

Cardiac tachyarrhythmias and patient values and preferences for their management

European Heart Rhythm Association (EHRA) document endorsed by the Heart Rhythm Society (HRS), Asia-Pacific Heart Rhythm Society (APHRS), and Sociedad Latinoamericana de Estimulación Cardíaca y Electrofisiología (SOLEACE)



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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www.escardio.org/EHRA



Document objectives

- To comprehensively review published evidence on patient values and preferences for the management of cardiac tachyarrhythmias
- To provide up-to-date consensus recommendations for use in clinical practice



Content of the document

- Patients' experiences of living with various cardiac tachyarrhythmias and their treatment preferences
- Covers **atrial fibrillation, supraventricular arrhythmias and ventricular arrhythmias**
- Identifies gaps in knowledge to help inform clinical practice and future research
- Key discussion points for patient consultations
- Provides links to arrhythmia-specific resources



Introduction

Cardiac tachyarrhythmias:

- are recurrent or chronic and in some cases life-threatening
- often highly symptomatic
- the psychological impact of the disease can be significant
- Patients' beliefs and knowledge influence health behaviours
- Important to acknowledge and understand the impact of cardiac tachyarrhythmias **on the patient**



Structure of this presentation

- Atrial Fibrillation
- Supraventricular Arrhythmias
- Ventricular Arrhythmias
- Areas for future research
- Consensus statements



Patients' experiences of living with AF

- Generally lower health-related quality of life (QoL) compared to healthy controls
- 33-50% of symptomatic patients with AF suffer from psychological distress
- At core of patient-centred care is an understanding of how AF affects **EACH** patient
- Difficulties and delays in AF diagnosis
- Patient stories in the document illustrate their experiences



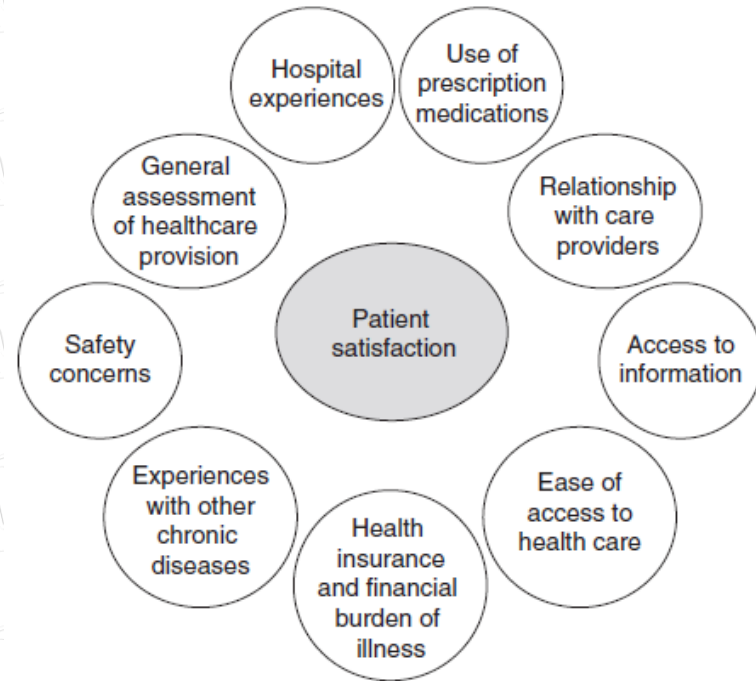
Patient's understanding of AF and preferences for treatment

- Little evidence on rate- or rhythm-control management
- Evidence on patient preferences for treatment focuses on antithrombotic therapy/oral anticoagulation (OAC)
- Generally poor patient awareness of AF and increased stroke risk associated with AF
- Shared decision-making is the 'patient-focussed' approach but may not be appropriate and/or desired by all patients
- Patients prefer education about AF and its treatment to be provided by physicians and/or healthcare professionals and for this to repeated over time



