Shared Decision Making in Atrial Fibrillation
Where We Are and Where We Should Be Going

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**Case Presentation**

You are seeing Mr Roberts, a 69-year-old retired office manager referred from the emergency department for treatment of atrial fibrillation (AF). He presented the previous night to the emergency department with shortness of breath and palpitations and was found to be in AF with a rapid ventricular response and a heart rate of 140 bpm. He was treated with intravenous diltiazem and spontaneously converted to sinus rhythm. He was then discharged from the emergency department with an outpatient cardiology appointment. He has a background history of hypertension but no other cardiac disease. His only medication is a thiazide diuretic. On questioning, he reports experiencing several episodes of palpitations over the last 2 to 3 years; typically, these are brief and self-limited. His transthoracic echocardiogram, thyroid studies, and electrolytes are all within normal limits. His ECG shows sinus rhythm with no other significant abnormality. His CHADS$_2$ score is 1 and CHA$_2$DS$_2$-Vasc score is 2. He has a family history of gastrointestinal hemorrhage–associated death and is uncomfortable about long-term anticoagulation. Additionally, he is reluctant about taking a daily medication plus his blood pressure pill. How might you present current best practice while ensuring that his treatment program is consistent with his goals, values, and preferences?

**Introduction**

AF is the most common arrhythmia requiring treatment, affecting ≈5 million Americans, with the prevalence expected to double by 2050. AF accounts for more than a third of all hospitalizations for cardiac rhythm disturbances. Hospitalization for AF has risen dramatically over the past 20 years and is projected to continue to rise as the population ages. Importantly, AF is associated with a doubling in patient-matched and adjusted mortality. Atrial fibrillation can range from completely asymptomatic to highly symptomatic and can negatively affect patients’ quality of life if left untreated.

Studies have demonstrated significant gaps in AF patient’s knowledge about their condition, as well as knowledge of the risks and benefits of the treatment they are currently taking for their AF despite their disease being treated for several years. A landmark study in 2007 observed multidisciplinary groups of clinicians and patients discussing AF management and noted that all groups recognized the difficulties in managing the disease, but no group agreed with the other on the optimal way to improve patient care. A meta-synthesis of qualitative studies from 2012 examined the perspectives of both clinicians and patients and found that patients often experienced a paternalistic model of decision making, whereas clinicians involved in these same conversations reported that a shared decision making (SDM) model was used. This discordance has been reported by other studies and indicates that patients wish for more information about their treatment options and that clinician bias and practice style, not patient preferences, influenced the outcome of starting oral anticoagulants. These studies support efforts to personalize the management of AF and demonstrate the current gap in the practice of patient-centered decision making.

The Institute of Medicine included patient-centered care as 1 of 6 key quality domains. One of the most important attributes of patient-centered care is active patient participation in the decision-making process. SDM, described as the pinnacle of patient-centered care, is characterized by patient and clinician partnership, exchange of the clinician’s research evidence and clinical expertise and the patient’s knowledge and experience with the options and their relative pros and cons, joint deliberation considering the pros and cons of each option, and agreement about which treatment to implement.

Early literature on SDM described the model as a “meeting of experts” in which clinicians possess expertise in physiology, disease, and the relevant clinical care research, and patients are experts about themselves and the role that the disease and therapies could have in their lives. These “meetings” provide opportunities for clinicians to inform patients on the medical issues at hand and for patients to educate the clinician on their beliefs, values, and preferences. During these discussions, both parties can deliberate and express their preferences and together agree on a course of action. A common perception among clinicians is that many of their patients prefer not to be involved in decision making but would rather defer to their provider. Evidence from decision aid trials suggests that once patients are engaged in SDM, their preferred style of decision making changes, and regardless of age or sex, patients

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report an interest in SDM during future interactions with their clinician.14,15 This must be distinguished from technical problem solving (e.g., what dose of antiarrhythmic to use), which is best left to those technically trained, that is, clinicians. Charles et al16,17 have described the 4 core components that define an SDM conversation (Table 1). The components in Table 1 represent the bare minimum required for a conversation to constitute SDM; others have proposed additional components for specific circumstances.12,18

SDM involves specific skills, procedures, and tools that fundamentally change the nature of the clinical encounter, promote patient-centered care, and as a result have the potential to improve the quality of care. A 2011 systematic review of decision aids across clinical applications found that SDM improved patient knowledge of treatment options and improved markers of patient comfort with the decision taken.19 To date, the evidence is inconsistent on other consequences of patient engagement such as adherence to therapy, healthcare use, and costs.

