

“Replace uncertainty with information”: Shared decision-making and decision quality surrounding catheter ablation for atrial fibrillation

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Abstract

Introduction: Shared decision-making (SDM) can support patients with atrial fibrillation (AF) to evaluate treatment options for rhythm and symptom control, but studies suggest it is not occurring meaningfully in routine practice. The objective of this study was to measure decision quality and describe decision-making processes among patients and clinicians involved in decision-making around catheter ablation for AF. **Methods:** We conducted a cross-sectional, mixed-methods study guided by a SDM model outlining decision antecedents, processes, and outcomes. Patients and clinicians completed semi-structured interviews about decision-making around ablation, feelings of decision conflict and regret, and preferences for the content, delivery, and format of a hypothetical decision aid for ablation. Patients also completed surveys about demographic characteristics and literacy levels, AF symptoms using the University of Toronto AF Severity Scale (AFSS), and aspects of decision quality using the Controls-Preferences, Decisional Conflict, and Decision Regret scales. Surveys were analyzed using descriptive statistics and qualitative data were analyzed using directed content analysis. **Results:** Fifteen patients (mean age 71.1 ± 8.6 years; 27% female; mean 7.0 [SD 7.0] months since ablation) and five clinicians (three physicians, one NP, and one PA) were recruited. Most patients preferred to either share or relinquish control in medical decision-making to clinicians. For most patients, decisional conflict and regret were low, and symptoms and cardiac health generally improved after ablation. However, they also reported low levels of information and agency in the decision-making process. Most clinicians report routinely providing patients with information and encouraging engagement during consultations. Patients reported preferences for an interactive, web-based decision aid that clearly presents evidence regarding outcomes using data, visualizations, videos, and personalized risk assessments, and is available in multiple languages. **Conclusions:** Disconnects between clinician efforts to provide information and bolster agency and patient experiences of decision-making suggest decision aids may be needed to improve decision quality in practice. Reported experiences with current decision-making practices and preferences for decision aid content, format, and delivery can support the user-centered design and development of a decision aid.

INTRODUCTION

Atrial fibrillation (AF) management remains challenging and recurrence is common even after several treatment modalities (lifestyle changes, medications, and catheter ablation) have been implemented.^{1–3} Patients may continue to report a variety of physical and mental symptoms, including dyspnea, chest pain, fatigue, anxiety, and palpitations, that limit daily functioning and health-related quality of life.^{2,3} Treatment options for AF include medication management and catheter ablation, a minimally invasive, percutaneous procedure to restore and maintain normal sinus rhythm, primarily comprised of antral pulmonary venous isolation.^{4,5} While clinical guidelines recommend ablations as a treatment strategy in certain clinical contexts,

in practice these decisions must be made by assessing procedure risks and benefits.⁶ Prior studies underscore the complexity of this decision choice; the recent Catheter Ablation vs Antiarrhythmic Drug Therapy for Atrial Fibrillation (CABANA) trial randomized controlled trial showed that AF recurred after ablation in 50% of cases, and almost 20% needed a repeat ablation.⁷ Yet, at the same time, AF symptoms^{8,9} and quality of life^{9,10} may independently improve after ablation and other studies have reported that patients feel symptom reduction represents success for an ablation, regardless of the effect on rhythm control.¹¹ Thus, the definition of a successful ablation may vary between patients, and depend on their specific clinical characteristics as well as their values and goals of care.

Shared decision-making (SDM) is the ideal paradigm for exploring the complex risk and benefit choices surrounding ablation to arrive at a high-quality decision. SDM involves a discussion of risks and benefits of treatment options in the context of a patient's values, expectations, and preferences with the goal of selecting a treatment that aligns with these priorities. Decision aids, structured instruments that explicitly describe the decision to be made and present unbiased information about options (including the option of taking no action), help patients become more involved in the SDM process and are demonstrated to improve patient knowledge, engagement, goals-values concordance of decisions, and satisfaction in SDM.¹²

SDM has been strongly encouraged for anticoagulation treatment decisions for AF patients with high stroke risk.^{13,14} Accordingly, a number of decision aids have been developed to support patients deciding on an anticoagulant for stroke prevention.^{15–18} However, SDM around rhythm and symptom control has yet to be explored. In fact, a recent study of nearly 1,000 patients with AF found that only 22% reported participating in SDM to select a rhythm control strategy, and 52% of patients who did not participate in SDM reported that they did not understand different rhythm control options.¹⁹ Moreover, very few decision aids exist to support patients in selecting a rhythm and symptom control strategy.^{20,21}

The objective of this study was to measure decision quality and describe decision-making processes among patients and clinicians involved in decision-making around catheter ablation for AF. The International Patient Decision Aids Standards (IPDAS) has determined that an important first step in developing a decision aid is to characterize patient involvement in the decision-making process and define decision quality.²² Thus, in this paper we report on the initial needs assessment conducted as part of a larger body of work to develop a decision aid for AF rhythm and symptom control.

