



## Living with an implantable cardioverter defibrillator: The patients' experience



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### ABSTRACT

**Objectives:** To explore the lived experiences of implantable cardioverter defibrillator (ICD) recipients.

**Background:** Previous research suggests ICD recipients experience significant psychological distress with a focus on shock anxiety. In response, avoidant behaviors are often used which can lead to reduced quality of life, cardiac fitness and increased risk of arrhythmia.

**Methods:** A qualitative study using semi-structured interviews with a purposive sample of 18 recipients who had either received or not received an ICD shock was conducted. Data were analyzed using a thematic approach.

**Results:** Three themes with sub-themes were defined: (i) physical consequences; (ii) emotional consequences (feeling vulnerable and uncertain; anxiety and depression); and (iii) coping with the ICD (avoidance/restrictive behaviors; acceptance; concealment).

**Conclusion:** ICD recipients might be helped by a psycho-social intervention that corrects false beliefs about exercise and offers some simple stress management techniques. Additional elements might include helping recipients to re-evaluate goals and find a valued sense of self which this study found aided ICD acceptance.

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### Introduction

In the UK and USA, approximately 30,000 and 326,000 people respectively experience an out of hospital sudden cardiac arrest (SCA) each year.<sup>1,2</sup> The delay between collapse and shock therapy is the most important determinant of survival.<sup>1</sup> The implantable cardioverter defibrillator (ICD) delivers an internal electrical shock to the heart within 10–15 s of an arrest, significantly reduces the risk of sudden cardiac death, and is deemed the 'gold standard' treatment for people at risk of sudden cardiac arrest.<sup>1</sup>

Despite evidence that ICDs prolong life, many recipients report significant psychological distress and a reduced quality of life.<sup>3,4</sup> Female ICD recipients acknowledge greater levels of anxiety and depression than male recipients.<sup>5</sup> The likely impact of an ICD shock forms a particular focus of fear and uncertainty. Those who have

not (yet) experienced a shock report a fear of this unknown experience.<sup>6,7</sup> Those who have experienced a shock typically report it as highly aversive and experience increased fear of future shocks.<sup>6–10</sup> In addition, while a minority of those who have experienced a shock report relief or assurance that the ICD was effective,<sup>8,11,12</sup> many also feel disappointed at being dependent on technology for survival.<sup>7,9</sup> Many are aware that an arrhythmic onset can be rapid, and feel vulnerable and anxious when out in public<sup>9,12</sup> and fearful of being alone.<sup>11,13</sup> Beliefs that a shock is associated with the process of dying tend to increase anxiety.<sup>13–15</sup> However, other responses to a shock have included positive life changes, including re-evaluating life goals, friendships and activities.<sup>9,10,15</sup>

Recipients use a combination of coping strategies as they adapted to their ICD,<sup>16</sup> including thinking positively, being confrontive, expressing emotions, being self-reliant and using evasive behaviors. Avoiding activities believed to increase heart rate, such as sex and housework, appears to be a common coping strategy used by recipients.<sup>6,9–11,13,17–19</sup> However, in many studies, it was not always made clear if ICD related beliefs and ways of coping had been influenced by a shock experience.<sup>7,9,10,14,15,18</sup>

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It is important to continue exploring the experiences of ICD recipients for several reasons. First, it is clear that recipients experience high levels of distress and this can directly increase the likelihood of an arrhythmia.<sup>20–23</sup> Risk of arrhythmia may be also increased indirectly as a consequence of reduced cardiac fitness due to reduced levels of exercise.<sup>24</sup> In addition, the avoidance of exercise or other ‘risky’ activities may result in poorer quality of life.<sup>25–27</sup> Greater understanding of the experience of individuals with an ICD, including exploration of positive means of coping with any concerns they may experience, may help facilitate personal or counseling strategies through which such problems can be reduced. Accordingly, the goals of the present study were to: (i) explore perceived concerns and benefits about the ICD; (ii) explore emotional responses to the ICD; and (iii) how recipients cope with their emotions and with the ICD.

## Method

### Design

A qualitative study design was used. This identified themes within the experiences of recipients living with an ICD and was based on the guidelines of Braun and Clarke.<sup>28</sup> Ethical approval for the study was obtained from the relevant NHS Ethics Committee.

