



# Cardiac tachyarrhythmias and patient values and preferences for their management: the European Heart Rhythm Association (EHRA) consensus document endorsed by the Heart Rhythm Society (HRS), Asia Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE)

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## Introduction

Cardiac tachyarrhythmias are recurrent or chronic and in some cases life-threatening conditions. Heart rhythm disturbances are often highly symptomatic and the psychological impact of the disease can be significant. Patients' beliefs and knowledge about their health (and illness), medications, and healthcare they receive are important determinants of whether or not they accept recommended treatments; influence their coping responses to their illness and treatment; adherence to recommended therapy; and ultimately affects health outcomes. Incorporation of patients' values and preferences for therapy should now be considered as an integral part of the decision-making process and treatment strategy.

It is important to acknowledge and understand the impact of cardiac tachyarrhythmias on the patient. To address this issue, a Task Force was convened by the European Heart Rhythm Association (EHRA), and endorsed by the Heart Rhythm Society (HRS), Asia-Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE), with the remit to comprehensively review the published evidence available, to publish a joint consensus document on patient values and preferences for the management of cardiac tachyarrhythmias, and to provide up-to-date consensus recommendations for use in clinical practice.

Hence this unique consensus document focuses on patients, summarizing the available literature on patients' experiences of living with various cardiac tachyarrhythmias and their treatment preferences, and identifies gaps in knowledge which will help to inform clinical practice and future research. The document will also summarize key points for discussions with patients during consultations regarding their condition, treatment options, disease trajectory, treatment goals, and outcomes. Finally, this document provides links to useful resources and patient advocacy groups and organizations and professional societies relevant to each group of cardiac tachyarrhythmias.

## Atrial fibrillation

### Patients' experiences of living with atrial fibrillation

The experience of living with atrial fibrillation (AF) has been investigated from several perspectives. Quantitative studies reveal that patients with AF generally report lower health-related quality of life (QoL) compared with healthy controls, particularly symptomatic AF patients.<sup>1–5</sup> In addition, between one-third to one-half of symptomatic patients with AF suffer from psychological distress (depression and anxiety),<sup>6–14,14a</sup> although the direction of the association between AF symptoms and distress is uncertain.<sup>15,16</sup>

Quantitative studies and clinical trials of interventions are limited in their ability to tell a 'patient's story'. Atrial fibrillation may affect people in a myriad of ways, and the diversity of AF symptoms enhances the importance of qualitative studies<sup>11,17–19</sup> and personal case histories. Examples such as those presented in Boxes 1–3 provide a more comprehensive insight into the patients' experiences and can be shared via patient support resources.

At the core of patient-centred care is an understanding of how AF affects each patient.<sup>20</sup> A minimally symptomatic patient might be more risk averse and favour a conservative treatment path, while an AF patient with disabling fatigue and dyspnoea might be more risk tolerant and more aggressive therapeutic measures might align well with their therapeutic goals.

Several themes identified by patients deserve to be recognized and addressed and are illustrated using patient stories (see Boxes 1–3).

- **Making a diagnosis** of AF can be difficult. Atrial fibrillation symptoms may be transient and non-specific—and hence attributed to other conditions. Delayed diagnosis or misdiagnosis of AF (due to incomplete diagnostic procedures and processes) may result in patient frustration or lack of referral for expert evaluation.
- **Time constraints** in the healthcare environment inhibit a nuanced assessment of symptoms. The true influence of AF on lifestyle may not be discovered and treatments that target QoL, such as rhythm control strategies, could be underutilized.
- Patients report a desire for **better communication** about their experiences with AF. Patient-specific approaches that include patient education by their physician and/or healthcare professionals and making use of a shared decision-making model are essential.
- **Understanding AF treatment** is daunting. Most patients feel they need repeated opportunities for education. Patients look to their healthcare providers to refer them to quality sources of information. A vital part of delivering AF care should include referral to high-quality unbiased resources, such as AF websites, decision aids and brochures, and a guide (in terms of coordination of care) to provide tailored information to the patient.
- Patients report that the **burden of living with AF** can extend to loved ones who may not appreciate the significance of symptoms. Educational efforts, therefore, should include family and carers.

## Patients' understanding of atrial fibrillation and education related to atrial fibrillation

### Rate and rhythm control

With the exception of one international survey,<sup>21</sup> the literature related to patients' knowledge about AF and rate- or rhythm-control management is limited to a few small descriptive studies that reveal a substantial portion of patients lack knowledge critical to effectively manage their AF. In a multi-ethnic study,<sup>22</sup> 37% of subjects were not aware of their AF diagnosis and 47% did not recognize that having AF put them at increased risk of stroke. Even after receiving education during hospitalization, many patients were unable to verbalize symptoms of AF, their treatment goal, purpose(s) of their medication, and the relationship between AF and stroke.<sup>23</sup> Similarly after 3 months of emergency room treatment, one-third of patients

### Box 1 Male, age 45, with paroxysmal lone AF for 5 years

As a triathlete in great shape who exercises regularly and maintains a healthy diet and good weight, why had he developed AF? He competes in triathlons several times each year, always ensuring that he is properly hydrated. He consumes alcohol only in moderation and has never smoked. AF has been very difficult to manage because beta-blockers, the standard medication his cardiologist prescribed, are banned in competition. His doctor recommends giving up competitive sport but he 'lives' to compete and his life would be empty without it. He is considering having an ablation to stop the AF, if his doctor will agree.

### Box 2 Female, age 55, recently diagnosed with paroxysmal AF

She had palpitations for several years, but each time she visited her general practitioner (GP), everything would be fine. Although she did not feel stressed, her GP prescribed anti-anxiety medication and stress management. At her next episode, which felt like a heart attack, she went to the emergency department. Numerous tests, including a 24-h Holter monitoring, yielded negative results. That was not surprising, because her episodes were sporadic. Ultimately, she sought a second opinion. Her new GP arranged for an ECG whenever she had symptoms and the strategy worked. After 2 years she was eventually diagnosed with AF. Following diagnosis, she became stressed and panicky, frightened of her medications, and terrified to go anywhere—and scared that for the past 2 years that she had been at risk of having an AF-related stroke. She feels nobody really understands how this has affected her. Her whole life has changed as her employer paid her to leave the business and she is now on welfare.

### Box 3 Male, age 70, silent AF

Atrial fibrillation was found during pre-operative assessment. When asked by his GP how he was, he replied 'Fine', so he was characterized as being asymptomatic and prescribed rate-control medication. He was referred to a cardiologist because of co-morbidities, where he was questioned about his life and current and past functional abilities. *'I can't mow the lawn, or work around the house. I get tired just walking upstairs, but I guess I am just getting old.'* His wife said that she did not understand why things changed so quickly—he was able to do these things just a few months before. Following a cardioversion he said, *'I cannot believe what a difference that made. I can now do things that I could not do previously. I feel like a different person.'*

believed AF would not reoccur on rhythm-control drugs, did not realize AF could occur without symptoms, and were unsure where to seek treatment for recurrent AF episodes.<sup>24</sup>

Patients prefer to receive education about AF from their healthcare providers,<sup>18,21,25</sup> but clinicians often report difficulty acquiring quality resources for education. Recently, professional societies (American College of Cardiology, American Heart Association, EHRA, European Society of Cardiology (ESC), and Heart Rhythm Society) and patient advocacy groups [StopAFib.org, Atrial Fibrillation Association (afa-international.org), and Arrhythmia Alliance (aa-international.org)] have produced web-based (and hard copy) AF-related patient education, but what is often lacking is guidance for clinicians and healthcare professionals on the optimal practice of educating patients about AF self-management. Assessment of patients' AF knowledge and self-management utilizing validated instruments<sup>26,27</sup> is essential to allow individual-targeted education.<sup>25</sup>

### Stroke prevention

Patients' understanding of AF and the treatment options available, particularly stroke prevention therapy, is often limited.<sup>23,25,28–31</sup> Patients should be made aware that AF is a chronic condition and is the most common sustained cardiac rhythm disorder in adults, it is often asymptomatic and the main complication of AF is stroke.<sup>32</sup> In addition, patients should also be made aware that AF-related strokes are more disabling and more frequently fatal.<sup>33,34</sup> Patients need to be aware of their individual risk of stroke and the benefits and risks of oral anticoagulant therapy. Educating the patient about how and why AF increases the risk of stroke is crucial to enable the patient to comprehend the necessity for oral anticoagulation (OAC) therapy and for lifelong use.<sup>25,35</sup> A brief educational intervention demonstrated improvements in patient knowledge, particularly regarding factors which affected international normalized ratio (INR) control.<sup>28</sup> Further, the TREAT study (TRial of an Educational intervention on patients' knowledge of Atrial fibrillation and anticoagulant therapy, INR control, and outcome of Treatment with warfarin, ISRCTN93952605)<sup>36,37</sup> demonstrated that patients who received the intervention understood the necessity of warfarin and perceived this as more important than their concerns about the treatment, which translated into better anticoagulation control [evidenced by time in therapeutic range (TTR)] 6 months later. This study also highlighted the importance of reinforcing information regarding treatment periodically to improve adherence.<sup>36</sup>

Sections 'Key discussion points with atrial fibrillation patients at initial and/or follow-up consultations' and 'Critical elements of discussions regarding oral anticoagulation' contain a summary of the key elements to discuss with AF patients at the time of diagnosis and subsequent appointments and critical elements of discussions regarding OAC, respectively. Patients should receive patient-friendly vitamin K antagonist (VKA)<sup>38,39</sup> or non-VKA OAC (NOAC)-specific<sup>40</sup> information as appropriate, and the amount and complexity of information, and the media used to convey the information, should be tailored to patients' preferences.<sup>11,25</sup>

## Patient's values and preferences and impact of treatment choices

### Rate and rhythm control including drugs, atrial fibrillation ablation, and atrioventricular node ablation with pacemaker implantation

The modern management of AF is increasingly patient-centred and symptom directed. However, there is very limited evidence on

patients' preferences for rate- or rhythm-control strategies for AF as the majority of the work in this area has focused on patients' values and preferences for OAC. Although evidence shows no significant difference between rate vs. rhythm control in terms of improvement in functional status or symptoms using either drugs<sup>41,42</sup> or catheter ablation [i.e. AF ablation<sup>43,44</sup> or atrioventricular (AV) junction ablation with pacemaker implantation],<sup>44</sup> available data suggest that patients generally prefer normal sinus rhythm,<sup>45</sup> even in the absence of AF symptoms or among those who are only mildly symptomatic.<sup>45</sup> Also some indirect evidence may be inferred from studies that compared QoL in AF patients randomized to rate- or rhythm-control strategy. However, AF pattern and AF burden are not always therapeutic targets, particularly in relation to thrombo-embolic risk.