Patient perspective on the management of AF in 5 European countries: EUPS-AF

- 1500 AF patients
- Mean (SD) age: 70.1(12.5) years; 49.8% male
- Average 6 prescription medications regularly
- Factors affecting patient satisfaction were **lack of**:
 - engagement in medication reviews
 - education
 - involvement in decision-making
 - self-management
- Education about AF management should include family and carers



Bakhai et al. *BMC Cardiovasc Dis.* 2013;13:108

AF patients' attitudes towards stroke prevention and bleeding risk

- Patients perceive moderate-major stroke as equivalent/worse than death¹
- Stroke prevention is most important to AF patients¹
- 12% were medication adverse even if oral anticoagulation was 100% effective against stroke¹
- Patients required a 15% risk reduction in stroke risk to motivate them to initiate antithrombotic therapy¹
- Patients willing to endure **4 major bleeds to prevent 1 stroke**¹

¹LaHaye S et al. *Thromb Haemost* 2014; 111:465-73



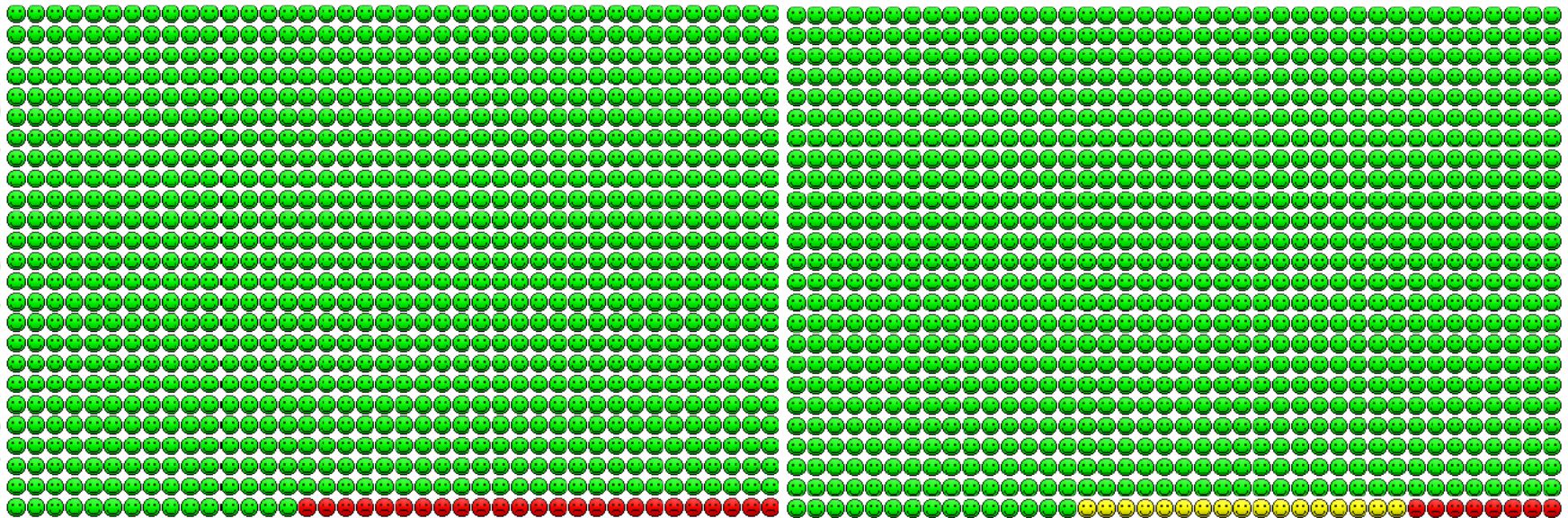
Patient decision aid for AF

Example of a patient decision based on stroke risk with and without anticoagulation

www.nice.org.uk/guidance/cg180/resources/cg180-atrial-fibrillation-update-patient-decision-aid2

No treatment: CHA₂DS₂-VASc score 2

Anticoagulant: CHA₂DS₂-VASc score 2



If 1000 people with AF and a CHA₂DS₂-VASc score of 2 take NO anticoagulant, over 1 year on average:

- 975 people will NOT have an AF-related stroke (green faces)
- 25 people WILL have an AF-related stroke (red faces)

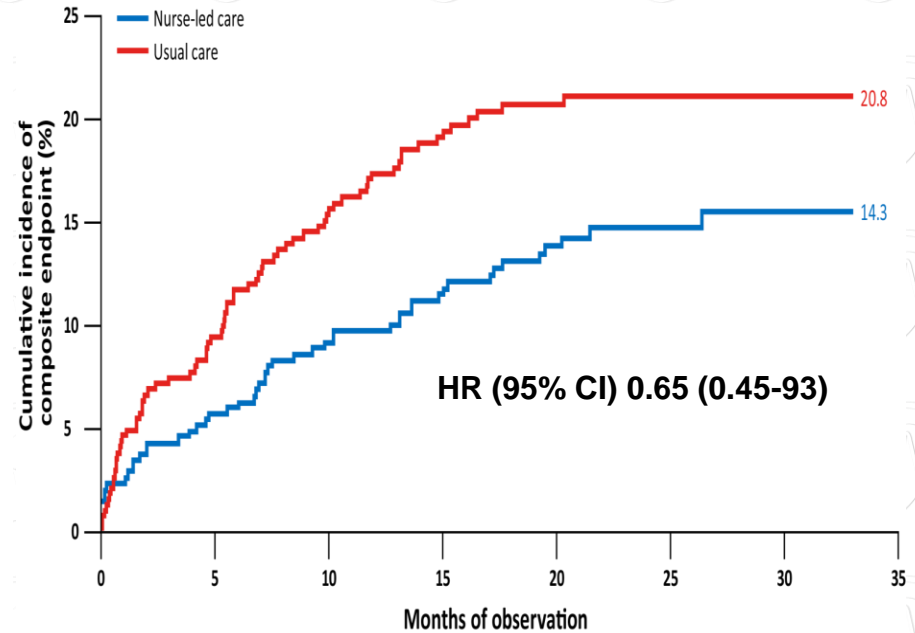
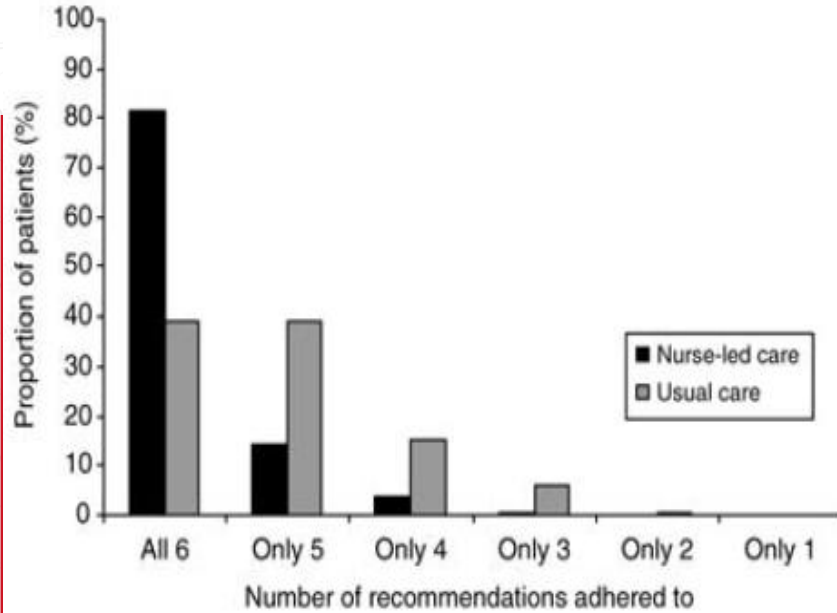
If 1000 people with AF and a CHA₂DS₂-VASc score of 2 take an anticoagulant, over 1 year on average:

- 975 people will NOT have an AF-related stroke (green faces), but would not have done so anyway
- 17 people WILL BE SAVED from having an AF-related stroke (yellow faces)
- 8 people WILL still have an AF-related stroke (red faces)

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Nurse-led integrated care improves AF management



712 AF out-patients randomised to:

- **Usual care** - regular outpatient visits with cardiologist
- **Nurse-led care** - 30 min nurse visits, guideline-based, software assisted, supported by cardiologist
- Greater adherence to clinical guidelines with nurse-led care
- Nurse-led care superior to usual care for composite endpoint of cardiovascular death and cardiovascular hospitalisation

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Key topics for initial discussions with AF patients

- Basic anatomy/physiology of AF
- Explanation of possible symptoms; emphasise that asymptomatic AF is common
- Factors increasing risk of AF development; focus on factors related to patient
- Trajectory of AF – what can the patient expect?
- Discuss consequences of AF
- Discuss treatment options (including OAC)
- Treatment education (pharmacological, non-pharmacological, lifestyle)
- Agree an action plan and follow-up care (who and when)



Critical elements of patient-healthcare professional discussions regarding OAC

- Explain link between AF and stroke and why OAC is usually recommended lifelong
- Patient's individual risk of stroke by CHA₂DS₂-VASc
- OAC treatment options
- Patient's risk of bleeding on OAC and risk/benefit profile
- Drug-specific education
- Emphasise importance of medication adherence
- Bleeding side effects and how to manage these
- In patients taking VKA, importance of anticoagulation control (TTR≥70%)

OAC, oral anticoagulation; TTR, time in therapeutic range; VKA, vitamin K antagonist

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

- What are the risks from having AF?
- What can be done to decrease the risks associated with AF?
- Is there anything I can do to reduce these risks or decrease amount of AF I have?
- Will the medication I need to take for AF be affected by other medication(s)?
- How often will I need blood tests to check how fast my blood is clotting (INR)? Where do I go for these blood tests?
- Will food or alcohol affect my AF or AF medication?
- Who should 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 and where can I find out further information?
- Are there any Patient Support Groups?

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Links to useful patient advocacy groups and organisations, professional societies and patient discussion forums*

Patient advocacy groups and foundations

Atrial Fibrillation Association

International: www.afa-international.org

Arrhythmia Alliance International:

www.aa-international.org

Sign Against Stroke in Atrial Fibrillation:

www.signagainststroke.com/en

StopAfib.org: www.stopafib.org/

My AFib Experience:

<http://myafibexperience.org/>

Anticoagulation Europe:

www.anticoagulationeurope.org/

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Anticoagulation Europe:

www.anticoagulationeurope.org/



EHRA AF Patient Website

<https://www.afibmatters.org>



AFIB MATTERS
ATRIAL FIBRILLATION

ENGLISH

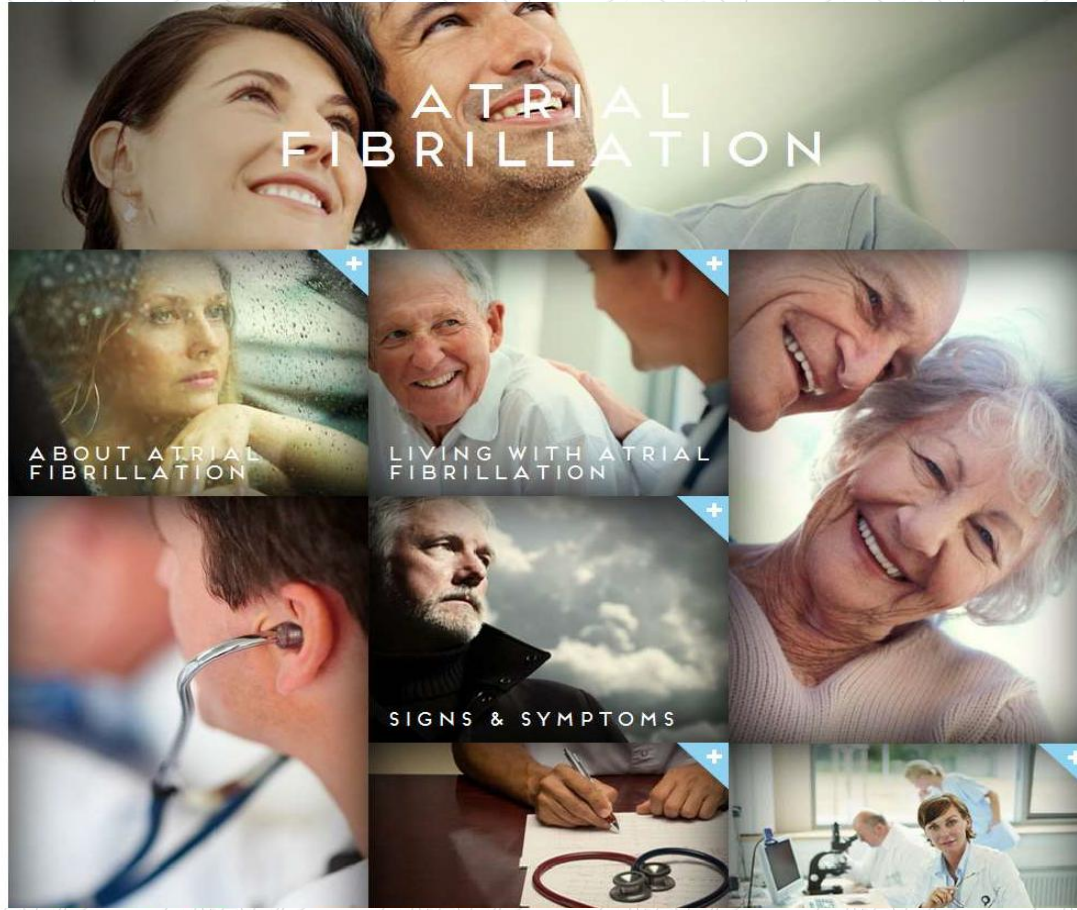
- ABOUT ATRIAL FIBRILLATION
- SIGNS AND SYMPTOMS
- TESTS AND INVESTIGATIONS
- TREATMENTS
- LIVING WITH ATRIAL FIBRILLATION
- USEFUL LINKS

SEARCH

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TERMS OF USE
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AUTHORS
CONTACT

www.afibmatters.org/Signs-and-symptoms



www.escardio.org/EHRA



Supraventricular arrhythmias

- Paucity of research characterising symptoms of patients with supraventricular arrhythmias
- Limited data on patients' experiences and impact of QoL¹
- Obtaining a correct diagnosis and accessing invasive treatment can be difficult, particularly for women²
- Patient knowledge of disease, its' trajectory, patient management strategies, & treatment options is poor²

¹Wood K et al. *Heart Lung* 2010;39:12-20

²Wood K et al. *Eur J Cardiovasc Nurs* 2007;6:293-302



Key discussion points for patients with supraventricular arrhythmia

- What causes the arrhythmia
- Natural trajectory of the arrhythmia
- Common symptoms and strategies for managing episodes
- Smart phone technology to monitor and capture arrhythmia
- Explanation and demonstration of Valsalva manoeuvres
- Detailed explanation of treatment options
- Psychosocial aspects of living with SVT
- Action plan and follow-up care
- How to know if treatment is not working



Patient's values and preferences for acute and chronic treatment

Lifestyle modifications

- Negative effect of SVT limiting everyday activities & resultant effect on QoL¹
- Profound psychological effect particularly patients with careers as athletes or high-risk occupations/professions²

Anti-arrhythmic drugs

- Impact of AAD drugs on QoL unclear
- Limited data suggests dissatisfaction with AAD³; may impact adherence

