

# The Key Role of Patient as Partner

**T**HE IMPORTANCE of well-informed self-care cannot be overstated for safe management of the patient with chronic atrial fibrillation, in particular for those patients who are prescribed chronic oral anticoagulation. Two strategies that contribute to safe and high quality self-care are patient education and the involvement of the patient in the shared decision-making process. Patient education is a critical underpinning of self-care and of shared decision-making.

In this era where patient-centeredness is a recurring theme, the American Medical Association framed the importance of effective patient education in the organization's 2007 monograph, *Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment* reflecting that "It is neither just, nor fair, to expect a patient to make appropriate health decisions and safely manage his/her care without first understanding the information needed to do so."<sup>1</sup>

## PATIENT EDUCATION

A survey of hospital admissions from 2007-2009 (this predates the availability of novel anticoagulants) demonstrated that 33% of hospital admissions for adverse drug reactions were related to warfarin therapy. While even well-managed anticoagulation therapy may be associated with complications, nearly all hospitalizations involving warfarin (95.1%; 95% CI, 91.7 to 98.4) resulted from unintentional overdoses.<sup>2</sup>

The Joint Commission (TJC) recognized the priority of patient safety strategies around anticoagulation therapy when in 2007, the commission identified "Reduce the likelihood of patient harm associated with the use of anticoagulant therapy" as one of the TJC's national patient safety goals.<sup>3</sup> Further, the provision of education regarding anticoagulant therapy to prescribers, staff,

patients, and families was identified as one of the strategies for safe patient care. TJC actually specifies the requisite components to be included into a comprehensive patient/family education program:

1. The importance of follow-up monitoring
2. Compliance
3. Drug-food interactions
4. The potential for adverse drug reactions and interactions

While drug/food interactions may not be relevant for patients prescribed the newer anticoagulants, no matter what therapeutic option for anticoagulation is chosen, the incorporation of a comprehensive, systematic approach to patient education is a critical safety component for this class of medications. Although the scope of the patient's understanding and participation as an active partner of his/her care is obviously greater with warfarin, patients prescribed dabigatran, rivaroxaban and apixaban also require an appreciation of the importance of long term persistence with therapy, avoidance of leisure and occupational activities that may raise bleeding risk, and the need to inform all providers (including dentists) who participate in his/her care regarding anticoagulation status. Since patients taking dabigatran, rivaroxaban and apixaban are required to interact with the healthcare system less regularly than

those taking warfarin, clinicians may have fewer opportunities to educate and confirm understanding.

Although patient knowledge levels have not always correlated with improved patient adherence, several small studies had demonstrated the relationship between patient education and patient safety. Insufficient patient education was identified as the major predictor of bleeding complications in a study of over 300 (aged >80 years) patients discharged home on chronic oral anticoagulation therapy.<sup>4</sup> Conversely, the safety of anticoagulation therapy in well-informed older adults was shown in a study in which those who reported receiving education from either physician or nurse/pharmacist team had a 60% reduction in risk of serious bleeding events.<sup>5</sup>

A quasi-systematic review of articles published from 1990-2011 appears to confirm that higher levels of patient knowledge result in better anticoagulation control. This same review also highlights that a great majority (between 50% and 80%) of older patients have inadequate knowledge about fundamental aspects of their anticoagulation therapy.<sup>6</sup> Still other studies have revealed surprisingly low knowledge levels among patients with atrial fibrillation, from an understanding about their condition to the benefits and associated risks of their current treatment.<sup>7</sup>

Although anticoagulation education may be provided to most patients in some form, the quality of the information varies, as does the readability. Diamantouros et al. reported the results of a survey to assess the accuracy, comprehensiveness, and reading level of print patient education materials on anticoagulation therapy provided to patients by community pharmacies in Ontario, Canada. In addition to gaps in accuracy and comprehensiveness of content, the findings revealed that the reading level of material provided to patients was at an approximate mean of grade 11.<sup>8</sup> This is concerning in light of what is known about the health literacy levels of Americans. It has been shown in a study of anticoagulation therapy with

warfarin, more than half of patients were unable to comprehend clinical terms at levels beyond grade 8.<sup>9</sup> Studies have shown higher levels of both nonadherence (although not all research confirms this correlation) and bleeding complications in those with low literacy levels.<sup>10</sup>

Issues related to low health literacy and its association with suboptimal adherence and safe patient care are ubiquitous in contemporary patient education literature. The Agency for Healthcare Research and Quality (AHRQ) has defined health literacy as "...the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions."<sup>11</sup>

Literacy levels are known to decline in older adults, no matter the baseline levels at age 65.<sup>12</sup> The National Network of Libraries of Medicine noted the following statistics associated with health literacy in older adults:

- 71% of adults older than age 60 have difficulty using print materials
- 80% have difficulty using documents such as forms or charts
- 68% have difficulty interpreting numbers and performing calculations.<sup>13</sup>

Given the demographic of patients with chronic atrial fibrillation, attention to providing easily understood, plain language patient education material is particularly important. Although there is of course a correlation between years of formal education and health literacy levels, it cannot be assumed that a patient with a college or even graduate level education will understand complex information or be familiar with medical terminology. Experts on effective clinician/patient communication recommend the "universal precautions" approach, that is, communicating with all patients in plain language.