Given the current paucity of information regarding patients' preferences for a specific AF management strategy (rate control vs. rhythm control), the fact that some patients will require both rate control and rhythm control whereas others may only require rate control, and that patients' and physicians' perceptions of the benefits and goals of treatment often differ,<sup>46</sup> some decision aids (<http://www.healthwise.org/products/decisionaids.aspx> and <https://decisionaid.ohri.ca/>)<sup>47</sup> have been developed in order to implement a more patient-centred and symptom-directed management algorithm for some aspects of AF treatment.

In the treatment of AF, the importance of *patient preferences* and *patient choice* is highlighted in the latest update of the ESC guidelines.<sup>48</sup> Thus, when faced with the decision whether to undergo ablation for AF, patients should be informed about the pros and cons, including the expected benefits and the potential for total or only partial resolution of the problem, including the need for repeating the procedure in cases of AF recurrence. Current consensus guidelines advocate that the individual stroke risk of the patient should determine whether OAC should be continued and that discontinuation of oral anticoagulant therapy post-ablation is generally not recommended in patients at risk for stroke (i.e. CHA<sub>2</sub>DS<sub>2</sub>-VASc  $\geq 2$ ), as AF is a chronic progressive arrhythmia, especially in patients at risk for stroke.<sup>49</sup> To add to the complexity, the psychological status of the patient may influence treatment success. One in three patients with AF presents with symptoms of anxiety and depression.<sup>7,50</sup> Although successful AF ablation may reduce psychological distress and improve QoL,<sup>51,51a,51b</sup> higher distress scores increase the risk of AF recurrence in patients with paroxysmal AF post-ablation.<sup>52</sup> This emphasizes the complex interactions between anxiety and depression and AF, as well as the need for personalized management of AF<sup>53</sup> and *shared decision-making*.<sup>54</sup> This also applies in cases where AV node ablation with pacemaker implantation is needed to achieve satisfactory ventricular rate control in patients who are unable to take drugs for rate control, or when such treatment is ineffective.

### Antithrombotic therapy including oral anticoagulants (vitamin K antagonists and non-vitamin K antagonist oral anticoagulants) and left atrial appendage occlusion

Most of the research on AF patients values and preferences has been directed towards antithrombotic therapy,<sup>25,55</sup> particularly with warfarin, and has shown that patients perceptions of such treatment are often influenced by the way in which risk information is presented,<sup>56,57</sup> their level of knowledge of AF and treatment

options,<sup>25,28,29,58</sup> and their previous experience and satisfaction with medication.<sup>25</sup> Crucial to the treatment decision-making process is the patient's understanding of antithrombotic therapy and their individual risk–benefit analysis. Patients need to be aware that the absence of AF (sinus rhythm achieved with drugs and/or ablation) and/or lack of AF symptoms (with/without treatment) does not remove their risk of stroke/thromboembolism, and that where OAC is indicated it is required lifelong. Nevertheless, some patients may make an informed decision not to take recommended treatments.<sup>59–63</sup> A recent study<sup>64</sup> of AF patient's preferences for OAC and their attitudes towards stroke prevention and bleeding risk found disparate response patterns, thus highlighting the importance of consideration of patient preferences in treatment decisions regarding OAC therapy. Overall, patients were willing to accept 4.4 major bleeds to prevent one stroke, but 12% of patients were opposed to OAC even if it was 100% effective.

Researchers have reported that patient and provider concerns about the bleeding risk associated with warfarin and the need for frequent INR testing have decreased the long-term adherence to recommended warfarin use.<sup>25,28,29,58,65–69</sup> As a result, a substantial proportion of AF patients starting OAC have been found to discontinue therapy within 1 year, resulting in increased risk for embolic stroke.<sup>65–69</sup> Investigators have reported that patients who discontinued warfarin are typically younger than patients who persisted.<sup>66,68</sup> Although elderly patients are prescribed warfarin less often, they tend to remain on treatment for a longer period of time than younger patients,<sup>68</sup> unless stopped due to safety concerns.<sup>66,67</sup> Patients who discontinued warfarin on their own were more likely to be newly diagnosed with AF, warfarin-naïve, or with low or moderate stroke risk (e.g. CHADS<sub>2</sub> score 0–1), whereas patients who persisted on warfarin were more likely to have a diagnosis of permanent AF.<sup>66,68</sup>

Clinicians and patients acknowledge that patients choose not to take OAC or stop anticoagulation for multiple reasons, including: lack of patient knowledge about the condition and medication, beliefs that the medication is difficult to manage, dislike of the need for and frequency of INR blood testing, travelling back and forth to a centre for blood testing, fear of bleeding, the negative connotation of warfarin being 'rat poison', and/or too many concurrent medications.<sup>65,68,69</sup> It is not simply a matter of improving education, since greater knowledge may not translate into greater uptake and adherence. Indeed, a recent Cochrane review of the impact of educational and behavioural interventions on TTR, adverse events, patient knowledge, anxiety, and QoL in AF patients receiving OAC reported that there was limited evidence to suggest benefit of such interventions and that future more comprehensive interventions were needed.<sup>70</sup>

Subsequently the TREAT study (ISRCTN93952605),<sup>36,37</sup> a randomized controlled trial of a psychological-theory driven educational–behavioural intervention in AF patients newly initiating warfarin, demonstrated that this comprehensive intervention significantly improved TTR at 6 months compared with usual care (attendance at a hospital anticoagulation clinic alone).<sup>36,37</sup> Importantly, patients in the intervention group viewed medication as less harmful than those patients receiving standard care.<sup>36</sup> In addition, an AF-specific nurse-led intervention<sup>71,72</sup> has also demonstrated a significant reduction in the number of cardiovascular deaths or cardiovascular hospitalizations [14.3 vs. 20.8%; hazard ratio (HR) 0.65; 95% CI

(confidence interval) 0.45–0.93] (discussed in more detail in the 'Nurse-led multidisciplinary programmes' section).<sup>71</sup> Thus proactive comprehensive interventions, incorporating education about the importance of OAC as a central facet along with other components, should be provided to all patients to increase uptake and adherence, reduce adverse events, and to prevent early discontinuation.

There is currently limited evidence to address patient values or preferences for the NOACs. Patient preferences for the use of dabigatran were generally positive when compared with warfarin, but gastrointestinal side effects with this drug often caused patients to stop taking the drug as prescribed.<sup>69</sup> There is a need for more patient education about how to use the NOAC drugs and their safety profiles. These researchers also reported a lack of patient understanding of the stroke risk with AF, especially after AF ablation.<sup>69</sup> There is no evidence to address patient preferences for left atrial appendage occlusion at this time based on the absence of any peer-reviewed publications in this area.<sup>73</sup> This is an important area of future research as the decision to use left atrial appendage closure turns on attitudes about anticoagulation.

## Individual management

### Hospital outpatient vs. out-reach management

As the number of AF-related hospitalizations increases globally,<sup>74</sup> there is an increasing imperative to cost-effectively improve health outcomes in affected individuals. Consistent with the broad development and application of models of care for chronic disease, there are a range of options to improve health outcomes via a coordinated (and preferably, multidisciplinary) approach. Beyond two recent innovative trials that adopted an outpatient model (AF clinic)<sup>71</sup> and an AF-specific out-reach (home-based) model of care<sup>75</sup> for patients with predominantly transient and chronic forms of AF, respectively, there is a paucity of evidence to recommend a specific approach for managing AF. Importantly, both models appear to provide significant health benefits relative to standard care. However, when one considers that AF is one of the most commonly reported co-diagnoses in chronic heart failure (HF),<sup>76</sup> the large body of evidence in support of multidisciplinary management programmes of this syndrome is highly relevant to the management of AF. Consistent with the overall evidence-base,<sup>77</sup> there do appear to be tangible benefits (for the patient and carers) in applying both a multidisciplinary management on a face-to-face (as opposed to remote) basis and for components of outreach care to reduce recurrent hospitalizations and improve QoL, as well as prolonging survival.<sup>78</sup>

### Self-care management (vitamin K antagonist patients)

Despite the emergence of newer therapeutic agents that provide equivalent and/or superior protection against stroke in AF compared with warfarin,<sup>79–82</sup> warfarin therapy will remain central to the management of AF in many individuals for the foreseeable future. The efficacy and safety of warfarin requires careful monitoring and adjustment of the warfarin dose to maintain a therapeutic INR range (between 2.0 and 3.0).<sup>83</sup> A systematic review of 11 trials of anticoagulation self-monitoring vs. standard management involving 6417 patients (not exclusively AF) found significant reductions in thrombo-embolic events with self-monitoring [HR (95% CI) 0.51 (0.31–0.85)] but no difference in the risk of major bleeding or death.<sup>84</sup> Four of the seven studies which reported mean TTR

over the first year demonstrated improvements in TTR with self-management.<sup>84</sup> However, the majority of individuals with AF are probably not suitable for this approach.<sup>83</sup> It is, however, suitable for those who have a good understanding of their condition(s) and warfarin therapy, are able to follow potentially complex instructions and advice, have a means of routinely checking their INR in a valid and accurate manner (e.g. via a point of care device in their own home), and have clear lines of communication with the healthcare team (with instructions to titrate therapy or seek immediate help as required).