¹Wood K et al. *Am J Cardiol* 1997;79:145-149

²Heidbuchel H et al. *Eur J Cardiovasc Prev* 2006;13:475-484

³Edvardsson N et al. *Patient* 2010;3:33-43



Patient's values and preferences for catheter ablation

- Removal/reduction of symptoms significantly improving quality of life (QoL)¹
- >95% success rate and <2% complication rate²
- QoL in all domains significantly improved by removal or reduction in AF symptoms^{3,4}
- Compared to AAD, catheter ablation associated with greater improvement in QoL and symptomatic relief³

¹Blomstrom-Lundqvist C et al. *J Am Coll Cardiol* 2003;42:1493-1531

²Sohinki & Obel. *Ochsner J* 2014;14:586-595

³Wood K et al. *Heart Lung* 2010;39:12-20

⁴Walfriddson U et al. *Heart Lung* 2011;40:405-411



Patients' experiences of living with Wolff-Parkinson-White and treatment preferences

- No studies on patient experiences exclusively in WPW
- Lack of knowledge and understanding
- Need for patient education is more pertinent due to risk of sudden cardiac death
- Catheter ablation significantly increases QoL and decreases symptoms¹⁻³
- More information needed for asymptomatic WPW patients regarding invasive procedures

¹Blomstrom-Lundqvist C et al. *J Am Coll Cardiol* 2003;42:1493-1531

²Wood K et al. *Heart Lung* 2010;39:12-20

³Spector P et al. *Am J Cardiol* 2009;104:671-677



Patient information and forums for WPW patients

Patient information

www.aa-international.org

www.childheartassociates.com/patient-information/svt-wolff-parkinson-white-syndrome

www.patient.co.uk/health/wolff-parkinson-white-syndrome-leaflet

Patient experiences and forums

<https://healthunlocked.com/hearthythmcharity>

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>

www.escardio.org/EHRA



Ventricular arrhythmias: Patient experiences

- Covers a wide spectrum of cardiac rhythm disturbances
- Single PVCs occur in ~80% of apparently healthy adults undergoing 24-48 hour ambulatory monitoring¹
- Patients may not be aware of differences between benign and life-threatening ventricular arrhythmias
- Symptoms can be frequent and disabling; often causing significant anxiety
- Patient experiences illustrated by patient stories²
- More tailored education needed on ventricular arrhythmias, treatment options and prognosis

¹Glasser SP et al. *Chest* 1979;75:565-568

²Lane DA et al. *Europace* 2015;17:1747-1769



Key topics for discussion with patients with ventricular arrhythmias*

- What is VT and how common is it?
- 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?
- What are the risks of VT if left untreated?
- Should patients with VT limit their physical activity?
- Psychosocial aspects of living with VT
- What should patients do in an emergency situation?

*Modified from www.cardiosmart.org/Heart-Conditions/Ventricular-Tachycardia/Questions-to-Ask-Your-Doctor



Inherited arrhythmias: Psychological response and quality of life

- Profound impact on patients
- **Adolescents:** lifestyle restrictions lead to feeling of 'not being normal' compared to peers
- **Adults:** experience loss of independence associated with work and driving restrictions
- Life-threatening arrhythmias associated with high levels of anxiety and fear
- Clearer information about purpose of genetic testing and cardiac symptoms
- Clear communication of arrhythmia-specific risk stratification to moderate psychological response



Key topics to discuss with a patient with an inherited arrhythmia

- Clear explanation of diagnosis
- Provide 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

ICD, implantable cardioverter defibrillator



Patients' understanding and experiences with ICDs for ventricular arrhythmias

- Differences in patients values and preferences for ICD implantation for **primary** and **secondary** prevention
- Patients' age and comorbidities will modulate treatment expectations of both patient and physician
- Patient need to be made aware of device deactivation; this should begin at implantation*
- Discuss end-of-life decisions at diagnosis and revisit when substantial changes in health occur*

*See Table 10 in Lane DA et al. *Europace* 2015;17:1747-1769



Key topics to cover when discussing ICD implantation as a treatment option

- Why has my doctor asked me to consider an ICD?
- Does an ICD require surgery?
- Can the ICD be turned off or taken out?
- How will having an ICD affect my life?
- Is it OK 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 fracture)