METHODS

Conceptual model

This project is guided by a tailored version of a published SDM framework²³ (**Figure 1**). This model outlines the constructs necessary to measure decision quality, defined as “the extent to which patients are informed, meaningfully involved in the decision-making process, and receive tests and treatments that reflect their goals and concerns.”²³ The model specifies key stakeholders and processes, which include consultations, care being delivered, and outcomes, with feedback loops relaying evidence about outcomes to inform future decisions. Decision antecedents include characteristics of the patients and caregivers, clinicians, and health system that influence the decision-making process, such as patient health literacy, clinician communication skills, and availability of decision aids in a health system. Relevant factors of the decision-making process include patient sociodemographic characteristics (including preferred language) and literacy levels, level of patient engagement in the consultation, decisional conflict and deliberation processes, the use of decision aids or other resources, and discussions of risks and benefits. After the care is delivered, relevant outcomes relate to the decision specifically (such as decision regret) and to the health outcomes after ablation (in this case, resolution of symptoms and restoration of normal cardiac rhythm).

Study design and eligibility criteria

We conducted a cross-sectional, mixed-methods study with a convenience sample of patients and clinicians from an urban hospital in Queens, New York, that is affiliated with New York Presbyterian Hospital/Weill Cornell Medical Center, a large New York City health system. The hospital cares for a patient population

that is highly diverse with respect to race/ethnicity and primary language, as there are a broad range of immigrant communities living in the surrounding neighborhoods. Eligible patients were age 18 and older and had undergone an ablation at the hospital within the past 18 months; the duration was chosen to reduce recall bias while still including a range of perspectives based on the amount of elapsed time since the ablation. Eligible clinicians included physicians, physician assistants, and nurse practitioners who are involved in the care of patients undergoing AF ablation at the hospital. Patients and clinicians provided verbal informed consent and completed semi-structured interviews. Patients also completed several validated surveys. Patients received \$25 as compensation for their time. The Weill Cornell Medicine Institutional Review Board approved this study.

Measurement

Patients completed surveys about demographic characteristics and literacy levels, AF symptoms, and aspects of decision quality. Patients self-reported age, gender, race, ethnicity, preferred language, marital status, financial resources (“Do you have enough, not enough, or more than enough financial resources to make ends meet?”), educational level, and disability status. Health literacy was assessed using a widely used three-item health literacy screener developed by Chew and colleagues.²⁴ Subjective numeracy was assessed using the three-item Subjective Numeracy Scale developed by McNaughton and colleagues, with scores ranging from 0 to 18 with 18 representing excellent subjective numeracy.²⁵

The University of Toronto AF Severity Scale (AFSS) was used to assess the severity of AF in terms of healthcare utilization, frequency and duration of AF episodes, and symptom severity.²⁶ The AFSS symptom subscale measures the severity of palpitations, shortness of breath at rest, shortness of breath during physical activity, exercise intolerance, fatigue at rest, lightheadedness or dizziness, and chest pain or pressure on a Likert scale of 0 to 5, with 5 being most burdensome. Total scores for the symptom subscale range from 0 to 35.

Surveys relating to aspects of SDM and decision quality included Controls-Preferences, Decisional Conflict, and Decision Regret scales. The Controls-Preferences Scale measures the degree of control an individual wants to assume when decisions are being made about medical treatment.²⁷ Five potential roles ranging from completely relinquishing control to clinicians to completely maintaining control over the decisions. The Decisional Conflict Scale measures the state of uncertainty about a certain treatment choice or course of action.²⁸ It includes 16 items and is reported as a total score reflecting overall decisional conflict and five subscales, all of which range from 0 to 100 with 100 representing extreme uncertainty about the best choice. Subscales include: “informed” about available options, risks, and benefits; “values clarity” about which benefits and risks are most important to an individual; “support” to make a decision with adequate advice but without pressure; “uncertainty” about the best choice for an individual, and perceptions of having made an “effective decision” based on perceptions of information and decision satisfaction. The Decision Regret Scale contains five items measuring distress or remorse after a medical decision.²⁹ Scores range from 0 to 100 with 100 representing high regret.

