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Life after ICD Implantation: Living with Uncertainty

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Declaration

This thesis submitted for the degree of doctorate in clinical psychology entitled ‘ Life after ICD implantation: Living with uncertainty’ is based on work conducted by the author in the Department of Clinical Psychology at the University of Leicester between September 2003 and September 2005. All of the work recorded in this thesis is original otherwise acknowledged in the text or by the references.

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1. Abstract

This article includes three sections relating to the conduct of a piece of research, which aimed to add to the theoretical understanding of psychological distress in implantable cardioverter defibrillator (ICD) recipients.

Literature review: The research literature and theories relating to psychological distress in ICD recipients is reviewed. Findings revealed that research in this area is limited, and compromised by significant methodological limitations. Theories advanced to explain psychological distress in ICD recipients were found to be under-developed and lacked robustness.

Research Report: The current research reports on interviews with ICD recipients conducted four months after device implantation. None of the participants had received appropriate shock therapy from the device. Their accounts were analysed using a grounded theory method. A core category was identified and termed ‘uncertainty and ambiguity’. This highlighted the uncertainty that recipients experienced in relation to their health. It also referred to the uncertainty as to whether the device represents a ‘threat or security, and whether it subsequently signifies a ‘second chance or limited life’. Therapeutic interventions were outlined that might address ‘threat ’ and uncertainty, so reducing anxiety and allowing individuals to continue to engage with life in a fulfilling way. Such engagement is crucial to prevent depression and maintain general self-efficacy in ICD recipients

Critical Appraisal: Reflections relating to the conduct of this piece of research were outlined. These included the importance of effective alliances, balancing comprehensive data collection with respect for the interviewee, and the role of supervision and self-reflection in ensuring quality research.

Section 1: Review of the literature

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2. Introduction

An implantable cardioverter defibrillator (ICD) is a device able to both detect, and automatically treat, unstable heart rhythms (arrhythmias) by delivering an electrical shock to the heart. The National Service Framework (NSF) for Coronary Heart Disease (Department of Health, 2005) highlighted that cardiac arrhythmia affects more than 700,000 people in England. Introduction of the ICD device has greatly reduced mortality rates in individuals experiencing once fatal arrhythmias (Antiarrhythmics versus Implantable Defibrillators Investigators, 1997; McCarthy, 1997; Moss, Hall, Cannon, Daubert, Higgins, Klien, Levine, Saksensa, Waldo, Wilber, Brown, & Heo, 1996; Trappe, Wenzalff, Pfitzner & Fieguth, 1997).

Seventeen implants per million people were carried out in the United Kingdom in the year 2000 and this figure is increasing (National Institute of Clinical Excellence, 2000). However, as the NSF for coronary heart disease states (Department of Health, 2005), individuals who have recently had the device fitted have a significantly greater risk of anxiety, depression and a poor quality of life.

The current report considers the focus of anxiety and depression in ICD recipients and levels of psychological morbidity. The theories that have been advocated to account for anxiety and depression following implantation are considered and clinical implications are discussed. To be incorporated in the review studies had to include more than five participants, and their method had to be clearly outlined. The studies needed to specify sample characteristics, recruitment procedures, measures used and means of data analysis so that studies could be evaluated.

3. The focus of anxiety and depression in ICD recipients

There has been limited research into the focus of the anxiety in ICD recipients, and investigation into depression in recipients is notably absent.

Anxiety in ICD patients has been reported to derive from worries about device malfunction (Bolles & Funk, 1995), pain and loss of consciousness during shocks (Ahmad, Bloomstein, Roelke, Berstein & Parsonnet, 2000; Craney & Powers, 1995) and battery failure (Cooper, Luceri, Thurer & Myerburg, 1986; Heller, Ormont, Lidagoster, Sciacca & Steinberg, 1998). Other concerns relating to the shock experience include blurred vision, syncope, palpitations and the possibility of multiple shocks (Bolles & Funk, 1995; Sneed & Finch, 1992). Seventy-nine percent of participants rated the shocks delivered by the ICD device as severe in intensity (Ahmad et al., 2000). Anxiety has also been related to the suddenness of the shock. In a small sample of 17 patients, Cooper et al. (1986) found that 85% expressed persistent anxiety related to the lack of warning before the shock. However, the reasons for this finding were not explored.

Worry in relation to ill health and fear of death have also been reported. Heller et al. (1998) found that health concerns rose in 62% of their sample of 58 people, and this increase was strongly associated with having received more than five shocks. Conversely, a significant reduction in fear of death two years following implantation has also been reported (Pauli, Weidmann, Dengler, Blaumann-Benninghoff & Kuehlkamp, 1999). However, this study used a questionnaire whose reliability and validity are not established and neither of these studies utilised a control group or took pre-implant measures.

Thus there has been limited research into anxiety focus, and none into the focus of depression in ICD. This appears to be because research has favoured establishing prevalence rates at the expense of determining the cause of anxiety and depression.

4. Prevalence of anxiety and depression in ICD recipients

The prevalence of anxiety and depression in ICD recipients is unclear. Studies in both areas appear subject to similar methodological limitations, yielding contradictory findings. Possible reasons for some of the discrepancy in anxiety and depression studies are outlined below. Notably, differing prevalence rates may result from sampling recipients with different device shock histories, and sampling at different time points following implantation. A lack of longitudinal studies makes this difficult to investigate and hinders examination of the process by which anxiety and depression develop over time.

The limited evidence that has accumulated regarding the levels of anxiety associated with ICD implantation is contradictory. Anxiety levels in ICD recipients have been reported as higher than in both the general population and other medically ill groups (Vlay, Olson, Fricchoine & Freidman; 1989), but also at levels comparable to a student population (Dougherty, 1995). Sample sizes in these studies were extremely small comprising eight and 15 patients respectively. None of the studies employed a control group or assessed anxiety levels prior to hospitalisation.

Discrepant findings may arise from studies comparing samples with different rates of shock discharge. Using validated measures, higher levels of anxiety have been reported to be associated with either no shock discharge (Dunbar, Jenkins, Hawthorne, Kimble, Dudley, Slemmons & Purcell, 1999) or a high number of device discharges (Dougherty, 1995; Schuster, Phillips, Dillion & Tomich, 1998). Other studies have failed to establish such a relationship (Chevalier, Verrier, Kirkorian, Touboul & Cottraux, 1996; Keren, Aarons & Veltri, 1991; Pauli, et al., 1999). With the exception of the Pauli et al. study (1999) none of these studies used validated measures or employed a control group. Only Dunbar et al. (1995) employed a longitudinal design, but these investigators only studied recipients up to three months post-implant. In addition, Dougherty (1995), Keren et al. (1991), and Chevalier et al.

(1996) all had sample sizes under 30 participants. Such difficulties accompanied by a lack of pre-implant measures severely compromise studies investigating shock frequency.

Discrepant reports of anxiety levels following implantation may partly arise from investigators employing differing definitions of numerically frequent shocks, or may result from differences in the time span over which the shocks were delivered (Burke, Hallas, Clark-Carter; White & Connelly, 2003). In addition, Ahmad et al. (2000) found that prodromes were more common and shocks were reported to be more painful by recipients who had experienced a higher number of device discharges. It is therefore unclear whether it is the frequency of the shock per se, or the qualitatively different experience of the shock that is associated with increased anxiety. However, the findings of the Ahmad et al. study are compromised: the study was retrospective; the authors failed to report the cardiac history of their participants and they used an anxiety questionnaire whose reliability and validity were not established. Elevated anxiety levels may also reflect the cause of the increased pain rather than the consequence (Melzack & Wall, 1963).

Studies examining prevalence rates of anxiety in ICD recipients have thus produced contradictory findings, which may be due to methodological weaknesses and differences in shock frequency between studies. Whilst the literature pertaining to anxiety is insufficient, there is even less research into depression levels, and the limited amount that has been conducted is subject to similar methodological weaknesses.

The prevalence of depression in ICD recipients has been reported at varying levels; similar to the rate of occurrence in the general population at one in four (Crow, Collins, Justic, Goetz & Adler; 1998); and higher, at approximately one third (Hegel, Griegel, Black, Goulden & Ozahowski, 1997) to a half of ICD recipients (Morris, Badger, Cheilewski, Berger, & Goldberg, 1991; Psycha, Calabrese, Gullledge, & Maloney, 1990; Kuiper & Nyamathi, 1991).

None of these studies utilised pre- implant measures or a control group, and sample sizes varied from 20 (Morris et al., 1991; Kuiper & Nyamathi, 1991) to 42 participants (Psycha, 1990). Also, only Hegel et al. (1997) conducted a longitudinal study, which took place over a two-year period. Discrepancies between studies may again arise from participants being sampled at different time points following device implantation and from sampling populations with different discharge rates. Levels of depression have been found to be significantly higher in participants who have experienced more shocks (Konstram, Colburn, Butts & Estes; 1996), and complementary research has reported shock frequency to be associated with gradually increasing levels of depression over a one-year period (Dougherty, 1995). However, both of these studies failed to utilise pre-implant measures or control groups, and had small sample sizes of 33 and 15 respectively. Keren, Aarons & Veltri (1991) found no significant effect of shock frequency on depression levels, but this study shares the same criticisms of no baseline measures and a small sample size of 18 participants. Since information about shocks is not defined, discrepant results may be due to studies defining high and low shock groups differently.

Thus studies of anxiety and depression in ICD recipients are limited in number, contain methodological weaknesses and appear to yield inconsistent findings. It is also worth noting that psychological morbidity in ICD recipients cannot be attributed to implantation with certainty, since methodological limitations mean that causality cannot be inferred.

5. Difficulties determining causality

Failure to utilise control groups and pre implant baseline measures has meant that increased levels of anxiety and depression in ICD recipients cannot be attributed to device implantation. Poor psychological status of recipients may typify patients who receive ICDs, rather than reflect the effect of ICD implantation itself. Thus there is a need to determine the psychological status of patients before they receive the device. In the studies with data on

pre-implant status, psychological status of ICD recipients appears similar to individuals with an underlying ventricular arrhythmia condition who are on medication alone (Keren, et al., 1991; Schron, et al., 2002). However, Schron et al. excluded approximately one fifth of their participants who did not survive the investigation, and thus the study may provide a biased view of the differences between the two groups.

A meta-analytic review by Burke et al. (2003) concluded that poor psychosocial outcomes in ICD patients occur as a result of factors associated with the underlying heart condition, rather than as a direct response to device implantation and shock therapy. It may be argued the apparent relation between shock frequency and psychological morbidity presents evidence for the role of the device in the aetiology of anxiety and depression. To this effect, Herrmann Von zur Muhan, Schaumann, Buss, Kemper and Wantzen, (1997) found that as discharge rates rose, the percentage of psychologically distressed ICD patients exceeded those in a comparison group. The authors acknowledge that comparing pre-existing groups who differed in other aspects such as cardiac diagnosis or gender may have compromised their findings. Also, preliminary evidence suggests that mental distress in ICD patients can potentiate lethal arrhythmias (Lampert, Jain & Burg, 2000), questioning whether device activity is the cause or consequence of emotional distress.

The possibility that device implantation is not causal to anxiety and depression severely undermines theories that have attempted to explain distress in this population, since they have been based upon this premise.

6. Theories of anxiety and depression in ICD recipients

There are few specific models explicitly devised to consider how ICD therapy can affect psychological morbidity. This section of the paper first outlines general psychological

theories related to implantation before considering the theories developed specifically for ICD recipients.

6.1 Classical conditioning and anxiety in ICD recipients

It has been proposed that ICD recipients develop a conditioned anxiety response to neutral stimuli that have been repeatedly paired with anxiety provoking shocks, resulting in elevated anxiety levels (Sears, Conti, Curtis, Saia, Footie & Wen, 1999). Thus, the reduced levels of physical activity reported by ICD recipients (Keren, et al., 1991) reflect an attempt to avoid stimuli that have become associated with the shock experience.

Supportive of the perspective of Sears et al., fifty percent of ICD recipients reported avoiding exercise due to fear of eliciting device activation, whilst 75% said that the device interfered with social interactions (Dubin Batsford, Lewis & Rosenfield, 1996). However, fear of shock may not be the sole or sufficient reason for reductions in physical activity: ICD recipients reported increased unemployment and experienced an enforced driving ban following implantation (Gallagher, McKinley, Mangan, Pelletier, Squire & Mitten-Lewis, 1997).

Many ICD recipients appear to specifically avoid sexual activity. Approximately 40% of ICD recipients reported being sexually abstinent (Cooper et al., 1986; Dubin et al., 1996; Steinke, 2003), but whether this is a conditioned response is debatable. Abstinence may be partly due to a negative body image due to the device (Sneed & Finch, 1992). Secondly, Dunbar et al. (1999) reported that over two thirds of their participants reported reduced sexual activity before implantation, suggesting that implantation alone was not the reason for the reduction.

There is also evidence that ICD recipients avoid activities more than places or objects (Lemon, Edelman & Kirkness, 2004). Yet, classical conditioning would predict an equal chance of each stimulus type becoming paired with the shock experience. A Pavlovian model would also predict that increased shock frequency would prompt greater anxiety, due to a greater number of pairings of the unconditioned stimulus with neutral stimuli. Yet, as mentioned previously the research at best is partially supportive, and at worst is non-confirmatory, reporting that those with no device discharge history are most anxious.

Sears' model (1999) can also be questioned since several studies have found no evidence that shocks have occurred in the avoided situations to create an association (Dubin et al., 1996; Lemon et al., 2004; Pauli, et al., 1999). It remains however, that whilst some situations have not been paired with a shock, certain emotional or physiological states may have been. Certain activities may be avoided because their associated physical changes have been paired with the shock discharge or a cardiac event. For instance, fear of exercise has been reported in ICD recipients (Van-Ittersum, de-Greef, Van-Gelder, Coster, Brugemann, & Van-der-Scahns, 2003), and beliefs about exercise- induced physical changes and device-fire needs further exploration. Similarly, Dunbar Warner and Purcell (1993) found that patients avoided arguments because the intense emotions they elicited were deemed to be the cause of some device discharges. Such findings highlight the importance of beliefs in adjusting to ICD implantation, suggesting that a cognitive theory may warrant consideration.

6.2 Cognitive models of anxiety

Wells and Matthews (1994) proposed that anxious individuals have exaggerated perceptions of threat. Their subsequent avoidance behaviour maintains anxiety because it prevents disconfirmation of this perceived threat. Such a process may be applicable to ICD recipients who appear to avoid stimuli such as exercise and arguments because they are

believed to prompt device-fire. However, there is evidence that anxiety levels in ICD recipients remains high even when the threat situation is unavoidable (Lemon et al., 2004).

In contrast, in Clark's model (1986), anxiety results from the catastrophic interpretation of bodily or mental events as signs of impending bodily breakdown (e.g. a heart attack). Such negative interpretations are treated as evidence of threat, furthering exacerbating anxiety. This vicious circle is maintained by selective attention to bodily events that contribute to a lower threshold for perceiving sensations. ICD recipients may be subject to this circle of panic (Pauli et al., 1999) since a life threatening cardiac disorder might sensitise detection of bodily sensations.

Arguably, patients who have pre-existing cardiac problems are likely to be attuned to bodily sensations and may be particularly vulnerable to developing the anxiety disorder. A small retrospective study using several well-validated measures noted that, from 14 patients who fulfilled the criteria for panic disorder, three had begun to develop the problem prior to implantation (Godemann, Aherns, Beherns, Berthold, Gandor & Lampe, 2001). Wells and Matthews' cognitive model (1994) appears to be supported by a study comparing 61 ICD recipients with 36 patients diagnosed with panic disorder and 29 healthy controls (Pauli et al., 1999). ICD patients who feared future shocks were found to be comparable to panic patients on measures of depression, extent of avoidance, and anxiety related to catastrophic interpretations of physical sensations. However, the groups differed upon a validated measure of loss of control, with ICD patients being comparable to healthy control participants. This would suggest that a different process may be operating in ICD patients, and that the panic model does not entirely encompass the presentation and experiences of ICD recipients.

Also, Clark's model (1986) does not explain the relation between shock frequency and anxiety. It is possible that attention to bodily cues leads to a misinterpretation that a shock is

about to be delivered, and the subsequent anxiety symptoms provide further evidence for this belief. Anxiety thereby increases to a level that actually causes the device to fire, due to the apparent relationship between intense emotional states and ventricular arrhythmias (Lampert, Jain & Burg, 2000). This leads to a greater number of discharges, which further increases hyper-vigilance thereby maintaining the process. However, to date there is no empirical evidence for this proposed relationship.

Neither of the above cognitive theories account for other anxiety disorders evident in ICD recipients (Bourke, et al., 1999). Moreover, each model currently fails to clarify the role of shock frequency in the disorder, and do not explain why some recipients are more prone to overly attending to bodily cues (hyper-vigilance) and misinterpretation (Godemann et al, 2001). The cognitive model may thus have limited applicability. Also, all of the above theories have failed to consider the relationship between anxiety and depression, despite evidence that anxiety is significantly related to avoidance and depression in this population (Hegel, et al., 1997).

6.3 Learned helplessness and depression

Seligman's (1975) studies on laboratory dogs demonstrated passivity and apathy subsequent to uncontrollable and inescapable electric shocks. This learned helplessness has been advocated as an explanation for depression in humans similarly exposed to stressful uncontrollable situations. Sears et al. (1999) has argued that this is a plausible explanation for depression in ICD patients, who may themselves be subject to apparently random device discharges. Whilst palatable for patients with high discharge rates, it is less convincing for those individuals with lowered mood who have not experienced a device shock.

Furthermore, studies of other chronic illnesses suggest that individuals take steps to restore lost control and believe they attain some control over their situation (Helgeson, 1992;

Reed, Taylor, & Kemeny, 1993; Taylor, Litchman & Wood, 1994). ICD recipients also appear to attempt to take control albeit via avoidance of perceived shock risk situations. To date this is the only theory of depression related to this population, evidencing a dearth of theoretical understanding in this area.