AF Treatment Overview

The management of patients with AF includes several steps. The clinician must first determine whether AF is secondary to other causes that are amenable to treatment such as hyperthyroidism or cardiac valve disease. The second step is to assess the impact of AF on the patient’s quality of life and then decide how to mitigate this impact. Furthermore, the clinician must also address the role of thromboembolism prophylaxis. These last 2 major decisions in AF management are highly appropriate for SDM. Although SDM has been studied in thromboembolism prophylaxis, the impact of various treatment options on quality of life has yet to be addressed with SDM. These decisions are iterative and ongoing, given the dynamic nature of AF and its manifestations, the associated comorbidities and their impact on AF and its treatment, and the dynamic nature of patients’ life circumstances. Figure 1 demonstrates a theoretical, SDM-based, ongoing approach to the management of AF.

Cardiology as a field often advances through strong inferences drawn from large, randomized trials, generating practice guidelines using the best available evidence.20 Outcomes are assessed with thousands of patients in multicenter, randomized trials showing the efficacy of one treatment regimen over another (often with regard to survival or major morbidity) while also showing the tradeoffs involved in terms of harms and costs. SDM then becomes a tool to translate this evidence into practice in a patient-centered way, rejecting one-size-fits-all approaches, which are not consistent with the modern conception of evidence-based medicine, which comprises the incorporation of patient context and values or quality of care involving patient-centered care.

SDM: What It Is and What It Is Not

The goal of SDM is to increase the likelihood that patients receive the care they need in a manner consistent with the best available research evidence and their values and preferences. When patients participate in making a decision with their clinician about their medical care, we can assess the quality of this encounter by assessing the quality of the process and the quality of the decision made. The former looks at the patient’s ability to identify that a decision needs to be made, that they are informed about their options, have a clear understanding of their values, and are involved in the final decision. The latter measurement pertains to the alignment of a patient’s stated goals and values with the final decision.21

Medical decisions are made frequently in patients’ lives, and there are many decision-making processes that can be used. Table 2 demonstrates different forms of decision making, including several forms of participatory decision making, and how these differ from SDM.22,23 Clinicians engaged in SDM must present sensible evidence-based options that they are willing to implement, along with the relevant evidence about the pros and cons of these alternatives and their likelihood for consideration and deliberation with the patient. Patients engage in the process to the extent they desire, making explicit their values and preferences and arriving at a consensus decision with their clinician. SDM, like informed consent, is therefore a process, but it differs from informed consent in that the latter involves obtaining permission for a given course of action rather than deciding

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Table 1. Core Components of a SDM Conversation as Described by Charles et al16,17

<table>
<thead>
<tr>
<th>Core Components of SDM</th>
<th>Example Statement</th>
</tr>
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<tbody>
<tr>
<td>Both the clinician and patient are involved (to the extent that they prefer) in the decision making process.</td>
<td>Clinician: “There are a few different treatments that are available to lower your stroke risk from atrial fibrillation. I would like to discuss these options and work with you to see which might be best for you.”</td>
</tr>
<tr>
<td>Information is shared in both directions.</td>
<td>Clinician: “Let me tell you about the available treatments and their side effects, as well as the risks and benefits of each. Please tell me what concerns you most about these treatments.”</td>
</tr>
</tbody>
</table>
| Both parties express their preferences and deliberate about the options. | Clinician: “I would prefer β-blockers first because they are relatively safe and often effective.”  
Patient: “But you told me that I can get tired and there might be some sexual side effects. That really concerns me. I would like to try a calcium channel blocker because it also seems safe and affordable.”  
Clinician: “That would also work to slow down your heart rate and is safe. It might interact with your cholesterol medication, and we may need to change cholesterol drugs. Would you be okay with that?”  
Patient: “I would be; my insurance has a good drug plan, and I think most of the cholesterol drugs would be covered if we had to change it.” |
| A stated treatment decision must be reached (including no treatment as a possibility). | Clinician: “We have agreed that we will treat you initially with a calcium channel blocker, and if this does not work, we will reassess our options and consider another rate-controlling agent, an antiarrhythmic, or possibly ablation.”  
Patient: “That sounds good.” |

