Section Two: Empirical Paper

The experiences of implantable cardioverter defibrillator shock-recipients: An interpretative phenomenological analysis

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[1] See Appendix 2-E for 'Author Guidelines'

Abstract

Background: Implantable cardioverter defibrillators (ICDs) are associated with psychological difficulties, particularly after five device-charges (shocks). Little is known about how multiple-shock-recipients experience these events. This qualitative study sought to yield understandings so that avenues for psychotherapeutic intervention could be identified.

Methods: Interviews of six ICD-recipients who had experienced 'electrical storms' (multi-shock episodes) were subjected to interpretative phenomenological analysis, allowing convergences and divergences across the accounts to be explored.

Results: Five themes were identified: 1. 'Fear of imminent death'; 2. 'Living with a sense of dread'; 3. 'Problematic attempts to regain control'; 4. 'Beliefs about what constitutes acceptable support'; and 5. 'The ongoing struggle to accept the device and its implications'.

Conclusions: Electrical storms provoked durable distress and despair. They triggered fears that death was imminent and provoked catastrophic reappraisals of recipients' heart conditions. Anxiety's impact on cardiac functioning exacerbated an acute post-storm stress response. Participants appeared to manifest a high internal locus of control and tendencies towards emotional inhibition, which heightened their distress. Difficulty accepting their ICDs, conditions, mortality and their lack of control over shocks contributed to ongoing distress. Implications for practice and future research were considered.

Implantable cardioverter defibrillators (ICDs) are an efficacious, well-established treatment for the prevention of ventricular arrhythmias and Sudden Cardiac Death [1]. They are fitted in response to life-threatening cardiac events (secondary prevention) and prophylactically in those at high risk of experiencing them (primary prevention) [1]. They detect then attempt to terminate life-threatening arrhythmias by delivering either fast pacing or electrical charges (shocks) to the heart, depending on the rate of the detected rhythm [2]. However, shocks also occur inappropriately i.e., in response to non-life-threatening arrhythmias or when there is either electromagnetic interference or some kind of hardware failure [3].

Appropriate and inappropriate shocks may occur in 23% and 16% of ICD-recipients respectively over five years [4], while inappropriate shocks may constitute 31.2% of all those delivered [5]. Furthermore, both types can also occur in clusters (‘electrical storms’), whereby a person is shocked repeatedly within a short period of time. Prevalence rates for this phenomenon vary between 4% and 28% within three years post-implant [6]; however, as these figures only account for storms comprising appropriate shocks, their actual incidence may be higher.

Reviews of research into the psychological effects of having an ICD concluded that anxiety and depression may be experienced by 46% of recipients [7], while shocks may reduce quality-of-life (QoL) [8]. However, another concluded that these difficulties may chiefly relate to coping with the underlying heart condition rather than with the device [9]. While two further reviews found that definitive conclusions regarding shocks’ psychological effects could not be drawn due to studies’ methodological inconsistencies [10] and contradictory findings [11], another review specifically summarising research into shocks' effects concluded that they are associated with a range of psychological and physical harms [12]. Thus, shocks appear to affect psychological wellbeing, but these effects may be mediated by other factors. The picture is further complicated by evidence that psychological difficulties may themselves precipitate the arrhythmias that trigger shocks [13].

Numerous factors may contribute to ICD-shock-related psychological difficulties. Research shows that the pain shocks inflict, likened to being "kicked in the chest by a big horse" [14], can be distressing in its own right [15]. Their uncontrollability and unpredictability can provoke durable feelings of helplessness particularly in people without a history of depression [16]. Furthermore, experiencing a higher frequency [17] and number of shocks [17] [18], particularly five or more [19], is associated with decreases on measures of wellbeing [17] and with the emergence of anxiety disorders [18] including posttraumatic stress disorder (PTSD) [19]. Electrical storms have been associated with anxiety disorders [20] including PTSD [21], depression and poorer psychological QoL [22].

In terms of factors relating to individuals, catastrophic cognitions about shocks' meaning [23], pain perception [15], and female gender, low optimism, anxiety sensitivity and 'Type-D' personality (denoting dual proneness to difficult emotions and emotional inhibition) [24] are stronger predictors of ICD-related anxiety than shocks. Elsewhere, recipients' concerns about [25], and acceptance of [26] the device itself have been identified as strong determinants of poor psychological wellbeing independently of shocks.

Although some interventions designed to alleviate ICD-related psychological difficulties have shown promise [27], little is understood about how multiple-shock- and electrical-storm-recipients experience, understand, respond to and cope with shocks. Although variables that can predict who is likely to experience ICD-related psychological difficulties have been delineated, quantitative research does not always readily translate into guidance on how best to support such individuals, numbers of whom are increasing as more uses for ICDs are indicated [28].

Conversely, qualitative research can capture detailed accounts of experiential phenomena and the meaning-making thereof, enabling the identification and explication of domains of psychotherapeutic intervention and academic inquiry. Although qualitative studies have explored ICD-recipients' experiences [29] [30] [31] [32] [33], few have specifically investigated shock experiences. Where this has occurred, it has either been done as an adjunct to a broader investigation of the experience of having an ICD [30] [34] or in a purely descriptive [35], therefore more limited, way than interpretative methods arguably allow [36].

In order to address the gaps in our understanding, the principal research question for the present study sought to explicate the ways multiple-ICD-shock-recipients understand their shock experiences. For several reasons, interpretative phenomenological analysis (IPA) was selected for this purpose. Firstly, it aims to gain an 'insider' perspective on experiential phenomena, rather than being theory-driven, thus facilitating the uncovering of new ideas [36]; secondly, as researchers are empowered to make data-driven interpretations of the accounts, a deeper and more nuanced understanding of such phenomena is theoretically achievable; and, thirdly, its focus on small, purposive samples facilitates insight into the meaning-making of groups whilst also accommodating variations between individuals, helping to maximise the potential for intervention-identification, theory-development and research-generation [36].

Methodology

Sampling and Participants

Participants were recruited via a UK tertiary cardiac centre. The inclusion criteria were: participants must have experienced five or more shocks in total, either individually or as part of one or more discrete episodes, as this is especially predictive of post-shock psychological distress [19]; the most recent episode must have occurred within three years of the interview, so recollections remained relatively salient and short- and longer-term impacts of shocks were captured within the sample; participants must not have received treatment for a psychological difficulty unrelated to their ICD, so shock-appraisals remained relatively uncontaminated by unrelated adverse experiences; finally, participants must be fluent in English and physically well enough to be interviewed.

These criteria are consistent with IPA guidance, which stipulates the recruitment of small, homogenous samples [36]. Small samples enable a more thorough analysis of each person’s perspective, enabling a more detailed and authentic rendering of the phenomenon under investigation whilst allowing the identification and exploration of convergences and divergences between accounts [36].

IPA studies should arguably recruit samples that share homogenous characteristics in terms of “obvious social factors or other theoretical factors relevant to the study” [36] (p.50). Applying limited criteria was partly pragmatic, owing to the relatively small sample pool available (representing a fraction of the 2000 ICD-patients treated by the cardiac centre). Also, due to the paucity of salient research it seemed appropriate to adopt an exploratory approach by interviewing people whose general pre-ICD experiences and routes to ICD-implantation differed, and to appraise the convergences among their accounts. Thus, the inclusion criteria ensured the sample shared essential characteristics that enabled the exploration of the relatively uncontaminated lived experience of multiple ICD-shocks.

12 ICD-recipients were invited to participate by cardiac clinicans during consultations. Eight volunteered, whose identities remained blind from the cardiac centre’s clinical psychologist (and study field supervisor). One was unavailable during the data collection phase; therefore, seven were individually interviewed. Six had experienced electrical storms; one (“Carol”) had experienced five single-shock episodes, two of which she could not recall. Her account was thus too divergent to meaningfully synthesise with the others’. Also, the preponderance of participants who had experienced electrical storms provided an unprecedented opportunity to qualitatively investigate this phenomenon. Hence, Carol’s interview was regrettably removed from the analysis. All six remaining interviewees had or were receiving treatment from the cardiac centre’s clinical psychologist. Table 1 presents participants’ salient demographics.

<Insert-Table-1-here>

Ethics

The study received ethical approval from the National Research and Ethics System and NHS trust Research and Development approval (see Ethics Section). Given the risk of participants experiencing distress consequential to the interview, they received a debrief sheet outlining appropriate support, including from the cardiac centre's clinical psychologist, if necessary. Specific instruction on containing others' acute traumatic stress was sought from a consultant clinical psychologist specialising in severe trauma.

Procedure

ICD-recipients meeting the inclusion criteria received the participant information sheet via post or from cardiac clinicians during incidental consultations. The sheet invited them to contact the lead researcher by post or email for further information. During subsequent telephone calls and email exchanges interviews were arranged with those wishing to participate.

The interview schedule was developed from extant research into ICD-shocks' psychological effects and with input from cardiac clinicians. This included the cardiac centre's clinical psychologist, who had treated increasing numbers of multiple-ICD-shock-recipients. Guidance was sought to ensure the schedule's congruence with the IPA approach [36], including from the study's IPA-experienced academic supervisor.