6.4 ICD specific theories

Two theories have been developed specifically in relation to ICD implantation. Whilst building upon general theories, they remain under-developed.

Sears' theory of cognitive appraisal of ICD activity (Sears et al., 1999) argues that recipients interpret device firings as a 'sickness scoreboard', believing that when the device fires their health is deteriorating. However, this theory fails to address the finding that people who have not experienced a shock at all are often those most concerned about their health (Dunbar et al., 1999). It also fails to clarify the emotional outcome resulting from the negative health evaluation.

In a more evolved cognitive model, Dunbar et al. (1999) proposed that personal factors (age, gender, and dispositional optimism), and situational factors (co-morbidities and device activation), determine how the illness or device discharge is appraised, and what coping behaviours are deployed. This model has its roots in Folkman's Stress and Coping Framework (1984), which argued that the appraised meaning of a stressor, as either a benign challenge or a threat, influences subsequent coping behaviours. Coping behaviours are the cognitive and behaviour strategies exercised to reduce the emotional response (through emotion-focused coping), or to address and resolve the stressor (through problem-focused coping). A challenge appraisal is proposed to result in more problem-focused behaviours, which are more effective in resolution of a difficulty, resulting in better mood, functional status and health states.

There is supporting evidence that problem-focused coping results in better adjustment in chronic illness (Fawzy, Cousins, Fawzy, Kemeny, Elashoff & Morton, 1990; Keckeisen & Nyamanthi, 1990). Data from 213 patients (Dunbar, et al., 1999) indicated that an appraisal of illness as a challenge, and subsequent problem-focused coping, contributed to the variance in both functional status and mood disturbance. There is also some evidence that personal factors are important. Dunbar, Jenkins, Hawthorne & Porter (1996) found that trait optimism and being female significantly correlated with greater challenge appraisal, problem-focused behaviours and lower mood scores. However, sex differences may be explained by gender-related differences in reporting (McNair, Lorr, Droppleman, 1993), or other differences between the groups due to a failure to utilize matched samples. Also, there is less evidence to support the role of situational factors in adjustment to implantation due to a lack of research in this area. Whilst studies have considered the impact of device activation on psychological morbidity, their findings have been contradictory.

The theory by Dunbar et al. (1999) develops past proposals and acknowledges the heterogeneity of ICD recipients and the importance of shock history, but is still under-developed. Further research into the impact of situational and personal factors on coping behaviour and subsequent mood is required. Elaboration is required as to why these factors influence coping in the manner that they are proposed to. There are also several research findings that the theory has not addressed; in particular **why** social relationships and pre-implant cardiac history appear to have an impact on adjustment. Neither does it consider the affect of implantation on self –concept, or the findings from qualitative studies. These factors are discussed in further detail below.

7. Neglected factors in the theoretical understanding of ICD implantation

7.1 The impact of cardiac history

There is growing evidence that ICD recipients who have experienced a life threatening cardiac event prior to implantation adjust better to living with the device, and would suggest the importance of cardiac history in psychological morbidity, largely ignored by theorists. Study of this issue may clarify psychological processes involved in the aetiology of anxiety and depression in some ICD recipients, and help clinicians identify those individuals most at risk of emotional distress.

Several findings indicate that ICD recipients are not homogeneous and that pre-implant cardiac history is important in adjustment. Patients who have experienced SCD (sudden cardiac death) have reported lower total mood disturbance at one month following implantation (Dunbar et al., 1999). Resuscitated patients report significantly fewer anxiety disorders than patients who received the implant for other reasons (Godemann et al., (2001), whilst a pre-implant arrhythmia is associated with less psychological distress (Artega & Windle, 1995).

The reasons for the above findings are unclear. There is a possibility that for those who have experienced a life-threatening event, the device may represent a second chance at life. It has been suggested that such experiences lead to a reprioritisation of life and attempts to 'live to the fullest', because individual mortality is acknowledged (Johnson & Morse, 1990). However, there is also some evidence that patients who have not experienced a life threatening arrhythmia before ICD insertion receive fewer shocks from the device (Begley, Mohiddin, Tripodi, Winkler & Fananapazir, 2003; Capoferri, Schwick, Tanner, Fuhrer & Delacretaz, 2004), once again suggesting that shock frequency may be an important confounding variable. Yet, one might expect less anxiety in these patients, since previous findings suggest that distress increases with discharge frequency.

The role of cardiac history in adjustment consequently warrants further research, potentially clarifying the psychological processes involved in the aetiology of anxiety and depression in ICD recipients.

7.2 Social factors

Research has indicated that social factors may play an important role in adjustment to chronic illness and ICD implantation, making this an important area of study. Whilst positive social support can reduce illness related stress, it appears that social support declines following ICD implantation and relationships can become a source of conflict. Social support appears to act as a buffer to stress (LaRocco, House & French, 1980), and aid recovery from illness (Berkman, 1995; Fontana, Kerns, Rosenberg & Colonese, 1989). Positive social support has also been associated with high self-esteem, increased optimism and lower levels of depression in chronic illness (Symister & Friend, 2003). Yet, ICD recipients have been reported to experience a decline in social support and less marital satisfaction within the first year of after ICD implantation (James, 1997).

Several reasons for the decline in quality of relationships have been indicated. These include a mismatch in expectations between recipients and others, difficulty negotiating changing roles and family over-protectiveness. Patients' inability to meet others' expectations of coping has been associated with poorer adjustment (Hatchett, Friend, Symister, & Wadhwa, 1997), and couples with less defined roles appear to experience less emotional distress (Simons, Cunningham & Catanzaro, 1992). This is possibly because ICD implantation leads to activity restriction, and less defined roles make it easier for both the recipient and carer to adapt to necessary task changes. It may also mean that it is easier for the recipient to find new activities that maintain self-efficacy and self-esteem, whilst reducing the role strain placed on their spouse by increased demands. Over-protectiveness by family members has also been found to correlate with anxiety (Schuster et al, 1998) with evidence of

a significant detrimental effect of over-protectiveness on self – efficacy (Coyne & Smith, 1994).

Social factors therefore appear to be important in adjusting to ICD implantation, suggesting that theorists need to consider systemic factors in their understanding of psychological morbidity in device recipients.

7.3 The impact of implantation on the self

Both researchers and theorists alike have failed to acknowledge the impact of ICD implantation on the self (self-concept, self-esteem and self-efficacy). Yet, creating a new positive sense of self may be necessary to adjust both physically and emotionally to living with an ICD device, if implantation has resulted in role disruption. Evidence of activity restriction in ICD recipients suggests that individuals do experience such role changes, and research has indicated that role disruption caused by chronic illness can affect self-concept (Binik, Chowanec, & Devins, 1990; Estroff, 1989).

It has been proposed that chronic illness may influence self-concept because it changes daily routines and daily activities upon which habitual self-definitions and self-appraisals are based (Charmaz, 2002). This role disruption is associated with negative affect, which increases as the disease intrudes further into valued identities (Abraido-Lanza, 1997). Illnesses that interfere with valued life activities have been described as ‘a fate worse than death’ (Ditto, Druley, Moore, Danks & Smucker, 1996) with evidence that activity restriction accounts for approximately 19% of variance in symptoms of depression in chronic illness (Williamson, 2000). In contrast, preserving or creating valued role identities contributes to self-esteem and self-efficacy, and reduces negative affect. There is evidence that accepting the status of self as chronically ill aids this process, as people aspire to more achievable goals and

cultivate areas of their life where personal control is still available (Devins, Beanlands, Mandin & Leendert 1997; Thompson & Kyle, 2000).

Given that activity reduction and the relationship factors outlined earlier may lead to role disruption, these findings suggest that a changed sense of self may contribute greatly to psychological morbidity in ICD recipients. A focus on the self could also explain why individuals without a pre-implant cardiac event appear to adjust better to the device. These individuals may experience a more sudden and dramatic change in how they see themselves, as they perceived themselves as healthy and able prior to having the device. The importance of self-concept in ICD recipients has also been suggested by qualitative research in the area.

7.4 Qualitative studies

Qualitative studies have the benefit of capturing the complexity and depth of participants' experiences. Based in participants' rich accounts of their experiences, they lack the assumptive bias of the deductive stance that characterizes quantitative research. Limited qualitative research has been conducted in relation to ICD implantation, and theorists have failed to incorporate their findings into their accounts of adjustment. This is possibly because qualitative studies have not clarified how their identified categories are related to the development of anxiety and mood disorders, which has been the main focus of theorists in this area.

The qualitative research has supported the importance of the self and social influences in adjusting to the device. Using a grounded theory method, Burke (1996) found that once ICD recipients accepted their need for the device, they began integrating this technology into their life, often through the use of social supports and contact with other ICD recipients. This study also indicated that people reshaped their attitudes towards their sense of self, but this was not the main focus of this American study. Also, theoretical sampling was not employed in this

study to ensure a comprehensive theory, and there was no reference as to whether theoretical saturation was achieved. Theoretical sampling involves actively seeking participants who will add to the developing theory, or selectively gathering information as the theory emerges. Theoretical saturation occurs when no further data collection will add to the emerging theory.

Fridlund, Lindgren, Ivarsson, Jinhage, Bolse, Flemme, Sandstedt, and Martensson (2000) identified feelings of safety, gratitude to the device and dependency on technology as important issues for ICD recipients. Also identified as important was having a social network, gaining awareness of their life situation and a belief in the future related to the device. Similarly, Dickerson (2002) reported three related themes consisting of ‘ technology as lifesaving yet changing everything, regaining control or conditional acceptance, and transformation or tenuous truce with the device’ (p.364). However, both the study by Fridlund et al. (2000) and Dickerson (2002) lacked quality control procedures. There is no evidence that these researchers used a reflective diary or supervision to consider how their own biases may have impinged upon the research process. They do not refer to the use of or peer support as a form of triangulation, and the findings lack coherence in their failure to outline how the themes are inter-related. Further more, as they did not use theoretical sampling the comprehensiveness of their data collection may be compromised. Importantly, all of the above qualitative studies fail to consider how their findings relate to anxiety and depression in ICD recipients, and the quantitative and qualitative research appears disjointed.

8.Clinical and Research Implications: Concluding remarks

Despite the growing number of people receiving ICD implants, little is known about the psychological impact of the device. There is a current dearth in the United Kingdom of longitudinal studies. Research is thus cross-sectional in structure, and small sample sizes with an absence of control groups, and pre-treatment measures compromise findings. The focus

has been on establishing the prevalence of anxiety and depression, without necessarily considering the processes involved in their aetiology. Subsequently, theories that have been offered to explain elevated anxiety and depression levels in ICD recipients are tentative and lack robustness.

The National Institute of Clinical Excellence (2000) has recommended a rehabilitative approach to ICD implantation aftercare, which includes psychological preparation for living with the device. Currently, this will be difficult to achieve without a comprehensive understanding of the psychological processes involved in the development of anxiety and depression in ICD recipients. Further quality research in this area is thus crucial. Existing evidence suggests that ICD recipients are not a homogeneous group, and treatment will need to be tailored according to shock and pre-implant history. Also, the potential role of the social network in adjustment suggests that a systemic, rather than an individual approach may be more appropriate in certain cases. However, beyond these tentative indicators, the route to effective psychological treatment is as yet unclear-a consequence of flawed research and an absence of adequate theory.

A qualitative approach is likely to prove the most effective means of further study, as it is able to investigate process, and contribute to a theoretical understanding of ICD implantation. Fruitful areas for future research are likely to include the influence of pre-implant cardiac history, the possible effects of implantation on sense of self and social dimensions. However, unlike previous qualitative studies, further research needs to consider how these factors relate to anxiety and depression in ICD recipients.

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Section 2: Research Report

1. Abstract

Objective: Individuals who receive an implantable cardiac defibrillator (ICD) are at risk of developing anxiety and depression. The present study aimed to add to the theoretical understanding of distress in ICD recipients.

Method: Seven ICD recipients were interviewed four months after device implantation. None of the individuals had received appropriate shock therapy from the device. Their accounts were analysed using a grounded theory method.

Results: A core category was identified and termed 'uncertainty and ambiguity'. This highlights the uncertainty that recipients experience in relation to living with the device. A process model pertaining to ICD recipients was developed, which indicated that ICD recipients engage in an appraisal of their health, before considering whether the device represents a threat or security, and subsequently whether it signifies a 'second chance or limited life'. The findings of this model are related to previous literature in the area, and clinical implications are discussed.

Conclusion: Therapeutic interventions are required to reduce uncertainty and 'threat'. This will reduce anxiety thereby allowing individuals to continue to engage with life in a fulfilling way. Such engagement is crucial to prevent depression and maintain general self-efficacy in ICD recipients

2. Introduction

2.1 Overview

The literature relating to the psychological impact of implantable cardioverter defibrillator (ICD) implantation is summarised below to provide a rationale for the current study and the research questions. These are shown in Table 2.8 at the end of the section

2.2 What is an Implantable Cardioverter Defibrillator (ICD)?

An ICD is able to detect and correct unstable heart rhythms (arrhythmias). If the rhythm disturbance is mild, the device will deliver a short series of electrical impulses (pacing), which will often correct the heartbeat without the need for further action. In the event of a more serious arrhythmia, the device will deliver a bigger electrical impulse (a shock) to the heart.

Introduction of the ICD device has greatly reduced mortality rates in individuals experiencing once fatal arrhythmias (Antiarrhythmics versus Implantable Defibrillators Investigators, 1997; McCarthy, 1997; Moss, Hall, Cannon, Daubert, Higgins, Klien, Levine, Saksensa, Waldo, Wilber, Brown, & Heo, 1996; Trappe, Wenzalff, Pfitzner & Fieguth, 1997). However, individuals who have recently had the device fitted have a significantly greater risk of anxiety, depression and a poor quality of life (Department of Health, 2005). Anxiety in ICD patients has been reported to derive from worries about device malfunction (Bolles & Funk, 1995), pain and loss of consciousness during shocks (Ahmad, Bloomstein, Roelke, Berstein & Parsonnet, 2000; Craney & Powers, 1995). Notably, the focus of depression in ICD recipients remains unexplored.

2.3 Why is more research needed?

Research examining the psychological and emotional impact of ICD implantation has been limited. It has produced contradictory findings compromised by small sample sizes, with an

absence of control groups and pre-treatment measures. There has been an over-emphasis on studying anxiety, and researchers have grossly neglected depression in ICD recipients. Crucially, the focus has been on establishing the prevalence of anxiety and depression, without necessarily considering the processes involved in their aetiology. Subsequently, theories that have been offered to explain elevated anxiety and depression levels following ICD implantation are tentative and lack robustness. This has hindered the development of effective interventions for anxiety and depression in ICD recipients. This is despite the National Institute of Clinical Excellence (2000) having identified rehabilitation and psychological preparation for ICD implantation as a priority.

Several issues have not been developed by theorists, and are empirically under-studied. Further research into these areas may serve to add to psychologists' theoretical understanding of ICD recipients, thereby enabling the development of effective therapeutic interventions. Each of these areas is considered below.

2.4 Shock frequency and the prevalence of anxiety and depression

Findings of prevalence studies of anxiety and depression in ICD recipients have been inconsistent. Anxiety levels in ICD recipients have been reported as both higher and comparable to the general population and other medically ill groups (Vlay, Olson, Fricchoine & Freidman; 1989). Similarly, depression levels in recipients have been reported to vary from approximately a quarter (Crow, Collins, Justic, Goetz & Adler; 1998), to a half (Morris, Badger, Cheilewski, Berger, & Goldberg, 1991; Psychia, Calabrese, Gullledge, & Maloney, 1990; Kuiper & Nyamathi, 1991).

Discrepancies in prevalence may arise from studies comparing samples with different rates of shock discharge (i.e. shock discharge not pacing). Using validated measures, higher levels of anxiety and depression have been reported to be associated with either no shock

discharge (Dunbar, Jenkins, Hawthorne, Kimble, Dudley, Slemmons & Purcell, 1999), or a high number of device discharges (Doughery, 1995; Schuster, Phillips, Dillion & Tomich, 1998; Konstram, Colburn, Butts & Estes; 1996). Other studies have failed to find this association (Chevalier, Verrier, Kirkorian, Touboul & Cottraux, 1996; Keren, Aarons & Veltri, 1991), and inconsistencies may be due to studies using differing definitions of what constitutes a high number of shocks, or the time period over which shock discharges occur (Burke, Hallas, Clark-Carter, White & Connelly, 2003).

It is unclear why a history of no device shocks, or experiencing a high number of shocks is associated with elevated anxiety and depression levels.

2.5 The impact of cardiac history

There is evidence that ICD recipients who have experienced a life-threatening cardiac event prior to implantation adjust better to living with the device (Dunbar et al., 1999; Godemann, Aherns, Beherns, Berthold, Gandor & Lampe, 2001), and a pre-implant arrhythmia is associated with less psychological distress (Arteaga & Windle, 1995). The reasons for such findings are unknown. For those individuals who have experienced a life-threatening event, the device may represent a second chance at life. It has been suggested that such experiences lead to a reprioritisation of life and attempts to ‘live to the fullest’ because individual mortality is acknowledged (Johnson & Morse, 1990).

The role of cardiac history in adjustment warrants further study. Such research may clarify the psychological processes involved in the aetiology of anxiety and depression in ICD recipients. It may also indicate who is at risk of psychological morbidity, thereby enabling a preventative approach and early intervention.

2.6 Social factors

Research has indicated that social factors may play an important role in adjustment to chronic illness and ICD implantation, making this an important area of study. Study participants have reported that social support can act as a buffer to illness related stress (Fontana, Kerns, Rosenberg & Colonese, 1989; LaRocco, House, & French, 1980), and aid recovery from illness (Berkman, 1995). It has also been associated with higher reported self-esteem, greater optimism and lower levels of reported depression in chronic illness (Symister & Friend, 2003).

