How Much Does An Implantable Cardioverter Defibrillator Patient Really Need To Know? - The Importance of ICD Counselling and the Role of a Cardiac Physiologist.

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Introduction

The benefits of an Implantable Cardioverter Defibrillator (ICD) over medical therapy for patients who are at high risk of dangerous arrhythmias have been widely established (1). An increasing proportion of the population is undergoing ICD implantation. The 2013-2014 National Audit of Cardiac Rhythm Management Devices showed the ICD implant rate in England alone increased from 66 per million population in 2012 to 72 per million population in 2013/14, however this rate is still well below the Western European average (2).

Resources such as ICD support groups and easily accessible patient literature have helped with the process of adjustment after the procedure but how well are patients educated prior to implantation? Although health care professionals are well versed in relaying the clinical benefits of an ICD to patients, there can be a distinct lack of discussion about the ‘cons’ and psychosocial impact of the procedure. The recent review of NICE guidelines took advice from patient experts who emphasised the importance of pre- and post-implant counselling as well as giving patients information on expected outcomes, living with the device and deactivation in the context of palliative care (3).

Discussion

In order to return to ‘normal life’, a typical ICD recipient must overcome the stress of experiencing life-threatening arrhythmias and the challenges of adjusting to the device (4). Current research suggests that psychosocial distress can occur in ICD patients (5). Psychological morbidity in adult ICD patients is well documented with the prevalence of anxiety ranging from 13% to 46% and depression in 24%-46% of patients (4). Those patients receiving an ICD for primary prevention indications are also likely to have additional concerns about why they need an ICD in the first place. Younger patients are often worried about lifestyle disruption, reduced social interactions, concerns about physical activity, body image, primary diagnosis and the impact on family due to need for additional screening (6).

As psychological and social factors often impinge on the broad health outcomes of cardiac patients with as many as 20-50% of cardiac patients experiencing significant psychological distress (7), the importance of counselling a patient before having the device is crucial. Initial success of an ICD implant is not solely determined by the success of the procedure but also how well the patient accepts the device. Acceptance of the device and the impact it has on lifestyle could positively influence quality of life (6) with those who have high positive health expectations and high optimism reporting better mental health and social functioning at follow up (8). The conversation required in order to address patient concerns and work towards acceptance is often time consuming. Increased workflow through most hospital catheter labs in addition to greater clinical and administrative demands on healthcare professionals can sometimes impact on the education a patient receives before undergoing an ICD procedure.

The challenge of educating a patient prior to implant is to provide information that is neither falsely optimistic nor scare mongering. The protection an ICD offers is well known and devices are becoming more sophisticated in order to increase the benefit to the patient. Advances in technology such as MRI safe ICDs, algorithms to optimise cardiac resynchronisation therapy and improved discriminators are all designed to improve the patient experience. However, there are aspects of an ICD which always have a huge influence on a patient’s lifestyle despite these technological advances - driving restrictions,
receiving appropriate/inappropriate shocks and deactivation in the setting of worsening cardiac disease. Driving restrictions, shocks and fear of shocks can be viewed as the negative aspects of having an ICD but are probably the most important to address.

What is sometimes overlooked is how much social and economic impact of not driving for whatever length of prescribed time can have on a patient. Instead of patients being told about the ban, there should be an attempt to make the patient understand why this is necessary. As patients live longer with the support of the device the question of deactivation arises. Patient should be afforded the opportunity to discuss their wishes in relation to deactivation of the shock function of their device. If attempted prolongation of their life by the device is no longer appropriate for them, deactivation of the shock function may spare them (and those close to them) the distress and indignity of ICD shocks (10). Having this topic covered in pre-implant counseling allows the patient to have control over such an important decision by giving them time to plan.

Approximately one third of patients who receive an ICD may experience a shock during the first year (11). Both meta-analysis and individual trials have indicated that shock is at least, temporally associated with decrements in quality of life (12). Although strategic programming and ATP reduces the incidence of shocks to 9% versus 17% in primary prevention patients over the first year (13), there is still a significant psychological impact on a patient. Versteeg et al, 2011 (14), published a brief report showing ICD shock experience was the strongest determinant of post-traumatic stress disorder at 3 months post-implant. It is therefore evident one of the most important steps in helping the patient accept the device, is for them to accept that they may experience a shock and educate them on how to cope with this. The focus is often placed on how a shock will stop a dangerous arrhythmia but not how a patient may feel afterwards as well as the risk of inappropriate shocks. In ICD recipients, depressive symptoms may be caused by the perceived lack of control over necessary defibrillation discharges (9). Although pre-implant counseling may not completely remove this anxiety should a patient receive a shock it lays a foundation which can be built on with ongoing counseling. This approach is also relevant to device or lead recalls which may have the same detrimental effect on quality of life.

So who is responsible for educating the patient? The British Heart Rhythm Society’s recent standards document for Implantation and Follow up of Cardiac Rhythm Management Devices in Adults (15), recommends a multidisciplinary approach to patient selection and management, but to what extent is this a reality in everyday practice? A truly multidisciplinary approach should acknowledge the role that cardiac physiologists and specialist nurse practitioners play in a patient’s clinical care. In the majority of centres, cardiac physiologists are solely responsible for the follow up of device patients with the pacing clinic being a channel between patient and physician. Through regular follow up, a relationship is built with those who have devices providing a forum where concerns are expressed, even though at times when it is clearly not related to the device. Both physiologists and specialist nurses are in a unique position where they can objectively represent the patients’ interests and provide continued education through specialist knowledge and counselling post implant. It therefore seems only natural that they should be involved in the educating of patients prior to ICD implantation.

At St George’s Hospital a system of pre-ICD counselling by highly experienced cardiac physiologists has been established as part of the assessment of patients’ undergoing ICD implantation with many patients now being electively referred for ICD counselling. Patients are provided with an uninterrupted opportunity to have a lengthy discussion about the device and related concerns. This pre-counselling is backed up with continuous support through regular follow-up and an ICD support group. The system of this pre-implant counselling is now so integrated into the patient pathway that it is now a tick box on pre-assessment checklists and referral forms. The success of this system was reflected by a recent study
performed at the centre showing high ICD acceptance and low concerns amongst as measured using the Florida Acceptance Survey score \(^{(16)}\).

**Conclusion**

From previous studies and centre experience we can conclude that providing detailed information allows a patient to make an informed decision which in turn protects their autonomy. Part of a healthcare professionals’ duty is to respect and uphold that autonomy and it can be achieved by providing education at a stage in the referral process which allows the patient time to fully understand all implications. Educating a patient prior to an ICD implant should not just address the clinical but also the psychosocial aspects of the device and therefore cover topics such as inappropriate shocks, driving bans and the possibility of deactivation in the context of worsening or terminal illness. It should be remembered that cardiac disease can be complex and patients can often find themselves in circumstances very different to those at the time of implant. Therefore, pre-implant counselling should be considered a foundation which can further be built on through regular follow up and the provision of continued counselling by those with specialist knowledge.
References