Topics covered by the schedule included: the circumstances leading to the ICD's implantation; initial adjustment to the device; what storm-experiences were like and what their short- and long-term effects were; how participants coped; shocks' impact on other people; what participants would like to have known prior to ICD-implantation; and how they felt about the future. The lead researcher and the academic supervisor examined the first-interview transcript, yielding strategies to increase and deepen reflective disclosures in subsequent interviews e.g., by prompting further reflection on emotion-related phrases. As this interview provided pertinent data it was included in the final dataset.

Five participants chose to be interviewed at the cardiac centre; two were interviewed at home. Participants gave written consent prior to their interviews, which were digitally recorded and lasted 66 minutes on average.

Analysis

IPA is a form of qualitative analysis moored in phenomenology, idiography and hermeneutics [36]. Phenomenology concerns the lived experience of a phenomenon. Idiography focuses on the individual not just the whole sample, enabling the presentation of nuanced and personal experiences in the analysis. Hermeneutics concerns interpretation, two levels of which are central to IPA. This so-called 'double hermeneutic' acknowledges the distance both researcher and interviewee are from the original experience. This distance requires the researcher to make interpretations about the interviewee's account, which itself results from their own endeavours to articulate the experience; thus, the researcher's interpretations may expose aspects of the experience inaccessible to the interviewee, producing a potentially deeper and more nuanced rendering of the phenomenon.

To preserve IPA's idiographic focus, interviews were analysed individually, then the separate findings were synthesised. Broadly echoing IPA guidance [36], the analysis unfolded as follows. Firstly, the interview recording was transcribed. The transcript was then repeatedly read and comments noted: descriptions of interesting textual or linguistic features, direct quotations, and interpretations penetrating the text's surface level [36] (Appendix 2 provides an extract). The transcript was reduced to its most parsimonious form by clustering these comments into themes. Narrative summaries of each theme were then written (Appendix 3 provides an example). Next, the findings were explicitly put aside ('bracketed') to facilitate fresh engagement with subsequent transcripts on their own terms.

The six resulting narrative summaries were then synthesised to produce the super-ordinate themes. This was achieved by firstly writing bullet-points summarising each participant's themes. These 'emergent themes' (Appendix 4) were then cut up and clustered together. Highlighting the iterative and recursive nature of this process, these super-ordinate themes (Appendix 5) were periodically compared with the narrative summaries and the original transcripts, facilitating their further refinement and the identification of supporting quotations for each one.

Ensuring the quality and credibility of the analysis

The ‘double hermeneutic’ stance IPA adopts takes into account the unavoidable influence of researchers’ own values, beliefs and assumptions on their interpretative efforts. The researcher is therefore both a necessity and a complication to the production of an interpretative account [36]. To mitigate the influence of the lead researcher’s biases and ensure that interpretations were grounded in the data, the academic supervisor audited comments and themes by comparing them with the transcripts. Early comments and themes referenced the psychodynamic defence called ‘denial’; this terminology was subsequently abandoned as it deductively superimposed a theoretical construct on the data, rather than allowing the data to determine the themes in an inductive way, as IPA guidance recommends [36]. The audit process assessed the analysis’s credibility and ensured data from all participants were captured. Thus, the researchers met frequently throughout the analysis phase.

Findings

The analysis identified five themes. These were: 1. ‘Fear of imminent death’; 2. ‘Living with a sense of dread’; 3. ‘Problematic attempts to regain control’; 4. ‘Beliefs about what constitutes acceptable support’; and 5. ‘The ongoing struggle to accept the device and its implications’. These will each be explored and evidenced.

Theme 1. “That bullet’s got your name on it”: Fear of imminent death.

The violence, pain, relentlessness and uncontrollability of ICD-shocks during electrical storms prompted acute concerns about mortality: “Every time it goes, is that ‘it’? Is it gonna kill ya?" (David). These catastrophic appraisals were emphasised by the violent imagery unanimously invoked to describe them. Shocks were likened to "a heavyweight professional boxer hitting you, trying to punch his way out of your chest" (Graham), "somebody hitting you in the chest with a baseball bat, very hard" (David), or an explosion (Chris, Claire and Steve):

> I suppose it'd be like holding a firework or something like that. It's like, you hold a firework on the outside, like with two fingers, it'll go off: 'bang'. If you held it in a clenched fist, that's when it feels like [vocalises explosion]. And there's a big explosion, and it just all comes out and you're…screaming (Steve).

While shocks were uniformly perceived as painful, some participants interpreted this as evidence that something was mortally wrong with their hearts: "I was panicking and, you know…I was in *that* much pain [becomes tearful]" (Steve). This was particularly so if their ICDs had been implanted in the absence of a painful cardiac event. For example, Claire's was fitted following a cardiac arrest, an experience that "didn't traumatise me, 'cos I don't remember it. I don't remember *anything* […] I never *felt* anything…But the *pain* of *them*".

Concerns about imminent death were not only provoked by shocks' violence and pain: their sheer relentlessness and uncontrollability worried some that their hearts or their ICDs' batteries would not endure the episodes: "And it's just hitting you and hitting you, and you think, 'Well, is it gonna stop?' It has to stop sometimes. Your heart can't keep, you know…" (Steve). While losing control of their bodies when shocks occurred ("you feel like a ping-pong ball" [Graham]) was disconcerting, it was their total powerlessness over shocks that often led participants to fear for their lives:

> I've been in some pretty tight spots, and I've been pretty scared in my life... But nothing- *nothing* at all compares to that. You've *no* control over it *whatsoever*. And *nothing* you can do can stop it... So, you think, well, "Goodnight Vienna" (David).

This quote also highlights how the sustained sense of helplessness was the aspect of storms that made them harder to tolerate and recover from than participants' previous traumatic experiences. Although hopes that shocks would stop, or at least diminish in intensity, were repeatedly dashed, Claire's sustained wish that hers were resultant of a faulty ICD lead prevented her from dwelling on the more fatalistic interpretations made by other participants.

Theme 2. "Walking around with a timebomb in your chest": Living with a sense of dread.

Electrical storms left participants in a state of permanent dread, which felt like "walking around with a timebomb in your chest all the time, [thinking] it's gonna go off" (David). The sense this could happen at any moment was amplified by shocks' unheralded violent intrusion on scenes of domestic normality. Participants' consequential sensitisation to their environment prompted fears that anything could potentially trigger shocks: "You're thinking, 'Yeah, this is gonna happen', and that's when you're looking round and everything becomes…you know, everything's gonna, gonna *cause* it to happen again" (Graham).

Places and activities participants had been experiencing when storms began provoked particular fear. Thus sofas, bedrooms, sleep and watching televised cricket became sources of discomfort for different participants: "That's when the demons come…That's when I start remembering all what had gone on and the pain" (Steve). Furthermore, a conditioned association sometimes emerged between post-storm situations and shock-anxiety, leaving Steve wanting to avoid the pacemaker clinic after becoming convinced a shock was imminent during a consultation.

Whether or not individual shocks were preceded by bodily sensations, most participants became intensely aware of these in storms' aftermath, especially those in the chest area: "*All* I kept thinking..*every* twinge, 'Oh, it's me heart, it's me heart!'. Oh, it's *awful*! *That's all* that's here, in the forefront of your mind. *Nothing* else, only your heart" (Claire). Thus, anxiety symptoms were frequently interpreted as signs of impending shocks, precipitating unnecessary trips to hospital for some. This was particularly so for participants who believed anxiety had triggered shocks during storms. A vicious circle of mutually reinforcing anxiety and chest sensations often emerged: "I *was* having palpitations, because it was a cycle of things. And *them* frightened me. I thought, 'If these go fast enough, *that'll* go off'" (Claire). For Claire, this was exacerbated by a lingering suspicion that the shocks had themselves damaged her heart.

Participants assumed a more sedentary lifestyle following storms, withdrawing socially and avoiding activities that might provoke shocks. It was as if the storm episodes had not really finished for the participants, a state that attenuated only gradually:

> It took me a while to get over that, a good couple of months, really, to try and get that sense of being able to go outside and not worry about walking up a flight of stairs for fear that something was gonna happen again (James).

The sense of their storms not being over was enhanced by the ‘flashbacks’ some experienced:

> I can actually *think* sometimes, you know, “What happens if it was gonna shock me in the next few minutes?”, and almost *feel* it and *feel* exactly the same sensations from what it feels like for it to, to shock you; the flash in your eyes and, you know, as if it was only yesterday. (James).

Overall, this theme showed that in storms’ aftermath, participants experienced reduced motivation and heightened sensitivity to environmental and physiological changes. While anxiety symptoms provoked a vicious circle of anxiety and chest sensations, some participants were also prone to ‘reliving’ their shock experiences.

Theme 3. “Just making me more anxious”: Problematic attempts to regain control.

Although feelings of helplessness were ubiquitous during storms, some participants attempted to exert influence where they could. Steve curled up in an effort to resist the force of the shocks, which merely served to increase the intensity of the pain when the next shock inevitably came. While Chris attempted to “rip” his ICD out “with me hands", David clung "for grim life" on to a magnet placed on his chest to deactivate the ICD and dissuaded a medic from removing it. The paucity of options at participants' disposal highlights how little control they had.