Data collection

A convenience sample of patients who previously underwent at least one ablation was recruited. A complete list of all patients undergoing ablation in the past 18 months was generated from the electronic health record by the clinical team. A researcher (MRT) contacted patients by phone and invited them to complete a one-time interview. During a phone interview, participants answered open-ended interview questions and questions from validated surveys, which the researcher recorded in the secure survey software, REDCap. A hospital interpreter service was used to facilitate recruitment and data collection with patients whose primary language was not English. A convenience sample of physicians, nurse practitioners (NPs), and physician assistants (PAs) working in electrophysiology at the hospital were invited to participate by email. Clinicians who agreed to participate joined a video conference in which they answered open-ended interview questions. Participants were recruited until theoretical saturation was reached.

One interviewer (MRT) conducted audio-recorded interviews with patients and clinicians over the phone or

via video conference and took corresponding field notes. The interviewer followed a semi-structured interview guide which included topics structured by the adapted SDM framework. Participants were asked about their experiences with AF, general preferences when approaching medical decision-making, and aspects of the process of deciding to have an ablation including information provided, feelings of conflict and regret, and level of involvement of patients, caregivers, and clinicians. Participants also described preferences for the content, delivery, and format of a hypothetical decision aid for ablation. Different versions of the interview guide were used for patient and clinician participants, and the guide was iteratively refined as new themes emerged during data analysis. All sessions lasted 30-45 minutes, and were audio recorded and transcribed verbatim using a secure transcription service.

Data analysis

Survey responses were summarized using descriptive statistics of frequency, mean, and central tendency using R statistical software.

A directed, emergent content analysis approach was used to analyze qualitative interview transcripts. In directed content analysis, qualitative themes are related to constructs from a theoretical model or framework; themes that are relevant but fall outside the pre-defined set of constructs are also identified and reported.³⁰ Two researchers (MRT and SM) developed an initial codebook based on the interview guide, structured by the adapted SDM framework. Together they analyzed one patient and one clinician interview transcript each and discussed the application of codes until consensus was reached, refining the codebook as needed for clarity. The researchers independently coded five additional transcripts from four patient interviews and one clinician interview and participated in an inter-rater reliability test to ensure high reliability. The remaining transcripts were coded by one researcher (MRT), and emerging themes were discussed with the other coding research (SM) during weekly meetings.

RESULTS

We present quantitative and qualitative results together, organized by the major components of the adapted SDM framework. Qualitative themes are summarized below and additional illustrative quotes are provided in **Supplemental Table 1**.

Description of the sample

The sample consisted of 5 clinicians (three physicians, one NP, and one PA) and 15 patients, whose demographic characteristics and literacy levels are presented in **Table 1**. Patients' mean age was 71.1 ± 8.6 years, one-third were female, one-third identified as non-White. Nearly one-quarter of participants did not speak English as their primary language, 20% reported inadequate financial resources, half had a high school education or less, and half had inadequate health literacy. The mean subjective numeracy score was moderate (mean score 12.7 ± 4.1), indicating moderate perceived ability to perform mathematical tasks and preference for numerical versus prose information.²⁵ In qualitative interviews, participants who reported high subjective numeracy frequently related it to their professional identities as a "businessperson" or a similar role that involves working with numbers.

The time since ablation ranged from 1 to 18 months (mean 7.0 [SD 7.0] months). Most patients rated their first episode of AF as severe (mean 7.3 ± 2.9 out of 10), 40% had a prior cardioversion, and 33% had a prior ablation to treat AF. In the past year, half had gone to the emergency room or the hospital and almost all (93%) had seen a cardiologist for AF. Prior to an ablation, patient symptom severity ranged from "barely noticeable" to extremely severe, with symptomatic patients reporting a wide range of symptoms. Most patients described long histories of trialing multiple medications and interventions (including cardioversions and previous ablations) to treat AF, which was a major source of anxiety and hardship. One patient stated that "*AFib was harder for me to get over than cancer.*" -Patient 6. Others described the burden that paroxysmal AF symptoms, which may come and go with little warning, had on their mental health before the ablation: "*I felt like it was a sword hanging over my head. I never knew when I would start to feel AFib, whether it was going to pass in an hour, whether it was not going to pass in an hour. And it made me more*

anxious. And it was anticipatory anxiety that I had.” -Patient 2.

