



## Building Atrial Fibrillation Awareness: Is it Time to get Beyond the Top Line?

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### Abstract

Public awareness of atrial fibrillation and its consequences is increasing. In the current environment, this is driven largely by promotion of individual therapies. This editorial discusses the need for greater depth in the discussion of the disease state, its progression and economic consequences as well as the risk of death and disability. The adverse effects of therapies on cardiovascular outcomes is a major need in public education. New initiatives should address these important new insights and needs

### Introduction

In 2013, promoting public knowledge of the disease state known as atrial fibrillation has become a major goal for a diverse set of medical groups and health care industry players. Arriving at this nexus is a result of a confluence of recent events. These have included increasing recognition of the impact of this disease on public health by governmental authorities, expanding medical capabilities for its detection and treatment and spiraling health care resource consumption in cash-strapped national health care systems across the globe. The burden of AF now has many faces to many different players in the health care arena. Serious efforts directed at enhancing its awareness in the general population of most developed nations are being put in place. Thus, any critical analysis of the need for more public awareness must take into account what is already in progress. Is there a need to do more, and if so, in what manner and what should be the nature of its content?.

### The Nexus in 2013

Epidemiologic studies in the late twentieth century initially highlighted expanding elderly segment of the population and their increasing vulnerability to AF, stroke and eventually, increased cardiovascular mortality.<sup>1-3</sup> this latter observation when coupled with

high profile mortality trials showing indifferent results with known antiarrhythmic therapies and repeated benefits of oral anticoagulant therapy in AF populations led to a series of clinical practice guidelines for physicians. Despite this, poor patient acceptance and compliance and spiraling economic costs of AF medical care have seriously galvanized the public health authorities. In 1998, a roundtable workshop of the National Heart, Lung and Blood Institute delved seriously into the epidemiology, basic and clinical science and potential new therapeutic directions in AF.<sup>4</sup> By the turn of the millennium, AF had earned a place in the top five national public health priorities in the USA. Pithy statements warning that 1 in 4 US citizens over the age of 40 years would develop AF captured the epidemic proportions of the disease. Other developed nations embraced have also this challenge.<sup>3</sup>

The Euro Heart Survey highlighted the AF condition in 49 nations in Europe.<sup>5</sup>

While medical knowledge has grown, public awareness efforts did not lag. Driven in part by development and availability of new therapies using new devices and drugs, the health care industry has embarked on public information campaigns in the lay media.<sup>6-8</sup> this, in turn, has spurred lay groups, supported in part by health care industry, to undertake important public awareness campaigns. In 2013, the convergence of these interests has been an important in enhancing public perception of this disease.

### What is happening now?

Prior efforts clearly identified that most patients lacked adequate knowledge of the disease state of AF, its risks, consequences and available modern therapies and AF monitoring. Initial efforts at developing a comprehensive campaign to enhance AF awareness

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are taking shape. Common themes are emerging in these initiatives. These fall in four main categories:

1. Improving the knowledge base of patients and their caregivers with respect to the disease states of AF and stroke, available therapies and monitoring of their disease. A wide array of patient and lay reading materials, handouts, online resources and how to promote lay awareness kits are now being disseminated.

2. Major medical society campaigns to highlight best clinical practices and guidelines compliance. These are being reinforced and disseminated by lay groups to primary care physicians, patients, advocacy groups and media relations campaigns linked to medical congresses.

3. Sensitization and lobbying of policymakers for AF health care support in health care delivery systems worldwide. The induction of health care economists into this discussion has been a key feature of the initiative.

4. Critical efforts to raise the profile of AF in the media. Major media outlets are now employing social media, medical spokespersons and physician bloggers to provide disease state information and current therapy updates

### What is in the works?

There is overwhelming recognition by all stakeholders of the need for more data with respect to AF prevalence, detection, health care costs, practice patterns and outcomes worldwide. Clinical epidemiologic studies are now being conducted on a continental and national basis.<sup>9,10</sup> The increasing impact of AF on health care systems has prompted a global economic assessment especially in developed and emerging nations. Estimates of hospitalizations, stroke and other linked statistics are now becoming available through the NIH. Patient presentation and practice patterns have been addressed by important clinical studies.

In the ALFA study, the behaviour of different types of AF and the response of French physicians was examined.<sup>12</sup> In a more recent survey performed in Belgrade, Serbia, patients showed the impact of arrhythmia progression and a preference for restoration of rhythm control or sinus rhythm, particularly if more effective therapies were now available.<sup>13</sup>

Organizing lay initiatives to highlight the disease are now a priority and are beginning to bear fruit and attract the public to local grassroots campaigns. In the UK, taking your own pulse for rate and regularity is now a major thrust of the Arrhythmia Alliance.<sup>14</sup> Local gatherings and events can and are sensitizing the layperson to the disease and its implications. In the United States and elsewhere, health fairs and wellness events, community charity events and national declarations of an AF awareness day bring attention to the condition.<sup>15</sup> These efforts still remain in their relative infancy with only pockets of robust and fruitful initiatives.

