



Psychological wellbeing and posttraumatic stress associated with implantable cardioverter defibrillator therapy in young adults with genetic heart disease

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ABSTRACT

Background: Sudden cardiac death is a tragic complication of a number of genetic heart diseases. Implantable cardioverter defibrillator (ICD) therapy plays an important role in prevention of sudden death. The psychological consequences of ICD therapy in young people with genetic heart disease are poorly understood. This study sought to better understand psychological wellbeing and identify symptoms of posttraumatic stress in young people who had experienced an ICD shock.

Methods: Eligible patients (ICD implanted over 12 months prior) with an inherited cardiomyopathy or primary arrhythmogenic disorder, enrolled in the Australian Genetic Heart Disease Registry were included. Ninety patients completed the Hospital Anxiety and Depression Scale (HADS). Those patients who had an ICD shock ($n = 31$) also completed the Impact of Events Scale-Revised (IES-R).

Results: While the mean HADS-Anxiety and IES-R scores were within the normal range in the total group ($n = 90$), a significant subgroup reported symptoms of anxiety (38%), depression (17%) and posttraumatic stress (31%) indicative of the potential need for referral to clinical care. Overall, greater psychological distress in ICD patients was associated with female gender, a history of syncope, other comorbid medical conditions, and reporting of other distressing events (i.e., ICD complications). In those with an ICD shock, higher posttraumatic stress scores were associated with female gender and longer time to first shock.

Conclusions: Patients with genetic heart diseases can experience psychological difficulties, including anxiety, depression and posttraumatic stress, related to ICD implantation and subsequent shocks. This signals the importance of offering patients access to targeted interventions, including psychological care and support.

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1. Introduction

Genetic heart diseases, including the inherited cardiomyopathies and primary arrhythmogenic disorders, pose a significant psychosocial burden [1–4]. This unique patient group is confronted with a range of clinical issues, including difficulty in coming to terms with the diagnosis as an adolescent or young adult, genetic inheritance, lifestyle modifications such as exclusion from competitive sports, lifelong medical surveillance and an ever present fear of sudden cardiac death (SCD). In those individuals determined to be at increased risk of SCD, the implantable cardioverter defibrillator (ICD) has proven to be the only effective therapy to prevent this tragic outcome [5]. While the shock delivered by the ICD may be life-saving, fear of a shock and

the psychological consequences following a shock, are important considerations [6].

A number of studies have sought to better understand the psychological and quality of life implications of ICD therapy, most often in older coronary artery disease patients [7,8]. The results of these studies are varied. The general consensus is that while most patients cope well with an ICD, there is a group who will experience significant psychological difficulties [9]. Factors such as younger age at implant (<50 years) and multiple ICD shocks (five or more) are associated with greater psychological distress [8,10]. The presence of anxiety, depression or posttraumatic stress has been shown to lead to poor compliance with recommended medication regimes, as well as increased morbidity and mortality [6,11,12]. Identification of patients who may be at risk of psychological difficulties and who require additional psychological support is therefore critical.

Limited literature exists regarding the impact of the ICD in younger (<50 years) genetic heart disease populations [13,14]. While the ICD is a life-saving therapy, choosing to implant a device in a young adult also gives rise to a lifetime of medical procedures and device interrogations,

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risk of complications and the possibility of inappropriate and painful shocks. This study sought to identify the prevalence of poor psychological adjustment among young adult patients with a genetic heart disease treated with an ICD, and posttraumatic stress symptoms in patients who have experienced an ICD shock.

2. Methods

2.1. Participants

Participants were recruited from the Australian Genetic Heart Disease Registry [15], and included those with a clinical diagnosis of a genetic heart disease (inherited cardiomyopathy or primary arrhythmogenic disorder), and an ICD implanted at least 12 months prior. Patients aged 15 years and older, and with sufficient language skills to complete the study questionnaire in English were eligible. The local Human Research Ethics Committee approved the study and all participants gave informed written consent.