Decision Antecedents

Controls-Preferences

Figure 2 displays the results of the Controls-Preferences Scale. While preferences varied, most participants preferred to either share control or relinquish some or all control to clinicians when making medical decisions. Four patients (27%) reported wanting to mostly keep control, which the creators of the scale state is the ideal place for a patient in order to promote agency in decision-making. Qualitative results suggested that patients with a family member with medical expertise felt able to take more control in the decision-making process, but overall they reinforced predominant preferences to either share or relinquish control with clinicians. For instance, one patient stated: *“Once I am in the hospital, once I have problems, I don’t make decisions for myself. I listen to the doctor, whatever the doctor says. The doctor gives me the way to treat a problem, treat my heart problem. And they are experts. I have no way to say. So I don’t make the decision. They make the decision. And all I do is just sign the paper. That’s all.” -Patient 4*

Clinician communication styles

PAs, NPs, and physicians described having different roles in the care of patients undergoing ablation. Physicians conducted the pre-ablation consults and had the most experience discussing AF and catheter ablations with patients. They aimed to be thorough and provide as much information as possible, encouraged patients to take time making decisions, and involved caregivers when possible. They described occasionally using literature and educational resources in the consults but acknowledged the need to involve different types of resources to support patients with decision-making. All described taking a shared decision-making approach to these conversations: *“I allow them to decide what they need; and I help them figure that out. So, even if I think the ablation is right, I don’t really find myself saying you need an ablation or you need to do this. What I do is I try to just let them reach their own conclusion... empowering them to make their own decisions.” -Clinician 4.*

Organizational characteristics and resources

Clinicians described the patient population served by the hospital as being extremely diverse with respect to racial/ethnic groups and language spoken; many patients immigrated from other countries. They also described challenges communicating with the medical practices affiliated with the health system, which tended to be independent with few shared resources or communication channels. Some patients recalled receiving pamphlets or brochures from the hospital but could not remember details, and clinicians reported that there were no specific materials that were routinely provided to patients considering or undergoing ablation.

Family and caregiver involvement

About half of patients described bringing a spouse or child to the ablation consultation appointment and discussing treatment options with family members. Clinicians noted this was most often the case for older patients.

Decision-making processes

Information and support

Risks and benefits of treatment options were a main focal point of the information provided during consultations. Clinicians describe giving very detailed information using statistics and evidence about how the procedure works and its risks and benefits: *“I actually go through all the complications. I tell them the percentage... I never miss those details... Because I don’t want them to be surprised.” -Clinician 5.* However, they also acknowledge that patients struggle to retain most of the information they receive: *“I’m pretty sure they’re not absorbing most of what I’m saying. There are some who try; and there are many who say... I’m not sure what’s going on, but I know you—we’ve been together—I trust you, so, let’s do this.” - Clinician 4.*

Most patients report having a vague understanding of what ablations entail but did not understand the details, and most were aware that AF could recur after ablation but did not recall the specific risks of the procedure. Many patients recalled a discussion about the risks of staying on medications, which was a major reason for having the ablation, but some had expectations about being able to discontinue both antiarrhythmic and anticoagulant medications after the ablation that they now report were unrealistic: *“I was aware of the operation, and it’s not such a big deal, and the success rate is like 95% positive... I was just hopeful that maybe I could get off of the Eliquis and maybe a couple of other medications. But, it didn’t happen. But, it might happen later, who knows.”* -Patient 6.

Patient agency

Many patients did not perceive themselves to have agency in the decision-making process and were eager to accept their doctor’s recommendation because they did not view themselves as the experts. Some felt more comfortable placing control in the hands of physicians, family members, and other sources of power (i.e., God): *“[I ask] no questions. Yes, the doctor told me everything. I follow him. They [my son and doctor] just talked about it; didn’t share anything. The doctor told my son, he told me everything... and I believe to God... God knows better.”* -Patient 7.

Clinicians described a mix of patients who are more engaged and involved in the process and those who are more passive; providers perceived low health literacy and feelings of being overwhelmed as primary reasons for less engagement: *“It depends on the patients. Some people, they are more inquiring. So they ask questions and they engage with the conversation, and they ask a lot of questions along the way. But again, a lot of patients, they might be overwhelmed with the conversation. So they may not ask questions right away.”* -Clinician 5.