### What needs to still be addressed?

Despite the progressive initiatives outlined above, there is overwhelming need for much more to be done. Perhaps the most neglected area from the patient and public is the role of the disease state in determining risk for, progression of and prognosis of atrial fibrillation. While scoring schemes such as the CHADS<sub>2</sub> score in some measure bring this to the forefront, the importance of the underlying disease and the link to AF is still fragmented. Hypertension public health initiatives highlight stroke, death, kidney,

and heart and eye damage but rarely acknowledge its role as the most common disease state associated with AF in the developed world. Similar thoughts apply to the second most common disease state, coronary artery disease or conditions such as heart failure. Little is said about the subpopulations of AF defined by such disease states. In a pooled analysis of the Natural history of AF study and the ASPECT trial, we described the dichotomous nature of AF progression based on the underlying cardiovascular history.<sup>16</sup> Patients with symptomatic drug refractory paroxysmal AF in the setting of bradyarrhythmias without the associated disease state rarely showed rapid progression to persistent or permanent AF in the intermediate term follow up. In contrast, those with a cardiovascular disease state would progress (22% within a mean period of 18 months) to persistent AF. Progression after the first episode of persistent AF was startlingly rapid occurring within 3-6 months to a state of continuous established AF in a majority of patients.<sup>17</sup> This kind of data defines the urgency of primary and secondary prevention measures.

The importance of upstream and life style modification behavior in patients with cardiovascular disease states and manifest or potential AF assume a central role. For example, patients with hypertension or heart failure need to know that early and effective management would have the potential to impact AF development. In contrast, patients without such disease states can be reassured regarding major morbid outcomes in the immediate future. Patient guides to living with AF that now provide succinct clear information on all aspects of the disease, lifestyle issues, therapies, and expectations could expand to include the progression issue.<sup>11</sup>

The AF progression issue builds the rationale and ground work in the patient's consciousness for the lifelong nature of AF, potential for its recurrence, the need for long term vigilance as well as the essential role of continuous therapies such as antiarrhythmic drugs, and anticoagulants. In a report published in Stroke, black patients were less likely than whites to be aware of having AF or to be treated with warfarin.<sup>18</sup> The report concluded that potential reasons for the racial disparity in warfarin treatment warranted further investigation the current disparities in AF knowledge among ethnic groups can be attacked by disease education since hypertension is being particularly targeted for public health education in this ethnic group.

In the elderly, special initiatives are warranted as they are the major subpopulation in AF. The relationship to cardiovascular mortality and sudden cardiac death is rarely emphasized. While the epidemiologic data that unearthed this association has stimulated research, it has rarely found its way into a lay forum.<sup>19</sup> This element brings home the importance of careful attention to this co-morbidity in the cardiac patient. The impact of progression of underlying disease states such as coronary artery disease and heart failure having secondary effects in atrial fibrillation patients resulting in hospitalizations and even increased mortality should be discussed.<sup>20</sup>

The high frequency of hospitalizations is of particular importance as this impact the quality of life of an elderly AF patient more than almost any other measure.

Finally, the use of antiarrhythmic drugs may have adverse effects such as increased hospitalizations, and in the case of amiodarone, increased mortality.<sup>20</sup> While catheter ablation of AF is widely mentioned, its limited application to the elderly due to increased risk and disease progression often consigns them to rate control strategies.

The options of other non-pharmacologic options in a hybrid approach are a major omission for this population. Our group has combined limited ablation, multisite atrial pacing and drug therapy in this approach to successfully address this challenging but very large AF population.<sup>21-23</sup> our long term data beyond five year of follow-up now confirms that this approach prevents AF progression and can reverse remodel the atrium in the long term. It is not uncommon for us to encounter patients who have expressed dismay that these options have not been mentioned by their physician or openly discussed in a public or lay forum so that they can make an informed judgment. We emphasize the fact that during the life history of the AF patient all forms of therapy may be needed to ensure rhythm control. The benefits of rhythm control continue to emerge from more detailed analyses of trials such as the AFFIRM trial.<sup>25</sup>

Finally, the wave of new oral anticoagulant agents is just emerging from clinical trials. The importance of this advance cannot be overemphasized. The availability of options in anticoagulation after decades of stagnation is an enormous step. The importance of this advance cannot be diluted by misguided advertising focusing solely on the safety and adverse effects of these agents by special interest groups that seek to advance their own agenda. Balance and careful public discussion is now warranted to permit careful scientific scrutiny of these drugs.

### Conclusions:

In conclusion, a great deal of lay education and information dissemination about the disease state and potential therapies remains to be done in the public forum. It is responsibility of health care organizations and allied groups to continue their efforts in these important new directions to achieve both an informed populace and comprehensive patient education.

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