### **Impact of cognitive impairment on self-management and role of carers**

Cognitive impairment, as a result of poor blood supply to the brain, and the equivalent of 'mini-strokes' affecting multiple parts of the brain can arise in person with a cardiovascular condition but particularly in those with AF.<sup>85,86</sup> Among healthy individuals aged 65 years or more, 10–20% have cognitive impairment<sup>86</sup> compared with 25–50% of those with AF.<sup>87</sup> A recent semi-systematic review reported that AF patients have a two- to three-fold increased risk of cognitive impairment compared with patients in sinus rhythm,<sup>88</sup> suggesting an association rather than cause and effect. Nevertheless, beyond simply forgetting to perform important tasks (such as taking daily prescribed medication) cognitive impairment is a barrier to performing vital self-care activities. This is due to an inability to learn new things (e.g. how to check the impact of warfarin therapy) and having trouble concentrating on the education their healthcare team might provide, impairing a person's ability to make important decisions related to their health (e.g. seeking emergency care at the right time). In those with a combination of AF and HF, the presence of cognitive impairment is marker of particularly poor health outcomes.<sup>89</sup> Thus, there is a clear and unequivocal role for the carer of such patients, as carers are able to fully comprehend, understand, and implement potentially complex instructions, to assist in the management of AF; but only if they have the capacity, motivation, and energy to do so.

### **Nurse-led multidisciplinary programmes**

Despite the potential advantages of applying nurse-led multidisciplinary programmes of care to address poor health outcomes in a growing number of individuals with AF requiring ongoing management and/or hospital admission, there is a paucity of research to support their application. Three notable exceptions to this require comment. In the first study of its kind, a team of European researchers demonstrated (via a single-centre) in a randomized trial involving 712 AF patients that a dedicated nurse-led, outpatient clinic applying cardiologist-supervised, guideline adherent treatment for optimal AF management reduced cardiovascular hospitalizations and death compared with standard care; from 20.8 to 14.3% during the average follow-up of 22 months and was cost-effective (slightly more life-years and lower cost quality-adjusted life-years).<sup>71,90</sup> Similarly, Australian researchers conducted a multicentre trial involving 335 patients to test the effectiveness of an AF-specific, nurse-led, multidisciplinary outreach programme to optimize the post-discharge management of chronic forms of AF. During an average follow-up of 30 months, intervention patients spent more days alive and out-of-hospital; on average 40 days more than standard care.<sup>75</sup>

Both studies reinforce the potential of nurse-led, multidisciplinary management to cost-effectively improve health outcomes (including lowering the risk of hospitalization and prolonging survival) in those requiring longer term management of AF. This should come as no surprise given the strength of evidence<sup>77</sup> for parallel programmes that typically manage patients with chronic HF with comorbid AF (upwards of half of all patients).<sup>76</sup> Another recent RCT compared a one-off educational–behavioural intervention (developed by health psychologists and cardiologists in conjunction with AF patients) vs. standard care for AF patients newly initiating warfarin, and demonstrated significant improvements in TTR at 6 months among patients receiving the intervention.<sup>36</sup> However, given the evolving treatment and complexity of care required to optimize health outcomes in AF, more research is needed to further develop and test such interventions and determine the optimal delivery criteria (particularly personnel) to improve outcomes. *Table 1* (based on the American Heart Association's Taxonomy of Care for those with chronic disease<sup>91</sup>) outlines how best nurse-led multidisciplinary programmes of care might be applied in the future.

## **Advice and recommendations for patients with atrial fibrillation**

### **Key discussion points with an atrial fibrillation patient at initial and/or follow-up consultations**

Owing to the lack of clinical trials to identify the essential components of education and counselling that promote effective AF self-management, the recommendations listed in *Tables 2* and *3* are based on clinical expertise and patients' opinions reported in descriptive research<sup>11,18,19,21</sup> and patient advocacy websites (see *Table 4*). Discussions should begin with an assessment of the patient's health literacy level (understanding of AF and its' treatment), preferred learning style (reading, discussion, and video), and current beliefs about AF. Identifying the patient's beliefs about AF in terms of its cause, consequences, acute vs. chronic timeline, and controllability may help to uncover misperceptions that could impede effective self-management.<sup>29</sup> The depth and amount of topics discussed in a single encounter should be tailored to the individual patient's preferences and health literacy level. It is useful to assess the patient's understanding of the topics by asking patients to restate the content in their own words. At subsequent clinical encounters, assess the patient's understanding of educational content discussed during prior encounters and correct or reinforce the content as indicated.<sup>92</sup> Patients report that written and video supplements are beneficial (see 'Links to useful patient advocacy groups and organizations and professional societies' section for resources).

### **Critical elements of discussions regarding oral anticoagulation**

Ensuring that patients understand why OAC is necessary, to reduce the risk of stroke associated with AF, and the benefits and risks of this treatment for them personally, are essential to enable the patient to make an informed decision about whether or not they want to take the medication that is recommended and it can also increase the likelihood of adherence. Patients need specific information about the OAC recommended for them and patient-focused/

**Table 1** Comparison of structured nurse-led multidisciplinary management vs. standard care

| Taxonomy                 | Nurse-led multidisciplinary programme of care  | Standard care  |
|--------------------------|--|--|
| Patient population       | Men and women with a diagnosis of AF requiring ongoing management via an outpatient clinic<br>Hospitalized patients with acute and chronic forms of AF   | Same<br>Same   |
| Intervention recipient   | Entry into programmes would be based on a careful analysis of need and benefit to identify high-risk patients who would benefit most<br>Carers<br>Wider healthcare team  | <i>Ad hoc</i> with no clear focus  |
| Intervention content     | Strategies to optimize gold-standard pharmacological therapy and non-pharmacological management. This includes prescribing and up-titrating drug therapy, providing education, promoting self-care behaviours, undertaking clinical surveillance and providing additional components of evidence-based therapies                       | <i>Ad hoc</i> and often non-evidence based   |
| Delivery personnel       | Predominantly applied by specialist nurses with clinical experience and post-graduate qualifications relevant to AF management in a coordination/facilitation role<br>Other key members of the healthcare team including cardiologists, primary care physicians, pharmacists, and social workers                                       | <i>Ad hoc</i> according to vicarious access to the healthcare system but often involving a cardiologist and primary care physician with minimal coordination of care |
| Method of communication  | Face-to-face (in the outpatient or home setting) with additional remote (e.g. structured telephone) support<br>Communications within the healthcare team delivered and facilitated by automated reporting systems and scheduled team meetings  | <i>Ad hoc</i> according to vicarious access to the healthcare system   |
| Intensity and complexity | Varied intensity and complexity of hospital and outpatient management according to the patient's clinical needs with a minimum requirement for contact with the healthcare team to establish individual risk and health priorities<br>Increased surveillance and review following a clinical event (e.g. unplanned hospital admission) | <i>Ad hoc</i> according to vicarious contact with the healthcare system (e.g. hospital admission triggering acute care)  |
| Environment              | Structured hospital outpatient setting but also the patient's own home   | Predominantly the clinical setting   |
| Clinical outcomes        | Reduced levels of hospital admissions (all-cause and cardiovascular specific), fewer adverse drug misadventures, improved quality of life and prolonged survival. Potentially fewer healthcare costs overall<br>Adherence to guideline-recommendations (diagnostics and treatment)<br>Patient satisfaction                             | A large component of preventable hospital admissions, adverse drug effects, poor quality of life and premature mortality   |

friendly educational tools are available<sup>38–40</sup> (see Table 4) to help facilitate this. It is the responsibility of the physician or healthcare professional who is prescribing the OAC to educate the patient appropriately about the OAC recommended.

The critical elements of discussions regarding OAC are summarized in Table 3. Oral anticoagulation can be administered as well-managed adjusted-dose VKA (with emphasis on good quality anticoagulation control), as reflected by an average TTR within an INR 2.0–3.0 of >70%<sup>93</sup> or by the use of a NOAC.

Patients need to be educated that maintaining a high TTR requires attention to many patient-centric clinical factors (dietary intake, alcohol consumption, taking the medication regularly, etc.), which can influence the likelihood of labile INRs, and in turn, the efficacy and safety of VKAs.<sup>94–96</sup> When calculating TTR, a validated method such as the Rosendaal method for computer-assisted dosing or proportion of tests in range for manual dosing should be used. Poor anticoagulation control, indicated by any of the following, also needs to be 'flagged': two INR values >5 or one INR value >8 within the past 6 months; two INR values <2.0 within the past

6 months; or TTR <65%. Bleeding risk also needs some discussion, and should reflect factors which the patient has control over [diet, excessive alcohol intake, concomitant medication (avoiding aspirin, non-steroidal anti-inflammatory drugs), VKA adherence, attending for regular INR testing, etc.] as discussed in a recent EHRA position document on bleeding risk assessment and management in AF patients.<sup>97</sup> It should be highlighted that AF patients usually value stroke prevention much more than the risk of serious bleeding, and the discussion should be balanced and framed accordingly.<sup>64</sup>

#### Important questions for patients to ask their doctor/ healthcare professional

Box 4 contains a list of suggested questions which patients may wish to ask their doctor or other healthcare professionals involved in the management of their AF and a list of topics which healthcare professionals should check with the patient and/or discuss as part of structured follow-up.

**Table 2** Key topics to discuss with an AF patient at initial and follow-up consultations

- Basic anatomy/physiology of AF
- Explanation of symptoms with emphasis that asymptomatic AF is common
- Factors that increase the risk for developing AF, focusing on factors pertinent to the patient
- Trajectory of AF as relevant to the patient's individual clinical status—what can the patient expect?
- Discussion of consequences of AF and importance of prompt and continued treatment
- Individual thrombo-embolic and bleeding risk assessment and OAC (see Table 3)
- Discussion of AF treatment options explaining the patient's individual characteristics that may favour one treatment over another
- Treatment education (pharmacological, non-pharmacologic, and lifestyle)
- Explanation of the influence of untreated comorbidities on progression of AF
- Discussion of the patient's individual risk factors to determine the patient's readiness to address lifestyle changes and recommended therapies
- Action plan
- Recommended follow-up care
- How to know if treatment is not working
- Signs and symptoms that require professional evaluation
- When to contact your healthcare provider
- Which healthcare provider should be contacted for specific concerns (general practitioner, cardiologist, electrophysiologist, anticoagulation clinic, etc.)
- When to seek emergency care
- Psychosocial aspects of living with AF
- Benefits of cognitive behavioural therapy to facilitate coping with challenges of living with AF (as indicated by individual assessment)
- Educational and support resources

**Table 3** Critical elements of patient-physician/healthcare professional discussions regarding OAC

- Explain link between AF and stroke and why OAC is usually recommended lifelong
- Patients' individual risk of stroke assessed by CHA<sub>2</sub>DS<sub>2</sub>-VASc score
- OAC treatment options
- Patients' bleeding risk on OAC, assessed by the HAS-BLED score, and their risk/benefit profile
- Drug-specific education
- How to take the medication—dose, frequency, with/without food, with other medications, what to do if dose missed
- Importance of strict adherence to OAC/NOAC dosing regimen and potential consequences of non-adherence
- Bleeding side effects and how to manage these
- In patients taking a VKA, attention to the quality of anticoagulation control [as reflected by an average TTR (INR 2.0–3.0) of >70%.

