EDITORIAL: Modern Atrial Fibrillation Care: Becoming a Pro at Using PROs

Samuel F. Sears, PhD,1,2 Scarlett Anthony, BA,1 & Aditi Naniwadekar, MD2

1 Department of Psychology, East Carolina University, Greenville, NC
2 Department of Cardiovascular Sciences, Brody School of Medicine, East Carolina University, Greenville, NC

Correspondence:
Samuel F. Sears, Ph.D. East Carolina University Department of Psychology Rawl Bldg 104 Greenville, NC 27858
Phone: (252) 328-6118
Fax: (252) 328-6283
Email: searss@ecu.edu

Word Count: 1,323

Short title: Becoming a Pro with PROs

Disclosures:
Samuel F. Sears, PhD: Honoraria/Consulting Fees: Medtronic, Abbott, Milestone Pharmaceutical, Zoll Medical; Research Grants: Medtronic, Zoll Medical. All grant funds are directed to East Carolina University. There are no other disclosures for the authors.

Funding: None

EDITORIAL: Modern Atrial Fibrillation Care: Becoming a Pro at Using PROs

Being a pro in the future of cardiac electrophysiology may increasingly involve expertise in understanding and addressing patient reported outcomes (PROs). The field of cardiac electrophysiology has made stunning progress over the last few decades with technological innovation in procedures and devices to identify, manage, and treat arhythmic disorders. The introduction and clinical utilization of PROs extends a health outcome assessment process that may begin to resemble a “dashboard” with a variety of indicators of treatment process and outcomes. The time for routine measurement and integration of PROs in atrial fibrillation (AF) has arrived. However, it is challenging to go beyond measuring PROs alone and toward delivering pathways of care to systematically address patient outcomes and behaviors.

In this issue of JCE, Zenger and colleagues1 report on the implementation of the Toronto AF symptom severity scale in all outpatients at the University of Utah spanning 1,338 patients. The authors reported
on rates of AF symptoms and compared this symptom report with AF burden and healthcare utilization over the subsequent six months of care. Their results in multivariate models show that AF symptoms were reported at higher rates by patients who were female, of younger age (<65 age), had a history of pulmonary disease, and reported depression. Similarly, younger patients, women and those with pulmonary disease or heart failure reported increased healthcare utilization. Increased symptom scores were also associated with more aggressive rhythm control strategies such as AF ablation, anti-arrhythmic drug (AAD) therapy, and cardioversion. While these results are not surprising, they represent innovation because seeking and valuing patient reports completes the circle of stakeholders. Quantitative patient reports can be more readily addressed if they are sampled! PROs have been employed in cardiology, but their utility has mostly been relegated to clinical research trials and not acted upon in clinical settings.

PROs provide a new perspective to the clinical encounter that may not be consistent with the time-honored metrics, such as device confirmed atrial burden. Measuring AF symptoms is a reasonable variable as a lead-off to initiate PROs, but they represent only a subset of the potential value that PROs could bring. For example, in ORBIT-AF, 61.8% of AF patients reported symptomatic experience, while 39.2% were not aware of any symptoms from AF. Moreover, 16.5% of the symptomatic patients reported that the symptoms were disabling. This suggests that AF symptom experience is highly individualistic, ranging from asymptomatic with no impact on quality of life to highly symptomatic and disabling. The patient perception of AF symptoms spans processes beyond the physiological and extend to the psychological and behavioral realm. Nonetheless, AF symptoms are an important place to start because AF symptoms drive health care utilization. In short, patients who are symptomatic are both motivated to seek care and to undergo procedures for symptom relief. Attending providers are motivated to intervene to reduce symptoms and suffering. Both seek to implicitly or explicitly improve another important PRO, quality of life (QOL), and prevent harm such as stroke. Indeed, symptom burden has been identified as the driver of QOL decrements, yet recent evidence exists that physician and patient correspondence on recognition of AF symptoms may be poor. Guideline directed medical therapy can address the medical treatment aspects but may not fully acknowledge or address the patient perspectives on AF.