They reported that elderly patients often have less agency in these decisions as children make medical decisions for them. All clinicians generally encouraged more patient agency in the decision-making process; they reported encouraging them to ask questions and framing options in terms of both the evidence and personal goals.

Decisional conflict

Overall levels of decisional conflict were low; the total DCS score was 13.3 (SD 17.8) out of 100. The informed subscale of the DCS was the highest at 20.2 (SD 30.8) indicating lower levels of perceived information in the decision-making process (**Table 2**). Qualitative data also supported generally low feelings of decision conflict about having an ablation, but patients who described low conflict also described limited agency in the decision-making process: *“Very easy [decision]. I don’t have a hard time making decisions. That decision, whatever the doctor gives me as advice, that’s my decision.”* -Patient 4. Other patients who took a more active role in decision-making reported wanting more time to do research on ablation and carefully consider risks and benefits. The greatest source of decisional conflict for patients was fear of serious complications and difficulties quantifying risks associated with the ablation. However for many patients, the decision to have an ablation was driven by symptom burden; when symptoms became unbearable or uncontrolled by medications, they felt ablations were the clear next step for them: *“I went through [the symptoms] for a number of months before it. But then I decided to go ahead with the ablation... I went to the ER [twice]. And I just began realizing that I wasn’t going to choose to live like this.”* -Patient 2.

Clinicians agreed that symptoms drive decision-making. They reported difficulties encouraging asymptomatic patients who had uncontrolled AF to consider ablations compared to symptomatic patients: *“For the patient who’s symptomatic, I think they’re much more open to getting treatment because they’re looking for relief... And whether they understand the health benefits or not, it doesn’t seem to be that important in what they decide to do because they just want to feel better. Whereas the patient who has no symptoms but, you know, has a very uncontrolled rhythm, there may be a non-significant risk of danger. And sometimes it’s much more difficult convincing them they need treatment, whether it’s ablation or otherwise, because they feel okay.”* -Clinician 4.

Educational resources and decision aids

None of the patients described using a decision aid to guide their decision to undergo ablation, but some recalled receiving educational materials from their physicians. Many proactively sought educational materials online before or after their consultation. Clinicians reported variable practices in providing online educational resources to patients considering ablation; one chose to share it with patients they thought would be most receptive to the information, others wished they shared it with everyone but struggled to routinely incorporate the materials into their consultations. Additional barriers included language, as most materials were only available in English, and comprehensibility to patients with low literacy levels.

Technology use in decision-making

Many patients described using technology to research AF and treatment options, many times with the help of more tech-savvy family members. Many patients described preferring to access educational materials on a webpage through a tablet, such as an iPad, instead of through a mobile app. Three patients described using a wearable device to monitor cardiac rhythm, which provided information about their status that helped them decide to have an ablation and evaluate postoperative recovery. Clinicians acknowledged that older adults and those with limited English proficiency may struggle to access the currently available online health resources and often need the help of family members.

Decision outcomes

Health and symptom outcomes

Patients reported high post-ablation quality of life (mean 7.3 [SD 2.0] out of 10) and low symptom burden on the AFSS (**Table 3**). Patients described feeling well post-ablation, but some struggled to quantify changes in cardiac rhythm, symptoms and quality of life without a tool to help them objectively measure: *“I even forgot almost how my status was before the ablation. And I feel comfortable now. And when you are okay, you forget when you were not okay.”* -Patient 10. One-third of patients reported having AF recurrence post-ablation, which aligns with the estimates clinicians in this study gave of the overall success rate in their practice. Clinicians report that patients begin to reframe their view of ablations if the initial ablation is unsuccessful and a repeat ablation may be needed: *“You’re always going to have a handful who have a recurrence, and then they’re upset that they have to possibly have another ablation. . . Those are the ones who say, ‘Why did I even bother doing this?’ or ‘How many ablations can I get? Is this even okay to have so many ablations?’”* -Clinician 3.

Match between treatment and goals

Nearly all patients described having one of two goals for the ablation: symptom treatment and antiarrhythmic medication discontinuation. Clinicians agreed these were the two most common goals. Many patients described wanting *“to get back to my normal life, doing what I was doing.”* -Patient 1. Most patients and clinicians agreed ablations helped them achieve these goals most of the time, although medication discontinuation post-ablation was often more nuanced and unpredictable than patients appreciated. One patient stated: *“I’m not real big on pill taking. It is one of the reasons why I got the ablation done. But, that didn’t happen. He said we’ll see what happens, especially with the blood thinner. I’m still on that two times a day.”* -Patient 6.