SDM indicates shared decision making.
among several possible courses of action. Informed decision making involves patients receiving technical information that they use to then deliberate and make the final decision with no additional clinician input. SDM is most appropriate for decisions in which there are multiple reasonable treatment options and the optimal choice is dictated by the relative value that patients place on the benefits, risks, burdens, and costs associated with each option. This includes situations in which there is high-quality evidence on the options and their relative merits and situations in which that evidence is lacking.

SDM has limitations just as it has strengths. SDM is not useful when there is only one “right answer” or one option among others that is clearly superior on the basis of factors that matter to patients. In these situations, clinicians can use informed consent or motivational interviewing. As bodies of medical evidence grow and our techniques and medications improve, consent or motivational interviewing. As bodies of medical evidence grow and our techniques and medications improve, the optimal choice is dictated by the relative value that patients place on the benefits, risks, burdens, and costs associated with each option. This includes situations in which there is high-quality evidence on the options and their relative merits and situations in which that evidence is lacking.

SDM has limitations just as it has strengths. SDM is not useful when there is only one “right answer” or one option among others that is clearly superior on the basis of factors that matter to patients. In these situations, clinicians can use informed consent or motivational interviewing. As bodies of medical evidence grow and our techniques and medications improve, it is possible for clearly superior techniques and therapies to develop and alter the nature of the conversation between clinicians and patients. It is currently uncertain which treatments for AF are superior and preferable for a given patient. This is a situation ideally suited for SDM.

Even when SDM is ideal, there are some practical challenges for its implementation. Clinicians may lack the disposition, skill, time, or tools to support SDM. AF is associated with a significant complexity of choices and options, each associated with several outcomes, favorable and unfavorable, that patients would value considering in making a choice. In AF, these would include options to achieve rate control (including the atrioventricular nodal ablation with pacemaker placement) or rhythm control (including catheter-based atrial ablation techniques). Ideally, clinicians would share with patients their individualized tailored estimates of risk for adverse outcomes and of the benefit of each option in ways that are clear, respectful, and effective. Presenting this information in an easily understandable manner across a broad range of levels of health literacy is difficult. In decisions as complex as this, decision aids become invaluable tools, and experiences in other disease processes can give us insight into how to design and test a decision aid in AF.

Table 2. Basic Models of Treatment Decision Making

<table>
<thead>
<tr>
<th>Decision-Making Model</th>
<th>Basic Description</th>
<th>Difference from SDM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental</td>
<td>Clinician reviews medical situation and decides on the course of action.</td>
<td>Clinician makes decisions based entirely on the medical situation at hand. There is no involvement of patient values or preferences, only minimal patient participation to satisfy legal requirements for informed consent.</td>
</tr>
<tr>
<td>Clinician as best-agent decision making</td>
<td>Clinician makes decision about treatment course but takes into consideration the patient’s values and preferences.</td>
<td>There is no exchange of preference. Clinician makes the final decision but seeks to understand and incorporate the patient’s values into the decision-making process.</td>
</tr>
<tr>
<td>SDM</td>
<td>Open discussion integrating the medical issues at hand and the patient’s preferences and context to arrive at a course of action. The final decision is made by the patient with clinician collaboration.</td>
<td>Patient acts as a consumer who chooses from the available options. Clinician does not state his or her preference and does not collaborate in the decision-making process.</td>
</tr>
<tr>
<td>Informed decision making</td>
<td>Clinician provides information on all available treatment options to the patient and leaves the final decision completely to the patient without further input.</td>
<td></td>
</tr>
</tbody>
</table>