### Links to useful patient advocacy groups and organizations and professional societies

The websites listed in Table 4 contain educational and support content that may supplement and enhance patient–provider discussions related to AF. The list provided is not exhaustive. The sites

**Table 4** Links to patient advocacy groups and foundations, professional societies and organizations, and patient discussion forums<sup>a</sup>

#### Patient advocacy groups and foundations

- Atrial Fibrillation Association International: [www.afa-international.org](http://www.afa-international.org)
- Arrhythmia Alliance International: [www.aa-international.org](http://www.aa-international.org)
- World Heart Federation: <http://www.world-heart-federation.org/what-we-do/awareness/atrial-fibrillation/>
- Sign Against Stroke in Atrial Fibrillation: <https://www.signagainststroke.com/en>
- Heart and Stroke Foundation-Canada: [http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.5052135/k.2C86/Heart\\_disease\\_\\_Atrial\\_fibrillation.htm](http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.5052135/k.2C86/Heart_disease__Atrial_fibrillation.htm)
- StopAfib.org: <http://www.stopafib.org/>
- My AFib Experience: <http://myafibexperience.org/>
- Anticoagulation Europe: <http://www.anticoagulationeurope.org/>

#### Professional societies or organizations

- European Heart Rhythm Association: <http://www.afibmatters.org/>
- American College of Cardiology: <https://www.cardiosmart.org/Heart-Conditions/Atrial-Fibrillation>
- American Heart Association: [http://www.heart.org/HEARTORG/Conditions/Arrhythmia/AboutArrhythmia/AFib-Resources-and-FAQ\\_UCM\\_423786\\_Article.jsp#](http://www.heart.org/HEARTORG/Conditions/Arrhythmia/AboutArrhythmia/AFib-Resources-and-FAQ_UCM_423786_Article.jsp#)
- Heart Rhythm Society: <http://www.hrsonline.org/Patient-Resources/Heart-Diseases-Disorders/Atrial-Fibrillation-AFib#axzz3L30TnUIT>

#### Patient discussion forums

- Arrhythmia Alliance: <https://healthunlocked.com/hearthythmcharity>
- AFIB Support Group: <https://groups.yahoo.com/neo/groups/AFIBsupport/info>
- Atrial Fibrillation Association: <https://healthunlocked.com/afassociation>
- StopAfib.org Forum: <http://forum.stopafib.org>
- Atrial Fibrillation Support Forum: <https://www.facebook.com/groups/AtrialFibrillationSupportForum/>
- Daily Strength Afib Support: <http://www.dailystrength.org/c/Atrial-Fibrillation-AFib/support-group>
- Lone Atrial Fibrillation Forum: <http://www.afibbers.org/toboard.htm>

<sup>a</sup>This is not an exhaustive list.

featured are sponsored by well-known and established foundations, advocacy groups, or organizations. Specific resources from those websites, some printable, are also listed in Table 4. Website sponsors frequently update the resources offered at their sites. To assure, the link is active and the resource is available and appropriate for the patient's needs providers are advised to check the specific link prior to referring patients.

## Supraventricular arrhythmias

### Patients' experiences of living with supraventricular arrhythmias and quality of life

Whereas the experience of living with ventricular arrhythmias (VAs) and implantable defibrillators has garnered much attention, characterization of symptoms in patients with supraventricular tachycardia



**Box 4 Questions for patients to ask their doctor/healthcare professional**

- What are the risks from having AF?
- What can be done to decrease these risks associated with AF?
- Is there anything I can do, such as lifestyle changes to reduce these risks or decrease the amount of AF that I have?
- Will the medication I am taking be affected by other medication(s)?
- How often will I need blood tests to check how fast my blood is clotting (international normalized ratio—INR)?
- Does the family doctor/GP surgery offer INR testing or where will I need to go for this?
- Will food or drink affect my AF or medication?
- How often will I need to have a ‘check-up’?
- Who can I call if I feel more unwell than usual?
- If my current treatment plan doesn’t work, what other treatment options might I have?
- What type of exercise can I do?
- How can I find out further information?
- Is there a local AF or atrial flutter patient support group?

| Check Points for Follow-Up Appointments                            | Yes                      | No                       | When (date) |
|--|--------------------------|--------------------------|-------------|
| • Did you have symptoms at the time of diagnosis?                  | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Have these symptoms been eased by treatment?                     | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Have you had an ECG?   | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Did this confirm AF?   | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Have you had blood tests?  | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Was the result from the test on your thyroid gland normal?       | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Have you been told you are diabetic?                             | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| • Have you been told what form of AF you have?                     | <input type="checkbox"/> | <input type="checkbox"/> | .....       |
| Paroxysmal AF  | <input type="checkbox"/> |                          |             |
| Persistent AF  | <input type="checkbox"/> |                          |             |
| Permanent AF   | <input type="checkbox"/> |                          |             |
| • Have you been referred to a cardiologist for further assessment? | <input type="checkbox"/> | <input type="checkbox"/> | .....       |

(SVT) has been less frequently investigated. The vast majority of patients with an SVT are healthy, young adults with no underlying cardiac or other co-morbid conditions.<sup>98</sup> Onset and termination of SVT episodes are sudden, with episodes lasting minutes to hours and recurring sporadically at random, from once a year to once a day.<sup>98–102</sup> The natural course of the disease is variable, and increasing duration and frequency of episodes are possible as the patient ages.<sup>98,100,101</sup> Patients have reported that SVT episodes are associated with a range of symptoms, from minimal, vague annoyances to pronounced, disabling symptoms.<sup>98–103</sup> The most common symptoms seen clinically in SVT patients appear to be palpitations, dizziness/pre-syncope, anxiety, and dyspnoea,<sup>98–108</sup> but frank syncope and sudden death have also been reported in patients with Wolff–Parkinson–White (WPW) syndrome.<sup>100,109,110</sup> A sensation of neck pounding has been noted as a distinguishing feature of AV nodal re-entrant tachycardia.<sup>106,107</sup> Patients have reported the most common and burdensome symptoms to be palpitations, fatigue, and dyspnoea with exertion; while rarely seen and much less burdensome symptoms included chest pain, dyspnoea at rest, dizziness, and diaphoresis.<sup>99,101,103,111,112</sup> The actual physical symptoms, as well as anticipatory fear and anxiety relating to when the next episode will occur, can be very disabling to patients, influencing their daily lives,<sup>99–101,103,104,111,112</sup> with patients reporting a reduction in their usual activities for a mean of 7 days per month prior to ablation treatment.<sup>99,112,113</sup>

Researchers have noted that patients with SVTs often know very little about the course of the disease, patient management strategies, and various treatment options.<sup>99,101,112,113</sup>

Of note, women with SVTs, as with other cardiac conditions, have a more difficult time obtaining a correct diagnosis and accessing invasive treatment.<sup>101,104,106,114</sup> Misdiagnosis of SVT as a panic attack in women is not uncommon.<sup>101,104</sup> Female patients with SVTs report being discounted and disbelieved in their efforts to obtain an initial diagnosis, taking longer than male SVT patients to access treatment.<sup>101,114</sup> It remains unclear whether the misdiagnosis and delay in accessing treatment for female SVT patients stems from a difference in physiological symptomatology, communication differences in how genders describe their symptoms, or providers’ gender bias in referring female patients for treatment.

The main goals of care should be symptom relief and curative ablation treatment when appropriate. Multiple studies have found improved QoL and decreased symptoms after ablation treatment for patients with SVTs.<sup>98,106,111,113–121</sup>

**Patient’s values and preferences for acute and chronic treatment**

**Lifestyle modifications**

Negative effects on abilities to carry out daily activities due to an SVT have been commonly reported.<sup>100,101,105,108,112</sup> Supraventricular

tachycardia has a significant impact on QoL<sup>111,113</sup> and can have a profound psychological effect on patients considering or involved in careers as athletes or in high-risk professions; however, the current management with catheter ablation leads to substantial improvement for many patients (see 'Patient's values and preferences for treatment of supraventricular arrhythmias associated with increased occupational hazard' section).<sup>98,122,123</sup> Patients report that SVT affects their recreational activities, enjoyment of life, mood, work, and sexual relationship with their significant other; however, the activities most affected were the ability to drive a car and participate in social activities. Researchers have reported that the influence of syncopal and pre-syncopal symptoms forces patients to change their driving habits.<sup>105,108,112</sup> Women reported syncope or near-syncope significantly more often than men, and 42% of the women had stopped driving because of fear of having these symptoms while driving.<sup>108</sup> Other studies have reported that 27–35% of SVT patients have stopped driving completely due to SVT symptoms.<sup>105,112</sup> Interference was also noted in personal relationships with significant others and the ability to sleep.<sup>99,100,108,112,113,121</sup> Patients with SVT also reported having to miss work or school and reduce activities they would normally have participated in for a mean of 9 days per month due to their SVT.<sup>99,112,113</sup>

When patients with different SVTs were compared, patients' lives were significantly more influenced by atrial tachycardia and inappropriate sinus tachycardia than with AV nodal re-entry tachycardia or AV re-entry tachycardia in WPW syndrome.<sup>100,101,112</sup>

### Antiarrhythmic drugs

Given that catheter ablation of supraventricular arrhythmias is highly effective and widely available, management of patients with supraventricular arrhythmias needs to include patients' values and preferences relative to available treatment options.<sup>124</sup>

Data derived mostly from AF studies show that QoL is altered in patients with supraventricular arrhythmias<sup>1,124</sup> but the contribution of the antiarrhythmic drug (AAD) therapy to reduced QoL is unclear,<sup>2</sup> with QoL appearing to be more affected in females.<sup>2,5</sup> Limited data show that the degree of satisfaction related to the pharmacological treatment in patients with supraventricular arrhythmias is generally low<sup>125</sup> which may result in reduced adherence. Understanding which outcomes are relevant to the patients with supraventricular arrhythmias can help the practitioner in developing reliable decision aids.<sup>126</sup>