Decision regret

Very few patients reported decision regret, and the mean decision regret score was 12.0 (SD 28.0) out of 100 (**Table 3**). However, one patient and most of the clinicians observed the challenges evaluating regret without knowledge of the counterfactual, i.e., what might have happened if they had waited and continued with medication management. They also acknowledged the need to evaluate ablation outcomes over a long window of time, as symptom and/or AF recurrence may happen months or years post-ablation. Clinicians felt symptom resolution drove perceptions that ablations were successful, especially when patients had endured multiple trials of different medications to treat symptoms: *“I think there’s a lot of relief; they’ve taken that*

last step. You know, we've been building up to it for weeks or months, or maybe even years in some cases; and they're extremely relieved that the hurdle is behind them. . . Are there people who feel symptoms again? For sure, but it seems like it's really—that's the infrequent case; and the frequent cases, they do feel better.” -Clinician 4.

Opportunities for improved decision quality

Participants provided recommendations for the content, format, and delivery of a decision aid focused on AF ablation, summarized in **Table 4**.

Desired decision aid content

Patients and clinicians alike suggested including an explanation of AF, how an ablation treats it, and the risks and benefits of ablation. Some patients also felt it was important to improve other patients' confidence in the procedure; testimonials were a commonly suggested strategy for communicating information and improving confidence. They noted the emotional power of testimonials: “I think people prefer hearing testimony from people that had it done. I think it's more persuasive to another client than reading a pamphlet because people actually see where this thing works for someone else. Usually if it works for someone else, you'll take a shot hoping it works for you.” -Patient 8.

Patients also wanted decision aids to help them quantify the possible outcomes of ablation and personalize the likelihood of outcomes based on personal characteristics: “Each person is unique. The idea is to replace some of the uncertainty with a little bit more information and possibilities. So if I hadn't had the procedure, the lingering thought would be should I have done this, and how would I be if I had this?” -Patient 13.

Decision aid format and delivery

The majority of patients and clinicians favor a web-based decision aid but acknowledged that paper options are important for those who are less tech-savvy. Several patients and clinicians suggested incorporating videos into the decision aid as an easily digestible platform to deliver information. Patients and clinicians wanted clear, concise data about outcomes, risks, and benefits: “I think people respond better not to vague [statements]. You can say risks, and bullet point them. . . pros and cons. If you give somebody; ‘We use this drug and it works in X number of cases. We know this is 70% effective. You might have some side effects. The side effects are. . .’ I think if you give people the information. I'm telling you, bullet points, one-line sentences or two-line sentences.” -Patient 2. Most also supported using visualizations whenever possible to reinforce clinician explanations and to contextualize data. About half of patients and clinicians felt the decision aid would be most useful prior to a consultation to prime patients for the conversation, while the other half favored viewing it after to reinforce the discussion: “After the appointment. . . I don't want to go on the website without. . . I needed to know what it was. I didn't even know how to pronounce the word properly, ablation.” -Patient 1. Finally, patients and clinicians felt translations to multiple languages were critical for accessibility among limited-English proficiency patients.

DISCUSSION

This is one of the first studies to report on SDM experiences around AF ablation, perceptions of decision quality, and opportunities to improve quality from the perspective of patients who have undergone ablation and clinicians routinely involved in decision-making and care surrounding AF ablation. Participants reported generally high perceptions of decision quality and low decision regret. However, quantitative and qualitative data also illustrated gaps in information, patient agency, and alignment of goals in the decision-making process. Although clinicians verbally provided information, occasionally complemented by written information and articles, and encouraged patient engagement during consultations, patients and clinicians alike acknowledged the need for information resources and decision aids in more accessible, digestible formats. Moreover, the study highlighted gaps between patient goals and realistic expectations following an ablation; specifically, many patients hoped to be able to discontinue all medications post-ablation, but clinicians supported that in most cases anticoagulants and other medications may need to continue. Together, these findings highlight

the need for a decision aid surrounding AF ablation. Towards this end, we also reported on the preferred content, format, and delivery of a decision aid focused on AF ablation suggested by participants.