### Sample

ICD recipients, who were in a long-term relationship and whose partners were their primary informal carer were separately invited to join this study. A parallel study of partners’ experiences is being reported separately. Participants were recruited from two UK hospitals. Suitable participants were identified by Arrhythmia Specialist Nurses responsible for their care. Inclusion criteria included: aged 18 or over, fluent in English and implanted with their first ICD three to 24 months previously. Using a purposive sampling procedure, 13 recipients who had received an electrical ICD shock (potential ‘shock’ participants) and 18 recipients who had not (potential ‘non-shock’ participants) were invited to take part in the study. Recruitment ceased at 13 non-shock participants (six female) after saturation of themes occurred and at five shock participants (one female) due to a low response rate coupled with a time limited recruitment period (see Table 1). Participants

represented a wide range of ages, jobs/occupations and family backgrounds.

### Data collection

Participants were invited by letter sent by a specialist arrhythmia nurse known to them. Interviews were conducted individually in participants’ home by NH and lasted approximately 1 h. All participants provided written, informed consent and were informed of their right to discontinue the interview at any time. Participants were assured of confidentiality. The interviews were semi-structured and specific topics were covered using set questions (see Appendix 1 for interview guide). The semi-structured nature of these interviews allowed the researcher to probe interesting areas that arose.

### Data analysis

Interview transcripts were analyzed using the phases outlined by Braun and Clarke.<sup>28</sup> The first phase involved transcribing the data. The interviews, which had been digitally recorded using an Olympus DS4000 digital recorder, were transcribed by the first author leaving large margins for notes to be made. The audio recordings were listened to several times, checking against transcriptions to ensure their accuracy. The transcribed interviews were then read and then re-read to facilitate data immersion. At the same time, initial thoughts and ideas were noted down in the margins.

Coding of the data was then completed, building on the notes and ideas generated through transcribing and immersion in the data. As the study was interested in patients’ beliefs and ways of coping, the coded extracts were organized around a theoretical framework. A cognitive-emotional-coping framework, with particular reference to Smith and Lazarus’s appraisal theory and model of emotion was used.<sup>29</sup> The data set was given equal attention so that full consideration could be given to repeated patterns within the data. The codes were reviewed by PB and RL, who have expertise in qualitative research, to ensure their trustworthiness to ensure the study’s rigor.

The third phase involved identification of themes by combining text labeled with similar codes. Themes that were too diverse or did not have enough data to support them were discarded. Phase four involved ensuring the coded data formed a coherent pattern, and that the themes accurately reflected what was evident in the data set.<sup>28</sup> Themes and sub-themes were discussed at review meetings with the other authors until a consensus was agreed. When there were discordant views, disagreements were resolved by reviewing the codes and themes to arrive at a consensus.

Phase five involved defining and naming the themes. In doing so, note was taken not only of the story told within individual themes but how they related to the overall narrative evident in the data. The final phase involved choosing examples of transcripts to illustrate elements of the themes.

Participants were not asked to check the accuracy of the transcripts due to possible changes in their perceptions and views as a result of temporal effects or changes in their situation or health and as a result of participating in the study.<sup>30</sup> Some respondents might also have wanted to modify their opinions if they their original comments were not socially acceptable.<sup>30</sup> Furthermore, as interviews had elicited strong emotional responses in some participants it was likely that checking interview transcripts might result in unnecessary upset.

**Table 1**  
Characteristics of participants.

Shock status	Gender	Age	Cardiac condition	Time with ICD	Primary/secondary
S	Male	66	Undiagnosed cardiomyopathy	≤1 year	Primary
N	Male	68	Heart failure	≤1 year	Primary
N	Male	47	Arrhythmogenic right ventricular dysplasia	≤1 year	Primary
S	Male	50	Idiopathic dilated cardiomyopathy	≤1 year	Secondary
N	Male	56	Out of hospital SCA	≤1 year	Secondary
N	Female	60	Undiagnosed cardiomyopathy	≤1 year	Primary
N	Female	65	Out of hospital SCA	≤1 year	Secondary
N	Male	49	Hypertrophic cardiomyopathy	≤1 year	Primary
N	Male	67	Sustained tachycardia	≤1 year	Primary
N	Male	67	Out of hospital SCA	≤1 year	Secondary
S	Male	68	Undiagnosed cardiomyopathy	≤1 year	Primary
N	Male	56	Brugada Syndrome	≤1 year	Primary
S	Male	64	Heart failure	≤1 year	Secondary
N	Female	48	Multiple SCA during operation	≤1 year	Secondary
N	Female	58	Bundle Branch Block Syndrome	≤1 year	Primary
N	Female	30	Post partum cardiomyopathy	≤1 year	Primary
N	Female	28	Long Q-T Syndrome	≤1 year	Secondary
S	Female	55	Long Q-T Syndrome	≤2 years	Primary

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