

**CARDIAC PACEMAKERS IN PAEDIATRIC PATIENTS: A QUALITATIVE STUDY OF PATIENT  
AND PARENTAL EXPERIENCE**

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## ABSTRACT

The aim of the study was to explore the experience of having a pacemaker as a child or young person and the experience of their parent in caring for them. Due to lack of research, very little is known about the impact that having a pacemaker has on children and their parents. However, evidence from the adult literature and clinicians' observations revealed that problems with adjustment can occur. Clinicians have also noted interesting differences in adjustment between families, with some coping well and others experiencing more difficulty. Both children and parents were interviewed because of the importance of systemic influences on children. Also, the literature suggests generational transmission of anxieties and coping styles between parents and children often takes place.

Given the exploratory nature of the study, a qualitative methodology was employed. Eight participants were interviewed (four parent-child dyads). All the child participants were aged between 11 and 16 years and had been fitted with a pacemaker. Data were subjected to Interpretative Phenomenological Analysis. The child and parent group data were analysed separately. Three main themes emerged from the child group analysis: *identity, coping with having a pacemaker and medicalisation of life*. Five main themes emerged from the parent group analysis: *guilt, adjustment as a process over time, coping with having a child with a pacemaker, the battle for control and my perception of my child*. Each of the main themes consisted of several subthemes further illustrating the complexity of the participants' experience. Overall it appeared that despite feelings of threat and anxiety at times, participants used a variety of coping methods to help them adjust to the presence of the pacemaker in their lives. The findings are discussed within the wider literature and clinical implications highlighted.

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## **INTRODUCTION**

### **Children with Chronic Illness**

It is estimated that chronic illness affects 10-20% of children (Aron, Loprest & Steuerie, 1996). A chronic illness is one that is long lasting and incurable or extremely resistant to treatment. It also usually requires regular trips to hospital and often gives rise to unpleasant symptoms that disrupt daily life (Eiser, 1990). Examples of chronic illness in children include asthma, diabetes, cystic fibrosis, renal disease and congenital heart disease. There has been a great deal of research into the impact of chronic illness on children and families (for a review see Knafel & Gillis, 2002). This has revealed that having a child with a chronic illness places many additional stressors on the child and the family as a whole. In particular parents experience significant additional practical and emotional demands (see Boekaerts, & Röder, 1999). Stressors of childhood illness include the period awaiting diagnosis and the shock of diagnosis itself. These are then followed by emotional and practical stressors such as anxiety about the child's health, disruption of daily life by numerous hospital visits and admissions, and ultimately, the challenge of adjusting to life-long health problems (Eiser, 1990; Cherry, 1989).

### ***Chronic Illness as a Risk Factor***

Large-scale epidemiological studies have shown that children with chronic conditions are at a greater risk of psychosocial adjustment problems than their 'healthy' peers (Rutter, Graham & Yule, 1970; Cadman, Boyle, Szatmari & Offord, 1987). Studies have found a higher instance of behaviour problems in children with a chronic illness compared with control groups of 'healthy' peers (Hamlett, Pellegrini & Katz, 1992; Gortmaker, Walker, Weitzman & Sobol, 1990) and normative samples (Furrow, Hambley & Brazil, 1989; Wallander et al., 1989). Increased levels of behaviour problems were also associated with higher levels of depression, anxiety, somatic problems and social withdrawal (Furrow et al., 1989; Wallander et al., 1989; Hamlett et al., 1992).

MacLean, Perrin, Gortmaker and Pierre (1992) found a significant number of the children they studied had emotional problems placing them in the clinical range on the

Child behaviour Checklist (CBCL; Achenbach, 1988). According to Pless (1984), this is twice the rate found in the general child population. One study on children with cystic fibrosis found that 58% of the children met the criteria for a major diagnosis of a psychological problem (Thompson, Hodges & Hamlett, 1990); 37% of the children were diagnosed with an anxiety disorder, 23% with oppositional disorder, 14% with enuresis, 12% with conduct disorder and 2% with depression.