Decision aids are intended to help translate information about the likelihood of different health outcomes for different patient populations, as well as the goals and subjective experiences of patients, in ways that are accessible in routine care; the goal is to provide informed and patient-centered decisions.²³ Importantly, decision aids support (but do not replace) the patient-provider relationship. Decision aids objectively improve patient knowledge and agency in decision-making, as well as patient feelings of being informed, particularly when they include detailed information.³¹ IPDAS is a widely recognized set of standards for developing decision aids that emphasize the importance of understanding patient and other stakeholder needs and preferences. However, a recent systematic review found that only half of the studies describing decision aid development included end users in efforts to understand the problem, and only one-third included end users in prototyping and redesign.³²

To ensure decision aids are usable and useful for end users, IPDAS recommends defining the scope, purpose, and target audience of the decision aid, establishing a steering group of patients and experts, and conducting several rounds of user-centered design activities including prototyping, testing, and redesign with end users.³³ An ongoing challenge of user-centered design is balancing end user suggestions with evidence that user-suggested features may actually be counterproductive. For example, participant suggestions to include testimonials in our study run counter to some evidence that testimonials introduce significant bias towards one treatment option over another because decision-making is strongly influenced by self-identification and other emotional experiences.²² Typically, decision aids aim to provide information without persuading, and if included, testimonials need to be carefully selected and balanced to avoid portraying one option more or less favorably than another.

In the context of AF, relatively little attention has been paid to supporting shared decision-making around symptom and rhythm management compared to selecting an anticoagulant. Studies of decision aids for anticoagulant selection show they improved patient satisfaction in treatment decisions, clinician communication and satisfaction, and reduced decision conflict.^{34,35} Prior work focused on anticoagulation may provide useful starting points for shared decision-making in other areas of AF care. Common design elements in anticoagulation decision aids include: (1) consideration of the patient's individual patient risk factors, such as age, sex, and past medical history, (2) predicted risks of events of interest, such as bleeding or stroke, (3) visualizations, especially 100 person icon arrays to portray probabilities of outcomes of interest, (4) and surveys assessing patient values and priorities when choosing a treatment option (i.e. costs, side effects).³⁴⁻³⁷ Most decision aids are web-based, contain interactive visualizations and videos, and include the option to print a decision summary or send it to a clinician or other recipient. Many of these elements were echoed in the suggestions of participants in our study, supporting the inclusion of these elements in future decision aids.

Strengths of this study include alignment with IPDAS recommendations to include end users in understanding the problem space as a first step in decision aid design, as well as the use of standardized scales to objectively measure multiple aspects of decision quality and regret. A limitation of this study is limited generalizability, as this study was conducted with a small convenience sample of patients and clinicians recruited from a single hospital. Of note, the hospital serves a diverse patient population with respect to age, race/ethnicity, and language, which is reflected in our patient sample. Nonetheless, future work should seek to expand the investigation of decision quality surrounding AF ablation in larger, more representative samples of patients, clinicians, and other key stakeholders. These interviews were conducted up to 18 months after the decision, which might have led patients to underestimate the decisional conflict they experienced while making the decision. In addition, we did not interview patients who considered ablation but decided against it. These two limitations together may mean that levels of decisional conflict are substantially higher among patients who are actually encountering this decision.

CONCLUSIONS

High decision quality during consultations for AF ablation is critical to ensure patients, caregivers, and clini-

cians align in their understanding of the appropriate treatment for a specific patient in light of demonstrated benefits and non-trivial risks. In this study we uncovered the need to bolster information and agency among patients considering ablation. Decision aids are a widely used strategy for delivering information in accessible, digestible formats and increasing patient engagement in the decision-making process. Future work can build on the recommendations for the content, format, and delivery of a decision aid focused on AF ablation suggested by participants in this study.

Data availability statement

There are legal and ethical restrictions on data sharing because the Institutional Review Board of Weill Cornell Medicine did not approve public data deposition. The data set used for this study includes sensitive patient information and is subject to federal legislation that limits our ability to disclose it to the public, even after it has been subjected to deidentification techniques. To request the access of the de-identified minimal dataset underlying these findings, interested and qualified researchers should contact the corresponding authors Meghan Reading Turchioe (mjr2011@med.cornell.edu).

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Conflict of interest disclosure

MRT is a consultant for Boston Scientific and is affiliated and has equity ownership in Iris OB Health Inc., New York, a startup company focused on postpartum depression.

Ethics approval statement

This study was approved by the Weill Cornell Medicine Institutional Review Board.

Patient consent statement

Participants provided verbal informed consent prior to participating in this study.

Permission to reproduce material from other sources

Not applicable.

Clinical trial registration

Not applicable – this is not a clinical trial.