A survey of AF patients and cardiologists demonstrated that physicians do not have good awareness of their patients' knowledge about treatment options, underestimating the benefits and overestimating the side effects of antiarrhythmic therapy.<sup>21</sup>

The adherence to AAD after hospitalization in the intensive care unit seems to be better than in the non-intensive care setting.<sup>127</sup> In the long-term, high rates of AAD treatment discontinuation within the first year of administration<sup>128</sup> and during the second year of follow-up are reported.<sup>129</sup>

A meta-analysis addressing the non-adherence to digoxin in patients with HF and/or AF found the rate of non-compliance to be as high as 43%. Of the 24 possible responsible factors, many were related to patients' values, such as understanding the medication or the illness, consultation duration or number of consultation visits, QoL or self-management of medication.<sup>130</sup>

Methods proposed for improvements of adherence to AAD in supraventricular arrhythmias were: closer monitoring of the treatment,<sup>131</sup> the use of an interactive voice response system,<sup>132</sup> or a computerized template with decision support included.<sup>133</sup>

### Catheter ablation

The main indication for ablation of SVT is symptomatic relief. Supraventricular tachycardia exerts a pronounced impact on QoL, affecting the patients' physical and psychological health, social relationships, and lifestyle.<sup>98,134</sup> Catheter ablation of SVTs is associated with over 95% success rates and <2% complication rates, thus improving QoL; this benefit has also been observed in paediatric patients.<sup>135–137</sup>

Significant improvement after ablation of SVT was noted in virtually all measures regarding physical, emotional, and social functioning.<sup>113,121,138,139,139a</sup> The high acute success of SVT ablation often persists for years after the procedure and translates into a significant improvement of QoL in most patients.<sup>117,121,140</sup> Compared with pharmacological therapies, catheter ablation was associated with greater improvement in QoL and symptom relief both in patients with highly symptomatic monthly episodes of SVT and in those with mildly to moderately symptomatic less frequent SVT.<sup>113,117</sup>

A systematic review of the cost-effectiveness of radiofrequency catheter ablation for treatment of SVT in adults concluded that catheter ablation is likely to be economically attractive compared with drug therapy in adult patients with frequent symptomatic SVT.<sup>141</sup>

## Patients' experiences of living with Wolff–Parkinson–White and preferences for treatment

Most of what we know about symptomatic WPW patients' experiences is what we can glean from studies with mixed SVT patient cohorts. The vast majority of patients with WPW are healthy, young adult males with no underlying cardiac or other co-morbid conditions<sup>98</sup>; however, WPW patients more typically present earlier than other SVT patients—from childhood up to late 20s.<sup>98,100,101,142</sup> These patients have the same lack of understanding about their condition as other SVT patients and the same need for information about treatment options from providers to make decisions about their care (see *Table 5*),<sup>101,111,113</sup> which is all the more pertinent given their propensity for increased risk of sudden cardiac death (SCD). Multiple studies have found improved QoL and decreased symptoms after ablation treatment for patients with SVT.<sup>98,111,113,114,120,142</sup>

There are no studies that report patient experiences with asymptomatic WPW. However, these patients may first present with HF (so-called arrhythmia-induced cardiomyopathy) resulting from altered ventricular synchrony caused by pre-excitation,<sup>143–145</sup> or even with SCD due to paroxysmal AF degenerating into ventricular fibrillation.<sup>146</sup> Although non-invasive exercise stress testing has been recommended as an initial step to identify candidates for invasive electrophysiology and/or catheter ablation of the accessory pathway,<sup>147</sup> risk stratification of asymptomatic WPW patients is variably applied in routine practice.<sup>148</sup>

Asymptomatic adult WPW patients or parents of the child with accidentally diagnosed asymptomatic WPW syndrome may have

**Table 5** Key discussion points for patients with a supraventricular arrhythmia at an initial consultation/follow-up consultation

- What causes the arrhythmia (with pictures for visual learners)
- Natural trajectory of the arrhythmia condition (increasing episode duration and frequency)
- Common symptoms and strategies for managing episodes
- New smart phone technology for monitoring and capturing episodes
- Explanation and demonstration of the various Valsalva manoeuvres
- Detailed explanation of treatment options (efficacy of drug therapy; procedure and efficacy of ablation)
- Psychosocial aspects of living with SVT
- How to know if the treatment is not working
- Action plan
- Pre-requisite tests for ablation
- What to expect in the immediate post-ablation period (symptoms; medications; physician follow-up; when to return to work, sports, lifting heavy items, sexual activity)
- When to seek emergency care
- Need for further drug therapy after ablation
- Offer links to patient support groups

**Table 6** Links to information for patients with Wolff–Parkinson–White syndrome and patients' experiences<sup>a</sup>

- Patient information
- <http://www.aa-international.org>
  - <http://www.childheartassociates.com/patient-information/svt-wolff-parkinson-white-syndrome/>
  - <http://www.patient.co.uk/health/wolff-parkinson-white-syndrome-leaflet>
- Patient experiences/forums
- <https://healthunlocked.com/heartrhythmcharity>
  - [http://www.medicinenet.com/wolff-parkinson-white\\_syndrome/patient-comments-1555.htm](http://www.medicinenet.com/wolff-parkinson-white_syndrome/patient-comments-1555.htm)
  - <http://www.patient.co.uk/forums/discuss/browse/wolff-parkinson-white-syndrome-2461>

<sup>a</sup>This is not an exhaustive list.

difficulties in accepting treatment with an invasive procedure such as catheter ablation (when advised), and more information is needed to assist their decision-making. *Table 6* lists some websites with educational and supporting content that may be useful for patients.

## Patient's values and preferences for treatment of supraventricular arrhythmias associated with increased occupational hazard

There is currently limited evidence to address patient values or preferences in this area based on the paucity of peer-reviewed published studies from the patient's perspective; however, there are consensus papers and scientific statements that guide management of these individuals.<sup>98,122,123</sup> Although researchers have concluded

that asymptomatic WPW individuals should generally be offered catheter ablation only under special circumstances, such as a family history of SCD, high-risk professions (pilot, miner, operator of heavy industrial equipment, etc.) and in athletes, many physicians recommend that the majority of patients with a pre-excitation electrocardiogram (ECG) pattern are treated by catheter ablation on the grounds that risk stratification is uncertain and a therapy is available which is both effective and safe. However, the latter approach is not evidenced-based and cannot be justified from the cost-effectiveness point-of-view.<sup>98,122,123</sup>

The success rates, risks, and other lifestyle considerations, including the potential cure for a chronic illness, are important issues when deciding whether a particular patient is a candidate for catheter ablation therapy.<sup>98,122,123</sup> A thorough understanding of the current state of catheter ablation therapy is critical to the recommendation of this procedure to the family of an asymptomatic paediatric patient with WPW syndrome. Patients participating at moderate–high level competitive sports should be counselled with regard to risk–benefit of ablation (Class IIA) and guidance should follow the recommendations of The European Task Force on SCD.<sup>149</sup>

A history of asymptomatic SVT or any arrhythmia arising from the atria, as well as ablation treatment, are disqualifying criteria in the Federal Aviation Administration for all flying class duties in the U.S. Air Force, Navy, and Army.<sup>150,151</sup> A waiver from these procedures may be considered after a 4-month post-ablation observation period. Only asymptomatic cases are considered for waiver after a 6-month grounding period, as symptoms are an indication of haemodynamic compromise.<sup>151</sup>

## Advice and recommendations for patients with supraventricular arrhythmias

In order to make informed choices about treatment options, patients need information about the natural course of their arrhythmia, what the various treatment options offer, and how their symptoms and QoL could change following these treatments. Although patient symptoms are greatly improved following ablation, in the majority of patients, patients should be prepared to experience isolated feelings of 'heart flutters' or 'skipped heartbeats' in the initial few weeks after ablation that should gradually disappear.<sup>98,101,113</sup>

## Ventricular arrhythmias

### Patients' experiences of living with ventricular arrhythmias

Ventricular arrhythmias include a wide spectrum of cardiac rhythm disturbances ranging from single premature ventricular complexes (PVCs) to sustained ventricular tachycardias (VTs). Ventricular arrhythmias may occur in apparently healthy individuals, either heralding the presence of previously undiagnosed underlying heart disease including congenital arrhythmogenic syndromes, or being referred to as 'idiopathic' in patients with no evidence of structural or other cardiac disorder. Life-threatening VTs usually occur in patients with underlying cardiac diseases, whereas idiopathic VAs generally confer a favourable prognosis.

However, patients may not be aware of these key differences, and the sense of very fast or irregular heartbeats may be equally frightening for otherwise healthy individuals and for those already experiencing symptoms of myocardial ischaemia or HF. It has been shown that patients with a range of cardiac arrhythmias suffer from frequent and disabling symptoms.<sup>99</sup> Indeed, post-catheter ablation, patients with frequent PVCs experienced symptom relief comparable with those with non-sustained or sustained VTs.<sup>152</sup>

Single PVCs represent one of the most common cardiac rhythm disorders in adults, occurring not only in patients with underlying cardiac or other diseases but also in ~80% of apparently healthy individuals undergoing 24–48-h ambulatory monitoring.<sup>153</sup> Regardless of the presence or absence of underlying cardiac disease, patients with PVCs may experience palpitations (resulting from the post-PVC hyper-contractility) or a sense that the heart stops beating (secondary to a post-PVC pause). The symptoms may be particularly prominent in a quiet environment (e.g. when resting) or when patients are lying on their left side and the heart is closer to the chest wall. Less often, frequent PVCs may cause a sensation of neck pulsation, light-headedness or even pre-syncope. The sense of altered heart beating may create pronounced fear and anxiety and a vicious cycle of anxiety, catecholamine surges and palpitations, and in some cases the cycle might be broken with authoritative reassurance.

On the other hand, many patients (particularly those with a structurally normal heart) have asymptomatic PVCs that are accidentally diagnosed during examination for other reasons. Although single PVCs, even if frequent, usually do not cause immediate true haemodynamic disturbance in patients with normal left ventricular

function, chronic frequent asymptomatic ventricular extrasystole arrhythmia may eventually result in so-called 'PVC-associated cardiomyopathy' with reduced left ventricular systolic dysfunction.<sup>154–156</sup> Hence, those patients may first present with symptoms of HF.