These are idealized forms of decision making. Often, true clinical interaction falls between these models or moves across them as necessary. The parental model does not require patient participation and thus is appropriate for purely technical or problem-solving decisions. SDM indicates shared decision making.
Decision Aids

Decision aids are tools that facilitate SDM by ensuring a common understanding of the available treatment options and the relative risks and benefits of those options. These tools can help clinicians and their patients deliberate jointly. Decision aids take many forms but often demonstrate statistical information based on current evidence in easy-to-understand pictographs (Figure 2).24–27 Decision aids communicate reliable estimates of the probability of patient-important outcomes such as quality of life, survival, stroke, and life-threatening bleeding, enabling patients to more accurately understand their personal risks when participating in treatment decisions. It is worth noting that these aids are distinct from standard informational materials because they are designed for interactive use to personalize the risk and benefits of various treatment options. Encounter decision aids are a subtype of decision aid designed to be used with the clinician during the patient visit as opposed to before or after the visit. Encounter decision aids are effective in that they facilitate a conversation; because of this, there has been an increasing focus on encounter decision aids in the literature.28

Because personalization of the risks and benefits of treatment is important to facilitate patients making informed decisions, decision aids often use validated scoring systems to assist in the estimation of risk. Well-known examples include the CHADS2 and the CHA2DS2-VASc scores.29 Similar to this individualization of stroke risk in AF, we can also estimate an individual’s risk of hemorrhage while on anticoagulation. The most common validated systems in AF are the HEMORR2HAGES, HAS-BLED, and ATRIA schemes.30,31 These systems can be used to estimate a patient’s risk of significant hemorrhage more accurately than population-based statistics and can be presented to the patient during an encounter, as shown in the example decision aid in Figure 2.

SDM in Symptom Management

Patients with symptomatic AF are faced with a decision on how to manage their palpitations, dyspnea, or fatigue. Symptoms are often highly subjective yet create a significant impact on patients’ quality of life.6 Typically, patients with AF are offered a choice of a rate control or an antiarrhythmic strategy. The first is aimed at preventing rapid heart rates and dyspnea and preserving myocardial function; the second is focused on achieving normal sinus rhythm and entails making a complex decision among medications, cardioversion, cardiac ablation, or a combination. Several large studies have shown the lack of a mortality benefit when comparing an antiarrhythmic drug strategy with a rate control drug strategy.32–35 More recently, evidence demonstrating that percutaneous catheter-based ablation procedures improve quality of life has placed this intervention within the standard of care for AF management.36–38 Its effect on mortality is still under investigation.39,40 Given the lack of mortality benefit between treatment modalities and the subjective nature of AF symptoms, SDM may be an ideal approach to align individual patient preferences with the available treatment options. Unfortunately, this has not been explored or included in any medical literature to date.

SDM in Thromboembolism Prevention

The evidence supporting the benefit of anticoagulation in select patients with AF in mitigating the risk of stroke is strong.41,42 Despite this evidence and the resulting practice guidelines recommending the use of anticoagulants, only 51% of patients with a guideline-based indication for anticoagulation are receiving therapy.43 The current reasons for this gap are not known and are likely multifactorial. Data from the Practice Innovation and Clinical Excellence Registry demonstrated significant interpractice and intrapractice variability, suggesting that there was no clear identifiable cause for this variability.43 All forms of anticoagulation also impart an increased risk of bleeding, including significant gastrointestinal bleeding and intracranial hemorrhage, as well as worsened minor bleeding, on a day-to-day basis. Warfarin as a sole agent can increase the risk of major bleed to 4% per patient-year in some groups (even greater with certain comorbidities and medications), and if a patient is also taking antiplatelet agents, this risk can triple.44 Other options include aspirin and newer anticoagulants (dabigatran, apixaban, and rivaroxaban) that have an efficacy similar to that of warfarin in stroke prevention and a reduced risk of major bleeding (especially intracranial bleeding) now in use.45–48 These agents do not require monitoring.