All were strongly motivated to regain control afterwards. While everyone eventually regained a measure of control over themselves by habituating to the anxiety provoked by the constellation of potential shock-triggers, some adopted strategies to expedite this. Each time he experienced bodily sensations he feared might culminate in a shock, Graham asked the cardiac team to remotely check his ICD's activity, which gradually reduced his anxiety. James adopted a more cognitive approach: "[Every time you get anxious] you think, 'Well, nothing happened that time, so actually it's probably all right'. Then you just try and reinforce it that way, really. It's always knocking down some of those beliefs, isn't it?" (James).

Participants attempted to prevent future shocks by intently monitoring their bodies for sensations that might herald them. Some experienced a reduction in these sensations and an increase in perceived control by physically responding to them:

> When I get these, like, *twinges* in me chest, [I] get into another position and see if it stops. And quite often it does, you see. Or else, other times I get up, go in the other room […] for a few minutes, and then..coming back. And it's right again, you see? (Chris)

However, monitoring increasingly consumed some, provoking distress and disrupting their lives. Believing they affected his chances of an arrhythmia, James monitored his consumption of water and certain foods and the frequency of his urination. Also, "[I] was probably checking [my pulse] maybe a hundred, two hundred times a day. Not really serving any purpose other than to make me feel more anxious". Despite this awareness, he felt powerless to curtail the behaviours, partly because they conferred perceived control over shocks, albeit fleetingly. Thus, participants were often engaged in a battle to control anxiety as much as the shocks themselves.

Participants' long-term anxiety-management strategies therefore became even more essential. However, these often proved untenable in storms' aftermath. While all extolled remaining physically active to control anxiety once the post-storm period of acute stress was over, Claire's anxiety was exacerbated by feeling initially unable to utilise exercise to this effect, as she had always done previously: "I walked three to four mile a *day*, I always have, and I got to the stage where I were frightened of going out!". Regaining this strategy contributed to marked increases in her subjective wellbeing.

Participants' psychological strategies for controlling anxiety also often caused problems or were untenable. Even after his first storm, James "did bury [his] head in the sand" about his condition, reducing his short-term distress but increasing his exposure to unnecessary risks: visiting remote places alone, "I could've experienced [shocks] more times than I did. So I do feel quite fortunate really to not have got meself in a pickle in those situations, really." While distraction techniques were commonly used to block shock-related thoughts, some participants were unable to access storm-related memories: "I get scared. And I start sweating. And I start trembling and, you know, I can't get [near them]" (David). These conscious and unconscious anxiety-management strategies afforded only short-term relief.

Finally, efforts to make sense of storms and participants' responses to them provoked confusion and dismay when they failed. Graham's inability to ameliorate his anxiety by applying logic to his situation, and for anxiety to inhibit this process and provoke behaviour he found inexplicable, was a source of bafflement and self-alienation: "Even sitting there and applying *logic* to it and trying to *think* about it, trying to make *sense* of it, it doesn't *change* […] And it's daft! Absolutely bone *bonkers*! It really is, isn't it?"

Overall, this theme concerned participants' efforts to regain the control lost during storms and the psychological barriers to this. These efforts often increased anxiety, which itself became the target of control efforts. Participants were especially adversely affected if their traditional methods of controlling anxiety proved untenable.

Theme 4. "You've gotta solve problems on your own": Beliefs about what constitutes acceptable support.

Most participants expressed a long-term orientation towards independence, reflected in the widely held belief that people should solve "problems on [their] own" (Graham). Storms threatened this independence not only during episodes, when partners summoned ambulances and medics provided sustained support, but afterwards, with fear of being alone during future storms. Moreover, managing shocks' ongoing emotional effects threatened participants' independence not only by necessitating further support but also by destabilising their apparent tendency towards emotional inhibition. This tendency was evident in the pervasive sense that none had spoken to their long-term spouses in any depth about their shock episodes or their feelings about them: “[I’ve] never [been] one for…talking through things, *anything*, anyway! My wife says to, ‘Come on, we’ll have to *talk* about this’. I’m not *talking* about it: we’ve nothing to say!” (David).

Engaging emotional support was problematised by some participants’ need to appear strong to and for others. When discussing his family, Steve said, “Maybe it’s just a man thing, probably, but you don’t wanna be seen to be […] weak in front of them”. Others’ reactions inhibited some participants from disclosing their feelings. For Claire, the lack of compassion and interest she was shown reinforced her tendency to withhold her feelings and confirmed her belief that she could only rely on herself: “You can’t feel sorry for yourself, ‘cos nobody will […] So you just learn, ‘So I’ve just gotta do this meself’”.

Reluctance to engage emotional support was often exacerbated, and in James’s case precipitated, by guilt about the perceived impact their storms and health conditions had on their loved ones, some of whom had received counselling and antidepressant medication: “You know, I mean, Phil, right, me husband, he knows *physically* what’s happened to me, but not prop- ‘cos I’ve not *bothered* him with it, really, he’s had enough to cope with” (Claire). Furthermore, managing shocks’ effects on themselves left limited resources for supporting their partners, as indicated by their use of qualifying phrases such as “I think” and “I imagine” when describing how loved-ones had been impacted; these issues had apparently not been explicitly discussed.

Guilt also resulted from participants' tendency to express distress and despair via anger and frustration: "'Cos I upset the granddaughter, because I had a *right* go at her one day, and there was no need for it […] And she was *right* upset" (Chris). Overall, participants felt compelled to withhold their feelings from their families, exacerbating their distress, frustration and isolation.

The eventual realisation that they needed support to address how they felt sometimes constituted an epiphany of sorts. Claire had felt increasingly alienated from her experience, from other people and from herself, and had ceased living her life because she was terrified of 'what-ifs':

> We were in a restaurant, me and me husband, and we were sat there and I thought, "I can't live like this"…And everything, I were *all shaky* inside. Everything were buzzing, and I says, "On the way back, drop me off at doctor's, I'll have to go" […] So I just went in and I says, "I'll have to see a doctor […] I'm having a living Hell".

Accessing professional emotional support provided the opportunity to express thoughts and feelings that participants had been suppressing. However, participants' tendency towards emotional inhibition often made it difficult for them to fully utilise this support. Graham in particular was embroiled in an ongoing struggle with this, having long intellectualised his experience in order to manage difficult feelings: "It's just my *head* that's a problem, and that's where people like *yourself* come in. And I've gotta realise that myself."

Highlighting the importance and acceptability of medical support to the participants, when this was felt inadequate the impact on their wellbeing was palpable. These inadequacies generally related to professionals' perceived lack of ICD knowledge, as indicated by the fear some apparently betrayed about touching participants during storms; for example, David recalled having to walk to the ambulance "on my own" due to paramedics' lack of expertise.

Ultimately, though, participants attributed any recovery they made to the social and professional support they had received: "[I improved thanks to] my family, the support I've received [in hospital], a realisation of *what* was going on, and *patience* by others" (Graham). However, there was a shared sense that support from fellow shock-recipients would be most effective and acceptable. Steve in particular yearned for this, making numerous references to it throughout his interview. This wish related to two principal issues. Firstly, some feared their responses to the shocks were unique and, by extension, a sign of personal failing: "Just to know if people are suffering the same as I am, you know: if it's just the experiences. Then I'll *know* if it was me" (Steve). Secondly, most expressed a sense of isolation and aloneness due to the perceived uniqueness of being an ICD shock-recipient: "Unless you've experienced [it], you don't fully *understand* it, and you think it's just happened to *you*" (Graham).

The inadequacy of information participants received about shocks prior to their ICDs' implantation also reinforced these points. However, while they also felt nothing could have prepare them for the reality of shocks, they unanimously reported that receiving explicit prior information about shocks and their possible effects would have been detrimental. There was a sense that such information would have frightened them unnecessarily, introduced doubt about a life-saving treatment they had no real choice but to accept, or might have even prompted them to decline it: “I knew it would do something if the heart started playing up again. But I’m glad I didn’t know about the extent of the shocks until it’s happened, because then I might’ve had second thoughts” (Chris). However, some felt storms’ effects were exacerbated because the risk of shocks had not been clearly explained to them:

> All it takes is *somebody* to explain what was going to happen to you, and I’d’ve been..a lot better. I mean, I’m not saying I wouldn’t’ve got anxiety; I would. But, I’d’ve *coped* with it. I wouldn’t’ve gone so deep down, I don’t think. (Claire).

Overall, this theme concerned participants’ appraisals of support they received and their difficulties with engaging emotional support. These difficulties related to their longstanding orientations towards independence and emotional inhibition. Although these issues contributed to participants’ increasing sense of isolation, this culminated in their eventual engagement of professional psychological support and a greater appreciation of social support.

Theme 5. “I’m just gonna have to try and live with it”: The ongoing struggle to accept the device and its implications.

Although participants benefitted from medical and mental health professionals’ interventions, at the time of interview all remained affected by some degree of shock-related distress/despair. This distress was increased by storms’ impact on their identities as partners, parents, grandparents, workers and enthusiasts of various pursuits had been irrevocably altered or remained threatened by shocks:

> When you've done something all your life, and now you can't do it […] it compounds and that then depresses you. 'Cos you can't do this and you can't do that, and that gets you down a bit further, and then it's a never-ending circle. (David).