Similar to patients with AF, VA patients need more education on their condition, treatment options, and prognosis. An example of a patient's experience with VT is shown in [Box 5](#), and issues to be discussed with VA patients are listed in [Table 7](#).

## Patient experience of living with inherited arrhythmias (long QT syndrome and short QT and Brugada syndrome)

### Lifestyle modification

Dependent on the type of inherited arrhythmia and subsequent treatment [e.g. implantable cardioverter-defibrillator (ICD) implantation], specific lifestyle recommendations apply. The extent of modifications depends on the patient's lifestyle. Careful consideration of daily routine, social, and occupational (aspirational) aspects of each individual is therefore of key importance to optimize adherence to these recommendations (see [Table 8](#)).

The recommendations also vary in type, ease with which to comply, and to a certain degree in significance. For instance, there may be restrictions. Rather straight forward and 'easy' to comply with are an absolute ban of (specific type of) sports or activities (e.g. driving). On the other hand, the recommendation to avoid stress (e.g. in Long QT syndrome) is much more difficult to translate into practical 'do's and don'ts' and more challenging to adhere to.

Apart from refraining from and/or avoiding situations, inherited arrhythmias might also require the patient to come into action (more than usual) for example, seeking medical attention in case

### Box 5 58-year-old male patient with a VT<sup>a</sup>

He was very active (running, soccer, and weightlifting) and had been healthy. Over the past several months he had experienced a steady decline in stamina and underwent several tests to try to find the cause. Finally, one evening he was trying to play soccer again and a doctor took his pulse and detected an abnormal rhythm. He was happy that he might have discovered the cause of his problems. However, that night he felt like his heart was going to jump out of his throat and the next morning he went to the ER. They restored his normal heart rhythm and confirmed that he had no blockages in his heart and that the heart muscle was fine. Ablation was attempted but was not successful and later they inserted an ICD. Unfortunately he continues to have symptoms plus minor chest pain. He is frustrated because the doctors seem very reluctant to allow him to do anything—no driving, no weightlifting (leisurely walks are ok). He is concerned that the rest of my life is going to be spent in an easy chair. He wonders about alternative treatment options. He questions if all VT patients so restricted and if this all he has to look forward to?

<sup>a</sup>modified from <http://www.medhelp.org/posts/Heart-Disease/How-do-you-live-with-ventricular-tachycardia/show/40523>

### Table 7 Key topics to discuss with a patient with a ventricular arrhythmia at initial and follow-up consultations<sup>a</sup>

- What is VT?
- What are the symptoms of VT?
- What are the complications of VT?
- How is VT diagnosed?
- What are the risk factors for VT?
- What are the treatment options for VT?
- How common is VT?
- What medications are used for VT and what side effects should the patient watch for?
- What are the risks of VT if left untreated?
- What is an electrophysiologist and when should the patient see them in addition to his/her general cardiologist?
- When will the patient need a pacemaker or defibrillator for VT?
- What is the difference between a pacemaker and a defibrillator?
- How often should the patient with VT be seen by a cardiologist?
- Should patients with VT limit their physical activity?
- Psychosocial aspects of living with VT
- What should patients do in an emergency situation?
- Include information on further resources from Patient Groups

<sup>a</sup>Modified from [www.cardiosmart.org/Heart-Conditions/Ventricular-Tachycardia/Questions-to-Ask-Your-Doctor](http://www.cardiosmart.org/Heart-Conditions/Ventricular-Tachycardia/Questions-to-Ask-Your-Doctor).

**Table 8** Key topics to discuss with a patient with an inherited arrhythmia at initial/follow-up consultations

- Clear explanation of diagnosis
- Provision of a list of drugs to be avoided
- Risk–benefit (e.g. with ICDs)
- Genotype–phenotype relationship
- Degree of work-up for risk assessment
- Familial screening
- Restrictions to daily activities, occupation, and social life
- Patient education about treatment options

of fever in Brugada syndrome. Another more ambivalent example is awareness of (over the counter) drugs (e.g. antibiotics, local anaesthetics, diuretics, etc.) which might provoke a pro-arrhythmic environment.<sup>157,158</sup> Here, an apparent need to treat comorbidities must be weighed against the potential harm. In case of psychological problems, given their mode of action, most anti-depressant and anti-psychotic drugs are not recommended in patients with inherited arrhythmias. Non-drug-based treatment, e.g. psychotherapy and cognitive behavioural therapy, is thus preferred and can fortunately be of benefit.<sup>159</sup>

In the absence of suitable alternative therapies for associated comorbidities, it is important to remain cautious. In addition, in the case of Brugada syndrome most of the evidence of drugs causing Type I ECGs is based on stand-alone case reports.<sup>157</sup> Cessation or withholding of certain drugs (essentially all drugs acting as sodium-channel blockers) might subsequently lead to unnecessary under-treatment and a potentially pro-arrhythmic milieu on its own (i.e. in case of hypertension or ischaemic heart disease).

### Psychological response to inherited arrhythmias and quality of life

Inherited arrhythmias have a profound impact on the patients' sense of 'taking normal life for granted'. In adolescents, not being able to participate in routine daily activities creates a feeling of not being normal compared with peers which is (partially) relieved by ICD implantation providing a sense of independence and support.<sup>160</sup> Whereas adults experience a loss of independence associated with work and driving-related restrictions.<sup>161</sup>

Patients with a known increased risk of life-threatening arrhythmias experience higher levels of anxiety compared with their peers and those with a clinical diagnosis opposed to patients at genetic risk suffer more fear.<sup>162</sup> A recent SCD in the family may lead to increased general anxiety and depression.<sup>162</sup> Importantly, a familial history of SCD in the 'elderly' Brugada syndrome patient does not imply an increased risk of such an event for that individual.<sup>163</sup>

Also, a substantial number of patients find information about both the purpose of genetic testing and their cardiac disease difficult to understand. A high level of anxiety about genetic testing and cardiac symptoms may lead to distress and confusion,<sup>164</sup> whereas a positive genetic result by itself may not necessarily impact patient well-being negatively.<sup>165</sup>

Thus, clear communication of arrhythmia-specific risk stratification is also important to help temper the psychological response.

### Key discussion points for patients with an inherited arrhythmias at initial and/or follow-up consultations

For key topics to discuss with a patient with an inherited arrhythmia at initial/follow-up consultations, see *Table 8*.

## Patients' understanding and experiences with treatment modalities for ventricular arrhythmias

### Implantable cardioverter-defibrillators for primary and secondary prevention

When a patient has to make the decision whether or not to have an ICD implanted, patient preferences and values may vary depending on whether the indication is related to previous experience of life-threatening VAs or SCD (i.e. secondary prevention indication) or to a prophylactic indication (i.e. primary prevention indication). Obviously, the patient's age as well as the clinical context, and particularly the presence or absence of left ventricular dysfunction related to structural heart disease, may modulate the reasonable expectations of patients and physicians. When patients are affected by purely electrical disease (e.g. channelopathy) ICD can be considered as a rescue treatment able to confer a near-normal life expectancy through its powerful impact on the reduction in the risk of SCD. The key elements of discussions with patients receiving an ICD are given in 'Critical elements of discussions regarding implantable cardioverter-defibrillator implantation' and 'Important questions for patients to ask their doctor/healthcare professional' sections. Implantable cardioverter-defibrillator implantation is associated with increased confidence in the recipient and 'carries' a sense of happiness with having the device.<sup>166</sup> However, up to one in four ICD recipients report some type of psychological distress following implantation,<sup>167</sup> which may not necessarily be attributed to the device but also the patients' pre-implant psychological make-up.<sup>168</sup>

Besides unique psychological disturbances such as altered body image,<sup>161</sup> ICD implantation in particular imposes anxiety and depression related to the unpredictable nature of (future) shocks.<sup>169–171</sup> The observation that, among others, limited understanding of the underlying medical condition and the ICD's function and purpose increase the risk for psychological distress again highlights the importance of adequate patient education and doctor–patient communication.<sup>161</sup>

However, given that the number of inappropriate ICD shocks is an independent predictor of overall psychological distress<sup>172</sup> there are also important technical considerations. This requires dedicated cardiologists/electrophysiologists to allow device adaptations such as limiting T wave over-sensing, only programming a ventricular fibrillation zone at high frequencies (i.e. >210) in case of high physiological heart rates, the use of anti-tachycardia pacing for VT and considering subcutaneous ICD devices given potential lead problems with subsequent replacements is important.

In patients with structural heart disease and left ventricular dysfunction, the ICD can be considered as one of the options for improving outcome, unfortunately acting only on ventricular tachyarrhythmia-related SCD.<sup>166</sup> These differences in expectations may translate into different patient values. Generally, there has been a tendency to believe that patients with a secondary prevention ICD

indication do worse and report more distress and poorer QoL than patients with a primary prevention indication. This is not supported by the literature,<sup>173–175</sup> while partners of patients with a secondary prevention ICD might be more anxious than partners of patients with a primary prevention indication.<sup>176</sup>

Direct or indirect experience with appropriate or inappropriate shocks delivered by the device, particularly if clustered into storms, will likely translate into anxiety and depression.<sup>177</sup> In the terminal phase of severe HF or any other life-limiting illness, issues related to QoL and having a ‘good’ death may prevail, leading to the issue of request for ICD deactivation.<sup>178</sup> In this context, discussion with patients and their relatives about their wishes in the terminal phase is paramount, and should be discussed well ahead of time and not at the moment when the decision has to be made.<sup>179,180</sup>

**Psychological responses to phantom shocks and electrical storm**

The impact of shocks on patients’ well-being has received considerable attention in the arrhythmia literature. Most evidence is available on the role of single shocks, and this is mixed.<sup>171</sup> Single shocks may lead to increased distress and poorer QoL in individual patients,<sup>170,181</sup> but overall the majority of patients with an ICD do well with little change in their psychological functioning during the first 12 months post-implantation.<sup>168</sup> Other factors such as symptomatic HF, comorbidities, and personality may be equally important determinants of patient well-being as shocks.<sup>171,182–184</sup> The risk of post-traumatic stress and extreme thoughts of wishing to be dead or to have the ICD explanted may increase if the patient moves on the continuum from no shock to multiple shocks, including electrical storm.<sup>177,185</sup> An electrical storm is defined as three or more ventricular tachyarrhythmias within a 24-h period which are terminated with anti-tachycardia pacing, shock, or left untreated.<sup>186</sup> Little systematic evidence is available on the impact of electrical storm on patient well-being,<sup>187</sup> with the primary focus having been on its demographic and clinical predictors.<sup>188–190</sup>

Phantom shock is another device-related aspect that a minority of patients (5–25%) experience.<sup>191–193</sup> It refers to patients’ experiences and beliefs that they have received an ICD discharge, while this is not supported by device interrogation. Although an older, smaller study confirmed an association between phantom shock and psychological distress,<sup>194</sup> this was not supported in two more recent and larger studies.<sup>191,193</sup> A study describing the subjective experiences of patients having received a phantom shock indicates that their emotional impact may be similar to that of an objective shock, and include anxiety, uncertainty, and distrust in the device.<sup>190</sup> Potentially, the distress-phantom shock hypothesis might be bidirectional, with distress, such as anxiety, post-traumatic stress, and depression, leading to a greater risk of phantom shock, while phantom shock may also lead to greater levels of distress and poorer patient-reported QoL.