Research has also revealed a higher rate of school non-attendance in children with chronic illness (Fowler, Johnson & Atkinson, 1985). However studies have so far failed to find evidence that this has a negative effect on school performance (Cadman et al., 1987; MacLean et al., 1992). Despite this, school non-attendance may have social implications with regard to disruption of peer relationships. So far research on the effect of chronic illness on social functioning and peer relationships is inconclusive. Miller & Wood (1991) proposed that these children are at risk of social isolation due to feeling different from their peers and their peers having misconceptions about their disease or condition. However a study by Spirito, DeLawyer & Stark (1991) found no differences in peer relationships between groups of chronically ill children and groups of 'healthy' children.

As mentioned previously, when a child has a chronic condition parents experience additional demands to those imposed by everyday life (Boekaerts, & Röder, 1999). Parenting these children can be both highly demanding and highly stressful (Austin, 1991). Hughes & Lieberman (1990) found that as many as 33% of parents of children with cancer (even those in remission) experienced such high levels of depression and anxiety that they required professional input. A meta-analysis of fifteen studies investigating parental adjustment to having a child with Spina Bifida found that parents experienced a higher level of psychological distress than controls (Vermaes, Janssens, Bosman & Geris, 2005). Relationship problems in parents are also common, leading to marital problems and even divorce (Sabbeth & Leventhal, 1984).

Examination of the literature on childhood chronic illness reveals its problem-saturated nature. A great deal of previous research into child health and illness has been based on a deficit model, focussing on risk, stress and negative psychological outcomes. However, research has shown that some children and parents adjust well, showing resilience in the face of the stressors of chronic illness (Midence, 1994; Stawski, Auerbach, Barasch, Lerner, 1995). Not all children and parents require professional help to support

them in dealing with the difficulties posed by chronic illness. Therefore although chronic illness is a significant risk factor for children and their parents, poor psychosocial outcome is not inevitable. There is a great deal of individual variation in adjustment (Kliewer, 1997). In light of this, it may be helpful clinically to examine what mediates this variability in adjustment. How do many children and parents manage to cope and adapt to their situation?

## **Adaptation to Chronic Illness**

### ***Models of Stress and Coping***

Chronic illness can be understood as a stressor for both children and their parents. In their seminal work on stress and coping, Lazarus and Folkman (1984, p. 19) defined stress as “a particular relationship between the person and the environment that is appraised by the person as being taxing or exceeding his or her resources and endangering his or her wellbeing”. The way people adjust to stress depends on the way they cognitively appraise potentially stressful events and situations, the way they appraise their own ability to cope and the coping strategies they ultimately use to manage. Different people may appraise the same situation differently in terms of whether it is a threat or not. In addition, people differ in their appraisals of their own ability to cope (Lazarus & Folkman, 1984).

An extensive literature has been established on coping. One of the most influential contributors to this field has been Lazarus, who defined coping as, “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman, 1984, p. 141). In other words coping is the process of managing stress and adapting to stressful circumstances through reducing these stressors and managing the resulting distressing emotions.

Coping is a dynamic process, requiring the use of flexible strategies that are attuned to the environment and the situation the person finds himself or herself in. Coping strategies are influenced by the nature of the stressor (for example its severity and duration). The ultimate goal of coping (whether or not this is achieved) is reducing distress and increasing psychological wellbeing. Many different types of coping have been identified in the literature. In their early work, Lazarus and Folkman (1984) divided coping

strategies into two broad categories: problem-focused and emotion-focused. Problem-focused strategies were those aiming to change the external circumstances, targeting the root of the distress and attempting to eliminate the stressor (e.g. problem-solving and planning). Emotion-focused strategies aim to manage the emotional response to a stressor if appraisal has led to the conclusion that nothing can be done to change the external circumstances (e.g. positive re-appraisal, acceptance, denial, avoidance, distraction). The trend of dichotomising coping strategies has continued in the literature. As well as problem-focused and emotion-focused strategies, other authors have differentiated between approach and avoidance-based strategies (Roth & Cohen, 1986) and between behavioural and cognitive coping strategies (Moos & Billings, 1982). Many other ways of categorising coping strategies have emerged in the literature and discussion of them all is beyond the scope of this literature review (see Martz & Livneh, 2007 for a comprehensive summary).