Yet, ICD recipients have described that perceived social support declines following implantation and that relationships can be experienced as a source of conflict. Research suggests this may be a function of a difficulty negotiating changing roles (Simons, Cunningham & Catanzaro 1992) and a mismatch in expectations between recipients and others (Hatchett, Friend, Symister, & Wadhwa 1997). Reported over-protectiveness by family members has also been found to correlate with anxiety (Schuster et al., 1998) with evidence of a significant influence of over-protectiveness on self-efficacy (Coyne & Smith, 1994). Such preliminary research suggests that further inquiry into the role of social factors in adjustment to ICD implantation may be beneficial.

2.7 The impact of implantation on the self

Creating a new positive sense of self may be necessary to adjust both physically and emotionally to living with an ICD device. Implantation may cause role disruption in ICD recipients through activity reduction, and research participants have indicated that such disruption may affect self-concept in chronic illness (Binik, Chowanec, & Devins, 1990; Estroff, 1989).

It has been proposed that chronic illness may affect self-concept, changing daily routines and habitualized daily activities upon which self-definitions and self-appraisals are based (Charmaz, 2002). This role disruption is associated with negative affect, which has been reported to become greater as the disease intrudes further into valued identities (Abraido-Lanza, 1997). In contrast, research suggests that preserving or creating valued role identities can enhance self-esteem and self-efficacy, and reduce negative affect. Accepting the status of self as chronically ill appears to facilitate this process, as research participants' reports suggest that they then aspire to more achievable goals and cultivate areas of their life where personal control is still available (Devins, Beanlands, Mandin & Leendert 1997, Thompson & Kyle, 2000).

These findings suggest that a changed sense of self may contribute greatly to psychological morbidity in ICD recipients who may experience role disruption as a result of activity reduction and changing relationships. Subsequently, sense of self in ICD recipients is an important area for further research.

2.8. Means of further investigation.

Several research questions thus require further exploration in order to develop a theoretical understanding of anxiety and depression in ICD recipients, and enable effective therapeutic interventions. The research questions outlined in Table 2.8 form the basis of inquiry in the current study.

A qualitative approach was selected as the most effective means of further study. Qualitative studies have the benefit of capturing the complexity and depth of participants' experiences. Derived from participants' own rich accounts, their findings lack the assumptive bias of the deductive stance that characterizes quantitative research (Charmaz, 1995). By capturing the richness of experience, the qualitative approach is able to investigate process,

thereby contributing to a better theoretical understanding of ICD implantation. Furthermore, quantitative research tends to focus on testing theory. As adequate theory is currently lacking in relation to ICD implantation, quantitative research was deemed a less appropriate means of inquiry.

Table 2.8 Research questions

<u>Description of study</u>
A qualitative study based on in-depth interview data with ICD recipients four months following implantation
1) What impact does ICD implantation have on a recipients reported sense of self?
2) What influence do ICD recipients perceive social factors to have on adjustment to the device?
3) How does frequency of device shock influence how ICD recipients describe their adjustment to implantation?
4) Why is a history of a life threatening cardiac event prior to ICD associated with better adjustment?

3.Method

3.1 Choice of Methodology

Lack of a comprehensive theory of the psychological impact of ICD implantation currently limits the clinical contribution of psychology to the treatment of recipients with emotional difficulties. As the purpose of grounded theory is to develop a theoretical analysis of the data (Charmaz, 1995; Strauss & Corbin, 1998), it was deemed the most appropriate research

method. Other methods of qualitative research, such as content or narrative analysis seem to belong to different strands of research that do not have theory generation at their core (Henwood, 1996). It was also felt that using grounded theory would better reflect the critical realist position taken by the researcher. This stance asserts that there is a fundamental reality but that the way we perceive it depends partly upon our beliefs and expectations. This position is consistent with Glaser and Strauss's original conceptualisation of grounded theory (Glaser & Strauss, 1967) as a method for discovering phenomena that have a fundamental reality. Interpretative phenomenological analysis (IPA) was not utilised, as its emphasis upon multiple understandings is more consistent with a constructionist approach.

3.2 Participants

The number of participants required for grounded theory is determined by the number of interviews required for theoretical saturation to be reached (Glaser and Strauss, 1967), whereby further data collection fails to conceptually add anything further to the developing theory. The study reached a position where it was felt that no more categories would be found with further interviewing, and the researcher met the generally accepted criteria for clinical doctoral research of 6-10 participants. (Turpin et al., 1997). A total of seven participants between the ages of 54 and 79 took part in the current study. They had all been fitted with an ICD approximately four months earlier at the same hospital. Patients differed in whether they had experienced an arrhythmia prior to implantation (secondary prevention patient) or were at risk of experiencing them in the future (primary prevention patients). Further details of participants and sampling order are outlined in Table 3.2 below.

The first two participants were sampled opportunistically but later participants were theoretically sampled. Theoretical sampling involves simultaneous data collection and analysis. It involves actively seeking participants who will add to the developing theory, or selectively gathering information about a specific concept by developing the interview

schedule (Strauss and Corbin, 1998). For example, participant 1 (P1) indicated that the perceived match between ability level and age was an important in adjusting to the device. Subsequently participant 3 was sampled because he was younger and could possibly add to the understanding of this relationship. Likewise, Participant 7 was sampled because he had experienced pacing, and earlier analysis had indicated that this experience was important to trusting the device. Regrettably, it was not possible to sample participants who had experienced shock therapy. The implications of this are outlined in the Discussion section.

Table 3.2 Participants' background information

Participant	Age	Prevention Type	Therapy delivered	Employment Status	Home Situation	Cardiac Rehabilitation Access?
1	69	Secondary	None	Retired	Lives with wife	No
2	62	Secondary	Inappropriate Shocks and appropriate pacing	Unemployed following heart attack	Lives with wife	No
3	54	Primary (Stroke)	None	Car park attendant	Widower	No
4	69	Secondary	None	Retired	Widower	No
5	71	Primary	None	Retired	Lives with wife	Yes
6	60	Primary	None	Unemployed	Lives with wife	Yes
7	79	Secondary	Pacing	Retired	Lives with wife	No

NB) Please note that P3 had experienced a stroke related to his heart condition

3.3 Procedure

3.3.1 Ethical approval.

Approval for the current study was sought and received from the relevant research and development department, and Research Ethics Committee in January 2005. A copy of the letter providing confirmation of approval can be found in Appendix 2.

3.3.2 Recruitment

Potential participants were approached at a hospital check up appointment by an ICD technician. The technician completed a participant details sheet (See Appendix 3) for each potential participant, which was subsequently given to the researcher. This tool provided the researcher with contact details, and access to key information that would facilitate the sampling process. Those individuals who expressed an interest in taking part were contacted by the researcher by telephone and given a one week 'cooling off period' to decide whether they wished to take part. At the time of the interview, participants were asked to review the information sheet and sign a consent form (See Appendix 4)

3.3.3 Data Collection

Interviews took place within the participants' own homes. This may have inhibited disclosure due to other family members being in the vicinity. However, home visits were felt necessary to avoid participants travelling long distances and to reduce anxiety elicited by negative associations with the hospital. An interview schedule provided 'points of departure' (Charmaz, 1995) to facilitate discussion. Such flexibility allows a participant to express what they feel is most relevant, rather than the interview being over-constrained by the researcher (Mason, 1996). Open-ended questions were asked where possible, and paraphrasing was used to confirm the researcher's understanding and to provide the opportunity to make implicit meanings in the data more explicit (King, 1996). Development of the schedule was initially led by the aims of the current study, but through theoretical sampling, the guide was refined as emerging categories indicated areas where elaboration, exploration and further differentiation were needed. A copy of the initial and final Interview Guide can be found in Appendix 5.

All interviews were audio taped for the purpose of subsequent transcription and analysis by the researcher, who changed participants' names and identifying features to protect their

anonymity. Copies of all the transcripts can be found in an addendum to this article. The guidelines used for transcription were adapted from those recommended by Burman (1994). See Appendix 6 for further details.

3.3.4 Data analysis

Data analysis followed the format outlined by Charmaz (1995) involving open coding, focused coding and memo writing. The researcher often engaged in different types of coding simultaneously, returning to open coding to reconsider the raw data in the light of new insights.

During open coding, the data was broken down on a line-by-line basis into discrete elements that were given a label across transcripts to signify the phenomenon they represented. The researcher then engaged in focused coding, whereby the most significant/frequent open codes were used to ‘sift’ through later transcripts. However, open coding was still utilized where data was not adequately described by existing focused codes. See Appendix 7 for an example of line-by-line and focused-coding.

Focused codes that appeared to represent different aspects of the same phenomenon were grouped together into categories with better explanatory power with regards to the data. The properties of each category were then defined, and as part of the constant comparative process many concepts were moved between categories during this process. Where categories lacked density or were unable to explain variability they became the focus of data review and data collection. A core category was identified which pulled together the other categories to form an explanatory whole, but also accounted for variation within categories. Diagrams also aided integration by facilitating clarity about the logic of relationships.

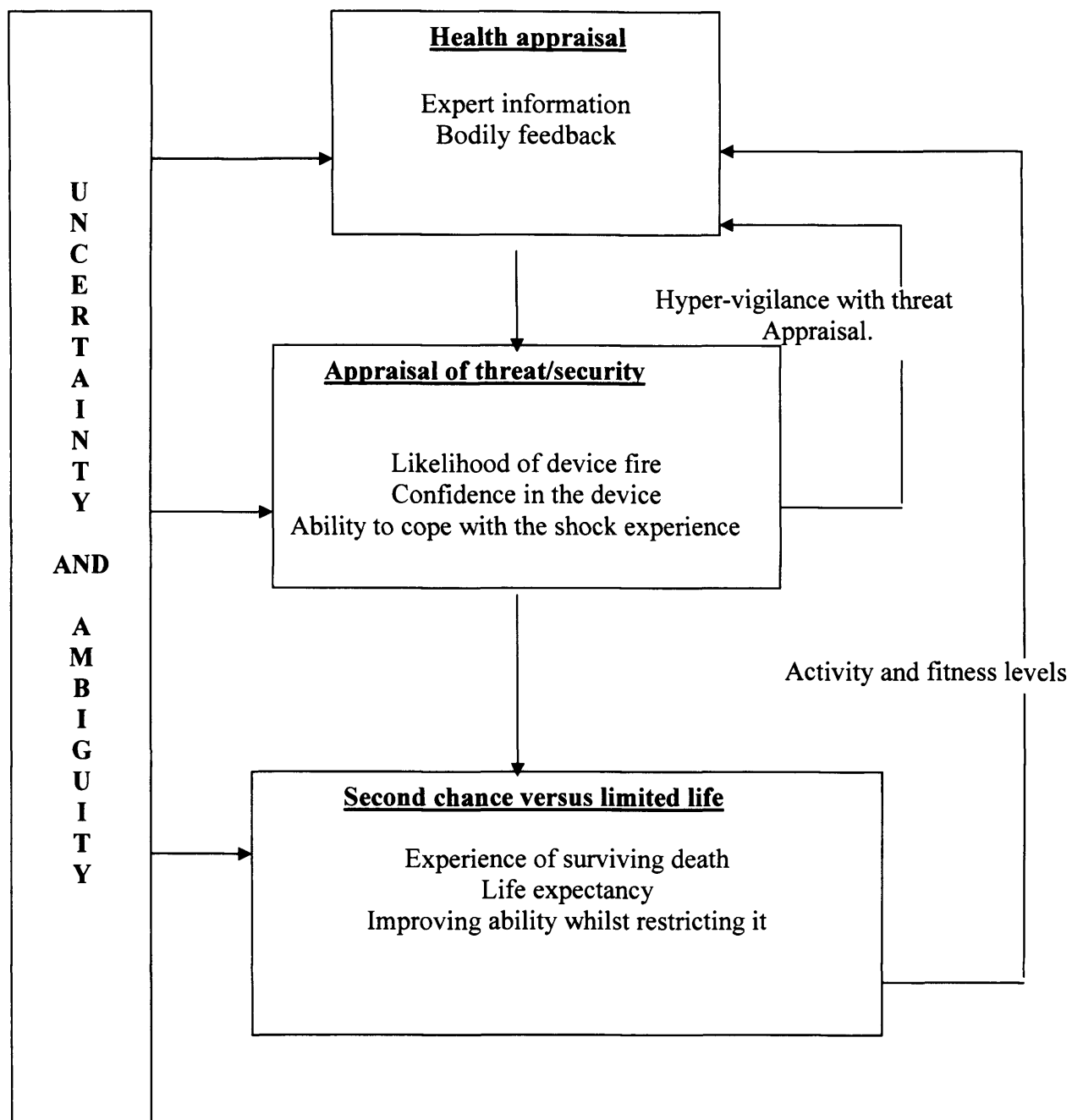
Writing memos was an important step between coding and theory formation (Charmaz, 1995). Memos may contain decision-making processes, hypotheses, and ideas about categories analytic properties and how they are connected. They make the researchers' ideas transparent and form a vital part of the data trail that is necessary for quality research (Elliot, Fischer & Rennie, 1999). Several steps were also employed to enhance the quality of the current study. These included: the use of theoretical sampling to ensure that the developing theory was comprehensive; comprehensive treatment of the raw data; ensuring that all analytic were supported by examples and using reflexive procedures such as a reflective diary. Triangulation, which involved seeking other perspectives on the data through the use of supervision and a peer-debriefing group, also ensured the quality of the study. It helped determine how the researcher's values and assumptions may be influencing what was being represented. For further details on procedures used in relation to quality control see Appendix 8.

4. Analysis

4.1 Overview

A model entitled 'living with uncertainty' is presented below. It is shown in diagrammatic form in Figure 4.1, and a core category entitled 'ambiguity and uncertainty' is described which summarises the analysis. This is followed by descriptions of higher order categories that make up the model. Categories are defined and supporting quotations are provided. Quotations are sampled from all participants to illustrate that the model is applicable to their experiences. Where there is variation in recipients' experiences, this is described. Section titles correspond to lower order categories, which together constitute the higher order category under description. The model is related back to the research literature and research questions within the Discussion, and the clinical implications of the model are highlighted.

Figure 4.1: Living with Uncertainty



4.2 Core category: Uncertainty and Ambiguity

Ambiguity and uncertainty were reported to infuse every aspect of living with the device.

- P4: “ *The overall picture is you’re still just a tad uneasy about everything, you know, the ticker and the the, there’s the uncertainty about anything and everything really (ll. 887-889)*”.

ICD recipients in the current study indicated that they appraise their health predominately on the basis of expert and bodily information, which is often unclear and ambiguous. This health appraisal was described to contribute to a threat/security appraisal by determining the likelihood of heart malfunction and the need for device-fire. Recipients’ responses suggested that as the health appraisal is experienced as uncertain, so is the likelihood of requiring shock therapy.

Recipients’ accounts suggested that perceived confidence in the device and ability to cope with device-fire contributed to this appraisal of threat/ security. This appraisal was reportedly characterized by uncertainty, particularly for individuals who had not experienced shock therapy. The ambiguity in the threat appraisal was seemingly made greater by the reported paradox that successful device-fire improved confidence in the ICD, but led to a more negative health appraisal.

Recipients then appeared to consider whether they had ‘a second chance or a limited life’. Cited aspects of this category included surviving death, life expectancy and being able to engage in valued activity. There was a paradox outlined in the activity subcategory in that the device is experienced as enabling physical activity whilst restricting it. Recipients described that uncertainty about activity is more when their social network holds contradicting beliefs about exercise. Their accounts indicated that uncertain life expectancy, and confusion over

safe activity levels results in ambivalence as to the whether the device presents a second chance, or limited life. This reported cycle may become self-sustaining as reduced activity levels and greater attention to bodily symptoms were perceived to influence the health appraisal.

4.3 Health Appraisal

Recipients described that they assess their health through two streams of information consisting of knowledge from medical experts and bodily feedback. Health appraisal is related to the core category of ambiguity and uncertainty by virtue of the lack of clarity of these sources of health information.

4.3.1 Expert Information

Recipients demonstrated evidence of having gained much understanding from health professionals about their heart problem and the ICD device (e.g. P4, ll. 71-75; P5, ll. 601-603). Yet, difficulties were outlined in relation to appraising health through this stream of information. These included a lack of understanding, difficulty seeking clarification, a belief that some medical information is withheld, bad timing of information delivery, and medical staff's perceived uncertainty about the heart problem.

4.3.2 Bodily feedback.

All participants described using bodily feedback in the health appraisal process, considering frequency/intensity of physical symptoms, ability to engage in physical activity, medication use and side effects, and device activity.

- Int: “ *AND WHAT SENSE OF THAT DO YOU MAKE WHEN YOU FEEL A TWINGE. WHAT DO YOU GENERALLY THINK?* ”

P3: “*I thought here we go, it's starting again (ll, 202-204)*”.

- P7: *“Erm (2) if you started getting really out of breath then you say okay hold on a bit here you’ve gone too far ... (ll. 543-545)”*.
- P5: *“So I thought I’ve cracked it now. I get no discomfort. I never have to use the spray although I still carry one. I never have to use it. I don’t get the angina effect (ll. 53-55)”*.

Ability to engage in physical activity was also highlighted by recipients as a major source of information about health, with greater perceived ability being seen as indicating better health.

- P5: *“.....it were Dr 2 on that occasion and he’s saying how are you, and I said fine, if you’ve got any DIY you want doing just give me a ring, I’m back to square one, and I thought, excellent (ll. 56-58)”*.

Participants also indicated that they viewed device-fire as indicative of ill health, increasing the perceived necessity of the device and need for immediate consultation with a medical professional.