**Strategies to manage patients’ psychological distress**

In order to help patients to adapt to life with an ICD and prevent distress becoming chronic and interfering with patient’s daily living and QoL, the following recommendations to manage distress are suggested (see Table 9). Table 11 provides useful patient resources and links to patient organizations.

**End-of-life decisions**

An ICD does not confer immortality and in nearly all cases, the implanted ICD will be present at the time when the patient dies.

Disease progression in patients with advanced HF may reduce QoL. Goals of care in these patients can change such that the potentially life-saving therapy of the ICD, may no longer be desired. Terminal patients may come to view the ICD as a barrier to a ‘good’ death. Patients with a life-limiting disease may also fear becoming a burden to their family.<sup>198</sup>

In the last weeks of their lives, 27% of patients with an ICD receive a shock.<sup>199</sup> Shocks at the end-of-life may result in significant pain, unnecessary prolongation of suffering, and distress to the family. Avoiding these adverse outcomes requires advanced planning (see Table 10).

Although clinicians are aware that device deactivation is possible, most patients are not.<sup>200</sup> A significant minority (38%) of those patients who are aware of device deactivation express a preference for ‘turning off’ ICDs under specified circumstances,<sup>179,201</sup> such as when death is imminent. Impaired QoL is also a frequently (48%) cited reason for deactivation.<sup>200</sup> Most patients, however, do not communicate their preferences to their attending physician,<sup>202</sup> with only 27% of patients engaging in a discussion regarding deactivation of their ICD, and only one quarter of those discussions occurring in advance of an imminent death.<sup>179,199</sup>

Many patients prefer to discuss end-of-life planning at the time of diagnosis, and not when their capacity for decision-making is diminished.<sup>203</sup> As such, education regarding device deactivation should begin at the time of ICD implantation.<sup>179,201</sup> Any expressed preferences should be incorporated into the patient’s advanced directives, along with any expressed preferences regarding ‘Do Not Resuscitate’ status. This should be revisited when the patient has had any substantial change in his/her health status.

**Table 9 Recommendations to manage patient distress**

| Step 1  | Step 2   |
|---|--|
| (1) Establish a trustful relationship with patients (and their partners)<br>(2) Listen to patients and their stories<br>(3) Explore: <ul style="list-style-type: none"> <li>• Patients’ beliefs about their distress</li> <li>• Patients’ resources</li> <li>• Patients’ needs and preferences for further referral and intervention enabling targeted advice and intervention(s) to the individual</li> </ul> (4) Provide reassurance<br>(5) Provide information<br>(6) Together with the patient in a shared decision-making process make an action plan choosing from step 2 or suggestions provided by patients | <ul style="list-style-type: none"> <li>• Make a shock plan</li> <li>• psychological education</li> <li>• Support groups</li> <li>• Cardiac rehabilitation</li> <li>• Referral to a mental health professional for:                             <ul style="list-style-type: none"> <li>◦ Cognitive behavioural therapy</li> <li>◦ Mindfulness</li> <li>◦ Prescription of pharmacotherapy</li> </ul> </li> </ul> |

**Table 10** Critical elements of discussions with patients regarding ICD implantation

| Element             | Discussion points  |
|---------------------|--|
| Prognosis           | <ul style="list-style-type: none"> <li>Inform patient of their estimated risk of death using the SHFM score<sup>196</sup></li> </ul>   |
| Mode of death       | <ul style="list-style-type: none"> <li>Inform patient of the nature of a SCD</li> <li>Inform patient of their estimated risk of SCD using the SHFM Score<sup>197</sup></li> <li>Inform patient of the nature of a death from progressive HF</li> <li>Inform patient of their estimated risk of death from progressive HF using the SHFM score<sup>197</sup></li> <li>Elicit patient preferences regarding longevity of life vs. the potential for death from progressive HF</li> </ul> |
| Benefits of ICD     | <ul style="list-style-type: none"> <li>Inform patient of the predicted reduction in the risk of SCD</li> <li>Inform patient that an ICD does not prevent all SCDs</li> <li>Inform patient that an ICD does not prevent death from progressive HF or non-cardiac causes</li> </ul>  |
| Risks of ICD        | <ul style="list-style-type: none"> <li>Inform patient of the procedural risks (pneumothorax, tamponade, bleeding, and infection)</li> <li>Inform patient of the long-term risks (lead failure, battery depletion, device recalls, and inappropriate shocks)</li> </ul>   |
| Advanced directives | <ul style="list-style-type: none"> <li>Inform patient of the future option of device deactivation</li> <li>Elicit patient preferences in regards to resuscitation</li> </ul>   |

Notes: ICD, implantable cardioverter-defibrillator; SHFM, Seattle Heart Failure Model<sup>197</sup>

### End-stage heart failure vs. sudden cardiac death

Patients with advanced HF have a survival rate that approaches many forms of cancer, with a 50% five-year mortality on optimal medical therapy.<sup>204</sup> The primary cardiac causes of death in HF patients are SCD and death from progressive HF, with 39 and 27% of HF patients dying from SCD and progressive HF, respectively.<sup>205</sup> Implantable cardioverter-defibrillators reduce the risk of SCD by 60%, but they do not affect the likelihood of death from progressive HF.<sup>206</sup>

The proportion of HF patients who die from progressive HF rises with increasing severity of functional limitation. Progressive HF is the cause of death in 12% of patients with NYHA functional class II symptoms and 56% of patients with NYHA functional class IV symptoms.<sup>207</sup> Therefore, ICDs offer little benefit to patients with end-stage HF.<sup>206,208</sup> Current guidelines recommend ICD therapy in patients with NYHA functional class IV symptoms, only if they are ambulatory and have a reasonable life expectancy with good functional status for more than 1 year.<sup>209</sup>

Patients with end-stage HF can expect to experience symptoms of breathlessness, physical pain, fatigue, anxiety, nausea, oedema, constipation, loss of appetite, and sleeplessness during the last 6 months of their life.<sup>210</sup> The possibility of an ICD implant

introduces substantial implications for end-of-life planning. Patients and caregivers need to consider the trade-off between dying quickly from SCD vs. living longer with progressive HF.<sup>211</sup> In other words, patients should determine whether the quality of their life is worth extending; this should be an individual decision. Patients who are older, have multiple co-morbidities, or live with a high burden of daily symptoms will need to carefully weigh the longevity they would gain with an ICD against the potential for a protracted death from progressive HF.

### Antiarrhythmic drugs

Ventricular arrhythmias represent a heterogeneous entity, therefore clinical trials of treatment differ substantially. Current guidelines recommend the use of ICDs<sup>212</sup> as effective care<sup>213</sup> for long-term treatment in most patients with VAs. With the exception of beta-blockers, all AADs have limited indications in VAs and 'have not been shown to be effective in the primary management of patients with life-threatening VAs or in the prevention of SCD'.<sup>212</sup> However, AADs may be needed as an adjuvant therapy to ICD, to reduce the occurrence of VAs triggering the ICD activation or the number of shocks in case of electrical storm. There is also a paucity of research investigating patient's values and preferences for treatment which is partly explained by the fact that in many instances the decision for an AAD is dependent on objective criteria (e.g. prevention of SCD) and not on subjective symptom evaluation. Indirect data regarding patient's understanding of AADs in VAs come from qualitative studies of patients with ICDs.<sup>211,213</sup> There is no published study addressing the issues of patient's understanding of and preference for AADs only for the treatment of VAs. Furthermore, AADs (particularly amiodarone) bear the burden of significant side effects. Based on medication discontinuation rates, a study evaluating AAD use in patients without structural heart disease reports a very high rate of discontinuation.<sup>129</sup> Information regarding beta-blockers can be extrapolated from the trials in HF demonstrating at least a neutral effect on QoL.<sup>214</sup>

Single PVCs arrhythmia treatment may be challenging in daily clinical practice. Although single PVCs are often considered to have minimal clinical significance, particularly in patients with a structurally normal heart, the association of PVCs with increased mortality has been shown in both apparently healthy individuals and patients with underlying heart disease.<sup>215–220</sup> Unfortunately, there is no clear evidence that PVCs suppression reduces the mortality risk. The treatment of underlying heart disease (e.g. myocardial infarction, HF, etc.) will usually reduce the frequency of PVCs, thus attenuating the symptoms of arrhythmia. Patients with structurally normal hearts should first be advised to avoid known PVC triggers (e.g. alcohol, cocaine, heroin, amphetamines, caffeine, nicotine, cannabis, synthetic drugs, weight reduction drugs, anticholinergic agents, etc.) although such strategies are associated with a variable efficacy.<sup>221</sup> Thereafter, beta-blockers or calcium channel blockers may be used or, less often, other AADs may be needed to reduce the PVC burden and attenuate the symptoms. Should these therapies prove ineffective, highly symptomatic patients and those with asymptomatic frequent PVCs and left ventricular dysfunction should be considered for catheter ablation.

