing so that was very helpful. It was all put in [a] folder along with my Coumadin® [information sheet] you know so that was very informational and again I can refer back to that a million times if I had question[s] at a later time. I didn't have to call the doctor; it was right there.” (p10)</p>	<ul style="list-style-type: none"> • Need to know basics at time of diagnosis • Reinforce and give more detailed information at follow-up—not too much at once <ul style="list-style-type: none"> • Give basic instructions at diagnosis, but supplement with additional materials for them to read at home • Each follow-up appointment could focus on a specific content area for education (e.g. first could cover treatment plan and medications; second could cover diet and activity, etc.)
	c. Answers to questions	<p>“I really did not feel like I got an explanation. They kept saying do you have any questions. I don't know what questions to ask. And so...I still feel like I'm in the dark [about] what is going on.” (p1)</p> <p>“I would have liked somebody that sat down and said 'this is what your test results mean.’” (p7)</p> <p>“It would have been nice if they had gone through the different blood thinner [medications].” (p6)</p>	<ul style="list-style-type: none"> • Phone call (<i>urgent questions</i>) • Asynchronous messaging • (<i>non-urgent questions</i>) • All questions addressed in appropriately timely manner to alleviate stress <ul style="list-style-type: none"> • At diagnosis, give patients with a flyer (both printed and virtual) containing examples of urgent and non-urgent questions. Instruct them on mechanisms for addressing both, including phone calls to clinic for urgent questions and messaging via a patient portal for non-urgent questions (or writing them down for follow-ups)

Abbreviation: NVAF, non-valvular atrial fibrillation; OAC, oral anticoagulant.

as a whole. The small homogeneous groups could have restricted the range of views expressed, which potentially limits the generalizability of the results. Additionally, the AF Knowledge Scale had several questions that were overwhelmingly missed by participants and may have been worded confusingly (e.g. question 2, missed by 60% of patients, required them to choose “severe consequences of the arrhythmia” over “heart attack or sudden death” for what OACs prevent; someone with AF could experience the latter as a result of a blood clot as well). This scale has been translated from its original language and was not found to be highly reliable by its creators (Hendriks et al., 2013; $\alpha = 0.58$). However, the patients reported gaps in knowledge within the focus groups as well, which suggest that some patients may have little knowledge about AF as a disease.

Overall, our results mirrored those of McCabe et al., (2011) indicating that, although the need for further education and emotional support among AF patients has been previously identified, knowledge gaps and psychological distress persist. Many patients diagnosed with AF are not at optimal levels of engagement in their care and feel they either do not receive enough education from their healthcare provider, or that the timing or delivery method is not conducive to their comprehension or retention. To compensate for these knowledge gaps and mitigate related anxiety, patients and support persons seek out other sources, looking for information they can easily understand and are able to access at preferred locations and times to enhance their self-care practices. However, they also may consume media that creates additional anxiety about their medication they desire reassurance from someone they trust; PHRs can be leveraged to mitigate these concerns by delivering information that patients can access at any time, directly from a trusted source, but with limited strain on clinical resources. Our prior research (Toscos et al., 2016) indicates that this population is open to the use of PHRs and future research should consider preferences from patients when designing tailored interventions.

Patients want a convenient manner of asking healthcare professionals questions about their condition and to be given information on a level they understand. Not receiving adequate education can adversely affect a patient's perceptions of health and their relationship with their healthcare provider, which, in turn, may negatively influence ability and interest in self-care. Follow-up education between office visits may improve AF patients' knowledge of their condition and need for OAC adherence—potentially preventing costly emergency room visits and the damaging effects of stroke. A tailored PHR intervention may offer a means to extend patient education beyond the face-to-face patient-provider interactions in the office.

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AUTHOR CONTRIBUTIONS

All authors have contributed substantively to this manuscript, providing help with study conceptualization, data analysis and interpretation/or drafting and editing the manuscript.

ETHICAL APPROVAL AND CONSENT STATEMENT

This research was approved by the Parkview Health institutional review board. All patients and support persons completed an informed consent form before participating in the focus group.

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