A great deal of research has been carried out in an attempt to establish which coping strategies are the most adaptive. However, little consensus on this topic has been reached. It would appear that adaptive coping strategies depend entirely on the situation and the nature of the stressor. What may be adaptive in one context may be inappropriate or ineffectual in another. Therefore what enables people to cope most adaptively is to have many different coping strategies at their disposal and to be flexible about which they apply and when, depending on their appraisal of the situation.

### ***Adjustment of Children to Chronic Illness***

Two related models (Thompson, 1985; Wallander et al., 1989) propose that child adjustment is determined by disease factors, family functioning, intrapersonal factors (e.g. the child's locus of control, temperament, or competence) and the child's coping strategies. In addition children must be considered as part of the family system. There is robust evidence for the influence of family functioning on adjustment of chronically ill children. Moos & Moos (1981) identified various dimensions of family functioning including cohesion, independence, expressiveness, organisation, and control. Many studies have investigated cohesion in particular. In his review of studies investigating the influence of family functioning on child adjustment, Drotar (1997) found supportive family relationships

(defined by high levels of cohesion) predicted fewer behavioural problems and better psychological functioning, including higher self-esteem. Poorer family functioning (defined by increased conflict) predicted poorer psychosocial adjustment and higher instances of behavioural problems. Burlew, Telfair, Colagelo & Wright (2000) found higher levels of family cohesion and expression led to fewer emotional problems in children with sickle cell disease. Finally, Wallander et al., (1989) found family cohesion had a significant effect on the child's social functioning.

### *Role of Parents in Child Adjustment*

Parents play a critical role in child adjustment (Williams, Holmbeck & Greenly, 2002). Studies have shown maternal adjustment predicts child adjustment; mothers who are poorly adjusted and showing high levels of distress tend to have children who are poorly adjusted (Drotar, 1997). Another predictor of child adjustment is level of parental stress; lower levels of parental stress are associated with better adjustment in children with congenital heart disease (O'Dougherty, Wright, Garnezy & Loewenson, 1993). Finally maternal perception of the severity of the child's illness is also a significant predictor of child adjustment. In their study of congenital heart disease, DeMaso, et al. (1991) found that maternal perception of the severity of the heart defect explained the majority of variance in child adjustment, with actual severity (as rated by their doctor) predicting very little.

Kliewer, Sandler & Wolchick (1994) hypothesised that parents influence their child's adaptation to illness by shaping the way their children appraise threat and the coping strategies they use. They do this by coaching the child to display certain emotional responses and use particular coping strategies in response to specific situations. In addition parents model their own coping styles and emotional responses to stress. Finally parents shape the home environment into one that either invites open communication and cohesion, or one that does not. This theory has not been tested empirically, however some support comes from a study by Bush, Melamed, Sheras & Greenbaum (1986). They observed mothers and children immediately before a paediatric clinic appointment and found that the children of mothers who were highly emotional, agitated or who ignored

their child, were more distressed. They also noticed the children of mothers who employed coping strategies such as distracting the child, were less distressed.

As well as having an important influence on their emotional reactions (Eiser, 1990), parents can also affect their child's adjustment by influencing their knowledge and understanding of their illness. Studies of children with congenital heart disease have shown the child's understanding of their heart defect is closely linked to their parents' understanding (Beerli, Haramati, Rein & Neer, 2001); if parents have good understanding and knowledge, then their children also tend to. Research in congenital heart disease has shown children and families with better knowledge and understanding of the condition demonstrate better psychosocial adjustment. They report higher satisfaction with services, display better compliance and have an improved emotional state, experiencing less distress (see McGrath & Kolwaite, 2006).