However, some also described experiencing positive identity changes: Graham felt that he now had more empathy for others, whereas Claire felt her interpersonal style was more conciliatory and both she and Steve felt that their outlook on life was more positive.

The ongoing struggle to readjust after storms was partly driven by participants' difficulties with accepting their lack of control over future shocks: "Like, if you've a very, very bad accident..it, it might be awful but what's the chances you seeing that again? Where with this, it *could* happen again" (Claire). Although Claire had come to accept this powerlessness to some degree, most had not: "I'm still not very accepting of the fact that I could come out of here now and go to my car and it could happen. You know, I'm afraid of it happening" (James). Interestingly, David's anxieties had persisted despite his ICD being removed, while James's continued even though he possessed a magnet that deactivated his if shocks occurred. Thus, even total control over shocks was insufficient to assuage their distress.

Another issue influencing participants' adjustment was their acceptance of their devices, the conditions that necessitated them, and the prospect of death. Although the participants who believed their shocks had been appropriate concluded their ICDs had saved their lives ("it's been a Godsend!" [Chris]), the perceived appropriateness or otherwise of shocks did not consistently influence device-acceptance. Although Claire thought the effects of her inappropriate shocks would have been less severe if they had been otherwise, likening her ICD to a "built-in paramedic" and inappropriate shocks to a medicine's "side effect" facilitated device-acceptance: "it's *annoying* that that happened, but..they work..it proves they work". Conversely, James and Steve believed their shocks were appropriate, yet both remained deeply unable to accept or trust their devices: "That's another big thing, I want to get the confidence that..it's there to do a job and it's, you know, it's not gonna shock me" (Steve).

Before their storms, some participants had been (intentionally) oblivious to the seriousness of their heart conditions, and therefore largely unaffected by them: "It was only then that I realised, when it shocked me, actually how serious, how serious it was" (James). Having to confront and accept the seriousness of their conditions was an ongoing challenge for James and Steve, in particular:

> I'd like to say that, yeah, I've got the device fitted because it's there to… save my life if, you know, I'm in trouble, but I still wish that I wasn't in this situation with, you know, needing to have this, this bit of kit and that I have this heart condition, so…Yeah, but I'm probably still no further along, I would say, than I was when it happened for the first time. I don't feel any better about it. Yeah. (James).

Reflecting how difficult this aspect of the experience continued to be, participants' frequent death-related disclosures were usually expressed in indirect and euphemised ways: “that’d be ‘it’” (Steve); “maybe I’m not gonna recover from this” (Graham). Death’s omnipresence was particularly evident in James and Steve’s accounts, seemingly exacerbated by their comparative youth and because their children remained dependants. Both made frequent references to the potential impact of their deaths on their families, concerns about whom had also increased their distress during storms:

> What I’m *afraid* of more than anything is that, you know, if it happens this time, is it gonna be the last time, when I, where I leave my, you know, where I leave my family behind? Erm, and that’s, that’s probably the most upsetting part, really (James).

Although all participants communicated concerns about having life-limiting conditions, often planning only for the immediate future, some demonstrated a degree of acceptance of this situation or sought solace by contrasting themselves favourably either with people experiencing other illnesses or with ostensibly healthy individuals who lacked the insurance ICDs provide. Most also expressed hope that time would improve how they felt. However, there was often a fatalistic dimension to this hope, as though they had no power to influence this progress themselves: “I’ll get there in the end, eh?” (Steve).

Overall, this theme showed how participants’ ongoing distress and despair related to difficulties with adjusting to storms’ impact on their identities, with accepting both their lack of control over shocks and their condition-reappraisals’ implications, and with their contact with mortality. Although Claire had been able to reframe her experiences to beneficial effect, others' adjustment and hope for the future were jeopardised by fears associated with perceiving both a foreshortened future and little influence over their situations.

Discussion

This study explored the experiences of multiple-ICD-shock-recipients. Participants had all experienced electrical storms, enabling the first qualitative investigation of this phenomenon. The chief findings were: storms prompted the belief that death was imminent over a sustained period and changed participants' appraisals of their heart conditions; most struggled to accept their reappraisals' implications and their lack of control over shocks; the acute stress response following storms was exacerbated by mutually reinforcing anxiety symptoms and chest sensations; efforts to prevent future shocks often caused further problems; orientations towards independence and emotional inhibition prevented participants from fully utilising available support; and, finally, storms had a durable impact on participants' identities.

Echoing previous findings [20] [21] [22], participants' wellbeing was profoundly affected by electrical storms. Appraising shocks as deadly and subsequently reappraising their heart conditions negatively revealed that storms can be triply traumatic: in themselves, due to the violent, overwhelming and unpredictable way they occur; because the pain inflicted and their uncontrollable relentlessness may prompt the catastrophic cognition that recipients' lives are in jeopardy [23]; and because they may provoke distressing reappraisals of recipients' heart conditions.

Participants' negative reappraisal of their heart conditions, and the difficulties they experienced accepting the implications, extends a review's conclusion that shocks do not influence QoL independently of recipients' appraisals of their heart conditions [9]. Storms may in fact profoundly influence beliefs about recipients' heart conditions, triggering significant distress. Therefore, the relationship between shocks, illness-appraisals and distress may be more complicated than previously thought.

Prolonged hopelessness during storms seemed particularly distressing. However, different attributions gave rise to different outcomes regarding self-reported wellbeing, as predicted by cognitive models of PTSD [37]. Afterwards, most participants positively reappraised shocks by recognising they had saved their lives; however, this was insufficient to eliminate distress, possibly due to difficulties with accepting shocks' perceived implications and the ongoing trauma symptomatology affecting some.

Extending previous findings that shocks can detrimentally affect device-appraisals [25], storms exerted this effect, and regardless of shocks' appropriateness or recipients' cardiac histories. Overall, the various relationships between electrical storms, peritraumatic attributions, shocks' appriopriateness, cardiac illness- and ICD-appraisals, and psychological distress merit further research attention.

The findings appeared to echo research that found that ICD-recipients whose devices were implanted following the sudden onset of their cardiac condition or for secondary prevention were more adversely affected by shocks [30]. The pain shocks caused seemed especially distressing for those who had not previously experienced a painful cardiac event, suggesting the possible salience of this aspect of ICD-recipients' cardiac histories. Tacitly supporting findings that recipients' age/stage-of-life may influence ICD-related psychological difficulties [3] [30] [38], those with dependent children appeared most profoundly affected by ongoing distress. This related not just to the gravity of the (often disguised) potential losses to them and their families in the event of their deaths, but also to their felt need to appear strong to their family-members. Owing to the study's small sample size, further research into the effect of device-indication, cardiac history and age/stage-of-life on electrical storm-related distress is merited.

Participants' application of personal heuristics to help predict shocks in response to 'shock anxiety' [39] reflected their lack of perceived control over shocks and the high internal locus of control most apparently evinced. These constitute novel findings for the electrical-storm population. Perceived control refers to the belief that one can influence a given situation. It is a construct arguably essential to successfully adapting to challenging situations in general [40] and to tolerating ICD-shock-related uncertainty in particular [30]. Locus of control (LOC) is considered a malleable trait conferring beliefs about the degree of perceived control one typically possesses; an internal-LOC denotes personal agency while having an external-LOC means individuals' ascribe experiences to external factors [41].

Although a high internal-LOC can benefit patients experiencing conditions over which they exert some control [42], it has been associated with depression in those experiencing some diseases e.g., HIV [43]. Furthermore, Kang [44] found that high internal-LOC was associated with the appraisal of uncertainty as dangerous in patients with atrial fibrillation (which causes irregular, fast heartbeats). This may explain why some participants continued monitoring-behaviours despite their futility: doing something unhelpful felt better than doing nothing, potentially conferring temporary perceived control. As found previously [45], however, the behaviours themselves eventually became distressing, possibly because the short-term nature of the relief they brought precipitated their disruptive escalation.

Interestingly, anxiety itself then became the target of control efforts. These arguably served three functions: increasing perceived control, providing distraction from mortality fears, and reducing anxiety made more intolerable by participants' tendencies towards emotional inhibition. However, the inadequacy and maladaptiveness of participants' longstanding strategies for managing distress served to increase it. Hallas, Burke, White and Connelly [30] found that adjustment to having an ICD was similarly impeded by unhelpful coping strategies; the present findings extend this by applying it to electrical-storm-recipients and explicitly linking it to long-term coping styles. Hallas et al. [30] also found that the best-adjusted ICD-recipients adopted 'problem-focused' coping strategies, such as accepting their experiences, normalising their feelings and realising (new) priorities, rather than the 'emotion-focused' strategies utilised by most of the present study's participants (e.g. hypervigilance and avoidance). While electrical storms' effects may make adopting such strategies generally harder, this may be especially so for people with high internal-LOC and proneness to emotional inhibition, for whom the degree of anxiety storms provoke may necessitate emotion-focused coping efforts at the expense of problem-focused ones.