- P5: *“But I would feel sorry for anyone who possibly, their heart was that bad that they’ve got problems with it and it’s got to keep doing it’s job (ll. 611-613)”*.
- Int: *“AND DO YOU THINK THAT CONFIDENCE WOULD BE DIFFERENT IF THE DEVICE WENT OFF. DO YOU THINK THE AMOUNT OF CONFIDENCE WOULD BE DIFFERENT?”*

P4: *“Confidence in the device wouldn’t change. I’d still be confident in that, but I would lose a lot of faith in what I’ve got left with the old ticker (ll. 860-864)”*.

However, participants identified that such sources of bodily information could be unreliable and ambiguous, with misattribution of physical symptoms, variation in bodily feedback, hidden signs of ill health and lack of awareness of device activity.

- P5: *“ I started having discomfort in me chest and discomfort in both legs when I walked far. Being a do it yourself man and a gardener I put most of this down (.) to pulling muscles or ligaments.. (ll. 8-10)”*.
- P2: *“Cos, well I said I came in last Tuesday and urm you know for them to check the pace [YEAH] and they said has it gone off at all? I said no not that I know it hasn’t. I said it might have gone off just before Christmas I woke up with a start, whether that was it or not I don’t know (ll. 186-189)”*.

Both expert information and bodily feedback were therefore experienced as ambiguous creating uncertainty in the health appraisal. This uncertainty was reported to be higher when expert and bodily information appear to contradict each other. For example, P5 spoke of his belief that due to improved vitality, his health was improving following his heart attack, and his subsequent shock in being told he required an ICD. However, there was evidence that ICD recipients often privileged bodily feedback over expert information in appraising their health. For example P5, frequently referred to his damaged heart, yet said he was fitter than most of his peers. P7 also asserted that how he felt physically was more important in assessing his health and capabilities than information from experts. Privileging bodily feedback appeared less likely when expert information had more clarity, and bodily information was perceived to be more ambiguous (e.g. P4, ll. 552-556).

- P5: *“I’m lucky I’m fitter than most. I mean there must be some 71 year olds that would leave me standing. It’s nice to think, Yeah your top of your health for your age (ll. 444-446)”*.
- P7: *“No I feel how, you know, I look at me own way and say you know, someone can’t tell me how I feel. I’ve got to do it meself and I do I feel good (ll. 278-279)”*.

Participants’ accounts indicated that uncertainty experienced in the health appraisal feeds into their appraisal of threat/ security, which is the next core category identified in this process model.

4.4 Appraisal of threat/security

This category refers to the assessment of threat versus security described by recipients in relation to the ICD device and heart malfunction. The constitutive elements of this process as indicated by the data in the current study are: an appraisal of the likelihood of heart malfunction; an appraisal of the need for device-fire; confidence in the device and perceived ability to cope with the shock experience. Ambiguity and uncertainty were reported to infuse all of these aspects of living with the device.

4.4.1 Likelihood of device-fire

Several factors were described to influence the perceived likelihood of heart malfunction and the need for device activation. These included a belief that good health and medication could prevent heart malfunction, and believing that it was unlikely, as medical staff had told them that the device was ‘only a back-up’. Due to the reported uncertainty of the initial health appraisal, recipients reported continued uncertainty in the assessment of likelihood of device-fire.

- P5: *"I'll admit I (.) don't actually (.) worry about it at all now because if anything I would say I now, I know I'm 71 years of age so you don't improve with age but I would think I now feel at least as fit now as I did 4 years before the heart attack (ll. 134-136)".*

P5: *"... it's supposed to regulate it like a pacemaker would but according to the second check it's not had to do either so the medication is holding my heart somewhere in what must be the ideal sort of situation (ll.110-112)".*

- P4: *"It hasn't gone off, touch wood, which I'm very pleased about. Dr 1 said in theory now that I've given you the by pass, he says, you shouldn't really need this (ll 227-229)".*

The 'fast-pacing' mechanism of the device was also seen to be important in reducing the need for a shock from the device and was perceived to be indicative of a more minor heart difficulty.

- P2: *"Well I suppose that thing I suppose it does (.) that has control over it doesn't it really, because it triggers it before it gets too high. So that gives you a bit more confidence then. [RIGHT] But it's not going to keep going up and up and up until it goes bang. That triggers it half way up whatever makes it better (ll. 612-616)".*
- P7: *"I think what it's doing is making the two weak parts of the heart operate steady all the time, and if they start to slow you just get that little niggles to say come on wake yourself up and it puts me back on balance er this is why I think I'm not getting no big ones because it keeps me ticking over all the time (ll.155-158)".*

Following this appraisal of likelihood of device to fire, individuals appeared to assess how much confidence they had in the device to save their life.

4.4.2 Confidence in the device

Several factors were reported to be associated with confidence in the device. These included: evidence of the device working; improved physical health attributed to the device; an understanding of the device; immediacy of device treatment and reassurance from medical staff. Recipients' accounts indicated that pacing and successful shock delivery was felt to contribute greatly to device confidence.

- P2: *"So that did give me a bit more confidence then as it (pacing) stopped it (.) on the way up you know when my heart is getting faster (ll. 195-197)"*.
- P6: *"I think initially I would have a lot more confidence in it because I would know the thing worked you know so-so that but regards the psychological side of it erm (.) I really don't know I mean the only thing you could do on that is perhaps come back when it's gone off (ll. 673-676)"*.

Pacing was even reported to improve confidence for P2 who had previously received inappropriate shocks from the device. Such was the influence of perceived successful shock delivery, that P3 who incorrectly thought that he had received a shock, asserted that the incident had greatly improved his confidence in the ICD. This suggests that there had been a strong psychological motivation for him to belief that he had received a shock with a good outcome. Confidence in the ICD was also reported to improve when the shock had been delivered during the course of testing the device by the medical team.

- P6: “...*I know it’s sitting there er waiting to you know for if I do overdo it for any reason sitting there waiting for me to er and I know it works because er they tested it (ll. 159-161)*”.

Gaining confidence through a medically induced shock may be more beneficial. Whilst an ‘in vivo’ shock reportedly provided reassurance about device efficacy, recipients also said it contributed to a more negative health appraisal. This creates ambiguity, as recipients outlined that successful shock delivery leads to greater security by improving device confidence, but also leads to greater threat due to perceived ill health. The other major cited contributor to device confidence, improved physical health may also be subject to uncertainty because of the ambiguity described in the health appraisal.

It appears that ICD recipients compare bodily feedback about their health before and after device implantation, and often attribute positive change to the ICD. Recipients’ accounts suggested that the improvement in physical health is utilized as testimony to the efficacy of the device. It is important to note that this is a misattribution since the device does not influence physical symptoms or directly improve health.

- P5: “*No. I would think if I needed it to it would actually definitely work. To say that err the heart attack damaged that left ventricle which I say you can’t cure, no drugs can replace that, and here I am on the third year after fitter than I was two or three years prior to having the heart attack (ll. 369-372)*”.

- P7: *“I think the most magnificent thing about this at the moment is we had at the same time as we had the defibrillator fitted we was having what they called recurring pneumonia every seven to eight weeks. Haven’t had it [REALLY] haven’t had it at all, it’s gone completely hasn’t it Wife? I can go out walking now and I can walk (2) well I can walk as good as you can now (ll.41-45)”*.

Individuals who had a lot of confidence in the device appeared to perceive it as a ‘safeguard’.

- P5: *“An excellent result but I say the biggest plus from having this fitted is thinking if the worst thing happened to me I’ve got this safeguard, that normal people wouldn’t have would they? (ll. 345- 347)”*.
- P6: *“ You know psychologically I know it’s there but erm (.) my little first aider as it were really (ll. 11-12)”*.

However, other individuals such as P4, who received no therapy from the device, said they experienced few physical improvements, or attributed better perceived health to other aspects of medical care expressed more uncertainty about the ICD.

- P4: *“ It’s it’s a bit of back-up just in case this (inaudible words). [YEAH] I hope it never does but errr but if it does it does. If this saves me fine if it doesn’t well then goodbye. I’ve led a very interesting life (ll. 640-643)”*.

- P1: *“Well I don’t know cause I’ve never had one have I? So I don’t know no. (3) I should think it would work. Well I hope it would any way (ll. 187-188)”*.

Uncertainty was therefore reported in relation to whether the device could be effective if it is required to deliver therapy. Also, participants expressed uncertainty as to whether they will be able to cope with the shock experience even if the device does function successfully.

4.4.3 Ability to cope with the shock experience

Participants expressed some concern over negative consequences of device-fire during certain activities, such as driving where loss of control could be physically detrimental. Concern was also articulated in relation to the pain that may accompany the shock, with a preference for pacing being expressed for this reason. As none of the participants had undergone appropriate shock therapy great uncertainty was also expressed in relation to coping with the shock, due to this experience being an unknown entity. The uncertainty of the experience did not appear to be reduced by having received a shock during the course of hospital monitoring. This may be due to possible differences in the experience as suggested by P4 (ll. 600-605).

Participants therefore reported that they consider their ability to cope with device-fire, the likelihood of heart malfunction and their confidence in device-fire in their appraisal of threat/security. This process appears to be plagued by uncertainty and ambiguity. When a person reported greater security in relation to the device, it appeared that awareness of the implant through physical touch or internal sensation was not considered to be problematic. However,

reporting a greater threat appraisal appeared to result in a greater degree of distress, with device awareness being a reminder of the heart difficulty.

- P4: *“You’re conscious of it being there because you’ve never had to think about anything like that before you see, it’s a foreign object. It, it takes some getting your head round knowing that there’s a thing there fixed in your chest to help your heart if it throws a wobbly. It, it’s. It takes a lot of (2) mentally adjusting to (ll. 178-182)”*.

Participants’ accounts also indicated that a greater threat appraisal is associated with more attention to bodily sensations as physical feedback is viewed as a source of information about impending heart malfunction.

- Int: *“RIGHT. YEAH. YOU SORT OF MENTIONED THAT ERM YOU KNOW SOMETIMES IT DOES MAKE YOU WORRY A LITTLE BIT AND YOU KIND OF NOTICE A BIT MORE WHEN YOU GET OUT OF BREATH”/*

P2: *“Yeah. That’s it. That’s it, that’s when you start to (.) you know, think a bit. You know.”*

Int: *“YEAH. I GUESS WHAT “// “Whether any other times, you might not have took no notice [NO, NO] but now (.) you know, if you say get a bit short of breath at all, or sort of feel your heart going you know it does make you think a bit more I suppose (P2, ll. 237-243)”*.

Greater attention to bodily sensation (hyper-vigilance) reported by some participants may feed back into a negative health appraisal, as physical symptoms were said to be

indicative of ill health. In this way, the threat appraisal is maintained by an elevated likelihood of threat. This relationship is shown in Figure 4.2. Once individuals describe having made an appraisal of threat/ security they appear to consider whether the ICD represents a second chance at life or a limited life for them. This dichotomy constitutes the third category in the model of living with uncertainty.

4.5 Second chance versus limited life

Second chance was described as characterized by a new appreciation of living and participants feeling fortunate that they were physically able enough to ‘make the most of life’. It was often expressed as a reversal in time, with participants reporting that they felt younger due to feeling more vital and physically able.

- P7: *“Oh God Yeah. Yeah there’s no doubt about that. I’ve. To be quite honest with you I-I must feel 20 years younger there’s no doubt about that (ll.13-14)”*.
- P5: *“Yeah, because I honestly believe now that erm (.) as I say I feel fitter now than I did four or five years prior to the heart attack (ll.211-212)”*.

Some individuals said that they had reprioritised their lives, emphasising the importance of enjoying life, looking after their health and valuing their relationships. Others stated that whilst their priorities had not altered, as these had been their values prior to implantation, they were now better able to engage in their fulfilment. Participants who saw the device as a ‘second chance’ cited feelings of gratitude and feeling lucky that they were able to have it

fitted. In contrast, those individuals who expressed the concept of a ‘limited life’ cited uncertainty over life span, and feeling restricted in their capabilities. The appraisal of life as a second chance or limited appeared to have three main contributors according to participant’ accounts. These include surviving death, life expectancy, and improved ability versus ability restriction. There is some overlap in describing these factors due to their close inter-relationship and connectivity.

4.5.1 Experience of surviving death.

All of the participants described the events leading up to having the ICD fitted, with many reporting that they had experienced a life-threatening event.

- P6: *“I could have been dead but I’m alive and as I say I’ve got me little lifesaver walking around with me (ll.109-110)”*.

Expression of a ‘second chance’ was more prominent in individuals 3, 5 and 6 who believed that they had nearly died. However, whilst P2 said “I thought I was on me way inside” (P2, ll.48-49), he did not express the belief that the device was a second chance. Similarly, P1 and P4 did not convey this sentiment. It appears these individuals did not feel that the device positively influenced what they were able to do with their lives, or were more uncertain about the life expectancy it afforded them. This highlights that whilst important in the appraisal of life, the experience of surviving death does not in itself constitute a ‘second chance’ if there is continued threat of death and people feel limited in living.

4.5.2 Life Expectancy

All of the participants referred to the hope that the device would extend their life, although there were varying degrees of uncertainty regards this prospect, due to different degrees of reported security. This was accompanied by accounts in which participants appeared to mentally project themselves into the future, considering whether they were going to be able to live active and fulfilling lives.

- P3: “ *Because I lived through it and it scared me real bad. It scared me that much I thought I was going to be in a box. I don’t want to be sitting in a wheelchair the rest of me life, I don’t want it. I’d rather stick me head in a gas oven or anything. I don’t want it at 62 (ll. 317-320)*”.
- Int: “*IT SOUNDS LIKE YOUR HOPES FOR THE FUTURE IN TERMS OF YOUR HEALTH HAVE CHANGED NOW*”.
- P5: “*Oohh Yeah. [YEAH, YEAH] Cause hopefully I’ve got many years of quite active life, cause I like to be active, go out and do things (P5, ll. 412-415)*”.

For P4, concerns over future ill health and physical disability appeared to be related to concern over who would support and care for him in the future. Variation was reported in relation to how positively the device had affected the individuals’ perceived life expectancy and trajectory. Participants appeared to relate their attitude to life to reports of whether they had been able to find new valued activities or preserve existing activities, which they saw as important to a positive life trajectory. For example, both P2 and P6 had to retire due to their heart problem, but were successful in finding new valued activities and capitalizing on existing ones centred upon relationships and socializing. This highlights the importance of the individual’s perceived ability to engage in valued activities.

4.5.3 Improving ability whilst restricting it.

This lower order category refers to the observed paradox that the device simultaneously appears to both improve perceived ability to engage in physical activity whilst simultaneously restricting it. Furthermore, this inconsistency takes place within a social context, where changes in activity need to be negotiated and dealt with within the social unit.

Restricting Activity

Activity limitation occurred due to imposed restrictions such as early retirement or the imposed driving ban following ICD implantation. With regards to employment, this restriction was seen as permission to give up an activity, which the individual had begun to devalue. Other activity restriction appeared to result from the belief that physical activity may be causal to heart malfunction and device-fire. There was also some concern expressed about sexual activity for this reason. Such activity restriction was not seen as a form of control over device-fire, but rather as the device controlling the individual.

- P2: *“Well I suppose if you start chasing and racing about its likely to go (l. 605)”*.
- P3: *“Well it has control over me”*.

Int: “RIGHT. IT HAS CONTROL OF YOU”?

P3: “I think so. Because err (2) as long as I take it easy I know I’ll be all right. If I start exerting myself, over exerting then I don’t know (ll. 417-420)”.

- P7: *“If you start going mad then expect it to hit Yeah er but if you’re normal I don’t expect anything (ll. 439- 440)”*.

Within this context, physical symptoms during physical exertion were viewed as evidence of impending physical disaster, as outlined in the health appraisal category outlined above.

This frequently resulted in the individual stopping the activity, but participants also expressed that at times they felt able to continue by ‘slowing the pace’.

Individuals who had attended cardiac rehabilitation did not express these ideas, suggesting that such programmes can influence beliefs about exercise, heart malfunction and device-fire. Whilst P6 was refraining from exercise due to a health complication, he reported looking forward to engaging in physical activity again in the future. Notably, P1 did not see the device as inhibiting exercise either, due to pre-implant low levels of activity, which he saw as consistent with his older age. Likewise P2, communicated that his beliefs about exercise and the device had not greatly restricted his life due to a pre-existing sedentary lifestyle (ll.59-63). Thus it appears that low pre-existing levels of exercise mediate the impact of the activity restricting aspects of the device.

Increasing activity

Participants reported instances of returning to old activities they had previously stopped engaging in due to physical symptoms and pain. For example P5 returned to doing ‘DIY’, and P3, 4 and 7 were able to walk further without discomfort, which was reported to result in a new sense of freedom.

Participants also described engaging in new activities to replace those that had become restricted, as was observed with P2. These new activities were frequently reported to centre upon relationships, and doing things with partners and family. It was not uncommon for a discussion of activity restriction to be immediately followed by remarks regarding a greater emphasis on the grandparent role (e.g.P1 ll. 321-322). Given this emphasis, ICD recipients highlighted the importance of good relationships.

- Int: *“I’M WONDERING WHATS HELPED YOU PERSONALLY WITH LIVING WITH THE DEVICE”?*

P2: *“Well, I don’t know just (.) that the wife’s at home, we always get on all right so [RIGHT] you know. [YEAH] No nasty remarks or anything so you know just (.) get on (.) I suppose some people are at home who don’t get on that well (laugh) you know. It can be a bit of a bind then, but we always get on all right you know so I think that helps as much as anything (ll. 392-399)”.*

This illustrates the perceived importance of relationships in enabling new activities following device implantation. The reported need to negotiate changes within the social network was also described to influence activity levels following implantation. This phenomenon is reviewed in greater detail in the discussion section.

Participants outlined that feeling more secure also enables greater activity levels because they are more certain that if exercise did result in a heart malfunction, the device would save their life (P6, ll. 334-352. Moreover, participants’ accounts suggested that pacing accompanied by physical symptoms helped them feel more able to engage in activity. P7 commented that pacing had enabled more activity by providing clearer bodily feedback about when further exertion would result in physical peril. It thus appears that experiencing uncertainty with regards to the meaning of physical symptoms during exercise may result in activity restriction. (P7, ll. 561-568). As activity levels were described to be central to the appraisal of second chance versus limited life appraisal, participants’ accounts indicated that uncertainty over safe activity levels introduced ambivalence into their view of life. This appeared to be particularly the case when uncertainty was also expressed about the life expectancy afforded by the device.