### **Cardiac Disease in Children**

Cardiac disease in children encompasses congenital heart disease, acquired heart disease and cardiac arrhythmias. Congenital heart disease describes a group of disorders caused by a combination of environmental and genetic factors leading to structural defects of the heart or coronary blood vessels during foetal development. The incidence of congenital heart disease is approximately 8 in 1,000 live births (Delamater, 2003). Acquired heart disease also includes a variety of disorders, but these generally result from viral or bacterial infections that damage the heart. Children with no previous illness may acquire such disease but it is thought children with congenital heart disease may be more susceptible (Delamater, 2003). Finally, cardiac arrhythmia is a disturbance in the heart's rhythm due to abnormal electrical activity. There are many different types of arrhythmias, some of which cause the heart to beat too quickly and some of which cause it to beat too slowly. Arrhythmias can occur spontaneously as a result of both congenital and acquired heart disease, but are particularly common in children with congenital heart disease. They can also occur as a result of damage caused to the heart's conduction system during corrective cardiac surgery. A detailed account of the many different types and causes of arrhythmia is beyond the scope of this literature review (see Wren & Campbell, 1996 for a full summary). Severe and untreated arrhythmia can lead to sudden death. Treatment

options include medication to control the heart rate and surgical intervention. If these treatments are inappropriate or unsuccessful in correcting the arrhythmia then the child may have a pacemaker implanted.

### ***Pacemaker Implantation in Children***

The number of children fitted with a permanent pacemaker is increasing due to advances in technology that allow improved diagnosis of arrhythmias. Also, although better results of surgical repair of congenital heart disease have meant increased survival rates, they have also meant more children emerge from surgery with damage to their heart's conduction system caused during the procedure (Delamater, 2003; Silvetti, et al., 2006). In 2007 in the United Kingdom, 196 new pacemaker implantations were carried out in children and young people aged 0-19 (European Heart Rhythm Association, 2007). A pacemaker consists of a unit containing a battery and circuitry, which creates electrical impulses that regulate the heartbeat. These impulses are transmitted to the heart from this unit by electrode leads. Implantation of a pacemaker is carried out under general anaesthetic and requires a hospital stay of only one or two days. In most children, as with adults, the unit is implanted under the skin in the chest, just below the clavicle. The leads are then passed through the child's veins directly into the heart. However, in infants or very young children, the unit must be implanted in the abdomen and the leads stitched directly onto the outside of the heart.

Throughout his or her lifetime a child with a pacemaker can expect to face multiple surgical procedures; the younger a child is when his or her pacemaker is first fitted, the more surgery he or she will have to undergo. After initial implantation subsequent procedures must be undertaken to replace units (where the batteries are housed) and, less frequently, the electrode leads. The battery life of a pacemaker varies, depending on its size and the amount of pacing it is carrying out for the heart. Some patients require their pacemaker to work constantly to regulate their heartbeat, whereas others are only required to work intermittently, as the heart's own natural pacing system works some of the time. An average estimate of battery life is around five years, with smaller pacemaker units designed for infants lasting less long. Although these surgical procedures are often relatively straightforward, there are risks associated with them. These include post-



operative infection, which occurs in 3-5% of children (Cohen, et al., 2002); vascular haemorrhage and the risks associated with a general anaesthetic. Replacing leads carries a particularly high risk, especially that of vascular haemorrhage. Aside from surgical risks there is also a small risk that leads may fracture or move position, preventing the pacing impulses from reaching the heart. Finally there is also the risk of the pacemaker unit failing, which although rare, is possible. In addition to surgical procedures, children and their parents must also attend regular outpatient appointments to enable monitoring of their pacemaker function.