Participants' tendency towards emotional inhibition was reminiscent of the so-called 'Type-D' personality, identified previously as a factor in ICD-related distress [24]. However, it was unclear whether they had longstanding tendencies to experience negative affect, the other principal feature of the Type-D personality. Furthermore, participants' difficulties with emotional expression were exacerbated by guilt about storms' impact on their families and their aforementioned need to appear strong to them. Therefore, the reasons why some electrical-storm-recipients withhold their emotions could be more complex than they initially appear.

Further to this, it may be that for people with a high internal-LOC and proneness to emotional inhibition, professional support may be more acceptable than social support to address psychological issues, as this would enable them to retain their independence and stoicism within their personal relationships. Thus, it may not have been a lack of social support that contributed to participants' distress, as previous ICD research found [46], but a difficulty with fully utilising this support. This novel finding may explain the preponderance of people within the sample who appeared to manifest these orientations: those with a different LOC orientation and who are less prone to emotional inhibition may utilise their social support to facilitate their emotional expression, and may therefore not require professional support.

Some participants' reluctance to fully engage with the emotional support they received may sometimes have reflected a struggle to integrate their lack of control over shock experiences into their identities, as proposed by the self-regulation model of adjustment to illness [47]. This holds that to assimilate appraisals of a severe illness as disabling, some patients develop rules enabling them to remain independent; for example, by asserting that their independence is preserved as long as they do not seek help. Further research specifically looking at the relationships between perceived control, LOC, emotional inhibition, coping, and psychological difficulties resulting from electrical storms is indicated by these findings.

The final novel finding related to the few indicants of posttraumatic growth, whereby people experience positive change in response to traumatic events, including those associated with severe illness [48]. This paucity may reflect the unique nature of living with an ICD that has delivered electrical storms: for posttraumatic growth to occur, it seems logical that the trauma must have finished, which cannot be the case for those still at high risk of traumatic experiences. Further research is required to investigate this issue.

Clinical Implications

As electrical storms may leave ICD-recipients with an altered sense of their condition and/or device, there is potentially a need for them to be re-educated about these; whether realistic or not, shifts in their condition-appraisals are likely to be distressing. Furthermore, cardiac specialists should consider raising the topic of mortality with electrical-storm-recipients, as this is likely to be a particular concern and one they may not volunteer themselves.

Promptly providing storm-recipients with information about storms' possible psychological and physical effects may help normalise their experiences and responses, thereby minimising harms. Arranging consultations to discuss how they are coping may also be advantageous and could facilitate psychoeducation about anxiety. Where services have cardiac nurses with a specialist focus on devices, these responsibilities could be carried out by them. Extra reassurance could be gained during appointments with consultants. If such consultations prove insufficient to facilitate the readjustment of maladaptive attributions/cognitions, cognitive-behavioural therapy may be of benefit.

The central role of helplessness and the ongoing lack of perceived control in participants' distress suggests that finding ways to increase storm-recipients' perceived control during and after episodes may be protective. Higher perceived control can reduce perceptions of pain intensity and anxiety during painful experiences [49], while perceived control may mediate the relationship between PTSD symptomatology and pain intensity on the one hand and psychosocial and physical impairment on the other [50].

Participants seemed to evince a high internal-LOC and proneness to emotional inhibition. If future research confirms that such individuals are especially vulnerable to electrical-storm-related distress, screening measures for these traits could be administered prior to ICD-implantation to facilitate targeted support.

These apparent tendencies motivated participants to exhaust many avenues in order to gain control over shocks and their emotions. Other ICD-recipients may conclude that nothing can improve their situations, so may stop taking medication or looking after themselves. Similarly, the post-storm reduction in activity levels participants experienced has clear health implications and may impact on ICD-recipients' healthcare usage. Again, an active approach to contacting storm-recipients may reduce such untoward consequences.

The findings highlighted the potential need for electrical-storm-recipients to cultivate acceptance of their emotions, their conditions, their mortality and their lack of control over shocks. An approach such as Acceptance and Commitment Therapy [51], which is designed to address not only these very issues but also to help recipients find new meaning in their lives, could help with this. However, for those who manifest symptoms of PTSD, specific treatment may firstly be necessary to help them process the trauma.

The often-expressed wish for peer support indicated the use of a ‘buddy system’ or support group for storm-recipients. These would help them normalise their experiences, share coping strategies, and facilitate connectedness with others. Individual factors, such as stage-of-life, should be taken into consideration when designing these.

Finally, given storms’ impact on recipients’ families, it seems important that family support is offered. Research looking at the experiences of electrical-storm-recipients’ significant others would appear to be imperative, given the likely detrimental impact of witnessing storms and supporting storm-recipients afterwards.

Limitations

The participants were all drawn from a single cardiac centre. Therefore, particular caution should be exercised in transferring the findings to other populations.

All the participants had received input from the cardiac team’s clinical psychologist. This increased the homogeneity of the sample but almost certainly influencing participants’ sense-making. Furthermore, the sample might have comprised those who struggled most. The observation that the participants appeared to evince a high internal-LOC and emotional inhibition suggests such individuals may be particularly prone to difficulties and/or more likely to accept professional psychological support. Alternatively, the preponderance of such individuals may be entirely coincidental. Future research might attempt to recruit psychotherapy-naïve people and to measure their LOC-orientation and proneness to emotional inhibition.

A related limitation concerns the retrospective nature of participants' accounts, which were likely influenced by general post-storm experiences. Future research might address this by prospectively following a cohort of ICD-recipients from pre-implant onwards.

A final limitation concerns the preponderance of males within the sample and the wide variation in participants' ages and stage-of-life. These issues were acceptable given the exploratory nature of the study; however, future research might recruit a more even balance of genders and ages/stages-of-life or investigate specific populations to yield avenues of inquiry pertinent to the respective groups.

Conclusion

Experiencing electrical storms may be triply traumatic: in themselves, because they can provoke fears that death is imminent, and because they can trigger catastrophic condition-reappraisals. Storm-recipients may experience an acute stress response afterwards which can be exacerbated by anxiety's effects on cardiac functioning. Coping strategies utilised by storm-recipients may prove insufficient and/or problematic, potentially leading to increases in distress. Difficulties may particularly affect those who manifest a high internal-LOC and/or tendencies towards emotional inhibition. Those who struggle to accept the device, their conditions, their mortality and their lack of control over shocks may be at particular risk of ongoing difficulties, as may those with depandants. These findings suggest that active efforts should be made to establish how well storm-recipients are coping and to facilitate support for those who are not so that these issues may be addressed.

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Table 1: Participants' demographics

Name	Age	Marital / employment status	Prior trauma	Diagnosis/ Date	Painful cardiac event prior to ICD	Device indication	Year ICD implanted	Number of episodes / Date(s)	Shocks per episode	Beliefs about shocks' appropriateness
'James'	38	Married / Employed	None disclosed	Arrhythmogenic right ventricular cardiomyopathy / February 2009	No	Primary	2009	5 /February 2011-October 2012	2-115	Appropriate
'David'	63	Married / Retired	Yes	Cardiomyopathy and arrhythmia / 2003	No	Primary	2005	2 /December 2005. December 2012	1 & 23	Inappropriate
'Claire'	58	Married / Retired	None disclosed	Arrhythmia following Sudden Cardiac Arrest / 2005	No	Secondary	2005	1 / March 2011	11	Inappropriate
'Steve'	51	Married / Employed	Yes	Heart murmur and Sudden Cardiac Arrest / Early 2012	No	Secondary	2012	2 / Early 2012	10 & 30	Appropriate
'Chris'	70	Married / Retired	Yes	Coronary heart disease / 1993	Yes	Primary	2009/2010	1 / July 2012	25	Appropriate
'Graham'	68	Married / Retired	None disclosed	Atrial fibrillation / 2010	No	Primary	2010	1 / Early 2013	7	Appropriate

Appendix 2-A. *Coding Extract*

Non-italicised text denotes descriptive comments / Italicised text denotes interpretative comments

Descriptive comment	Transcript
Unable to remember much of the episode or even to think about it without consciously “turning it off” – *whatever happened is too frightening for him to actively contemplate, although he is able to reflect on what it put him in touch with at the time i.e. his own mortality. Intellectually ‘knows’ what the experience meant, but the feelings associated with it remain unprocessed?* Thoughts occur particularly in bed, which is where the episode began.	David: I- I can’t get that far in the d- in the thoughts process. You know…for a GOOD number of months afterwards…you…I mean, it’s got less now, but even- even now, y- you start thinking about what went on. It just- constantly- usually when you’re lying in you bed and you, and you think about s- what’s, you know, and I can only get so far…in…and I…then consciously turn it off.
	Me: What happens?
When he tries to think about what happened during major episode, he experiences somatic symptoms of anxiety, then he “switches it off” - *before the feelings, thoughts and their meaning become connected and he is overwhelmed?*	David: I get scared. And I start sweating. And I start trembling and, you know, I can’t get… As soon as I start thinking about it I switch it off now.
	Me: Right.
Been quite content recently. Last night he began thinking about the episode unexpectedly and doesn’t know why – *because he knew talking about it today might stir up those feelings and risk them becoming connected to his recollection of the experience? He copes by maintaining that separation, although it paradoxically*	David: Even NOW. I mean, odd because I- this last week I haven’t been s- I’ve been quite content. But last night for some UNKNOWN reason, I was thinking about it, and I had to switch it off, cos it still worried- it still bugged me.