As mentioned previously reports of greater attention to the body were associated with reports of greater physical symptoms and a more negative health appraisal. Also, as participants said that they appraise their health according to what they feel able to do, activity reduction appears to contribute to a negative health appraisal. Likewise, poor fitness levels due to lack of exercise may result in more symptoms such as breathlessness, which are subsequently treated as evidence of ill health. This reported negative health appraisal appeared to 'feed' into participants' appraisal of threat with further activity reduction. Conversely improved activity levels with fewer physical symptoms were associated with a positive health appraisal and greater security within participants' accounts. This feedback cycle is depicted in Figure 4.2.

5. Discussion

In this section each of the research questions outlined in the introduction are addressed in turn. The relationship between the main findings of current study, and the existing theoretical and empirical literature is discussed, and implications for clinical practice and future research are raised. Finally, the general strengths and weaknesses of the current study are considered

5.1 Addressing the research questions

1) What impact does ICD implantation have on a recipients reported sense of self?

Self-concept can be encapsulated by the question 'who am I?' whilst global self-esteem is the value people attach to themselves following such an assessment. Self-efficacy refers to people's beliefs about their capabilities to exercise control over events that affect their lives. There was little evidence that participants' self-concept in the current study changed following implantation, but self-efficacy and esteem appeared to improve for those

individuals who had perceived an improvement in their health and physical ability levels. It is important to note that participants themselves did not directly refer to the device influencing their self-efficacy or esteem. However, it was felt by the researcher that many of the participants' accounts of feeling more or less able, and feeling differently about themselves were implicit expressions of these psychological aspects of the self.

Chronic illness has been argued to influence self-concept by changing daily routines upon which self-definitions are based (Charmaz, 2002). The apparent lack of change in self-concept in the current study may be attributed to the reported success with which participants maintained activities either by slowing down or emphasising other activities that were important to them. Also, participants indicated that they maintained a positive sense of self by emphasising aspects of themselves that were non-activity related such as, sense of humour.

- P2: *"Well she knows I'm feeling alright as I'm always taking the mickey out of her. You know (laugh) well in a joking way you know, but um she knows if I'm feeling alright (laugh) sort of thing, but no (2) I don't think its altered me at all really (ll. 384-386)".*
- P6: *"I'm the same person anyway. Em I don't think I've altered in er me sense of humour is still there (ll. 355-356)".*

Participants commonly described a belief that reduced activity was consistent with increasing age. This may have afforded older participants protection against dramatic self-concept change. Individuals who see reduced activity as consistent with aging may already have a more sedentary lifestyle, and be more psychologically prepared for reduced physical

ability due to their beliefs. As indicated by accounts in the current study, this preparation may involve finding other valued activities, meaning that activity disruption following implantation is perceived as less severe. Also, many participants indicated a belief that they could still completely ‘recover’ as they were feeling better according to their bodily feedback. Charmaz (2002) argued that such a belief protects people from having to adjust their self-concept as changes are seen as temporary.

However, participants who had experienced a perceived improvement in physical ability did indicate better self-esteem and self-efficacy through their descriptions

- Int: **“YEAH, YEAH. AND HAS THAT AFFECTED HOW YOU SEE YOURSELF”?**

P5: *“Yeah, I think it has Yeah. There’s virtually nothing today that I’d be frightened of having a go at (ll. 260-261)”*.

- P5: *“But I think now when you do something you do a job and you feel quite proud. Oh Yeah that’s excellent (ll. 568-569)”*.

- Int: **“HAS HAVING THE DEVICE MADE A DIFFERENCE TO HOW YOU FEEL ABLE TO COPE IN GENERAL WITH LIFE?”**

P3: *“Well I suppose. Let me describe it this way. If I was mugged I’d take two on, 10 years ago I wouldn’t have thought of taking on one of them. [RIGHT] But now (ll. 391-392)”*.

It thus appears that reports of greater activity attributed to the device were associated with improved participant self-efficacy in the current study. The reverse is also likely to

apply, whereby a perceived decline in physical ability may result in reduced self-efficacy. The impact of changes in self-efficacy on mood and anxiety following implantation are discussed below.

2) What influence do ICD recipients perceive social factors to have on adjustment to the device?

Participants reported that the social unit was an important determinant of their activity levels. Firstly, friends and relatives were often experienced as key to helping participants engage in new activities that were centred on relationships. The apparent emphasis on relationships following implantation appeared to be partly due to the reprioritisation that was described following a near death experience (Johnson & Morse, 1990).

Participants' accounts also indicated that a need to negotiate changes within the social unit influenced activity levels following implantation. A mismatch was commonly described between what the ICD recipient felt able to do, and what family members perceived them to be capable of without negative health consequences. The experience of such a discrepancy may lie in people possibly privileging different sources of health information, (i.e. expert and physical) since the recipient's bodily feedback is not available to family. A similar mismatch may also occur between medical staff and the recipient, due to the latter apparently privileging bodily feedback.

The data indicated that participants felt that the perceived mismatch between their view of their ability, and others peoples' view could grow or diminish over time. For example, P2 said that initially his wife would not let him do anything. However, he reported that this gradually altered as he began to engage in activity without observable detriment to his health. In

contrast, P3 indicated that the mismatch grew as his bodily experiences informed him that he could engage in activities safely, but he was unable to communicate this to work colleagues (ll. 286-290). The frequently described mismatch in perceived ability was very prominent in the last two interviews where both the recipients and their wives were present.

- P7: *“You get loads of pamphlets you read them they tell you what to do and what not to do and if you actually looked at those pamphlets (2) I’m doing things they tell you not to do [MMMM] and I know I can do them [YEAH] but er you know I think that is the main thing if you know you can do it you do it (ll. 457-461)”*.
- P7: *“ Erm even if I’m doing too much now I get told off erm (2) even though I feel ok I still Wife still worries to that extent erm she’ll have a moan at me to sit down or slow down or steady up and OK we take note and most of the time (ll. 355-358)”*.

The latter quote illustrates that a perceived ability mismatch between family members can result in reported activity reduction, even if the recipient himself describes having more confidence in his capabilities. Perceived family anxiety may also contribute to participants’ uncertainty about their physical ability. However, P2 indicated this situation may be avoidable if the individual is given an early opportunity to illustrate to himself and others that he can engage in certain activities without health detriment (ll. 280 –283). The reported family concern about role change may also be a source of tension for couples, particularly when the recipient himself believes that he is capable of performing the activity (P6, ll.569-775).

For P4 the experience of being told by people that he should ‘get on with life’ resulted in a reported sense of resentment and isolation. He described conflicting feelings of irritability with his social network and gratitude that he felt he was being treated normally. These

feelings appeared to mirror his reported uncertainty about his ability to safely engage in life. P4 also emphasised the importance of family and partners as a source of support in changing health related behaviour, and as a source of reassurance that medical help would be sought in the event of a medical emergency.

Participants indicated that the social network impacts on perceived activity levels following implantation. This appeared to influence their self-efficacy, their appraisal of their health, and whether they saw life as limited or a second chance. When the perceived mismatch involved others asserting that the individual could do more, feelings of isolation and resentment were described.

3) How does frequency of device shock influence how ICD recipients describe their adjustment to implantation?

This question was difficult to explore due to the difficulty- recruiting people who had received shock therapy. Nevertheless, the current study tentatively suggests why individuals who have not had any shocks appear to suffer from greater anxiety (Dunbar et al., 1999). The results suggest that these individuals experience a greater perceived threat for two reasons. Firstly, participants expressed an uncertainty about their ability to cope with the shock, due to the device not firing to date. These individuals also described having less confidence in the device because a history of a successful shock was seen as evidence of device efficacy.

However, the current results also indicate that an important factor may have been neglected in the literature in considering device activity and adjustment. All previous research has focused on shock therapy, but it appears that pacing mechanisms also play a crucial role

in adaptation. Like shock therapy, many participants described that the experience of pacing improved their confidence in the device. They outlined a smaller perceived threat that they related to feeling more able to cope with pacing sensations and a belief that loss of physical control was less likely. Perceived threat was also reported as lower due to pacing being seen as indicative of a more minor difficulty, and as preventative of a more serious heart malfunction and shock therapy. Thus, it is insufficient to simply consider shock therapy in relation to device activity and adjustment; pacing also appears to be a key factor for recipients.

4) Why is a history of a life threatening cardiac event associated with better adjustment?

The current results suggest that surviving a near death experience makes it more likely that the device is seen as presenting ‘a second chance’ rather than a limited life. Johnson and Morse (1990) have also reported the concept of a ‘second chance’ in cardiac patients. They suggested that life-threatening events lead to a reprioritisation of life and attempts to ‘live to the fullest’ because individual mortality is acknowledged. The current study elaborates on this concept, indicating that in conjunction with surviving death, a perceived improvement in life expectancy and physical ability also contribute to participants experiencing device implantation as a ‘second chance’.

Contrary to previous findings reported by Arteaga and Windle (1995), secondary prevention patients who had experienced a life-threatening arrhythmia before ICD insertion did not report less psychological distress. The fact that all the primary prevention participants in this study had experienced a life-threatening cardiac event related to their health may partly explain this finding. It is possibly the experience of a threat to life that is important, rather than the specific cause of the risk. It is also important to note that the threat to life does not need to be verified by objective medical reports, as it is the subjective experience of the

participant that is important, as highlighted by the post-traumatic stress literature (Weiss, 1993; Perkonig, Kessler, Stortz & Wittchen, 2000).

Participants who were most positive about the device perceived themselves to be ‘poorly’ before implantation, with the device leading to better health according to bodily feedback. Conversely, it can be hypothesised that if an individual feels physically worse following implantation, or privileges expert information about their ‘damaged heart’, they will adapt less well to implantation. This was difficult to explore in the current study since most participants reported health status that was the same or better. Nevertheless, the present results suggest that it is the patient’s perception of their change in health that is important, rather than simply whether they have experienced an arrhythmia prior to having the device fitted.

5.2 Accounting for anxiety and depression

This section outlines how the findings of the current study may contribute to the theoretical understanding of how anxiety and depression develop in ICD recipients. Self-efficacy and uncertainty are cited as two major psychological factors potentially relevant to the development of psychological distress following ICD implantation. Levels of anxiety and depression have been reported as similar in ICD recipients and their counterparts with an underlying ventricular arrhythmia condition (Burke et al., 2003; Keren, et al., 1991). However, the uncertainty and reduced physical ability reported by ICD recipients may mean that different psychological processes are at the core of this distress.

5.2.1 Self-efficacy

As outlined above, changes in perceived physical activity by the ICD recipients in the current study appeared to influence both their reported general and physical self-efficacy. A

number of studies have demonstrated that depressed mood and anxiety are associated with low self- efficacy.

For example, self- efficacy independently predicted depression in patients with end stage renal disease (Devins, Binik, Gorman, Dattell, McClosky, Oscar & Briggs, 1982), and in multiple sclerosis and spinal cord injury (Shnek, Foley, LaRocca, Gordon, DeLuca, Schwartzman, Halper, Lennox, Irvine, 1997). Perceived self-efficacy has also been found to predict depression in older elective surgery patients (Kurlowicz, 1998), and in rheumatoid arthritis patients (Lefebvre, Keefe, Affleck, Raezer, Starr, Caldwell, & Tennen, 1999). This finding has more recently been replicated with hemodialysis patients (Takakori, Nishi, Shimoyami, Inado, Matsuyami, Kumano, & Kuboki, 2003) and in a normal adolescent sample (Muri, 2002). Physical self-efficacy in particular has been reported to influence mood with increasing age. Using the Physical Self Efficacy Inventory (Ryckman, Robbins, Thorton & Cantrell, 1982), Davis-Berman (1990) found that physical self-efficacy was a better predictor of depression than either general self-efficacy or objective measures of physical status.

Self-efficacy has also been found to predict phobic anxiety (Jones & Menzies, 2000; Williamson & Watson, 1985; Williamson & Zane, 1989), trait anxiety and anxiety disorder symptoms (Muri, 2002; Williams, 1995), and state anxiety during stressful cognitive tasks (Endler, Speer, Johnson, & Flett, 2001). Moreover, in people with multiple phobias, treatment for one phobia may generalize if the intervention has improved general self-efficacy (Williams, Kinney & Falbo, 1989).

Given that activity changes following ICD implantation appear to affect self-efficacy, it appears that this may contribute to anxiety and depression in device recipients. Perceived self-efficacy to cope with shock delivery also appears to contribute to the perception of heart malfunction and device threat.

5.2.2 Uncertainty

As outlined in the Results, the ICD recipients reported living with a great deal of uncertainty regarding their health and the device. This uncertainty may contribute to anxiety and depression following implantation.

Uncertainty exists when individuals are unable to form a cognitive framework for understanding their situation and are consequently unable to predict the outcomes of their behaviours. It is characterized by vagueness, ambiguity, unpredictability and inconsistency and lack of information (Weitz, 1989). Research has demonstrated a strong relationship between high uncertainty and emotional distress, mood disturbance, and anxiety (Bennet, 1993; Hawthorne & Hixon, 1994; Wong & Bramwell, 1992). Uncertainty has also been associated with poor psychosocial adjustment to illness (Christman, 1990; Mishel & Sorenson, 1991). There is evidence that individuals who experience high uncertainty and emotional distress utilize predominately emotion-focused strategies like cognitive avoidance or wishful thinking, rather than problem-focused coping (Buelow, 1991; Hilton, 1989). Mishel (1992) suggested that this is because high uncertainty is accompanied by high emotional arousal, which must be managed through emotion-focused coping, before problem-solving strategies can be engaged in.

The findings of the current study, in conjunction with previous literature, suggest that perceived uncertainty may be associated with anxiety and depression in ICD recipients. Whilst coping styles in response to uncertainty were not examined, the findings indicate that further research in this area may add to the theoretical understanding of ICD recipients. Notably, coping styles have been highlighted as important in a previous theory relating to psychological distress in ICD recipients (Dunbar et al., 1999). This theory and others are discussed below in terms of how they relate to the findings of the current study.

5.3 Relating findings to previous theories

Briefly outlined below are some previous theories of anxiety and depression in ICD recipients, and how they relate to findings of the current study. These theories were selected for discussion because the current research was deemed to partially support and elaborate upon certain of their aspects. In particular, theories specific to ICD implantation are highlighted as these are more developed, acknowledging the importance of shock history and the heterogeneity of recipients. However, it is first noted that the current model supports a proposal made by Leventhal, Idler and Leventhal (1999) in relation to illness representations.

Leventhal et al. (1999) proposed that illness representations are formed through two interacting streams of information processing, which consist of abstract conceptions about the disease/ treatment, and how the disease is experienced at a physical level. He argued that the latter information source is given privilege if the two streams of information are conflicting. The findings of this study supported this proposal, as participants indicated that they appraise their health via expert information and bodily feedback. There was also some evidence that they privileged bodily feedback over information from bodily experts when there was conflict. The reasons for this were unclear, as both channels were reported to be ambiguous at times. Possible reasons as to why this reported channel of information was seen to be more influential requires further investigation.

The findings of the current study also appear to partially support past theories of anxiety and depression in ICD recipients. For example, Dunbar et al. (1999) proposed that personal factors (age, gender, and dispositional optimism), and situational factors (co-morbidities and device activation), determine whether device discharge is appraised as a challenge or a threat. This appraisal subsequently influences whether emotion- or problem-focused behaviours are deployed, and the emotional outcome. In congruence with Dunbar et al., participants' accounts in the current study suggest that situational factors such as shock history determine

whether there is a perceived threat. They also indicated that many participants viewed age as a personal factor that affected adjustment, by influencing perceived levels of appropriate physical ability.

However, the current study supported a threat/ security distinction rather than a threat/ challenge dichotomy. This better communicates recipients' appraisal of the device, not just the shock discharge situation. Also, participants highlighted several situational and personal factors they perceived to be key to the adjustment process (i.e. age, shock history, cardiac history, social support etc), and indicated why they appear influential. The current model consequently gives a fuller account as to the possible processes by which such factors can exert an influence. In contrast, Dunbar et al. (1999) failed to state how, and often in what direction factors influence the threat appraisal and subsequent adjustment.

Another ICD specific theory (Sears, Conti, Curtis, Saia, Footie & Wen, 1999) suggested that individuals interpret device firings as a 'sickness scoreboard', believing that when the device-fire their health is deteriorating. The current model supports this theory, but builds upon it by highlighting that a negative health appraisal expressed by the recipient may be offset by reports of greater confidence in the device. Thus, as supported by the literature (Dunbar et al., 1999), a history of no shocks is not necessarily consistent with a low threat perception and low anxiety.

A cognitive model (Clark, 1986) has also been advocated to explain anxiety in ICD recipients, whereby anxiety results from the catastrophic interpretation of bodily or mental events as signs of impending bodily breakdown (Lemon, Edelman & Kirkness, 2004). Such negative interpretations are treated as evidence of threat, furthering exacerbating anxiety. This vicious circle is maintained by selective attention to bodily events that contribute to a lower threshold for perceiving sensations.

Some participants in the current study described that they became overly attentive to bodily cues and perceived them to be a sign of heart malfunction and device-fire. Such hyper-vigilance was most commonly reported when participants expressed a higher appraisal of threat. Higher threat was associated with perceptions of poor health, and reports of having little confidence in the device and their ability to cope with device shock. Symptom misinterpretation was more likely in individuals who communicated a belief that physical exercise is connected to heart malfunction and device-fire, particularly with increasing age. The current study consequently supports the suggestion that hyper-vigilance and misinterpretation of bodily symptoms are present in ICD recipients. However, the model also elaborates upon why some individuals may be more at risk of this than others.