### ***Psychosocial Impact of Pacemaker Implantation in Children***

Little is known about the psychosocial impact of pacemaker implantation in children. Only three studies investigating this area could be identified (Galdston & Gamble, 1969; Alpern, Uzark & Dick, 1989; Andersen, Horder, Kristensen & Mickley, 1994). In their anecdotal study Galdston and Gamble (1969) studied sixteen children with implanted pacemakers and their parents. They hypothesised that the threat to life posed by cardiac arrhythmia would generate sufficient anxiety to cause a high incidence of psychological dysfunction in both the children and their parents, and some degree of developmental regression in the children. The methods of investigation employed were direct observations and unstructured interviews with both the children and their parents, carried out by a psychiatrist. The study focussed on behaviour, mood, appetite, interest and ways of contending with the stress of having a pacemaker. The author described the style of this interviews thus; “no effort was made to conduct interviews in depth or to search for fantasy material other than that presented in the course of the unstructured, sympathetic interviews”.

The authors concluded that both the children and their parents showed little evidence of reduced psychological functioning. They defined this as lack of any evidence of hyperactivity, tics, enuresis, encopresis, nail biting, antisocial behaviour, conversion disorder, sleep disorders or appetite problems in the children. Among parents, the authors concluded that the lack of any ‘gross depression, ‘paranoid reaction’, ‘break down in family operation’, ‘alcoholism’ or ‘other failure in maintenance of ego function’ meant that all the parents were functioning well psychologically.

Galdston and Gamble then went on to attempt to explain the process by which children and parents achieved this good psychological functioning despite the stresses they were under. The authors described the children using humour as a way of managing stress; they gave themselves nicknames inspired by the pacemaker. They also concluded that the parents relied on gaining good knowledge of cardiac and pacemaker function to help them manage the situation. In addition, they reported parents' denial of the emotions associated with the situation. Galdston and Gamble were of the opinion that parents coped by holding these emotions at bay indefinitely to allow them to cope with "the demands of the immediate adversity".

It should be noted that this paper is describing devices based on much less sophisticated technology than the present day, which may limit the relevance of some of its findings. When this paper was written the rate of pacemaker failures and other complications was much higher. In addition, despite being much bigger, the battery life was shorter than it is now. Therefore surgical procedures were required more often. Moreover this study is methodologically flawed to some extent. It does not appear to be informed by any specific theoretical framework. No information was given on how data were analysed and no justification was given about the specific markers of psychological functioning used, which appeared to be based on subjective individual clinical opinion. From the authors' description of the interview process it is also difficult to know whether the psychiatrist asked directly about these markers or whether he assumed their absence if participants did not volunteer the information themselves.

The second study uncovered was a poorly designed Danish study investigating the psychological wellbeing and body image of fifteen people who had pacemakers implanted as children (Andersen et al., 1994). It employed methods including the Draw a Person Test (Koppitz, 1968), the Rorschach test and a semi-structured interview carried out by a psychiatrist. One of the methodological limitations of the study is that although all the participants had pacemakers implanted when they were children (age of implantation ranged from 6 months to 18 years of age), the investigation into adjustment was carried out some time later when some had reached adulthood (age range 3-34).

The study concluded from the drawings made by the participants that having a pacemaker "severely disturbed" their body image. Unfortunately the study contained no details as to how this interpretation was done, or by whom. The authors used these

interpretations to conclude that pacemaker implantation affected the development of the individual's identity and caused them to feel different to others. All participants were considered to show emotional problems in terms of anxiety, while eight of the fifteen participants were considered to have an unspecified "psychiatric illness". The researchers did concede, however, that this could be due to social class and lifestyle variables, which were not controlled for. Despite the obvious limitations of the study it does appear to indicate the possibility of disruption of body image and psychological well being in some children fitted with pacemakers, although no firm conclusions can be drawn.

In a well-controlled study, Alpern et al. (1989) examined the psychosocial adjustment post pacemaker implantation of 30 children and young people aged 7-19 years. They employed two comparison groups, one of children with similar congenital heart disease but no pacemaker, and one of children with no health problems. They made comparisons between the groups on standard personality measures and responses to a semi-structured interview. The interview used a displacement technique aimed at ascertaining participants' ideas of what life for someone with a pacemaker would be like in terms of social relationships, physical activities and anxieties or concerns. The purpose of this was to elucidate concerns of pacemaker patients with regard to the device and gain an idea of the perceptions of their peers (both healthy and those with congenital heart disease) as to what life would be like with a pacemaker.