maintains his vulnerability?	
Suggests he hasn't been thinking or talking about it all recently, despite his ongoing difficulties – avoidance of difficult feelings preferable to David?	Me: Ok.
Still unable to think about it without switching it off, despite feeling quite content – *unprocessed trauma?*	David: It's, er…
	Me: And what is, and what is the worry? If you were to start thinking about it, what's the end-point of that?
Anxiety that it might go off persists even though he doesn't have an ICD anymore – *reflects how deeply the trauma is buried? Supports my interpretation that his ongoing anxiety relates to unprocessed trauma resulting from being put in touch with his mortality and being out of control?*	David: It's gonna go off. It's never GONNA go off, cos I haven't got one!
	Me: Oh, right.
Made the decision himself not to have it replaced, in consultation with his surgeon – empowered to take control by his surgeon's agreement that it wasn't vital – *sense of hesitation around this. Not happy to have had to take responsibility for this decision?* Experienced and witnessed some very traumatic things in his life, but the shocks were worse – *although he has been blown up, there was something about this experience that made it especially traumatic: the duration / uncontrollability / presence of his wife / sanctuary of home / unexpectedness / all of the above*?	David: We…I- I decided that I wasn't gonna have it replaced… My decision. Dr Goode, who's my surgeon, erm, agreed with it, that I didn't have to have a re- I mean, if he'd have turned round and said, "You HAVE to have one; it's life or death", I would've had to- I would've had it. But he said, "if you don't want it, you don't HAVE to have it", so… [Inaudible] I wasn't having it. I wasn't gonna go through that again. I mean, as I said before, I've been through some things in my early life, but NOTHING like that. Nothing at all. And I've seen some things like that, a lot of them, but THAT just

Although he feels he has improved, even a year after the ICD was removed he still has some way to go. Still experiences ‘shocks’, especially when half asleep – phantom shocks? *Difficulty comprehending/making sense of phantom shock experience reflected in difficulty articulating it?* *When half-asleep – time of greatest vulnerability/need of safety – sleep and bed no longer the refuge they should be*	[exhales]… I still- And it’s a year down the line nearly and I’m still not there yet… I’m better.. than I was, but I’m not, heh, you know, I have to… I still get… shocks. It’s like get-, you know, you can’t-… Y- y-, even though I haven’t got a device, I can shock meself… Especially if I’m, sort of, half asleep. It’s, erm…

Appendix 2-B. *Narrative summaries and emergent themes for "Claire"*

"Claire's" Narrative Summary of Themes	Emergent Themes (Final theme in brackets)
1. The pain of the shocks connected her to her mortality in ways she had not previously experienced.	
The lack of pain Claire recalls during her cardiac arrest made the intense agony of the shocks all the more frightening, putting her in touch with feelings of mortality for the first time. Although these were not assuaged by the effect of the shocks on others around her, being assured that her heart was fine and focusing on a hope that the shocks were the product of a faulty lead prevented her from being overwhelmed by the thoughts during the episode. However a belief that the shocks had seriously damaged her heart persisted, *giving rise to a sense that she was living on borrowed time afterwards.*	The lack of pain Claire experienced during her cardiac arrest made the intense agony of the shocks all the more frightening. (1) Characteristics of the shocks vs the arrest put her in touch with feelings of (proximal) mortality for the first time, despite cardiac arrest. (1) Reactions of husband and professionals during the shocks did not assuage her concerns. (1) Focusing on the hope that the shocks were caused by a faulty lead rather than her heart prevented her from becoming overwhelmed with terror and thoughts of death during the episode. (1) A belief that the shocks had damaged her heart persisted, giving rise to a sense that she was living on borrowed time. (2)
2. Anxiety became the real enemy – "Anxiety hit me like a tonne of bricks".	Anxiety in the aftermath was even worse than the shock experience. (2)
As difficult as the shock episode was, the anxiety she experienced in its aftermath was worse. *Although she has always been a worrier, she had previously managed this by being very active, a strategy denied her after the shocks, first of all by her convalescence and then by anxiety about her heart, which increased markedly once*	Shock impact prevented her from using her 'stay active' coping strategies to manage her long-term anxiety, first due to need to convalesce (3) Anxiety about her heart disrupted her ability to draw on her 'stay active' coping strategies once she convalesced. (3)

she had physically healed and then attempted to get back to normal. Normality was dramatically altered, with normal bodily sensations threatening to confirm her fears about her heart being damaged, *activities that had given her life meaning and respite from worry now being sources of threat,* and her permanent state of alert priming her to await shocks and to respond with fright when ordinary but unexpected noises occurred. *Her tendency to experience her anxiety somatically, combined with her lack of knowledge about this response, persuaded her that anxiety itself might be deadly,* prompting her to monitor her body more intently and to reduce her activity further. Beliefs about the danger of palpitations persist into the present.	Normality was dramatically altered, with bodily sensations, unexpected experiential phenomena, and activities that gave her life meaning now becoming sources of threat. (2) Believed that anxious sensations themselves might be deadly, an effect increased by her tendency to experience anxiety somatically and be her lack of understanding about anxiety. (2) Monitored her body intently. (3) Beliefs about danger of palpitations persist into present. (5)
3. Increasing alienation from her experience led to two epiphanies. Convinced that something was wrong with her heart, she was unable to accept physicians' assurances that this was not the case or to make sense of her experience. *This exemplified the alienation she was feeling from her experience and from other people*. She became more distant from herself, from others and from reality as time went on. *This culminated in Claire experiencing an epiphany about the tragedy of her situation and the futility of her trying to prevent a 'what if' from happening.* This prompted her to take action.	Disparity between doctors' assurances and how she felt left her unable to accept these assurances or to make sense of her experience. (4) Became increasingly alienated from her experience, herself, from other people and from reality – realised is was pointless trying to control what-ifs. (4) Eventually, Clare experienced an epiphany about the tragedy of her situation and the pointlessness of trying to prevent 'what-ifs' from happening. This prompted her to take action. (4)

4. Gaining knowledge about anxiety and taking action against it has been central to her recovery. Unable to make sense of her experience, Claire saw a clinical psychologist, who helped her to understand what was happening and *empowered her to begin adopting her old activities/coping strategies* and gave her some new ones. *She conceptualises anxiety as being primarily physiological and distinguishes it from worry; this has enabled her to address anxiety as a foe to be bested primarily through physical action and by cognitively distancing herself from both it and the thoughts it* engenders. This also negates the need for her to make sense of these thoughts (although this lack of sense-making is the source of occasional self-criticism). *In combination with medication, she feels that this "Just gotta do it!" approach has reduced her anxiety to a level she is prepared to tolerate. Furthermore, it has enabled her to reduce her worry about other potential health difficulties by enabling her to attribute these to anxiety, too.* Although she believes that too much knowledge about ICDs can be dangerous and that an awareness of how painful the shocks are prior to implant would be counter-productive, Claire feels that developing an understanding of anxiety was so important to her that receiving information about this immediately after the shock episode would have made the most significant difference to her post-shock experience, even if this had itself been the cause of anxiety.	Claire saw a psychologist, who helped her to understand what was happening and equipped her with new coping strategies. (4) Her psychologist empowered her to begin adopting her old activities/coping strategies – this enabled her to reclaim herself and to manage her anxiety. (3) She conceptualises anxiety as being primarily physiological and distinguishes it from worry, enabling her to externalise the anxiety and address it as a foe to be bested. (3) She tackled her anxiety through physical action and by cognitively distancing herself from the thoughts it engenders. (3) Although cognitively distancing from thoughts negated the need for sense-making, the perceived lack of sense is a source of occasional self-criticism. (3) Medication and her "just gotta do it!" attitude has reduced her anxiety to manageable/acceptable level. (5) Now attributes other health difficulties to anxiety, too, giving her control over worry about these. Too much knowledge about ICDs could be dangerous and awareness of the shocks prior to implant would be counterproductive. (4) Information about anxiety immediately after the shocks would have been the most beneficial intervention she might have received. (4)