2.2. Clinical data collection

Clinical data was sought from the Australian Genetic Heart Disease Registry database, and included basic demographics (i.e., age, gender and comorbidities), disease status (i.e., New York Heart Association [NYHA] functional class), syncope and previous resuscitated cardiac arrest, and details regarding the ICD (i.e., indication for ICD implantation, date of implant, time to first shock, time since last shock, number of shocks and appropriate versus inappropriate shocks). Participants were asked to provide details of any ICD shocks (i.e., number of ICD shocks and dates of the events), and additional information was collected or confirmed from medical records. Patients were also asked an open-ended question “are there any other events related to your ICD that have been distressing to you?”

2.3. Psychosocial evaluation

Eligible participants were sent a study information sheet, consent form and survey by mail, and those who did not respond were sent a reminder six weeks later. Participants were divided into two groups, i.e., those who had received an ICD shock (“ICD shock group”, which included both appropriate and inappropriate shocks) and those who had not (“no shock group”).

All participants completed the Hospital Anxiety and Depression Scale (HADS), a widely used and validated measure for assessing general psychological wellbeing in the past seven days [16]. HADS is a 14-item self-report scale, comprising two subscales evaluating symptoms of anxiety (HADS-Anxiety) and depression (HADS-Depression). The HADS has been used extensively in the hospital setting as a screening tool for emotional disorders. Each subscale includes 7 items, generating possible scores of 0 to 21 for anxiety (Cronbach's $\alpha = 0.89$) and depression (Cronbach's $\alpha = 0.91$). A score of ≥ 8 is widely used to indicate elevated symptoms of depression or anxiety that may warrant further psychological investigation, as previously shown in a HCM population [17]. The scale was used with permission from GL Assessment.

In addition to the HADS survey, the ICD shock group also completed the Impact of Events Scale-Revised (IES-R), a validated measure of self-reported posttraumatic stress symptoms experienced in the past seven days in relation to a specific stressor [18]. The IES-R consists of 22 items, each ranging from 0 (“Not at all”) to 4 (“Extremely”), with the total score ranging from 0 to 88. Three symptom clusters associated with posttraumatic stress are assessed with the IES-R, including *intrusion*, *avoidance* and *hyperarousal*. Intrusion relates to intrusive thoughts, nightmares and imagery associated with the traumatic event (8 items; Chronbach's $\alpha = 0.90$), avoidance relates to avoidance of any feelings or situations (8 items; Chronbach's $\alpha = 0.95$) and hyperarousal is an inability to concentrate, anger, irritability and hypervigilance (6 items; Chronbach's $\alpha = 0.96$). Higher scores indicate more symptoms of posttraumatic stress, with scores above 24 indicating the potential need for clinical assessment and care. Importantly, while the HADS measures general psychological wellbeing, the IES-R measures a specific type of stress related to the ICD, with patients asked to respond specifically regarding their most recent ICD shock.

2.4. Statistical analysis

Data were analysed using SPSS (v20.0). Differences between participants and non-participants for non-psychological variables were assessed using chi-squared and *t*-tests, as appropriate. Total IES-R scores were calculated by summing the item responses and those who scored >24 were considered as having posttraumatic stress symptoms potentially warranting clinical assessment and care [19]. Continuous and categorical variables (i.e., clinical and demographic characteristics) were analysed using independent *t*-tests and chi-squared tests respectively. General linear models (for categorical independent variables) and simple linear models (for continuous independent variables) were used to determine univariate correlates of anxiety (measured by the HADS-Anxiety subscale) and posttraumatic stress symptoms (by IES-R scores).