AHRQ has provided a patient education booklet and video, *Blood Thinner Pills: Your Guide to Using Them Safely* (available in both English and Spanish), covering the requisite information for patients on chronic OAT. The piece has been updated to include information about other anticoagulants besides warfarin.<sup>14</sup> Although printed patient education pieces are an important adjunct, face-to-face communication regarding oral anticoagulation remains integral, and is one of the components of the Joint Commission's national patient safety goals. In their 2007 publication, *What Did the Doctor Say?*, the

following evidence-based techniques are recommended for use in the face-to-face encounter<sup>15</sup>:

- Use plain language always
- Use "teach back" and "show back" techniques to assess and ensure patient understanding
- Limit information provided to two or three important points at a time (At this point, before moving on, confirm understanding with teach-back. This has been termed "chunk and check.")
- Use drawings, models or devices to demonstrate points
- Encourage patients to ask questions

It is important for the clinician to introduce the concept of teach-back as a tool with which the clinician is assessing his/her effectiveness in communicating; not a means of testing the learner (patient). An example of such an introduction might be: "I know we have gone over a lot of information this morning. I want to be sure I made clear the three major things you need to remember about this medication. Can you review with me what those are?"

If the patient is unable to name the major point, the clinician would then reinforce the information, possibly stating it in a different or simpler and clearer fashion.

## SHARED DECISION MAKING

Shared Decision Making is a process by which a fully informed patient participates actively in a decision about the treatment of a "preference sensitive condition," that is, one for which there is more than one clinically appropriate treatment option for the condition, each with benefits and drawbacks. The SDM process may involve the use of decision aids, or tools that clarify the decision at hand, provide information about the options and outcomes, and help identify personal values. Interestingly, a paper in the patient education literature reviewing the perspectives of clinicians and patients on decision-making revealed discordance between the two views of the process. While clinicians perceived that patients had been involved in the decision-making process, patients reported experiencing a more paternalistic approach.<sup>16</sup> As the culture of our healthcare systems evolve more deliberately into a more evidence-based, patient-centered approach, it is intuitive that SDM be integrated into plans of care. SDM has been termed "the pinnacle of patient centered care."<sup>17</sup> There are various definitions of

the concept. A definition by the Informed Medical Decisions Foundation, "... a collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences" is helpful in framing SDM for the patient with atrial fibrillation.<sup>18</sup> Descriptions of the SDM model include, at minimum, the following components<sup>19</sup>:

1. Both clinician and patient participate
2. Bidirectional sharing of information
3. Both clinician and patient express preferences and explore options
4. A treatment decision (options include no treatment) is reached.

The SDM process has further been conceptualized as two expert parties meeting to share their perspectives: the clinician as an expert on the disease process, various treatment options with their potential risks and benefits and the patient, as the expert on his own goals, preferences and values. There are actually two touch points in the trajectory of treatment of the patient with atrial fibrillation for which SDM is appropriate for the clinician/AF patient dyad: (1)the evaluation of the impact of AF on quality of life- which will inform treatment options for symptom control, and (2)management of thromboembolic risk.

The options for symptom (fatigue, dyspnea, palpitations) management are complex. Despite their obvious subjectivity, the impact of symptoms associated with AF is quite variable, can be significant, and may change over time. The two major categories of choices are rate control and rhythm control. The overarching category of rhythm control (achievement and maintenance of sinus rhythm), of course, contains a plethora of additional options- pharmacologic, cardioversion, and/or ablation. A SDM approach taking into account the impact of symptoms on quality of life seems particularly well-suited to the rate control/rhythm control discussion, since research to date has not demonstrated a mortality difference in the two major categories of treatment options.<sup>19</sup> Decision-making would of course include the consideration of thromboembolic risk reduction as part of the "mix" for those who opt for rate control. Actual standardized decision tools for rate/rhythm management choices have not been reported in the literature.