5. Although she believes she could not cope with shocks on her own, she has felt alone throughout her recovery. Although having others' support during the episode was the source of significant comfort to her, and continues to be so in the face of her worst fear coming true (i.e. that shocks will occur when she is on her own *and that this will lead to her death*), *she believes that she has been fundamentally on her own during her recovery. Friends, family and medical professionals alike have typically responded to her in ways that have alienated her or discounted her experience at best or made her feel uncared for at worst. This reinforced her tendency to withhold her emotional experience from others and to see herself as the only person she could rely on.* This has been particularly evident with her husband; *although they have long provided each other with crucial practical support and companionship, and his calm demeanour has long been a source of containment for her worries, his difficulty with empathising with her after the shocks left her feeling alone and uncared for.* This was compounded by the guilt about the perceived and observable impact of her difficulties on him. *Because she has come through the experience by relying so heavily on herself, she feels that this approach has been helpful. However, a sense that she would have preferred different support is apparent at various times, particularly in her repeatedly expressed wish to support others who have experienced shocks and for others to learn from her experience via the present*	Others' support during the episode was the source of significant comfort to her. (4) The potential absence of others during future shocks is a source of considerable anxiety to her in the face of her worst (unspoken) fear coming true. (4) Feels she has been fundamentally alone during her recovery. (4) Others have often responded to her in ways that have alienated her, discounted her experience, or made her feel uncared for. (4) Others' responses reinforced her (pre-existing) tendency to withhold her feelings and confirm to her that she only has herself to rely on. (4) Relationship with husband has long been the source of strength/containment for her, but his difficulty with empathisising with her has left her feeling alone and uncared for. (4) Feels guilt about the perceived and observable impact of the shocks on her husband. (4) Because she feels she has come through the experience, this has confirmed that relying solely on oneself is the best approach. (4) Sense that other support would have been preferable is evident at different times – uncared for. (4) Would like to support others who are struggling with shocks. (4)

research.	
6. Shocks and their impacts are counterbalanced by some positive effects and outweighed by the insurance the ICD provides. Although she feels the shocks ruined her life and that she has been permanently altered by them, she also feels she is stronger as a result, that she has a more positive outlook and interpersonal style, and that she now worries less about things that she regards as unimportant. Although she feels that the impact of the shocks would have been less if they had been ‘appropriate’, she also has various ways of thinking about the ICD and the shocks that mitigate her anger about this and help to assuage her anxiety about potential future shocks. She likens inappropriate shocks to side-effects of medication and points out that they prove the device works. Moreover, she is reassured by the insurance the ICD provides and by her belief that, as everyone is at risk of a cardiac event, the device means her level of risk is below that of other people.	Feels the shocks have ruined her life and permanently altered her. (5) Feels stronger as a result, and has a more positive outlook and interpersonal style, and worries less about things she now regards as unimportant. (5) Feels that the impact of the shocks would have been less if they had been appropriate. (5) She likens inappropriate shocks to side effects of medication and points out that they prove the ICD works, both of which help her to feel more positively about the ICD. (5) Insurance provided by the ICD outweighs the risk of more shocks and the difficulties caused by them. (5) Believes her level of risk is below most people’s, not have the insurance she has. (5)

Appendix 2-C

Table showing emergent themes and supporting quotes relating to each theme

Theme	**Emergent Themes**	**Example supporting quotes**
Fear of imminent death	Violence, pain, relentlessness, prolonged duration and uncontrollability of shocks made death seem likely	"That bullet's got your name on it" (David) "Every time it goes, is that 'it'? Is it gonna kill ya?" (David). "And it's just hitting you and hitting you, and you think, 'Well, is it gonna stop?' It has to stop sometimes. Your heart can't keep, you know…" (Steve) "I was panicking and, you know…I was in *that* much pain [becomes tearful]" (Steve) "You feel like a ping-pong ball." (Graham)
	Lack of painful previous events made contact with mortality more intense	"[My cardiac arrest] didn't traumatise me, 'cos I don't remember it; I don't remember ANYTHING. I was thankful when I was going in hospital that my heart was fine..but..that-that's IT, you see, 'cos if..you have something WRONG with your heart..like, me heart, I never FELT anything, but the PAIN of THEM!" (Claire)
	Shocks worse than previous traumatic experiences	"I've been in some pretty tight spots, and I've been pretty scared in my life... But nothing-*nothing* at all compares to that. You've *no* control over it *whatsoever*. And *nothing* you can do can stop it... So, you think, well, 'Goodnight Vienna'" (David).

	Violent imagery invoked to describe shocks	"And it feels as though it's, you know, you had a heavyweight professional boxer..hitting you, erm, trying to punch his way out of your chest. Very difficult, very frightening." (Graham) "I suppose it'd be like holding a firework or something like that, it's like, you hold a firework on the outside, like with two fingers it'll go off, 'bang'.. If you held it in a clenched fist, that's when it feels like… And there's a big explosion, and it just all comes out and you're..screaming.." (Steve) "Like somebody hitting you in the chest with a baseball bat […] Very hard." (David)
	Hope repeatedly dashed	"You knew what was coming, so I knew, I knew what to expect, and.. It was- so I was thinking, "Well, er, the next one might be a bit better". You knew it wasn't gonna be. You knew EXACTLY what it was gonna do." (Steve)
Living with a sense of dread	Permanent dread/alert for environmental and physiological changes	"It felt like walking around with a timebomb in your chest, all the time." (David) "You're thinking, 'Yeah, this is gonna happen', and that's when you're looking round and everything becomes…you know, everything's gonna, gonna *cause* it to happen again" (Graham) "And I might have a- EVERY SINGLE THING in your body that..you notice, and it's like..pain or.. you think- you think, "Well, what if that's any-" and especially round this area.. you think, and then it, it just..gets you- it just gets me wound up." (Steve)

		"*All* I kept thinking..*every* twinge, 'Oh, it's me heart, it's me heart!'. Oh, it's *awful*! *That's all* that's here, in the forefront of your mind. *Nothing* else, only your heart" (Claire)
	Anxiety itself felt to be potentially deadly	"I was thinking, before I got meself all worked up and silly, anything like that can kick in and just- I'll think, 'Well, what if it sets me, me ICD off?'" (Steve). "she TAUGHT me that anxiety..was..it wouldn't KILL you" (Claire)
	Conditioned association between shocks and places	"..after I'd had the first few shocks..and she said "Are you all right?". I said, "Yeah, but I don't wanna, don't wanna go to sleep", 'cos I was struggling at the time, and I said, I said "That's when the demons come". She said, "What do you mean, the demons?" I said, "You know, that's when I start remembering all what had gone on and the pain" (Steve). "I come back for check-ups at the pacemaker clinic… [while I was there] it just felt like I'd had a bit of a shock. Anyways it, nothing ever come of it, but..I just, you know, don't like going in the pacemaker clinic now." (Steve)
	Constant alert attenuated over time	"It took me a while to get over that, a good couple of months, really, to try and get that sense of being able to go outside and not worry about walking up a flight of stairs for fear that something was gonna happen again" (James).
	Sedentary lifestyle after shocks	"You know, I joined the gym, trying to get a bit of weight back off, 'cos I, I come home from work and sit in the chair.. I don't wanna do

		anything." (Steve)
	Flashbacks	"It brings back everything that happened that night. Brings it all rushing back. The three.. ghouls sat- stood at the end of the bed, which was the thr- the ambulance people. Yeah. The dark room. The pain. The terror." (David)
Problematic attempts to regain control	Attempts to exert control during episodes	"And then..you can- it's undescribable..the pain. And, er, you just roll up in a foetal, in a..foetal position and you just try to stop it." (Steve) "I even, at the time, I tried to rip it out, with me hand, you see? But, er, I couldn't..and that." (Chris) "So, anyway, they put this magnet on my chest and THAT stopped it. Errr, and I held onto that magnet for grim…life. […]Anyway, one of the technicians came in to switch the device off, and he says, "well, we'll just lift the magnet off", and I says, "You're not! [laughs] No way you're touching that! You're not going anywhere near it!"" (David)
	Conscious efforts to expedite habituation to potential shock triggers	"[Every time you get anxious] you think, 'Well, nothing happened that time, so actually it's probably all right'. Then you just try and reinforce it that way, really. It's always knocking down some of those beliefs, isn't it?" (James).
	Success, difficulty utilising & inadequacy of (long-term) strategies for managing anxiety – behavioural strategies	"When I get these, like, *twinges* in me chest, [I] get into another position and see if it stops. And quite often it does, you see. Or else, other times I get up, go in the other room […] for a few minutes, and then..coming back. And it's right again, you see?" (Chris)

		"[I] was probably checking [my pulse] maybe a hundred, two hundred times a day. Not really serving any purpose other than to make me feel more anxious" (James) "I walked three to four mile a DAY, I always have, and I got to the stage where I were frightened of going out! I was sat in the home, just waiting for me husband coming home" (Claire)
	Inadequacy of (long-term) strategies for managing anxiety – cognitive strategies	"I did bury my head in the sand…you know, about having it, and even the condition… And I think even *then*, having had that experience [of being shocked] I was still kind of putting it down as something stupid that I did instead of actually, yeah "you've got this condition that's," you know… I could've experienced [shocks] more times than I did. So I do feel quite fortunate really to not have got meself in a pickle in those situations, really." (James) "I have NO IDEA.. I can't, I can't get myself t-, I CAN'T think about it. It- I can't think about it, it just doesn't- No, I don't, don't play that tape. I know I SHOULD. I get scared. And I start sweating. And I start trembling and, you know, I can't get [near them]" (David). "Even sitting there and applying *logic* to it and trying to *think* about it, trying to make *sense* of it, it doesn't *change* […] And it's daft! Absolutely bone *bonkers*! It really is, isn't it?" (Graham)