Figure 1: Adapted framework of shared decision-making for atrial fibrillation ablation

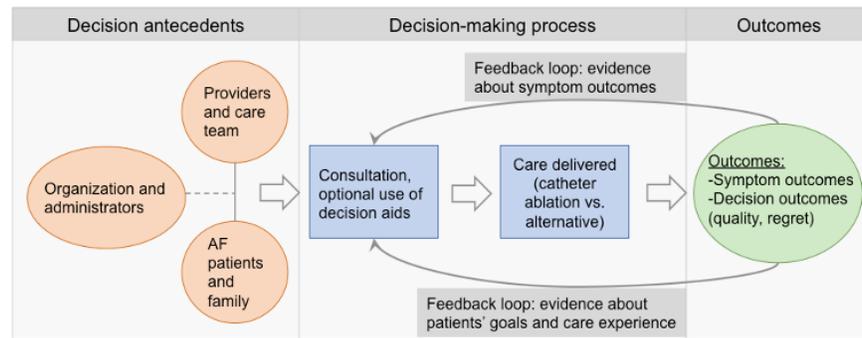


Figure 2: Controls-Preferences among patients (n=15)

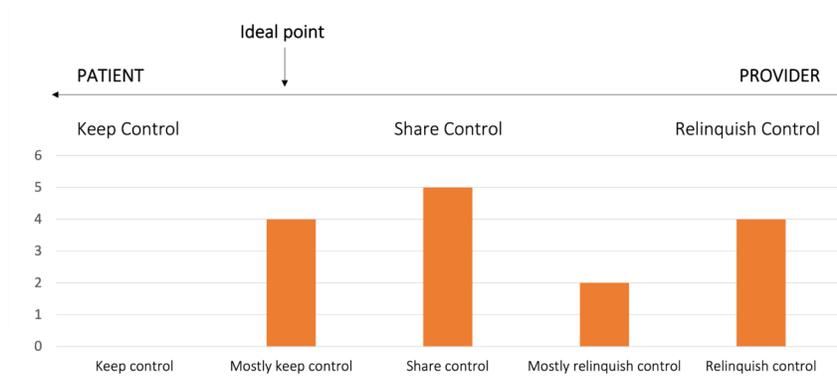


Table 1. Characteristics of patient participants (n=15); mean (SD) or n(%)

Demographic characteristics

- Age
- Gender: Female
- Race: White
- Ethnicity: Hispanic or Latino
- Preferred language: English
- Marital status: Married/ partnered
- Financial resources
- More than enough
- Enough
- Not enough
- Education
- High school or less
- College
- Master's
- Reported disability
- Health insurance
- Medicare
- Medicaid
- Employer-based
- Health literacy: Adequate
- Subjective numeracy

Clinical characteristics

- Time since ablation (months)
- Severity of first AF episode (1-10)
- History of prior cardioversions
- History of prior ablations
- Any ER visits for AF in past year
- Any hospital visits for AF in past year
- Any cardiologist visits for AF in past year

Health literacy was measured using the three-item screener.²⁴ Subjective numeracy was measured using the 3-item Subjective

Table 2. Decisional conflict among patient participants (n=15); mean (SD)

Total score
Uncertainty subscale

Table 2. Decisional conflict among patient participants (n=15); mean (SD)

13.3 (17.8)
11.7 (17.5)

Informed subscale	20.2 (30.8)
Values clarity subscale	16.7 (23.6)
Support subscale	15.0 (17.9)
Effective decision subscale	7.5 (14.6)

Table 3. Clinical and decisional outcomes of patient participants (n=15); mean (SD) or n(%)	Table 3. Clinical and decisional outcomes of patient participants (n=15); mean (SD) or n(%)
Overall quality of life post-ablation (0-10)	7.3 (2.0)
Any AF recurrence post-ablation	5 (33%)
AFSS symptom score	1.6 (3.2)
Any symptoms post-ablation	4 (27%)
Type of symptoms post-ablation	
Palpitations	3 (20%)
SOB at rest	1 (7%)
SOB during activity	2 (13%)
Fatigue during activity	3 (20%)
Fatigue at rest	1 (7%)
Lightheadedness/dizziness	1 (7%)
Chest pain/pressure	1 (7%)
Decision regret	12.0 (28.0)

Table 4. Summary of participant suggestions for content, format, and delivery of an AF ablation decision aid
Content
Description of AF, how the ablation treats it, and risks/benefits Improving patient confidence in the procedure Predicting p

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