Psychological response to ICDs

Significant amount of research regarding psychological response to ICDs

- ICD implantation increases confidence in recipient
- Up to 25% report psychological distress following implantation¹
- Lack of patient understanding/ knowledge of underlying medical condition and ICD's function/purpose
- Appropriate patient education and good doctor-patient communication is essential
- Patient expectations of the device need to be addressed prior to implantation and misconceptions corrected

¹Magyar-Russell G et al. J Psychosom Res 2011;71:223-231



Psychological response to ICD shocks and strategies to manage distress

- Most evidence relates to single shocks which can lead to psychological distress and poorer QoL in some patients¹
- Multiple shocks or electrical storms can lead to PTSD and desire for ICD explant²
- Limited evidence of impact of electrical storm on patient well-being
- Phantom shocks experienced by 5-25% patients^{3,4}

¹Pedersen SS et al. *PACE* 2010;33:1430-1436

²Hamner M et al. *Psychosomatics* 1999;40:82-85

³Berg SK et al. *Europace* 2013;15:1463-1467

⁴Kraaier K et al. *Neth Heart J* 2013;21:191-195



Strategies to manage psychological distress related to ICDs

Step 1

- (1) Establish a trusting relationship with patient (and partner)
- (2) Listen to patients and their stories
- (3) Explore
 - Patients' beliefs about their distress
 - Patients' resources
 - Patients' needs and preferences for further referral and intervention
- (4) Provide reassurance
- (5) Provide information
- (6) Together with the patient (shared decision-making) form an action plan (choosing from Step 2 or patient suggestions)

Step 2

- Make a shock plan
- Psychological education
- Support groups
- Cardiac rehabilitation
 - Referral to mental health services for:
 - CBT/mindfulness
 - pharmacotherapy



Links to useful patient resources and patient organisations*

Patient organizations

Arrhythmia Alliance International:

www.aa-international.org

The Mended Hearts:

<http://mendedhearts.org>

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

www.hjerteforeningen.dk/ [Danish]

Sudden Death Cardiac Arrest Association:

http://www.suddencardiacarrest.org/aw/s/SCAA/pt/sp/home_page

<http://brugadadrugs.org>

<http://www.torsades.org>

Useful resources for patients

American Heart Association Resources and FAQs:

www.heart.org/HEARTORG/Conditions/Arrhythmia_UCM_002013_SubHomePage.jsp

Cardiosmart:

<http://www.cardiosmart.org>

Heart Rhythm Society:

www.hrsonline.org

Patient.co.uk:

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

<http://icadapp.com/>

<http://www.symplur.com>

<https://patientdecisionaid.org>

*These are not exhaustive lists



Strategies to improve education for patients with cardiac tachyarrhythmias

- Greater public awareness of cardiac arrhythmias and the potential consequences
- Elicitation and discussion of patient preferences for treatment
- Improved patient support and education and availability of educational materials; involvement of family members
- Tailoring patient education to the individual
- Greater understanding among the medical profession of patients' needs
- Improved physician education (clinical decision support tools)
- Improved communication between patients and physicians



Areas for future research

Across all cardiac tachyarrhythmias

- Routine assessment of health-related quality of life
- Identifying incidence and prevalence of psychological distress
- Development of structured arrhythmia-specific educational programmes and integrated care programmes
- Evaluation of efficacy and cost-effectiveness and in different cultures and ethnic groups
- Incorporation of Patient Reported Outcomes (PROs) as outcome measures



Consensus statements

- Education is an essential component of arrhythmia management to enable patients (and their carers/family members) to understand their condition, the available treatments, disease trajectory, and possible outcomes
- Individually tailored disease- and treatment-specific information from healthcare team
- Patients' preferences for treatment should be discussed, documented, and incorporated into management decisions
- Shared decision-making should be approach adopted
- Regular audit and review of patient pathways and shared care management
- Patient representatives should contribute to arrhythmia guideline development and implementation