**Why Are PROs Important?**

The importance of PROs in AF was recently underscored by an international working group convened by the International Consortium for Health Outcomes Measurement (ICHOM) in which a standardized set of outcomes for AF were developed. This working group categorized AF outcomes into three major domains: long-term consequences of disease, complications of treatment, and *patient reported outcomes*. The subset of PROs recommended included health related quality of life, physical functioning, emotional functioning, exercise tolerance, symptom severity, ability to work, and cognitive functioning. While this list might seem exhausting to some, it highlights that AF is particularly sensitive to the patient perceptive set. Specifically, the group identified the importance of both generic PROs, as well as AF-specific PROs. AF-specific instruments provide more face validity and ecological validity to an AF clinic and represent the key domains relevant to both providers and patients. Generic PROs allow for normative comparisons to other same-aged peers who do not have AF. Both approaches have value depending on the comparison of interest.

**Who is More Likely to Experience AF Symptoms and Why?**

Differences in AF symptom experience and severity trigger a number of questions about the correlates and processes involved. A recent meta-analysis suggested that women with AF report poorer QOL and more AF symptom. Similarly, sex differences were noted in the Zenger data and a variety of explanations could be posited, such as societal expectations and excess social stressors for women that may lead to the symptom differences between men and women. Women report significantly more severe symptoms, but may delay in seeking medical attention as a result of factors such as fear of troubling others with their symptoms, caregiving work, and social obligations. Although women are more likely to report their symptoms, cardiovascular symptoms are perceived by their providers as unrelated to their heart (53%) significantly more often when compared to men (37%). Collectively, these various processes may prompt women to be judicious in symptom reporting unless or until the symptoms are clearly troubling and interrupting of daily life.
The use of PROs has long been employed in assessing patient experience related to psychosocial functioning in other settings. The prevalence of anxiety and depression was recently found to be approximately 24% and 28% in AF samples and previously been shown to be associated with symptom severity, QOL and health care utilization. Depression has also been associated with a stepwise, progressively adverse change in outcomes of individuals with AF, highlighting the need for assessment and intervention among this population. Similarly, when clinical variables and psychological variables were assessed, only psychological function predicted AF symptom burden and QOL. The long-term management of AF is burdensome, and depression and anxiety are strongly associated with both treatment adherence and the subjective experience of the condition. The ambiguities of AF causes, symptoms, treatment options, and outcomes may contribute to a patient’s perception of their condition. Collectively, these studies highlight that there is not likely a “pure AF symptom experience”, but rather symptoms are interpreted through a lens affected by a broad set of factors, including co-morbidities such as psychological distress.

Beyond Symptom Perception to AF Patient Engagement

The process of engaging patients can be difficult to achieve in the electrophysiology suite. Scientific statements and international guidelines have now clearly delineated a multi-pillar or multi-pronged, disease management approach to AF that activates the four pillars of rate control, rhythm control, anticoagulation and lifestyle behavioral approaches. PROs can emerge as a useful tool as the daily behaviors of sleep apnea, alcohol use, anxiety/depression, weight management, medication adherence, sedentary behavior are known to be contributory to the clinical picture. Addressing these behaviors will require assessment that is mostly dependent on patient reports. Figure 1 illustrates the side-by-side of key variables that at least partially rely on patient reports. The creation and evaluation of multi-disciplinary approaches is needed to address this host of divergent behaviors across a range of expertise including sleep medicine, psychology, nutrition, pharmacy, and exercise physiology further transforms EP. Understanding what each patient wants and need initiates a process of change of delivery of care. Clearly, the primary limitations of this approach are patient burden of reporting and provider capacity to effectively synthesize and address the information obtained. The challenges are real but the potential value is significant for patient outcomes.

In summary, PRO-guided rhythm control management is a key strategy and an integral part of a comprehensive program for management of atrial fibrillation. This can help standardize patient care and outcomes for heterogenous populations. A PRO-guided approach towards AF may help in engagement of patients in understanding their disease process, identify and risk stratify AF patients for optimum intervention, and improve healthcare utilization.

References

1. Zenger, JCE citation pending
Figure 1: Key Patient Reported Outcomes and Behaviors in AF Patients