The researchers found no significant differences in standardised measures of trait anxiety, self-competence or self-esteem between the groups. However they did find that pacemaker patients were significantly more external in their locus of control than those in the control groups. They perceived that they had less personal control over their lives than other children with congenital heart disease (but no pacemaker) and children with no health problems. It should be noted, however, that with such a small sample the statistical power of this study is very limited.

The semi-structured interviews identified several potential fears or worries including pacemaker malfunction, pacemaker trauma (physical trauma or exposure to electrical fields), compromised future health and well being, pacemaker replacement, dying and social rejection. However when the groups were compared, the researchers found that pacemaker patients were actually less likely to express such concerns than the control groups. The most common fears expressed by the pacemaker group were of

pacemaker malfunction and social rejection, but to a lesser extent than predicted by the other children in both control groups. None of the participants with pacemakers expressed a fear of dying, despite 23% of their peers with congenital heart disease and 60% of their healthy peers predicting that they would have such fears. Using their clinical judgement and experience of working with pacemaker patients, the authors hypothesised that low reporting of fears of dying resulted from denial of such fears rather than their absence. Finally, the interviews revealed that the pacemaker group perceived themselves to be similar to their peers. However it emerged that their peers (both those with congenital heart disease and those with no health problems) perceived those with pacemakers as physically and emotionally different.

Overall, the authors concluded that the children they examined showed good psychosocial adjustment to pacemaker implantation. Results from both the standardised measures and semi-structured interviews showed that they suffered from minimal anxiety and were able to maintain a positive self-image. The authors also concluded from the pacemaker group's good knowledge of their condition and their denial of fears of death that they were using coping styles involving intellectualisation and denial. The authors saw this as adaptive in helping them to get on with tasks of daily living. Despite concluding good psychosocial adjustment, the authors hypothesised that the pacemaker group's reduced perception of personal control may have a negative effect on their ability to develop autonomy and separation in the transition to young adulthood. Finally, the authors felt there was the potential for them to experience social isolation and peer rejection due to the differences perceived by their peers.

In summary, there is very little literature on the impact of pacemaker implantation on children and their parents and some of this is methodologically flawed. What little research there is demonstrates contradictory findings. Some studies suggest children and parents adjust well to the presence of the pacemaker, whereas others suggest pacemaker implantation leads to poor psychological well-being and body image disturbance. The studies agree on the fact that both children and parents find denial is an effective coping strategy. In light of the paucity of research, it may be helpful to look at the literature examining the effect impact of pacemaker implantation in adults. It is reasonable to assume that there may be some overlap in their experiences, despite the developmental differences. It may also be appropriate to examine the literature on children with

congenital heart disease. Many children who have pacemakers also have a diagnosis of congenital heart disease, although the population of children with pacemakers is much smaller than that of children diagnosed with congenital heart disease. As mentioned previously, pacemaker implantation is often the result of either congenital heart block (a congenital problem with electrical conduction in the heart) or damage to the electrical conduction system caused by corrective surgery to repair structural defects caused by congenital heart disease. Although the present study is interested specifically in the experiences of having a pacemaker, issues arising in the general literature on congenital heart disease may throw light on the experiences of those who go on to have pacemakers inserted.

### **Psychosocial Impact of Pacemaker Implantation in Adults**

The literature in this field is not extensive, however many more studies have been carried out with adults than with children. Hesse (1975) found that although the majority of adult patients adjusted well after pacemaker implantation and had no significant psychological symptoms, a significant number did find adjustment difficult. Other studies have described patients with symptoms of anxiety, depression and hypochondria (Krylov, 1990; Duru et al., 2001). Ayemir et al. (1997) found pacemaker patients were more depressed in mood, more anxious and had more somatic concerns than the general population. In addition Goldman, Noble & MacGregor (1972) described the phenomenon of “pacemaker panic”, where patients felt as though their bodies were deteriorating and were worried about depending on a mechanical device for support. In a French study Dodinot (1990) also found patients were anxious about pacemaker malfunction. Thus anxiety and difficulty with adjustment as a consequence of feeling dependent on a potentially fallible technological device to stay alive, were recurrent themes in many of the studies examined.