There remains a gap in the application of evidence-based guidelines for the reduction of thromboembolic risk for patients with NVAF. As reported in the American College of Cardiology's NCDR PINNACLE registry, only slightly over half of NVAF patients in the registry 2007-2009 who meet evidence-based criteria for anticoagulation were actually on (warfarin) anticoagulation, despite the clear evidence for stroke risk reduction.<sup>20</sup> A more recent study of the percentage of patients with AF on anticoagulation, after the availability of the first novel agent, demonstrated that the percentage of patients on warfarin decreased as the number on dabigatran increased, but the percent receiving no anticoagulation remained at 40%.<sup>21</sup> In December 2012, a consensus meeting was held in which leaders from academia, government, industry, and professional societies to address the barriers to optimal anticoagulation use. Among the many recommendations that rose from this meeting was enhancement of patient education efforts regarding stroke prevention as well as the incorporation of SDM into the clinical encounter.<sup>22</sup>

Development of a decision aid, or tool, to facilitate SDM around anticoagulation versus no anticoagulation for the patient with NVAF is based in part on a validated scoring system used for individual stroke risk estimation, such as the CHADS<sub>2</sub> or the CHA<sub>2</sub>DS<sub>2</sub>-VASc scores combined with a parallel tool to estimate bleeding risk, such as HEMORR2HAGES, HAS-BLED, and ATRIA. This is then combined with detailed information about the treatment options, and questions for the patient regarding how he feels about the options, and how he ranks the importance of the associated pros and cons. One example of an AF anticoagulation decision tool can be viewed at: <http://www.nice.org.uk/guidance/cg180/resources/cg180-atrial-fibrillation-update-patient-decision-aid2>.

Certain web-based tools can be accessed independently by patients outside of the space of the clinical encounter; these can be used in preparation for the clinic appointment. Other SDM tools are designed as "encounter tools"<sup>21</sup> and used as a tool to frame the conversation during the clinical encounter. Key to wide adoption will be the efficiency with which these tools can be integrated into the clinical flow.

With the current novel anticoagulation options in addition to warfarin, clinicians and patients can also work together to

decide on the use of appropriate agent. Not all patients are candidates for all of the new agents, based on their individual clinical characteristics including stroke history and renal function. Some patients may prefer to opt against twice-daily treatment options.

In patients for whom warfarin is chosen, options for method of follow up may also be offered—traditional office based follow up with INR measurement done at an outpatient laboratory facility, point-of-care testing in a physician office setting or follow up at an anticoagulation clinic, many of which are staffed by clinical pharmacists or advanced practice nurses. Additionally, home INR monitoring is an appealing option for some patients. A meta-analysis measuring the impact of Patient Self-Testing (PST) and on Clinical Outcomes demonstrated that PST was associated with fewer deaths and thromboembolic events, without any increase in serious bleeding risk, compared to usual care.<sup>23</sup> In general PST compares favorably to traditional testing, but it is not suitable for all patients.

The potential for more frequent (weekly) INR measurement when testing is done at home appears to increase the time in therapeutic range (TTR). In the recently published STABLE study, of patients taking warfarin who did home self INR testing on a weekly basis, weekly testers achieving a TTR of 74% versus 68.9% for variable PST (1–4 tests per month) self-testing.<sup>24</sup>

## CONCLUSION

Comprehensive patient education using plain language, clear information and incorporating methods to confirm patient understanding is important to safe management of the patient with atrial fibrillation, especially those who are prescribed chronic oral anticoagulation therapy. The use of shared decision making to include the patient as a true partner in care is a growing mandate in our evidence-based patient centered culture. New options for choice of anticoagulants as well as new options for anticoagulation management processes will increase opportunities for individualized option that achieve quality outcome metrics, including the satisfaction of individual patient values, preferences, and needs. ■

## REFERENCES

1. *Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*. AMA, 2007.