3. Results

3.1. Clinical features of the study cohort

Of the 139 patients initially approached to take part in the study, 90 surveys were returned (response rate 65%). Demographic and clinical characteristics of the sample are shown in Table 1. The mean age of participants was 49 ± 14 years and mean age at ICD implant was 45 ± 15 years. The mean time since implant was 5 ± 3 years (range: 1–16 years) and 73 (81%) had their ICD implanted for primary prevention. The disease presentations included 70 participants with an inherited cardiomyopathy (62 hypertrophic cardiomyopathy; 4 arrhythmogenic right ventricular cardiomyopathy; 2 familial dilated cardiomyopathy, and 2 left ventricular noncompaction), 16 with a primary arrhythmogenic disorder (8 long QT syndrome; 5 catecholaminergic polymorphic ventricular tachycardia; and 3 Brugada syndrome), and 4 with other unascertained genetic heart diseases (e.g., family history of sudden unexplained death in the young). Based on limited available information (age and gender), non-responders were found to be slightly younger (43 ± 15 versus 49 ± 14 years, $p = 0.018$), with no difference in gender.

3.2. Psychological wellbeing in the total study cohort

Overall, mean scores for anxiety (6.63 ± 4.11) and depression (4.03 ± 3.38) were within the ‘normal’ range, and comparable to normative data [20]. General anxiety and depression scores potentially warranting clinical intervention were reported by 38% and 17% of the sample, respectively.

No difference was observed between mean anxiety (6.42 ± 3.62 versus 6.75 ± 4.37 , $p = 0.72$) and depression (4.17 ± 3.81 versus 3.97 ± 3.17 , $p = 0.79$) scores when comparing the ICD shock group and those who had never experienced a shock (Table 1). Nine (29%) participants in the shock group and 25 (42%) participants in the no shock group reported elevated levels of anxiety (Fig. 1). Lower levels of depression were reported, with 5 (16%) participants in the shock group and 10 (17%) participants in the no shock group meeting the criteria indicating the potential need for clinical intervention (Fig. 1).

3.3. Posttraumatic stress symptoms in the ICD shock group

Approximately one-third (34%) of participants had experienced at least one ICD shock (14 patients (45%) received only inappropriate

Table 1
Characteristics of the sample by ICD shock.

| | Total | Shock | No shock | p-Value |
|---------------------------------------|-----------------|-----------------|-----------------|-----------|
| n (%) | 90 (100) | 31 (34) | 59 (66) | – |
| Current age, years | 49 ± 14 | 48 ± 15 | 50 ± 14 | ns |
| Male gender | 45 (50) | 16 (52) | 29 (49) | ns |
| Age at implant, years | 45 ± 15 | 40 ± 13 | 47 ± 15 | 0.03 |
| Time since implant, years | 5 ± 3 | 7 ± 4 | 3 ± 2 | <0.0001 |
| Primary prevention | 73 (81) | 25 (81) | 48 (81) | ns |
| NYHA class II–IV | 25 (27) | 8 (26) | 17 (29) | ns |
| Family history of SCD | 47 (52) | 12 (39) | 35 (59) | ns |
| Previous unexplained syncope | 45 (49) | 17 (55) | 28 (47) | ns |
| Previous OHCA | 17 (19) | 6 (19) | 11 (19) | ns |
| Other medical conditions | 26 (29) | 10 (32) | 16 (27) | ns |
| Other distressing events ^a | 32 (36) | 15 (48) | 17 (29) | ns |
| HADS-Anxiety | 6.63 ± 4.11 | 6.42 ± 3.62 | 6.75 ± 4.37 | ns |
| HADS-Depression | 4.03 ± 3.38 | 4.17 ± 3.81 | 3.97 ± 3.17 | ns |

Abbreviations: SCD, sudden cardiac death; OHCA, out of hospital cardiac arrest; NYHA, New York Heart Association functional class; HADS, Hospital Anxiety and Depression Scale. Continuous variables are expressed as mean \pm standard deviation, while categorical variables are presented as n (%).

^a Other distressing events were described by participants as complications related to their ICD, pain or awareness of the device and fear of shock.

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