CHA2DS2-VASc score of 3
HEMORR2HAGES score of 3

<table>
<thead>
<tr>
<th>No anticoagulation</th>
<th>On anticoagulation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>3 people</strong> will have a stroke</td>
<td><strong>1 person</strong> will have a stroke</td>
</tr>
<tr>
<td><strong>97 people</strong> will not have a stroke</td>
<td><strong>2 people</strong> will be saved from having a stroke</td>
</tr>
<tr>
<td><strong>8.5 people</strong> will have a bleed significant enough to require transfusion</td>
<td><strong>99 people</strong> will not have a stroke</td>
</tr>
</tbody>
</table>

Figure 2. Pictogram showing the annual stroke risk of a patient with atrial fibrillation and a CHADS2 score of 3.
of the international normalized ratio or adherence to a special diet, enhancing patients’ convenience compared with warfarin but at increased cost.

SDM with regard to anticoagulation therapy in patients with AF has been explored to some degree in a small, randomized trial.49 This study included 287 patients from the aspirin arm of the Stroke Prevention in Atrial Fibrillation (SPAF) III trial and reported that the use of a decision aid improved patients’ understanding of their disease compared with a standard counseling arm. However, there did not appear to be a significant difference in decisional regret (patient’s feelings of regret or remorse after a healthcare decision) or the rate of changing from aspirin to warfarin between groups.49-51 It is important to note, however, that the group of patients examined were at low risk of stroke according to the SPAF III trial inclusion criteria and had already been using aspirin for at least 2 years. The decision aid in this case was presented as an audio booklet (which did not individualize the bleeding risk) and an interactive worksheet completed before (but used during) the clinical encounter.49,51 More recent SDM studies in AF have reported decreased decisional conflict (the state of uncertainty surrounding a decision, a more accurate measure of the quality of the decision-making process because regret is strongly affected by the outcome the patient experiences, not the communication of the visit), increased patient satisfaction, and a trend toward increased knowledge compared with “traditional counseling” or guideline-based therapies groups, yet the findings have not been consistent.52-56 Table 3 summarizes the evidence from these studies.52-56 However, it is critical to note that with the advent of the novel anticoagulants mentioned above since these studies, the number of options for stroke prevention has more than doubled, making this a far more complex decision.

**Future Studies**

Previous SDM studies in AF have been small and frequently enrolled patients living with AF for some time. Both of these variables will ultimately affect study outcomes and decisions. Further investigation of SDM requires practical, randomized trials of patients facing decisions at the time of diagnosis of AF or when the medical conditions change for both thromboembolism prophylaxis and symptom management in different clinical settings. Existing studies on SDM in cardiology are not powered to assess how SDM and decision aids influence eventual patient choice but focus on intermediate outcomes such as knowledge and decisional comfort. Larger trials could, for example, focus on how decision aid–led conversations contribute to choices of aspirin versus warfarin versus novel anticoagulants. Along with evaluating the efficacy of SDM in this context, it will be important to determine how best to implement SDM in the workflow of clinicians caring for these patients. The best estimates indicate an increase of ≈3 minutes in the average length of the clinical encounter, which is similar to the time spent in SDM in the studies our group has conducted in fast-paced environments such as primary care and the emergency department, as well as specialty settings.14,15,19,57,58 There are insufficient data on SDM for AF in community practices to produce estimates specific to this issue. Larger trials can help assess patient and setting subgroups in which the effect of SDM could be different. Finally, quality-of-care measures for SDM in AF need to be developed and validated so that health systems will value this activity, make it visible, and

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Table 3. Recent Studies Examining SDM in AF Thromboembolism Prophylaxis