2. Budnitz DS, Lovegrove MC, Shehab N, Richards CL. Emergency Hospitalizations For Adverse Drug Events in Older Americans. *N Engl J Med*. 2011;365:2002–2012.
3. The Joint Commission Accreditation Program: Hospital. Emergency Hospitalizations for Adverse Drug Events in Older Americans. National Patient Safety Goals Effective January 1, 2011. 2010. The Joint Commission. Available at: [http://www.jointcommission.org/assets/1/6/2011\\_NPSGs\\_HAP.pdf](http://www.jointcommission.org/assets/1/6/2011_NPSGs_HAP.pdf). Accessed Sept 1, 2014.
4. Kagansky N, Knobler H, Rimón E, et al. Safety of anticoagulation therapy in well-informed older patients. *Arch Intern Med*. 2004;164:2044–2050.
5. Metlay JP, Hennessy S, Localio AR, et al. Patient reported receipt of medication instructions for warfarin is associated with reduced risk of serious bleeding events. *J Gen Intern Med*. 2008;23(10):1589–1594.
6. Nasser S, Mullan J, Bejorek B. Challenges of Older Patients' Knowledge About Warfarin Therapy. *J Prim Care Community Health*. 2012;3(1):65–74.
7. Lane DA, Ponsford J, Shelley A, Sirpal A, Lip GY. Patient knowledge and perceptions of atrial fibrillation and anticoagulant therapy: effects of an educational intervention programme: the West Birmingham Atrial Fibrillation Project. *Int J Cardiol*. 2006;110:354–358.
8. Diamantouros A, Bartle W, Geerts W. Patient Information About Warfarin: An Assessment of Accuracy and Readability. *JAMA Intern Med*. 2013;173(7):582–583.
9. Wilson FL, Racine E, Tekieli V, Williams B. Literacy, readability and cultural barriers: critical factors to consider when educating older African Americans about anticoagulation therapy. *J Clin Nurs*. 2003;12(2):275–282.
10. Diug B, Evans S, Lowthian J, Maxwell E, Dooley M, Street A, Wolfe R, Cameron P, McNeil J. The unrecognized psychosocial factors contributing to bleeding risk in warfarin therapy. *Stroke*. 2011;42(10):2866–2871.
11. Health Literacy Interventions and Outcomes: An Updated Systematic Review, Agency for Healthcare Research and Quality. Publication # 11-E006-1. March 2011. Available at: <http://www.ahrq.gov/research/findings/evidence-based-reports/litupsum.html>. Accessed November 25, 2014.
12. Baker DW, Gazmararian JA, Sudano J, Patterson M. The association between age and health literacy among elderly persons. *J Gerontol B Psychol Sci Soc Sci*. 2000;55(6):368–374.
13. Health Literacy. National Library of Medicine. (Originally produced by Penny Glassman, Head, Technology Initiatives, Lamar Soutter Library, University of Massachusetts Medical School, former NN/LM New England Region Technology Coordinator). Available at: <http://nmlm.gov/outreach/consumer/hlthlit.html#A4>. Accessed October 1, 2014.
14. Blood Thinner Pills: Your Guide to Using Them Safely. Agency for Healthcare Research and

- Quality. Publication # 09-0086-C. August 2010. Available at: <http://www.ahrq.gov/patients-consumers/diagnosis-treatment/treatments/btpills/index.html#about>. Accessed October 1, 2014.
15. What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety. The Joint Commission. February 27, 2007. Available at: [http://www.jointcommission.org/assets/1/18/improving\\_health\\_literacy.pdf](http://www.jointcommission.org/assets/1/18/improving_health_literacy.pdf). Accessed October 1, 2014.
  16. Borg Xuereb C, Shaw RL, Lane DA. Patients' and health professionals' views and experiences of atrial fibrillation and oral-anticoagulant therapy: a qualitative meta-synthesis. *Patient Educ Couns*. 2012;88:330–337.
  17. Berry MJ, Edgman-Levitan S. Shared decision making: the pinnacle of patient-centered care. *New Engl J Med*. 2012;366:780–781.
  18. What is Shared Decision Making? Informed Medical Decisions Foundation. Available at: <http://www.informedmedicaldecisions.org/what-is-shared-decision-making>. Accessed October 1, 2014.
  19. Seaburg L, Erik P. Hess EP, Megan Coylewright M, Henry H. Ting HH, Christopher J. McLeod CJ, and Victor M. Montori VM. Shared Decision Making in Atrial Fibrillation. *Circulation*. 2014;129:704–710.
  20. Chan PS, Maddox TM, Tang F, Spinler S, Spertus JA. Practice-level variation in warfarin use among outpatients with atrial fibrillation (from the NCDR PINNACLE program). *Am J Cardiol*. 2011;108:1136–1140.
  21. Kirley K Qato DM, Kornfield R, Stafford RS, Alexander GC. National trends in oral anticoagulant use in the United States, 2007 to 2011. *Circ Cardiovasc Qual Outcomes*. 2012;5(5):615–621.
  22. Hess PL, Mirro MJ, Diener HC et al. Addressing barriers to optimal oral anticoagulation use and persistence among patients with atrial fibrillation: Proceedings, Washington, DC, December 3-4, 2012. *Am Heart J*. 2014;168(3):239–247.
  23. Bloomfield HE, Krause A, Greer N, et al. Meta-analysis: effect of patient self-testing and self-management of long-term anticoagulation on major clinical outcomes. *Ann Intern Med*. 2011;154:472–482.
  24. DeSantis G, Hogan-Schlientz J, Liska G, et al. STABLE Results: Warfarin Home Monitoring Achieves Excellent INR Control. *Am J Manag Care*. 2014;20(3):202–209.