The results of this study build upon findings reported by previous qualitative ICD implantation studies too. Using grounded theory, Burke (1996) reported that recipients minimised negative aspects of implantation when they saw improvements in their ability after implantation. However, the current study suggests that seeing the device more positively depends upon perceived activity levels, and a perception of having survived death and an extended life span. Burke (1996) identified that patients reported uncertainty as a characteristic of living with the device at three months post-implant. This author also reported that recipients described reshaping their attitude towards their sense of self. The current study elucidates upon the reasons why participants describe uncertainty in their lives at this time point, and indicates the importance of reported changing activity levels to attitudes toward the self. The uncertainty described by participants in the current study may help account for the ambivalence Burke (1996) described during the stage she entitled 'integrating technology into life'. Burke (1996) outlined that such ambivalence is reported to decrease over time and people described that they came to 'live life through technology'. This begs the question whether this final stage of acceptance is characterized by a reduction in reported participant uncertainty.

The current study also supported results of a qualitative study by Fridlund, Lindgren, Ivarsson, Jinhage, Bolse, Flemme, Sandstedt, and Martensson (2000). These authors also identified feelings of safety, having a social network, and a belief in the future related to the device as important issues for ICD recipients. Participants' experiences were reported to belong to either a positive or negative pole within each category. The current study suggests greater complexity, as the participants often expressed great ambivalence and uncertainty in relation to each of the identified categories. Dickerson (2002) also reported ambivalence towards the device in a qualitative study employing a phenomenological approach. However, the current study contributes towards an understanding of the source of this ambivalence.

Thus it can be seen that although the present model partially supports some previous theories in this area, it expands upon them, presenting a more comprehensive theoretical understanding.

5.4 Clinical implications

The current study indicates that several clinical measures may have efficacy in reducing psychological distress in ICD recipients.

Using a cognitive behavioural approach, recipients' negative beliefs about physical activity and heart malfunction need to be addressed. An explicit aim of exercise in cardiac rehabilitation programmes could be to normalize physical symptoms during physical activity, and challenge the commonly reported assumption in the current study that exercise results in device-fire. It is hoped that such an approach would help people maintain activity levels, thereby maintaining their self-efficacy. This is important given the association between low self-efficacy and anxiety and depression. For reasons outlined above, negative exercise beliefs of key individuals in the recipient's life would also need to be addressed. This would require a systemic element to be incorporated into cardiac rehabilitation programmes. Clinicians should

endeavour to discuss and problem-solve with recipients any difficulties they may be having negotiating ability levels with others.

Where valued activities have been limited by imposed restrictions or general ill health, therapy should help individuals to find ways to continue with activities, or find new ones that they find pleasurable. This may be particularly important for individuals who do not have a good social network to help them mobilise new activities. This was indicated in the current study, and by research by Duke, Leventhal, Brownlee & Leventhal (2002). These authors reported that individuals who were able to replace lost activities following illness had higher positive affect levels one year later. This supports the importance of helping recipients maintain and diversify activity.

Participants in the current study also indicated that increasing or maintaining activity levels was an important contributor to how they perceived their health. There is also evidence from other studies (Benyamini, Leventhal & Leventhal, 2003; Hoeymans, Feskens, Kromhout & Van-Den-Bos, 1997) that vitality and ability levels are used to assess health. Helping ICD recipients engage in more activity may lead to better health appraisals, which appeared to be related to a lower sense of threat of heart malfunction and device-fire in the current study. Likewise, increasing exercise would lead to better fitness levels and fewer physical symptoms during exercise. This is important as the frequency and intensity of physical symptoms were reported to contribute to how participants appraised their health. To this effect, it has been reported that higher levels of body awareness are associated with significant longitudinal decreases in self-assessed health over a one-year period (Hansell & Mecanic, 1991). For this reason, distraction techniques may be beneficial for recipients who overly attend to bodily feedback.

There are several other means of potentially influencing the ‘threat or security’ appraisal outlined by participants. Stressing that the shock discharge is only one element of medical care may reduce perceived threat. Medication and pacing appeared to be related to a lower perceived likelihood of heart malfunction, and more confidence in the device in the current study. Pacing in particular was related to reports of reduced worry, suggesting that where it is medically feasible, this function should be considered. Increasing device confidence may also reduce threat appraisals. This may be achieved by providing regular feedback about device activity, and contact with ICD recipients who have had a successful device-fire outcome. Increasing perceived self-efficacy to cope with device shock, through vicarious success or imaginal experiences, could also reduce threat. Evidence suggests that modelling can produce marked beneficial effects on self-efficacy (Bandura & Adams, 1977). Other studies indicate that imagined success experiences benefit anxious individuals both lowering fear and increasing perceived ability to cope (Kazdin, 1984; Leitenberg, 1976).

It can be argued that all of the above interventions aim to reduce uncertainty, by decreasing threat and increasing security. Likewise, normalization of bodily symptoms during exercise may seek to reduce the reported uncertainty about what this bodily feedback means about physical well-being. It may be difficult to address uncertainty deriving from contradictory information from expert and bodily information, as participants’ reports in the current study suggest that they are reluctant to devalue the latter. As the motivational interviewing philosophy would suggest (Miller & Rollnick, 2002), discussing the contradiction openly may be more beneficial than simply attempting to exert the medical view. Great sensitivity is also required with regards to some recipients’ apparent misconception that health improvements are due to the device. Challenging this belief may lead to a greater perceived threat, by undermining device confidence and contributing to a more negative health appraisal.

Finally, the current model gives some indication as to the risk and protective factors related to psychological distress following implantation. These are shown in Table 5.4. Such information is crucial in enabling early intervention and preventative measures.

Table 5.4 Risk and protective factors related to psychological distress in ICD recipients

Risk factors	Protective factors
Perceived poor health	A history of pacing or successful shock discharge
Little improvement or deterioration in health following implantation	High self-efficacy in relation to coping with device shock
Privileging knowledge of ‘damaged heart’ over improved bodily feedback	Good social network to mobilize new activities
Activity restriction due to a belief that physical activity is linked to heart malfunction and device-fire	History of surviving a life threatening cardiac event prior to implant

5.5 Strengths and weaknesses of the current study

As outlined in Appendix 8 the researcher took several steps to improve the quality of the study. Theoretical sampling ensured that the developing theory was comprehensive (Lincoln & Guba, 1985), and accounted for different experiences of ICD recipients. Reflexive procedures, such as a reflective diary (See Appendix 9) were used to ensure that the researcher’s own assumptions did not bias the results. Analytic claims were transparent and supported by examples so that the reader can examine the fit between the data and the researcher’s understanding of it. In addition, as described in the following sections, it is felt that the findings contribute to the theoretical understanding of ICD recipients with clear clinical implications.

However, the proposed model is less transferable to those recipients who have not experienced shock therapy from the device, as it was not possible to sample individuals who had received appropriate shock therapy. It is felt that most elements of the model would still transfer to recipients who have received a shock, but the uncertainty about their ability to cope with the shock may be less. A threat appraisal may be greater with shock therapy, as participants in the current study communicated that device-fire indicates ill health and contributes to a greater perceived likelihood of heart malfunction. However, participants' accounts also suggested that this could be balanced by more confidence in the device to work successfully. Further research is required to affirm the applicability of the model to recipients who have experienced a shock.

It should also be noted that this proposed model is less transferable to ICD recipients who have not had the device for four months. The researcher investigated recipients who had had the device for this length of time so that she could investigate the early adjustment phase. This time point was chosen because most studies indicating anxiety and depression in ICD recipients have been conducted within the first 6 months. Also, a four-month period was easier for recruitment purposes, as most recipients have a follow-up appointment at this point. A longitudinal study would have better enabled the study of adjustment over time. However, time constraints precluded this possibility. It is hoped that future qualitative research may be able to clarify similarities and differences between recipients at different time points following implantation.

The current findings are not transferable to women or much younger ICD recipients due to recruitment difficulties within the sampling period. Nevertheless, it is felt that the findings may help explain why some research has indicated age differences in adaptation to the device (Sears, Burns, Hanberg, Sotile & Conti, 2001). As outlined above, since aging was often reported as consistent with reduced physical ability, many older individuals may experience

the activity restriction following implantation as less dramatic. Also, if lower physical activity levels are seen as consistent with age as many participants indicated, older adults may be less likely to see activity reduction as indicative of ill health. The hypothesised result is that an appraisal of a 'limited life' following implantation may be less likely in older adults. However, older adults who do not hold these beliefs about aging may still experience the device as limiting, explaining some of the discrepancy in studies considering the relationship between age and adjustment.

Such possibilities require further investigation to extend the transferability and utility of the model. Attitudes to aging in older ICD recipients also highlight the importance of cultural beliefs in adjusting to the device. Unfortunately, it was not possible to recruit recipients from other cultures, and all of the participants in the current study described themselves as white British.

Another issue affecting the quality of the current study was the presence of recipients' partners in the last two interviews. This occurred as these individuals wished to be present during the interview, feeling that they could contribute. This may have inhibited some disclosure by recipients, but it is also noted that these interviews provided more information about the importance of the social unit.

A further criticism of the current study is its failure to reach theoretical saturation due to time constraints and recruitment problems. The study's progression toward theoretical saturation is illustrated in Appendix 10. It is felt that whilst no more categories would be found with further interviewing (no new categories were indicated after Transcript 3), further category properties may have been elucidated. For example, the researcher would have liked to investigate further why bodily feedback was privileged in some cases, and whether personal factors, such as optimism were deemed to affect the adjustment process. It may have

also been beneficial to investigate further whether exercise was deemed more likely to be related to heart malfunction with increasing age. This was prohibited by a failure to recruit recipients for further interviewing.

Despite these caveats, it is felt that the current study is able to contribute towards the theoretical understanding of anxious and depressed ICD recipients.

6. Summary and conclusion

Uncertainty and ambiguity are reported to infuse every aspect of living with the ICD device. There is subsequently expressed uncertainty as to whether the device represents a ‘threat or security’, and ultimately whether it presents a second chance or a limited life. Therapeutic interventions are consequently required to reduce ‘threat’. This may have the impact of reducing anxiety, particularly in relation to physical activity, thereby allowing individuals to continue to engage with life in a fulfilling way. Such engagement may be crucial to prevent depression and maintain general self-efficacy in ICD recipients.

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Section 3: Critical Appraisal

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Critical Appraisal

1. Abstract

This article outlines several reflections relating to the conduct of this piece of qualitative research investigating ICD implantation. Obstacles and levers to the process are discussed and factors relating to motivation maintenance are highlighted. Several major learning points are highlighted. These include the importance of effective research alliances, balancing comprehensive data collection with respect for the interviewee, and the role of supervision and self-reflection in ensuring quality research.

2. Introduction

Qualitative studies are able to capture the complexity and depth of participants' experiences, and are a valuable form of research. This section outlines the major issues that were encountered in relation to investigating ICD implantation using a grounded theory approach.

3. The literature review: Implications for choice of method and the interview schedule

The area of study was selected because it was believed to have clear clinical implications for the psychological treatment of Implantable Cardioverter Defibrillator (ICD) recipients experiencing psychological distress. A member of the doctorate in clinical psychology course team had a clinical interest in this patient population. This meant that supervision could be provided from someone who had expertise in the area, and had links to the cardiac department from where potential participants could be recruited.

Two literature reviews were conducted in September 2003 and November 2004. This revealed an extensive general literature on ICD implantation. Articles were prioritised in terms of the quality of the publishing research journal, and their relevance to the research area.

‘Sifting out’ articles that did not primarily consider the psychological impact of ICD implantation helped identify key articles. Review articles were accessed first to determine which of the other articles would be most valuable. The literature on cardiology and chronic illness was also consulted to provide further context to the ICD recipient’s experiences.

To aid the research appraisal process each article was numbered and assigned an index card, which outlined the study and provided a critique of its methodology. There was a paradox in the detail required in critiquing studies, and the need to overview a large quantity of health literature that may be relevant. The paradox was managed by reading a great many articles briefly, before ear marking those articles of greatest relevance for more detailed analysis. The findings of the literature review were the main determinant of both the research questions and the method of inquiry.

A qualitative approach was deemed appropriate as the research aimed to capture the complexity of people’s situations, thought, feelings and actions. Grounded theory was deemed to be the most appropriate methodology, as it seeks to build theoretical understanding, which is currently weak in relation to ICD implantation. The literature review also partly determined the initial content of the interview schedule, which was devised to address gaps identified in the ICD literature.

4. Developing the interview schedule

In the initial stages of developing the interview schedule, the researcher became aware of attempting to devise questions based on possible previous responses. This alerted the researcher to the possibility that she had set expectations about what she was going to find which might constrain data collection and analysis. Subsequently, it was necessary to ‘step back’ and identify areas that were of interest, but avoid being too specific or constraining in what was asked. This difficulty is a likely consequence of having taken a literature review from a more

positivist stance. It has been recommended that lit reviews are conducted after analysis for this reason, but the course format precluded this. It is however the researcher's belief that without the literature review, it would have been difficult to know what area of investigation was most needed.

Conducting a literature review first can be fruitful providing that the researcher has the flexibility to discard invalidated assumptions, and accept and elaborate upon new concepts as they emerge. In this way qualitative research is both inductive and deductive. The process can be compared to theoretical sampling across researchers. That is, one researcher may find a phenomenon, and upon the basis of this finding another researcher may ask further questions to elaborate upon it or discredit it. This flexibility is inherent in the psychologist role. Psychologists are trained in theory and models, and this adds to their thinking about patients. However, if a model does not fit the data presented by the patient it is altered or elaborated upon within formulation. Data analysis in many ways appears to mirror the formulation process-both the therapist and researcher develop an understanding from the data, identify areas for elaboration, and ask further questions to add to their developing theory.

The development of the interview schedule was difficult for other reasons. It felt extremely difficult to ask certain questions without potentially intervening in the processes under study, and evoking participant distress. For example, trying to unearth why ICD recipients privilege physical sensation over the more negative, but accurate information from health professionals. Great sensitivity was therefore required in thinking about how to phrase particular questions.

Question formation also became more difficult as the model began to progress, with new questions tapping more complex and abstract ideas. There was a paradox in working with the necessity of clear and simple questions, and the complex abstract phenomena under study. It was also very difficult in certain cases to ask open questions as this appeared to complicate

sentence structure and require that the researcher made a particular assumption. For example, ‘how do you think you think your relationships have been affected’ makes the assumption that they have been. Consequently closed questions were used but were followed up with prompts to help patients elaborate upon their initial answers. It is acknowledged that failure to adhere to an interview schedule can mean that the interviewer is more easily lured to asking closed questions. In such cases a tentative and a less pressured style of interviewing was found to be helpful as it allows the interviewee to better reflect and elaborate upon their answer.

The interview schedule evolved through the process of theoretical sampling. This occurred at the micro level through negative case analysis, and by changing the focus of the questions asked. Negative case analysis occurred very early on in the process, because initial themes were indicative of who may have a different view. However, the interview schedule did not begin to change more substantially until later in the process when a model was emerging and there were clear gaps in the data that required elaboration.

However, at no time in the research process was the interview prescriptive. Instead the interview was constructed around certain topics, and the phrasing of specific questions relating to that topic was flexible. The detail in the interview schedule was designed to help the researcher clarify what would be important issues to address and think about how questions may best be phrased to maximize clarity and elicit information. The researcher also became very familiar with the interview schedule so that it did not need to be read verbatim. This was felt to be crucial to the naturalness of the interpersonal exchange, and to allow flexibility in ordering questions. It also felt important that the schedule was not read verbatim to prevent constraining the researcher, permitting venture into relevant territories that were un-chartered by the schedule. In this manner, some theoretical sampling was also able to occur in situ. Failure to do this would result in the data elicited being determined and shaped by the interviewer, leading to a theory that is not truly grounded in participant’s experience

5.Ethical submission and recruitment difficulties

Although the researcher prepared for ethical submission in a timely fashion, the process was delayed by staff shortages in the relevant Research and Development department (R and D). This experience was extremely frustrating and anxiety provoking, particularly as the researcher had to maintain a positive relationship with the department, and was reliant on their support and co-operation. Ethical approval was finally granted in January 2005, but there was a further delay because most potential participants fulfilling criteria were not available until mid-March. To address this issue consideration was given as to whether to recruit participants who'd had the device longer, but this would have required re-submission to ethics for a major amendment. A limited recruitment pool meant that it was necessary to begin recruiting individuals outside Leicestershire. This was possible without re-submission to the ethics committee, as the researcher had sought permission to recruit outside Leicestershire in case of this eventuality.

These recruitment problems highlighted the importance of considering possible difficulties from an early stage, and 'building solutions' to these problems into the ethics submission. To deal with the time pressure the researcher had to consider carefully how her time was spent during these delays to maximize productivity. This was extremely difficult given the reliance of much of the write up on completed the data analysis. By May five interviews had been transcribed and analysed by the researcher. This had been extremely difficult to achieve since theoretical sampling slows the process, requiring analysis and reflection between interviews. Yet, this process helped maintain morale and motivation. It provides diversity in the work, and by ensuring regular contact with recipients, helped keep the clinical importance of the research in mind. Close liaison with the cardiac team was also extremely valuable as a source of practical support and a boost to morale.

6. Forging alliances with medical staff

The researcher worked closely with the ICD technicians who recruited the participants and with a cardiac nurse specialist who had an interest in the research. The nurse, who was known to the researcher's supervisor, contacted the technicians about the study in the first instance.

To ensure their engagement in the process, it was made clear to the medical staff that their input was extremely valuable, and that one of the aims of the current study was to ask questions that were meaningful to their practice. This was difficult to achieve with staff members who felt that physical and psychological aspects of care were separate. An important aspect of working with the medical team was also relating to them as individuals, whilst maintaining a professional stance. This was extremely important in developing the mutual trust and respect necessary for collaboration, and ensuring staff motivation in the research.