Beliefs about what constitutes acceptable support	People should solve problems on their own and be strong for and around others/essential aloneness	“Well, you’ve gotta solve the problems on your own”. (Graham) “the nurse come to me one time, and that.. [coughs] halfway through..and she said..do you want me to bring the wife in [coughs] But I knew she’d be at home..I knew she wouldn’t be asleep… But I said, “No”…[long pause] ‘Cos I think… me own willpower and determination.. [blows nose]…helped me come through it…” (Chris) “[I’ve] never [been] one for…talking through things, *anything*, anyway! My wife says to, ‘Come on, we’ll have to *talk* about this’. I’m not *talking* about it: we’ve nothing to say!” (David). “Maybe it’s just a man thing, probably, but you don’t wanna be seen to be, you know..giving in, […] I don’t wanna..seem weak in front of them..” (Steve).
	Reactions of family and professionals not always helpful/impact on others increased distress/difficulty supporting loved ones	“You can’t feel sorry for yourself, ‘cos nobody will. ‘Cos you look all right, you don’t get pitied. You don’t- ‘cos y- at the beginning, you sorta think, “well, you’ve been poorly, you’ve had this and that”, but the longer it goes on..people get fed up with you. I’ve found that people were asking, “How are you?” and you start telling them about it: “Oh, right..yeah..yeah” [mimes looking around disinterestedly] and they start..you know? So you just learn, “So I’ve just gotta do this meself” (Claire) “You know, I mean, Phil, right, me husband, he knows *physically* what’s happened to me, but not prop- ‘cos I’ve not *bothered* him with it, really, he’s had enough to cope with” (Claire)

		"'Cos I upset the granddaughter, because I had a *right* go at her one day, and there was no need for it […] And she was *right* upset" (Chris) "But, yeah it affected Sarah a bit. She- SHE'S a lot better now, she went to First Step..she went for counselling as well and..it did her a lot of good. Erm, me son went for a while.. He was very angry..we put it down to that.. You know, he worried. He's a lot better now.. even when he's got a job now, he's a lot, he's a lot better. Katy: she went for a while, First Step, but she, she after four or five sessions she said, "No, I don't think I need 'em anymore, so-". I said, "Well don't give up unless you need to" (Steve) "I think it frightened my wife. I mean, obviously I only had to put up with it; she had to WITNESS it..stand by, so.. You'd have to ask her about that, I don't know." (Graham) "And she STILL hears my screams.. Which is..you know, for a grown man of sixty- you know 39, as I am... scream like a..schoolgirl... It's, erm, pretty terrifying, I would've thought." (David)
	Support from others essential but sometimes problematic and difficult to fully utilise/need for 'buddy' system	"We were in a restaurant, me and me husband, and we were sat there and I thought, "I can't live like this"…And everything, I were *all shaky* inside. Everything were buzzing, and I says, "On the way back, drop me off at doctor's, I'll have to go" […] So I just went in and I says, 'I'll have to see a doctor […] I'm having a living Hell'". "It's just my *head* that's a problem, and that's where people like *yourself* come in. And I've

		gotta realise that myself." (Graham) "the ambulance man wouldn't touch me, cos they were scared of the ICD. They didn't know what they were dealing with. So I walked down the stairs and I walked to the ambulance…on my own…" (David) "[I improved thanks to] my family, the support I've received [in hospital], a realisation of *what* was going on, and *patience* by others" (Graham). "I've never met anybody yet who's had one; you know, like a shock like mine or..who's had an ICD fitted.. I don't know of anybody [...] so if you could sort that out!" "Just to know if people are suffering the same as I am, you know: if it's just the experiences. Then I'll *know* if it was me" (Steve). "Unless you've experienced [it], you don't fully *understand* it, and you think it's just happened to *you*" (Graham).
	Ambivalence about information received prior to implantation	"I knew it would do something if the heart started playing up again. But I'm glad I didn't know about the extent of the shocks until it's happened, because then I might've had second thoughts" (Chris). "If someone had one fitted and they said to me, "What's it like?" I don't think I'd tell 'em..what I'd been through." (Steve) "All it takes is *somebody* to explain what was

		going to happen to you, and I'd've been..a lot better. I mean, I'm not saying I wouldn't've got anxiety; I would. But, I'd've *coped* with it. I wouldn't've gone so deep down, I don't think" (Claire).
The ongoing struggle to accept the device and its implications	Identities altered by shock experiences	"When you've done something all your life, and now you can't do it […] it compounds and that then depresses you. 'Cos you can't do this and you can't do that, and that gets you down a bit further, and then it's a never-ending circle." (David). "completely, completely changed me, really." (James) "I won't argue with anybody or anything. […] And I just..I look on the bright side of things now. Where I know there's not a lot to look at sometimes, but I just..go. Because I, I used to worry over BITS of things, what dun't matter." (Claire) "I DO appreciate things more now. It's funny, you do. Lots more and more stuff." (Steve)
	Acceptance of the lack of control	"Like, if you've a very, very bad accident..it, it might be awful but what's the chances you seeing that again? Where with this, it *could* happen again" (Claire). "I'm still not very accepting of the fact that I could come out of here now and go to my car and it could happen. You know, I'm afraid of it happening" (James).
	Acceptance of mortality - Ongoing fear of dying	"It's, erm, sheer panic, erm, you, you just, I guess more than anything you just want it, er, want it to stop, erm, an- and yeah sometimes you

	implicit in euphemised death-talk	get a feeling of helplessness, really, and being out of control, erm, that this thing is gonna, you know…" (James) "that'd be 'it'" (Steve) "maybe I'm not gonna recover from this" (Graham)
	Acceptance of the device	"It's been a Godsend!" (Chris) "I'd like to say that, yeah I've got the device fitted because it's there to…save my life if, you know, I'm, you know, in trouble and…erm, but I still wish that I didn't- I wasn't in this situation with, you know, needing to have, you know, this, this bit of kit and that I have this heart condition, so… Yeah, but I'm probably still no further along, I would say, than I was when I was originally, you know, when it happened for the first time. Erm, I don't feel any better about it. Yeah." (James) "The thing that helps me is that I'm being..I've got a built-in paramedic. It can get to ME quicker than a paramedic can get to somebody else." (Claire) "it's *annoying* that that happened, but..they work..it proves they work" (Claire) "That's another big thing, I want to get the confidence that..it's there to do a job and it's, you know, it's not gonna shock me" (Steve).
	Acceptance of condition	"It was only then that I realised, when it shocked

		me, actually how serious, how serious it was" (James) "It's just that fear of..that's why it's there..you know..even..feeling it in me chest.. You know, WHY it's there, WHAT it's there for.. And you just can't get away from it, I'm afraid." (Steve)
	Ongoing threat to families	"What I'm *afraid* of more than anything is that, you know, if it happens this time, is it gonna be the last time, when I, where I leave my, you know, where I leave my family behind? Erm, and that's, that's probably the most upsetting part, really" (James).
	Contrasting with others helped to protect participants	"sometimes I feel I'm BETTER than some people. Say for instance YOU..I mean, if anything happens to me I- I've got a pacemaker, I've got a defibrillator and I've got me beta-blockers. You've got nothing. Now, I look at it THAT way. And THAT way, I'm very lucky." (Claire)
	Time may bring healing	"I'll get there in the end, eh?" (Steve) "I..hopefully will get there and..this time next year..we'll be in a better place. I hope." (David) "I'm hopeful that..given the evidence SO FAR, that things are gonna be all right. But, NOBODY can give you any guarantee" (Graham)

Appendix 2-D

Pacing and Clinical Electrophysiology – Author Guidelines

Aims and Scope

Pacing and Clinical Electrophysiology (PACE) is the foremost peer-reviewed journal in the field of pacing and implantable cardioversion defibrillation, publishing over 50% of all English language articles in its field, featuring original, review, and didactic papers, and case reports related to daily practice. Articles also include editorials, book reviews, Musings on humane topics relevant to medical practice, electrophysiology (EP) rounds, device rounds, and information concerning the quality of devices used in the practice of the specialty.

PACE - INSTRUCTIONS FOR AUTHORS

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Title Page

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References

Abbreviate titles of periodicals in the style of Index Medicus. **List first seven authors followed by et al.** Follow the format (arrangement and punctuation) shown below:

Periodicals

1. Shaber JD, Fisher JD, Ramachandra I, Gonzalez C, Rosenberg L, Ferrick KJ, Gross JN, et al. Rate Responsive Pacemakers: A Rapid Assessment Protocol. Pacing Clin Electrophysiol 2008; 31:192–197.

Books (edited by other than author of article)

2. Hayes DL. Newest Developments in Rate-Adaptive Pacing. In I. Singer, et al. (eds.): Nonpharmacological Therapy of Arrhythmias for the 21st Century. Armonk NY, Futura Publishing Co., Inc., 1998, pp. 797–818.

Books (edited by identical author and editor)

3. Lüderitz B. History of the Disorders of Cardiac Rhythm, Second Revised and Updated Printing. Armonk NY, Futura Publishing Co., Inc., 1998, pp. 107–118.

Personal Communications

4. Smith I. December 10, 1986, Personal Communication. Only written Personal Communications, available upon request may be referenced.

Abstracts

5. As for periodicals but with (abstract) before the periodical title.

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