<table>
<thead>
<tr>
<th>Author</th>
<th>Journal (Year)</th>
<th>Type</th>
<th>n</th>
<th>Therapy Studied</th>
<th>Primary End Point</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Man-Son-Hing et al49</td>
<td>JAMA (1999)</td>
<td>RCT</td>
<td>287</td>
<td>Audio Decision Aid</td>
<td>Ability to choose therapy, adherence at 6 mo</td>
<td>Slight increase in ability to decide, no difference at 6 mo</td>
</tr>
<tr>
<td>Porterbee et al52</td>
<td>BMJ (2000)</td>
<td>Observational</td>
<td>97</td>
<td>Decisional analysis counseling</td>
<td>Difference between consensus guidelines and patient preference</td>
<td>Significant difference between guidelines and patient preference both for and against starting warfarin</td>
</tr>
<tr>
<td>Man-Son-Hing et al53</td>
<td>Medical Decision Making (2005)</td>
<td>Systematic review</td>
<td>890 (8 studies)</td>
<td>Decision analysis, probability tradeoff assessment, decision aids</td>
<td>Trends in the impact of current SDM modalities to affect the decision to initiate warfarin</td>
<td>Significant variability between patient choice and guideline recommendations to start warfarin in all studies</td>
</tr>
<tr>
<td>McAlister et al54</td>
<td>CMAJ (2005)</td>
<td>RCT</td>
<td>434</td>
<td>Decision aid</td>
<td>Change in proportion of patients on correct therapy based on ACCP recommendations</td>
<td>No change immediately after intervention, 12% improvement at 3 mo; significant improvement in knowledge about AF</td>
</tr>
<tr>
<td>Holbrook et al55</td>
<td>CMAJ (2007)</td>
<td>Randomized trial (no control)</td>
<td>98</td>
<td>Decision aid (various forms)</td>
<td>Change in knowledge about AF and stroke risk</td>
<td>Significant increase in AF knowledge from baseline; demonstrated that unblinding to medicine name resulted in many patients changing their decision</td>
</tr>
<tr>
<td>Thomson et al56</td>
<td>Quality and Safety in Healthcare (2007)</td>
<td>RCT</td>
<td>109</td>
<td>Computerized decision aid</td>
<td>Decisional conflict</td>
<td>Significant decrease in decisional conflict, no change in knowledge or anxiety around decision point; showed a decrease in the number of patients choosing to start warfarin vs control</td>
</tr>
</tbody>
</table>

ACCP indicates American College of Chest Physician; AF, atrial fibrillation; RCT, randomized, controlled trial; and SCM, shared decision making.
hold clinicians accountable for ongoing and continued involvement and support of patients taking part, to the extent that they prefer, in shared treatment decision making.

Important outcome measurements that need to be assessed with the implementation of SDM in AF include patient knowledge about their options, patient participation in deliberations during the visit (consistent with their preference), decisional quality (defined as congruence between the patient’s choice and their values), patient satisfaction with the experience of choice, and clinician visit duration.99 Additionally, assessment of the treatment choice and the associated clinical outcomes, including adherence to therapy, might be important to assess the potential impact on population health and outcomes of a program of SDM in AF.

As is always the case in medicine, knowledge continues to evolve, improving our understanding of AF and its therapies. It will be important in all studies of SDM to incorporate the best possible and most up-to-date evidence in the study. As the knowledge surrounding AF improves, so must clinicians work to improve the quality of their communication of that evidence and their ability to partner with patients to make decisions that reflect their individual preferences using the most up-to-date evidence possible.

Conclusions

SDM characterized by patient participation in clinical decision making is a potentially powerful tool to increase the patient-centered nature of AF management. SDM in AF involves patients and their clinicians actively engaging in the assessment of the risks and benefits of various treatment options for symptom control and stroke prevention and determining which course of action best fits the patient’s circumstances, goals, and preferences. Patients with AF appear uniquely poised to benefit from SDM, given the number of sensible options available; the availability of risk calculators and tools; the importance of patient goals, values, preferences, and context in determining the best treatment decision; and the importance of patient ownership of decisions that require patient action (eg, taking warfarin daily while adhering to a diet and scheduled monitoring of the international normalized ratio). Further work is needed in this area to develop and test the SDM tool set in AF, to expand evidence and tools to assist in decisions about symptomatic control, and to ascertain the extent to which SDM implementation can improve the quality of care and life for patients with this very common disease.

Disclosures

None.

References


Key Words: atrial fibrillation ■ decision making ■ patient-centered care ■ patient education as topic
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