The researcher made weekly contact with the ICD technicians to collect participant names, to help them keep the research a priority, and to jointly address any difficulties that had arisen. It was important to arrange a meeting with staff early in the research process to establish how hospital procedures would influence research, and ascertain individuals' roles in the process. Consequently, initial meetings were in October 2004 and the researcher shadowed the cardiac nurse specialist and technicians to understand the care process. This experience was important in establishing rapport with medical staff, and in planning the logistics of the research. Close liaison with medical staff was also important given the researcher's lack of medical training.

My lack of medical knowledge presented a difficulty in understanding medical differences between patients, which might contribute to adjustment. It also made it more difficult not to be drawn into sharing interviewee's inaccurate assumptions about the device and their health. For example, many interviewees were persuasive in the belief that mild exercise could cause the

device to fire. However, some distance from the medical perspective also allowed greater reflection on the recipient's psychological and emotional inner world. The researcher's lack of medical expertise also enabled a better insight into patient's experience of receiving information about their health. Such issues highlight the need for psychologists to work closely with medical staff when conducting such research, whilst still maintaining their own professional stance.

7. Theoretical stance

The researcher took a critical realist approach to the current study affirming that there is an underlying reality to the world, although interpersonal issues in the interview, and researcher biases may distort this truth. The researcher does not dismiss the idea that people do partly construct their experiences, but believes that this construction is based in and constrained by an underlying reality. It is this belief in an underlying reality that places the researcher nearer the realist rather than the constructionist end of the theoretical continuum. It was also felt that the ideological origins of grounded theory were fundamentally critical realist, and that this stance was therefore more consistent with this approach. However, Charmaz's account of the grounded theory (1995) procedure has been followed, rather than Strauss and Corbin's more critical realist account (1998), as it was felt that her language was more penetrable for a first time qualitative researcher.

It was also felt that a constructionist stance to research undermines the concept of generalisability if findings are constrained to those individuals with whom the model was developed. This would mean that theories and models inherent to the underpinning of psychology would lose their explanatory power of general phenomena, and limit therapeutic implications to the specific individuals studied. In the initial phases of the current study it was difficult to reconcile the critical realist stance with the study of the self, which it can be argued, is essentially a construct. However, the sense of self is still constrained by the physical reality

of the individual, their age, physical disability, appearance etc. In this manner the self can still be seen in a realist light.

The researcher still experiences a certain amount of dissonance and uncertainty about her theoretical stance. It is felt that this is appropriate given that she is a novice qualitative researcher, and ideas about stance evolve and change with further engagement in qualitative research. Indeed, such uncertainty may be considered as necessary at any stage of a researcher's development, given that it reflects an openness to engage with information incongruent with beliefs and expectations. It is this flexibility and openness in thought, which appears to be essential to conducting good, grounded theory research. It is also recognised that the critical realist stance may be partly an artefact of the researchers more quantitative background and it might therefore be expected that her stance may alter as her familiarity and understanding of the qualitative literature develops.

As the researcher came from a more quantitative background shaking off the 'shackles' of this approach, and adopting a new terminology and stance to data collection and analysis was at times difficult. It required immersing oneself in the grounded theory literature and 'packing away' more quantitative ideas. For example, in the initial stage it was difficult to think that the current study would not require an equal number of matched primary and secondary prevention patients. Whilst quantitative and qualitative methods can be used in conjunction, to be simultaneously fluent in both requires great familiarity with both approaches. The researcher's experience is that if this familiarity is not present it is not possible to hold both methods accurately in mind and exercise them effectively.

8. Use of supervision

Supervision was provided from an academic supervisor, providing an opportunity to discuss the model, discrepancies and areas in need of elaboration. The opportunity to explain the findings to someone else facilitated the process of ‘stepping back’ from the data, and seeing it more holistically, rather than in a fragmented manner. Supervision was also important in the initial stages of the research, as the supervisor was familiar with the involved cardiac department. This made forging effective alliances easier, as it better ensured that the priorities and aims of the concerned parties were congruent. Supervision acted as a source of containment for anxiety relating to the lack of clarity in initial analysis phase. The researcher’s experience was that this anxiety causes the individual to disengage from the data, or want to jump beyond that data in order to make sense of it. Supervision also provided an opportunity to identify potential biases that may be operating in the analysis.

For example, a potential bias that may have impeded the research process was the researcher’s initial assumption that ICD implantation would be problematic for most individuals interviewed. This assumption was derived from the findings of the literature review and from communicating with staff in the cardiac department. This assumption may have meant that the findings were distorted. However, as the results reflected variety in adjustment to the device it is felt that this potential bias was kept in check. This was achieved via careful self-monitoring both during the interviewing and analysis stages. For example, researcher frustration or anxiety during interviewing indicated that the interview data was dissonant with what was expected or desired. These cues were treated as a warning to continue to be open and follow the participant’s ‘lead’ rather constrain them.

Peer support was also an important source of supervision in the form of a staff facilitated qualitative group. This group helped maintain the researcher’s morale and motivation by providing a forum for normalization of feelings of frustration and bewilderment. It was also

important in the development of theoretical stance to the research, by providing time to discuss the philosophical underpinnings of the realist and constructionist approaches and their practical implications. Peer supervision was also important from a critical realist stance as a source of confirmation and disconfirmation of the codes/ categories that were emerging. This is less relevant to a constructionist approach where multiple interpretations of the data would be valid.

It became apparent during peer supervision that whilst there are core components to grounded theory, there is also diversity and flexibility inherent in the approach. For example, where open codes are written in the initial instance, and how the data trail is recorded. The researcher found that trial and error was necessary in determining what was best suited to the researchers' analytic style. Such issues are also determined by whether model development has felt like a slow piecing together of a picture, or a 'eureka moment' as described by some peers.

There is also diversity in whether researchers choose to perform their own transcribing, as the current researcher did. This was felt to be extremely beneficial as it enabled the researcher to immerse themselves in the data, and analyse implicit meanings in the data. It is noted that such immersion can make it difficult to later step back from the data and see the models outline. Yet, without this immersion, subsequent models fail to capture the complexity and diversity of the phenomena they allude to.

9. Issues in conducting interviews

9.1 Gathering data versus respecting the interviewee:

There was a tension in the research process between eliciting the most information possible and protecting the individual's privacy and well-being. Some participants may have been reluctant to divulge how the device had emotionally affected them, and their sense of self. Such disclosure may have felt embarrassing or shameful, requiring great trust in the researcher. Interviewees may not want to talk about certain issues because they know that they cannot be

addressed and 'packed' safely away again after an hour. For this reason questions that were potentially very sensitive were phrased very loosely, to allow the individuals to decide themselves whether to discuss them. For example, the question 'how has the device affected your relationship with your wife' presents the opportunity to discuss sexual activity only if desired. It seems clear that if people defend against a dramatic change in self-concept as Charmaz (2000) has suggested, then pushing people to discuss this when they are reluctant may be harmful.

There is a balance to be achieved between quickly gaining accurate and full information, and preserving interviewee privacy and well-being in the power dynamic. Whilst it is acknowledged that the subsequent model may not be as comprehensive, it is important to maintain the well-being of the participants. Such individuals are after all being researched by virtue of their vulnerability to distress. For the above reasons, it may be preferential to conduct multiple interviews with people over time to allow trust to develop and let people know that their distress can be contained. This however, needs to be balanced against the time resources and commitment of the interviewee. There is also the potential danger that multiple interviews may encourage the perception of therapy rather than research, which can be the agenda for some people participating in such studies.

9.2 The agenda and expectations of the interviewee

Participant agendas for contributing to a study require consideration. For example, one individual in the current study appeared to have taken part in the study as a 'thank you' to the hospital. He appeared to see it as an opportunity to convey a positive message about the care he had received. This impeded his desire to discuss any negative feelings he may have had about the implantation process and subsequent adaptation. Another participant saw the interview as a vehicle for human contact, and was reluctant for the researcher to leave. Some of these agendas were more compatible with the researcher's than others. For example, the first case outlined

above was disruptive as it hindered discussion of the research area. In the second incident, the researcher managed the agenda by spending time in more general conversation before and after the interview.

Participants also have expectations about the researcher that impinge upon the research process. For example, some participants assumed that the researcher was from a medical background, and saw a medical account of implantation as the research focus. The participant may believe that the researcher holds certain values and so on by virtue of age etc, and this may affect disclosure. This situation is difficult to rectify because such assumptions may vary and are rarely made explicit. Differences between the researcher and interviewer can therefore affect study validity. The difference in age between the researcher and interviewees in this study was very apparent in some interviews. Participants commented that the researcher would learn how physical health and life outlook change, as you get older. One interviewee also commented that it is difficult to communicate an experience to someone if they have not shared it.

Such comments were treated as an honest acknowledgement of difference, and of the difficulties inherent in communicating feelings. It is felt that acknowledging the validity in these comments helped individuals feel that difference was valued, and that the researcher was interested in learning from them. It also felt important to reflect back to interviewees their implicit statement that the researcher herself would be old one day, as aging is universal. Failure to do this may have made the age discrepancy more painful at a time when many participants appeared to reflect a desire for youth and health. Whilst such issues are not about data collection, they are about respect and rapport, without which the research tool of questioning is rendered useless.

9.3. The write- up phase

It can be difficult to sustain motivation during qualitative research, as the process is not entirely linear due to the constant comparative approach. Progress can feel evasive, particularly if new data requires modification of previous analysis. At such times it was helpful to see this as inherent to the process, reflecting an evolution of thought rather than researcher error. The circularity is also felt in the write-up phase. Earlier drafts were substantially longer, containing reflections, questions, and greater detail about the studies. They were also 'wordier' as the researcher was initially grappled with making sense of new information, concepts and terminology.

The write-up itself was therefore experienced as a vehicle for thought and development. Equally, the timing of the write up of the various part of the research was deemed to be important. The researcher was under extreme time constraints making time for the necessary reflection in the analysis stage extremely difficult. Interspersing the write up between intense bouts of analysis, provided space for the results to be consolidated without compromising the time scale of the project further.

10.Concluding remarks

The researcher took several major learning points away from her experience of conducting this study. These included the importance of balancing comprehensive data collection with reverence for the interviewee, and the role of supervision and self- reflection in ensuring quality research. The importance of building effective working alliances was extremely evident. In the above study, this was in terms of the researchers relationship with the cardiac team, supervisory relationships, and fundamentally, the rapport and respect between the researcher and participant.

11.References

Charmaz, K. (1995). Grounded Theory. In J.A. Smith, R. Harré & L.K. Langenhove (Eds.), *Rethinking methods in Psychology* (pp.27-49). London Sage.

Charmaz, K. (2002). The self as habit: The reconstruction of the self in chronic illness. *Occupational Therapy Journal of Research*, 22(1), 31-41.

Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, US: Sage Publications

Appendices

Appendices

Appendix 1: Notes for contributors of the British Journal of Health Psychology

Notes for contributors

The aim of the *British Journal of Health Psychology* is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journals is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Pressure on Journal space is considerable and papers should be as short as is consistent with clear presentation of the subject matter. Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Refereeing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations ('In our earlier work...')).

4. Submission requirements

- (a) All manuscripts must be submitted online via *Editorial Manager*® at www.bpsjournals.co.uk. Submission of a paper implies it has not been published elsewhere and it is not being considered for publication in another journal.
- (b) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.
- (c) Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- (d) Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- (e) All articles should be preceded by an Abstract of up to 250 words with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- (f) Bibliographic references in the text should quote the author's name and the date of publication thus: Smith (1994). Multiple citations should be given alphabetically rather than

chronologically: (Jones, 1998; King, 1996; Parker, 1997). If a work has two authors, cite both names in the text throughout: Page and White (1995). In the case of reference to three or more authors, use all names on the first mention and et al. thereafter except in the reference list.

- (g) References cited in the text must appear in the list at the end of the article in current APA style. The list should be typed in double spacing in the following format:
Herbert, M. (1993). *Working with children and the Children Act* (pp. 76-106). Leicester: The British Psychological Society.
Kanvil, N., & Umeh, K.F. (2000). Lung cancer and cigarette use: Cognitive factors, protection motivation and past behaviour. *British Journal of Health Psychology*, 5, 235-248.
Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- (h) SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- (i) In normal circumstances, effect size should be incorporated.
- (j) Authors are requested to avoid the use of sexist language.
- (k) Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.
- (l) For guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

5. Publication ethics

Any study published in this journal must pay due respect to the well-being and dignity of research participants. The British Psychological Society's Ethical Guidelines on Conducting Research with Human Participants must be shown to have been scrupulously followed. These guidelines are available at <http://www.bps.org.uk/about/rules5.cfm>. Before submitting an article to the journal, it is recommended that all authors read *Principles of Publishing* which is available on the BPS website: www.bps.org.uk/documents/principlesofpublishing.pdf

6. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

7. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.

8. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

9. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymized)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- Tables, figures, captions placed at the end of the article or attached as separate files.

Appendix 2: Confirmation of ethical approval

University Hospitals of Leicester **NHS**

NHS Trust

DIRECTORATE OF RESEARCH AND DEVELOPMENT

Director: Professor D Rowbotham
Assistant Director: John Hampton
Co-ordinator: J Horsley
Direct Dial: 0116 2588239
Fax No: 0116 2584226
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Leicester General Hospital
Gwendolen Road
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05 January 2005

Miss Claire Pollitt
Trainee Psychologist
Leicestershire Partnership NHS Trust
The University of Leicester
104, Regent Road
Leicester, LE1 7LT

Dear Miss Pollitt,

ID: 09662

The psychological and emotional impact of ICD (implantable cardiac defibrillator) implantation.

LREC Ref: 04/Q2502/89

We have now been notified by the Ethics Committee that this project has been given a favourable opinion by the Ethics Committee (please see the attached letter dated 21.12.04 from the Ethics Committee).

Since all other aspects of your UHL R+D notification are complete, I now have pleasure in confirming full approval of the project on behalf of University Hospitals of Leicester NHS Trust.

This approval means that you are fully authorised to proceed with the project, using all the resources which you have declared in your notification form.

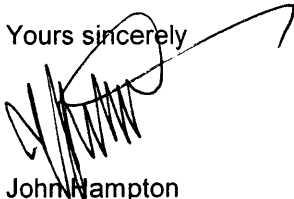
The project is also now covered by Trust Indemnity, except for those aspects already covered by external indemnity (e.g. ABPI in the case of most drug studies).

We will be requesting annual and final reports on the progress of this project, both on behalf of the Trust and on behalf of the Ethical Committee.

In the meantime, in order to keep our records up to date, could you please notify the Research Office if there are any significant changes to the start or end dates, protocol, funding or costs of the project.

I look forward to the opportunity of reading the published results of your study in due course.

Yours sincerely



John Hampton
Assistant Director for Research and Development

Appendix 3: Participant details sheet

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Appendix 3: Participant details sheet

Seen by:

Date seen:

Name of participant:

Address:

Contact number:

Ethnicity:

Gender:

Age:

Employment status:

Number of times shock therapy delivered:

Inappropriate therapy delivered?

Primary or secondary prevention?

Additional information:

Appendices

Appendix 4: Participant information sheet and consent form

Appendices

(To be on University Hospitals of Leicester NHS Trust paper)

Date: 26/11/04
Department

Version: 2

Clinical Psychology

104 Regent Road
Leicester
LE1 7LT
Tel:0116 223 1648

Patient Information Sheet

The psychological and emotional impact of ICD (implantable cardiac defibrillator) implantation.

Principal Investigator: Claire Pollitt, Trainee Psychologist

You are invited to take place in a research study. Before you decide whether you wish to take part it is important you understand why the research is being done, and what it will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is unclear to you or if you would like more information. Take time to decide whether or not you would like to take part.

What is the purpose of the study?

The study is investigating the emotional experiences of people who have had an implantable cardiac defibrillator fitted. Very little is known about what people think about their health and themselves after having the device fitted, or how this affects how they feel emotionally. It is hoped that this research will help professionals to understand the experiences of people who have had the device fitted so that they can develop supportive and more effective services.

Why have I been chosen?

You have been asked to take part as you have had an internal cardiac defibrillator fitted within the last four months. Up to ten people will be approached to discuss their experiences.

Do I have to take part?

No. It's up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form, but you are still free to withdraw your consent at any time and without giving a reason. A decision not to take part or to withdraw will not affect the standard of care you receive.

What will happen if I decide to take part?

If you decide to take part you will be asked whether having the device fitted has affected how you feel, or how see your self and your health. This will be in the form of a one off interview lasting approximately 60 minutes, which will be audio taped. The interview will take place at the University of Leicester at a time that is convenient to you. If this is unsuitable an arrangement may be made to visit you at your own home if desired. You are free to stop the interview at any point you wish.

Are there any benefits to taking part?

The interview may help you clarify for yourself what you find helpful and unhelpful in adapting to living with the device. In the long term, the study's results can help to inform the rehabilitation process following ICD implantation, and help the service to tailor their care appropriately according to the specific characteristics and needs of the individual patient.

Are there any drawbacks to taking part or study limitations?

It is possible that you may become upset or embarrassed talking about certain issues during the interview. If this happens you will be asked if you wish to change topic, take a break, or end the interview early. You may want the tape to be turned off during the interview so that you and the researcher can address how you are feeling. Travelling to the interview may be inconvenient, but any travel expenses will be reimbursed. A limitation of the current study is the small number of people

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who will be involved. This means that the results of the study cannot be said to apply to a large number of people living with an ICD. However, the aim of the study is to develop a model of how living with an ICD device affects a person's psychological well-being. It is hoped that future research will then be able to test the accuracy of this model, and test how well it applies to people living with an ICD device in general.

What will happen to the results of the study?