### Box 6 Questions patients may wish to ask their doctor/HCP

- Why has my doctor asked me to consider an ICD?
- Does an ICD require surgery?
- Can the ICD be taken out, or turned off?
- How will having an ICD affect my life?
- Is it okay to have sex when you have an ICD?
- How does it feel to get a shock?
- Will an ICD make me feel better?
- Will I live longer with an ICD?
- Would I survive a dangerous heart rhythm without an ICD?
- Can the ICD do 'something bad' to me? (inappropriate shocks, device infection, lead fractures)

#### Ablation

Catheter ablation has an increasing role in the treatment of various VAs. Although catheter ablation is generally more successful in patients with monomorphic, haemodynamically stable VAs, and a structurally normal heart, the procedure has been increasingly used as a first-line therapy for frequent single PVCs in highly symptomatic patients or asymptomatic patients with left ventricular dysfunction and for complex VAs, not only as an additional therapy to ICD, but also as a means of postponing the ICD implantation in selected patients (e.g. VTs in patients with coronary artery disease).<sup>222</sup> Patients who are considered for a VA ablation should be informed about the procedure-related risks [e.g. stroke (in <1% of cases) or pericardial effusion requiring intervention (in 1–2% of cases)], as well as the expected efficacy in terms of symptom relief and malignant VA/SCD risk reduction. Overall, the success of VT ablation depends on the underlying heart condition, and in patients with otherwise normal hearts the success rate exceeds 90%. In patients with structural heart disease (e.g. myocardial scar or cardiomyopathy), success rates are lower, ranging from 50 to 75% at 6–12 months. However, in the case of VT recurrence, most patients will still have less VT than before, and re-intervention may further improve the treatment efficacy.<sup>223,224</sup>

#### Revascularization for arrhythmia management

In patients with cardiac arrhythmias or left ventricular dysfunction, correction of myocardial ischaemia through revascularization is a crucial step of patient management, since it may allow for (i) improvement of ischaemia-related symptoms (angina), (ii) impairment of LV dysfunction if related to stunned or hibernated myocardium, (iii) reduction in the risk of VA secondary to symptomatic or silent ischaemia, and (iv) slowing of the progression of ischaemic heart disease. Revascularization can be achieved with coronary artery bypass graft (CABG) surgery or through percutaneous coronary intervention (PCIs). Consensus guidelines report specific recommendations for both these therapeutic options, either in the setting of urgent or elective indications to revascularization.<sup>48</sup> In some cases, when the indication to prefer one option above the other is not absolute, patients' preferences may become the basis of therapeutic choices. In such cases, shared decision-making should consider

the risks of the procedures (usually higher for CABG), the risk for repeat procedures (usually higher for PCI in view of the risk for restenosis), and the invasiveness of the procedures (higher for CABG), as well as the negative cosmetic effect of cutaneous sutures.

#### Critical elements of discussions regarding implantable cardioverter-defibrillator implantation

For critical elements of discussions about ICD implantation, see *Table 10*.

#### Important questions for patients to ask their doctor/healthcare professional

*Box 6* contains a list of suggested questions which patients considering/with an ICD may wish to ask their doctor or other healthcare professionals involved in their management.

#### Links to useful patient resources and patient advocacy groups and organizations

For useful links for patients with ventricular arrhythmias, see *Table 11*.

## Areas for future research

### General

- Cardiac arrhythmias clearly influence the QoL of affected individuals, while the extent of impairment depends on the rhythm disorder and individual patient characteristics. Available data suggest that QoL is not routinely assessed in clinical practice or clinical trials in patients with cardiac arrhythmias.
  - Identifying existing valid disease-specific questionnaire(s) to assess QoL, and if not currently available, developing and validating a disease-specific measure(s) would facilitate routine QoL assessment in patients with cardiac arrhythmias, with relevant implications for disease management.
- Anxiety and depression may be more frequent in patients experiencing cardiac rhythm disturbances. The prevalence and incidence of anxiety and depression in patients with cardiac arrhythmias is largely unknown (or underestimated), with the exception of those with ICDs. Identification of the true incidence and prevalence of pronounced adverse psychological responses in patients with various cardiac arrhythmias and development of appropriate interventions to reduce psychological distress (with determination of their efficacy and cost-effectiveness) is needed to optimize the effects of various arrhythmia treatment modalities and to improve the QoL of affected patients.
- Patients generally have insufficient knowledge on the cause(s), natural history, risk of complications, and treatment options regarding their cardiac rhythm disorder. Treatment modalities for cardiac arrhythmias are rapidly evolving, and patients' understanding of the disease and available treatment options (and their limitations) is essential for shared decision-making and adherence to treatment.
  - Thus, the development of structured educational arrhythmia-specific programmes and integrated care programmes, with evaluation of their efficacy and cost-effectiveness against usual care is warranted.



**Table 11 Useful patient resources and patient advocacy groups and organizations<sup>a</sup>**

## Patient organizations

Arrhythmia Alliance: <http://www.hearrhythmcharity.org.uk/www/index.php>

The Mended Hearts: <http://mendedhearts.org>

Women Heart: <http://www.womenheart.org>

<http://www.stin.nl> [Dutch]

<http://www.hjerteforeningen.dk/> [Danish]

Sudden Death Cardiac Arrest Association: [http://www.suddencardiacarrest.org/aws/SCAA/pt/sp/home\\_page](http://www.suddencardiacarrest.org/aws/SCAA/pt/sp/home_page)

<http://www.brugadadrugs.org>

<http://www.torsades.org>

## Useful resources for patients

American Heart Association Resources and FAQs - [http://www.heart.org/HEARTORG/Conditions/Arrhythmia/Arrhythmia\\_UCM\\_002013\\_SubHomePage.jsp](http://www.heart.org/HEARTORG/Conditions/Arrhythmia/Arrhythmia_UCM_002013_SubHomePage.jsp)

Arrhythmia Alliance: <http://www.aa-international.org>

CardioSmart: <https://www.cardiosmart.org>

Heart Rhythm Society Patient resources: <http://www.hrsonline.org/Patient-Resources#axzz3Kyq5K9xk>

Patient.co.uk: <http://www.patient.co.uk/health/abnormal-heart-rhythms-arrhythmias>

<http://www.s-icd.eu/>

American Heart Association HeartHub for Patients: <http://www.hearthub.org/>

<http://icdapp.com/>

<http://www.symplur.com>

<https://patientdecisionaid.org/>

## Literature for patients

Hazelton AG *et al.* Cardiology patient page coping with my partner's ICD and cardiac disease. *Circulation* 2009;120:e73–6.

Sears SF *et al.* Cardiology patient page how to respond to an implantable cardioverter-defibrillator shock. *Circulation* 2005;111:e380–2.

<sup>a</sup>This is not an exhaustive list.

- Many aspects of patient values and preferences are ethnicity- and culture-specific. Prospective evaluation in different ethnicities and cultures would inform a generalisable approach to patient management.
- Patient-reported outcomes (PROs) are defined as the patient's direct responses and interpretation regarding their health and healthcare<sup>225</sup> and typically include symptoms and QoL.
  - The incorporation of PROs as measures of healthcare success and satisfaction is gaining momentum and future research on cardiac arrhythmias should consider inclusion of PROs as outcome measures to enable a better understanding of the impact of interventions on patients with cardiac arrhythmias.
- To develop integrated care programmes (utilizing cardiologists, specialist nurses, other physicians, and healthcare professionals) for the management of AF incorporating standardized specific topics for patient education (e.g. self-screening for AF in vulnerable populations, explanation of rate or rhythm control concepts, stroke risk explanation, education on OAC, and the importance of adherence to treatment, use of patient decision aids) and to evaluate the efficacy and cost-effectiveness of such programmes against usual care.
  - Any shared care pathways need prospective validation against patient-centred outcomes, as well as surrogates for efficacy and safety, for example, quality of anticoagulation control (as reflected by the average individual TTR) in AF patients.

## Atrial fibrillation

- Research suggests that QoL is impaired in patients with AF but QoL is not routinely assessed in clinical practice or clinical trials. Identifying existing valid disease-specific questionnaire(s) to assess QoL, and if not currently available, to develop and validate a disease-specific measure.
- To identify the prevalence and incidence of anxiety and depression in the 'general' AF population and to develop appropriate interventions to reduce psychological distress and to determine their efficacy and cost-effectiveness.
- To assess the impact of the NOACs on PROs in routine clinical practice and the effect on medication adherence.

## Supraventricular arrhythmias

In addition to a structured educational programme, patients with supraventricular arrhythmias may benefit from a standardized follow-up programme addressing their QoL, misperceptions of the disease, treatment effects, etc. Patients who have undergone successful catheter ablation treatment may need a periodical reassurance of their optimal health status and/or follow-up with screening for arrhythmia recurrence (or new arrhythmia development). The structure of such measures, their impact on the patient's QoL and overall cost-effectiveness needs prospective evaluation.

## Ventricular arrhythmias

- Patients with VAs comprise a very heterogeneous population with respect to individual cardiovascular status, risk of sudden death, and overall prognosis. Hence, they may need a range of supportive interventions starting from simple reassurance of their low risk status and favourable prognosis to shared decision-making about complex treatment procedures or even end-of-life decisions.
- More research is needed to identify the optimal way to communicate complicated key messages at a patient-specific level throughout the process (e.g. pre- and post- i.e. ICD implantation, genetic testing, etc.), including structured education programmes, definition of healthcare providers responsible for providing patients relevant information at each stage (e.g. trained nurses, family physicians, general practitioners, general cardiologists, electrophysiologists, HF specialists, etc.) or dedicated to provide psychological support, etc. Ideally, standardized protocols for communicating relevant information to each subgroup of patients with VAs (i.e. patients with idiopathic VAs, those with inherited genetic arrhythmic syndromes or patients with underlying structural heart diseases), at each stage of their disease would be prospectively evaluated against usual care in adequately powered trials.

### Consensus statements

- Education is an essential component of the management of cardiac arrhythmias to enable patients (and their carers/family members) to understand their condition, the available treatments, disease trajectory, and possible outcomes.
- All patients should receive individually tailored disease- and treatment-specific information from their healthcare team which is reiterated over time and when new management strategies are discussed.
- Patients' preferences for treatment should be discussed, documented, and incorporated into management decisions.
  - Shared decision-making should be the approach adopted to accomplish this target; incorporating both the patient and the physician/healthcare professional, mutual shared information, bilateral (patient and physician) deliberation about preferences and options, and reaching a shared treatment decision (including no treatment as a possibility).
- Regular audit and review of patient pathways and shared care management is necessary.
- Patient representatives should help contribute to arrhythmia guideline development and their implementation.

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