Each interview is transcribed, and analysed line-by-line to look for themes and patterns. These themes or categories are compared with those found in other people's interviews to discover any links, differences or commonalities. You may be asked to verify the accuracy of the transcript, and the themes discussed at a later date. The results of the study will be written up both for the purpose of doctoral research (Doctorate in Clinical Psychology, University of Leicester) and will also be submitted for publication to a national journal. The publication may include direct quotations, but your identity will be completely anonymous. You will not be identifiable from any publication, and you will be informed when the study is published. You are free to withdraw your consent to be included in the study even at this point. Presentations of the research will also be held for the cardiac rehabilitation staff working at Glenfield hospital, and for mental health professionals working in the field of physical health. Again your identity will be completely anonymous. A separate presentation of the results will be held for the people who took part in the study.

Will taking part in this study be confidential?

With your consent your general practitioner and the team involved in your follow up care at Glenfield Hospital will be told whether you are participating in the research, but no other details will be given. The researcher may wish to review any relevant sections of your medical record, but this will be treated with the strictest of confidence. The interviews will be audio taped and transcribed. Both the tapes and the transcripts will be assigned a code so that the information you have given us is anonymous. All information held on computer will be password protected, and transcripts and audiotapes will be locked in a filing cabinet to which only the researcher will have access. Transcripts will be kept for 15 years in accordance with the General Medical Council Guidelines. The University of Leicester Library will contain copies of the transcripts for six years after the completion of the study. However, open access to these will not be available in order to protect confidentiality. Recording of interviews will be stopped immediately if requested, and you have the right to request any information to be omitted from the transcription. All analysis of the data will take place by the researcher in a private room. All audiotapes of interviews will be destroyed after their content has been transcribed

What if I am harmed by the study?

If taking part in this study harms you, there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for legal action, but you may have to pay for it. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of the study the normal NHS complaints mechanism is available to you. In the event that you become distressed during the interview it will end early, and opportunity will be given for you to discuss your feelings with the interviewer informally before leaving.

Who is organising and funding the research?

The research forms part of the investigators Doctorate in Clinical Psychology. The University of Leicester and Leicestershire Partnership Trust will be funding the research costs, but the research is being conducted by the University Hospitals of Leicester NHS Trust.

Who has approved the study?

The study has been ethically approved by the Leicestershire Local Research Ethics Committee Two. An NHS Research Ethics Committee must approve all research that involves NHS patients or staff; information from NHS medical records or uses NHS premises or facilities before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision'.

What now?

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If you expressed an interest in taking part in the study to the technician who gave you this sheet, and agreed that the researcher (Claire Pollitt) could contact you by telephone to tell you more about it, you will hear from her shortly. If you did not agree for her to make contact but are now interested, you can call her on **telephone number 07773075351**

Likewise, if you have any further questions please feel free to contact the researcher on the same number. Thank you for reading this.

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(To be on University Hospitals of Leicester NHS Trust headed paper)

Version: 1

Date: 14/09/04

104 Regent Road
Leicester
LE1 7LT
Tel:0116 223 1648

Consent Form

Title of Project: The psychological and emotional impact of ICD (implantable cardiac defibrillator) implantation.

Name of Researcher: Claire Pollitt

Please Initial Box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions
2. I understand that my participation is voluntary, and that I am free to withdraw at any time, without giving reason.
3. I understand that the researcher may look at sections of my medical notes where it is relevant to my taking part in this research. I give permission for her to have access to my records
4. I understand that psychological research is covered for mishaps in the same way as for patients undergoing treatment within the NHS, i.e. compensation is only available if negligence occurs.
5. I agree to take part in the above study.

☐☐☐☐☐

.....
Name of Patient

.....
Date

.....
Signature

.....
Name of Researcher

.....
Date

.....
Signature

1 for patient, 1 for researcher, 1 to be kept with hospital file

Appendix 5: Initial and final interview guides

Initial Interview Schedule

The psychological and emotional impact of ICD (implantable cardiac defibrillator)
implantation.

Participants details

Age

Sex

Employment status

Driving status

Concurrent health problems

Family situation

Prior to device Implantation

- How did you first become aware that there was a problem with your heart?
- How did this affect your attitude to life?
- What did you think about having the device fitted?
- How necessary did you think it was?

The shock experience

- Have you experienced shock therapy from your device?
- What do you think this experience might be like? (Prompt for feelings)
- Were you aware it was happening? (prompt for thoughts, feelings)
- How did it compare with what you thought it would be like?

Please bear shock in mind, i.e. answers may have been different before and after having experienced a shock

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View of health

- How did you see your health before having the device fitted? And now?
- Has having the device fitted made a difference to how healthy you feel you are?
- How necessary do you feel the device is to your physical well-being?

Activities and routines

- Has having the device fitted affected what you feel able to do?
- Prompt: physically, socially, career wise, in your relationships?
- Why has it affected these activities (health/social concerns)?
 - How important were these activities?
 - What impact has this had on how you see your self?(Prompt: Are changes valued and why)
 - Your health?
 - Your mood?

Relationships

- Do you think having the device fitted has changed the way people treat you?
- Do you think it has changed the way other people see you? (Over protectiveness, expectations)
- What impact has this had on how you see your self? (Prompt: Are changes valued and why)
 - Your health?
 - Your mood?
 - Has it affected your relationships? (Prompts: friends, colleagues, family roles)
 - How difficult has this been and why?

Self Concept

- In what ways, if any do you think you have changed as a person since having the device fitted?
- (Prompt: Are changes valued and why, subsequent feelings?)

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General

- How has having the device affected your attitude to life?
- How have your hopes for the future altered since having the device fitted?
- What has helped in learning to live with the device?
- What have been the costs of having the device?
- What have been the benefits?
- Given your experiences what suggestions would you offer staff on how to improve their service?
- Is there anything important that you think I haven't asked you about?

Debrief

Note to self: be aware that all of the above will have had a time course over the four months

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Final interview schedule

The psychological and emotional impact of ICD (implantable cardiac defibrillator)
implantation.

Participants details

Age

Sex

Employment status

Driving status

Concurrent health problems

Family situation

Prior to device implantation

- How did you first become aware that there was a problem with your heart?
- How did this affect your attitude to life?
- What did you think about having the device fitted?
- How necessary did you think it was?

The shock experience

- Have you experienced shock therapy from your device?
- What are your thoughts about the device possibly firing?
- How much confidence do you have in the device- why?
- Were you aware that therapy was being delivered? Were there any warnings?
- How did it compare with what you thought it would be like?

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-What do you think the role of other people might be if you had a shock- how important would this be?

Pacing

-Have you experienced pacing from the device?

-What was this like?

-What did you think about it?

View of health

-How did you see your health before having the device fitted? And now?

(Link to mood)

-How necessary do you feel the device is to your physical well-being?

- How do you think you'd see your health if you had a shock from the device?

-How much did you used to think about your health – and now?

-At what point did you start to think about your health more?

-How much trust do you have in your body to let you know when there is something wrong?

-What do you think is more effective in knowing how healthy you are- how you feel physically yourself or what medical people tell you- why?

-What happens when these two sources of information about your body don't match?

-Do you think your body has told you in the past when you've not been well? How has this affected how much you trust it as a source of information?

- Has this affected how much attention you pay to bodily symptoms- why?

-How much attention do you pay to bodily symptoms and why?

- What role do you think exercise has in the likelihood of device-fire?

- Has the device affected what you thought you'd be doing in your life at this stage- how?

- How consistent do you feel your ability level is with your age- what affect does this have?

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Activities and routines

-Has having the device fitted affected what you feel able to do?

Prompt: physically, socially, career wise, in your relationships?

-Why has it affected these activities (health/social concerns)?

-How important were these activities?

- Have you taken up any new activities?

-What impact has this had on how you see your self? (Prompt: Are changes valued and why)

Your health?

Your mood?

-Has what you feel able to do affected how you see your health- in what ways?

Relationships

-Has having the device fitted affected what others feel you are able to do-why?

-What impact has this had?

-Do you think having the device fitted has changed the way people treat you?

-Do you think it has changed the way other people see you? (Over protectiveness, expectations)

-What impact has this had on how you see your self (Prompt: Are changes valued and why?)?

Your health

Your mood

-Has it affected your relationships? (Prompts: friends, colleagues, family roles)

-Has it affected roles within the family?

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-How difficult has this been and why?

Self Concept

-What affect if any has the device had on your priorities and values in life?

-In what ways, if any do you think you have changed as a person since having the device fitted?

(Prompt: Are changes valued and why, subsequent feelings)

-Have these changes affected how you compare yourself to others?

Control/ Self-efficacy

-Have these changes in how you see yourself affected how able you feel you are to cope with life? (generally and in relation to the device firing) Why?

-How much control do you feel you have over your heart condition? And the device firing?

-How does this make you feel?

-In what ways have you control over it?

-How confident are you in your ability to cope with the device firing- why?

-Has your mood been affected by having the device fitted- why?

General

-How satisfied are you with the care that you received? (E.g. in hospital)

-Has this affected how much confidence you have in the device- why?

-How have your hopes for the future altered since having the device fitted?

-How has having the device affected your attitude to life?

-Given your experiences what suggestions would you offer staff on how to improve their service?

- Is there anything important that you think I haven't asked you about?

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- What has helped in learning to live with the device?
- What have been the costs of having the device?
- What have been the benefits?

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Appendix 6:Transcribing guidelines

Appendix 6: Transcribing guidelines

Verbatim transcribing

The interview is transcribed verbatim. Every word spoken by both interviewer and participant must be transcribed exactly, as are stammers (*pri-*, *prison*), indications of assent or dissent (*mmm-hm*, *prison*) and place-holders (*he came from erm*, *erm*, *prison*). Words spoken with emphasis should be underlined and non-speech sounds, e.g. laughing or crying, should be indicated.

Names/identifying features

All names and places are first transcribed into the record as spoken. Following transcription of the complete interview, each name and place should be anonymised in the form Nurse 1, Nurse 2 etc.

Distinguishing speakers

The interviewer's speech should be typed in capitals. Each major speaking turn by each speaker is assigned its own paragraph. There is no need to put 'I' for Interviewer or 'R' for respondent, as the different type distinguishes speakers.

Very brief remarks or sounds by the other speaker during a main speaking turn should be inserted in square brackets and in the appropriate lower or uppercase type.

E.g. **AND HOW DID YOU FIRST FIND OUT THERE WAS A PROBLEM WITH
YOUR HEART?**

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P1 I went for err, a test one day with Dr 1 [RIGHT] and I got on the treadmill and I sort of faded out [RIGHT, RIGHT] and then from there on it went on and I finished up at Hospital 1.

Interruptions

Where one speaker interrupts the other, this should be indicated with a forward slash for each speaker, e.g.

RIGHT. I WAS WONDERING IF//I was at Hospital 2 two, three weeks before I went to Hospital 1

Transcriber notes

Where the transcriber makes a note in the text, this should be in italics e.g. (*can't hear*).

Indistinct parts of the tape

If the transcriber cannot hear several words, the duration should be indicated, e.g. (*can't hear for 9 secs*). If the transcriber is not sure which of two alternatives is correct, these both possibilities should be indicated in brackets

Speech errors and omissions

Any mis-speaking should be accurately transcribed. Dropped words should not be put in, and mis-spoken words should not be corrected.

If a speech error is particularly difficult to understand, the transcriber can step into the text with (*sic*) to indicate the words really were spoken as transcribed.

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Punctuation

Commas and full stops need to reflect the actual rhythm of the speech. Sentences that do run on and on should not be ‘artificially’ punctuated to make them easier to read.

Pauses and interruptions

Suggested notation as follows:

(.) pause

(2) two second pause

Line numbering

Continuous line numbers should be inserted into the whole transcript.

Appendix 7: Example of line- by- line and focused coding

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Open codes	Transcript	Focused Codes
-Waste of medical time - Belief in recovery - No palpitations -Heart in dangerous state -Lack of information -Heck of a bang and unexpected	<p>P5: So I wrote a letter and I took it back and I said I was sorry to waste their time, the palpitations hadn't occurred and I was going on excellent./ No, no problems at all. And I thought that will be it, I shan't need anything now. Instead of that I got a letter from them bringing my out patient appointment forward four months which I still thought they were going to discharge me/ But when I turned up there, the same doctor, Dr 2, takes me in and says ummm. Yeah, I said I was sorry about the ECG test you did on me sir, I said unfortunately no palpitations I said not only did they not occur that weekend; I said I've only had them about twice since. I said, so I'm just sorry I wasted/ ... He said you didn't waste his time, your hearts in ahh, well, fairly dangerous state/ He said I'm going to have to have you in and fit one of these ICD and as I say I've never heard of one.</p> <p>P4: <u>It's a heck of a bang you know</u> when they go Well I wasn't expecting it you see/ I didn't take no notice, I went downstairs and thought well at least its doing its</p>	<p>Difference in expert and bodily information</p>

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- At least it's working - Shock linked to activity	<p>job. Said to the wife says, must be working./</p> <p>Afterwards I thought all I'd done was walk upstairs so it shouldn't have (.) you know, gone as easy as that.</p> <p>You know what kind of procedure is that? I mean I walk all round the village and everything I keep getting a bit of exercise.</p>	Shock linked to physical activity
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Appendix 8: Ensuring quality research

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- 1) Trustworthiness: The constant comparative approach and comprehensive treatment of the raw data ensured that analysis remained close to the meaning of the text (Silverman, 2000) Theoretical sampling also ensured that the developing theory was comprehensive (Lincoln & Guba, 1985), and accounted for different experiences of ICD recipients. Reflexive procedures such as ‘owning one’s perspective’ through a reflective diary (Elliot, Fischer & Rennie ,1999) and attending a qualitative research group for triangulation purposes also improved the quality of the study. Such peer debriefing may be viewed as consensus validity (Stiles, 1993), which taking a more realist stance, relies on agreement of a reality of a situation. Reflexive procedures and triangulation help to determine how the researcher’s values and assumptions may be influencing what was being represented.
- 2) Confirmability: Analytic claims were transparent and supported by examples so that the reader can examine the fit between the data and the researchers understanding of it (Lincoln and Guba, 1985).
- 3) Coherence: Integration was achieved through the use of figures depicting the hierarchical relationships between core categories, main categories and subcategories (Elliot, Fischer & Rennie ,1999).
- 4) Replicability: Within a critical realist stance reliability stands as a measure of quality. There is some evidence that qualitative studies are somewhat replicable in their results and that different accounts are often compatible, resulting from a difference in emphasis rather than findings. (Helstone, Van Zuuren & Houtkooper ,1999). To ensure that the

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study could be replicated the procedure has been stated and the sample has been clearly situated (See Table 3.2).

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Appendix 9: Example from reflective diary

Appendix 9: Extracts from the reflective diary

15th January 2005

Feels difficult to keep schedule fairly succinct as so many different avenues of questioning depending on how the individual responds to the last question. I can't write them all down as questions. I perhaps need to trust the ability to go with the flow more within the interviews, as possible ways of answering any given question are endless! Perhaps my need to have questions leading on from one another to such an extent is also telling me something about my preconceptions and I should avoid trying to 'predict' answers.

18th March 2005

I feel that self -presentation issues were operating in this interview. For example, I feel they are apparent in relation to his references about having 'lady-friends' my age. How has this affected the account he's given? How do these self -presentation issues relate to how his self-concept may have been affected by his health problems and device implantation? Are they protective?

28th March 2005

I have spent the weekend open coding. Difficult to know how close to the text to stay in coding or whether some codes can be more abstract. Also, some bits of text take on new meaning when they are seen in the context of the whole conversation and participant presentation within the interview.

Appendix 10: Record showing saturation process

Appendix 10: Record showing saturation process

Illustrated below in Box 8 is the study's progression toward theoretical saturation.

Categories, subcategories and focused codes indicating key category properties are shown.

Box 8: Record showing development towards saturation.

Transcript 1:

- Expert information (Subcategory of category 'health appraisal')
- Bodily feedback (Subcategory of category 'health appraisal')
- Negotiating ability with others
(Focused code: property of subcategory 'increasing activity whilst restricting it')
- Consistency if ability level with life stage
(Focused code: property of subcategory 'increasing activity whilst restricting it')
- Uncertainty in understanding expert information
(Focused code: property of category 'health appraisal').

Transcript 2

- Physical activity linked to device-fire
(Focused code: property of subcategory 'increasing activity whilst restricting it')
- Likelihood of device-fire (Subcategory of category 'security versus threat').
- Ability to cope with the device shock
(Subcategory of category 'security versus threat').
- Confidence in the device (Subcategory of category 'security versus threat').
- Successful history of pacing and device shocks leads to more confidence
(Focused code: property of subcategory 'confidence in the device')

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- Restricting activity (Category 'increasing activity whilst restricting it')
- Enabling activity (Category 'increasing activity whilst restricting it')
- Surviving death (Subcategory of category 'second chance versus limited life')
- Greater importance of monitoring with health uncertainty
(Focused code: property of category 'health appraisal').
- Uncertainty in bodily feedback (Property of category 'health appraisal').
- Physical symptoms indicate health (Property of category 'health appraisal').

Transcript 3

- Life expectancy (Subcategory of category 'second chance versus limited life')
- Bodily feedback privileged (Focused code: property of category 'health appraisal')
- Confidence and self-agency
(Focused code: property of subcategory 'enabling activity')
- Projection of self into future
(Focused code: property of category 'second chance versus limited life')
- Improvement in physical symptoms related to more confidence in the device
(Focused code: property of subcategory 'confidence in the device')
- Device-fire indicates ill health
(Focused code: property of subcategory 'bodily feedback in health appraisal')
- Reversal of time
(Focused code: property of category 'second chance versus limited chance')
- Physical activity levels indicate health
(Focused code: property of subcategory 'bodily feedback in health appraisal')

Transcript 4

- More attention to bodily sensations with threat appraisal.

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(Focused code in category 'security versus threat')

Transcript 5

-No new categories

Transcript 6

-No new categories

Transcript 7

-Pacing reduces ambiguity in bodily feedback (focused code)

(Focused code in category 'health appraisal')