In contrast to this, studies examining health related quality of life generally demonstrated a positive improvement for most patients (Lamas et al., 1998; Catipovic-Veselica et al., 1990). However one study found that only 41% of their 72 working age adults reported an increase in their quality of life, 43% reported no change and 13.9% reported an actual deterioration (Mickley, Petersen & Nielsen, 1989). This reduction in quality of life was perhaps due to feelings of anxiety; the researchers reported 11.1% of

participants were anxious (most frequently due to thoughts of device failure). However the study did not report on whether the same patients who were reporting reduced quality of life were also reporting anxiety, so it is impossible to make any causal links.

Another area of concern mentioned in the literature is the effect of pacemaker implantation on body image. However there have been very few studies investigating this aspect directly; a search of the literature only revealed one study (Davis et al., 2004). Here the researchers found that 73.2% of the 383 patients they studied stated pacemaker implantation had not changed the way they felt about their body. It should be noted the mean age of this sample was 74 years and therefore these participants are at a very different stage of life to that of children and adolescents. Children and adolescents may perceive a more dramatic impact on body image, as their attitudes to their own body are still developing. It may be a particularly relevant and difficult issue with regard to adolescents, whose body image is going through significant changes due to puberty. Adolescents are also at the stage where they want to look attractive and look the same as their peers.

The adult literature shows many people adjust well to pacemaker implantation, but a significant number do not. Models of adjustment involving three stages have been proposed by both Dlin (1966) and Blacher & Bach (1970). Dlin (1966) described the first stage as shock, followed by the person feeling the pacemaker is “controlling” them. Finally came integration, a development of “oneness” between the pacemaker and the self. In Blacher and Bach’s model (1970), first came the acute hospital phase, characterised by fear of complications and death. The second phase they described was after discharge, when feelings of depression were common. The third phase consisted of acceptance and adjustment, where the pacemaker had become incorporated into daily life and was often forgotten or ignored. Unfortunately both these theories are merely descriptive and neither explains how people move between the stages of adjustment to reach acceptance of the pacemaker, nor what influences this movement.

Wingate (1986) found no significant differences in the level of pacemaker acceptance according to the variables of age, gender, length of time since implantation or severity of pre-operative illness. However this was only a relatively small sample of 86 participants. Beery and Baas (1996) hypothesised that the suddenness of implantation may affect adjustment. For example, when implantation is carried out as an emergency

procedure, the lack of time to prepare may reduce a person's ability to accept the pacemaker. However there has been no work to empirically support this hypothesis.

One qualitative study examined the experiences of eleven women with cardiac pacemakers and how they integrated them into their lives and bodies (Beery, Sommers & Hall, 2002). It emerged from the analysis that the process of adjustment was a complicated one that happened over time. It involved tensions between themes of relinquishing control to the pacemaker, and themes of the women taking control of their lives. In addition there were tensions between 'owning' the pacemaker and integrating it into their sense of self, and distancing themselves from the pacemaker, and between normalising the experience and recognising the risks involved. Participants strongly emphasised how "normal" they were, but then went on to describe experiences that were most definitely outside the norm (such as device failure, or problems with the positioning of the pacemaker leads and subsequent risk to life). The women that had successfully incorporated the pacemaker into their identity were characterised by having a relief from symptoms, a functionally reliable device and a positive attitude to their pacemaker. The women expressed relief at having a device that allowed them to live their lives how they wanted. Despite this, they also indicated some continuing sense of threat.

To summarise, the majority of adult patients adjust well to pacemaker implantation. However, a minority of patients have difficulty adjusting, and pacemaker implantation has a negative psychosocial impact on them, resulting in feelings of anxiety and depression. It appears that adjustment to having a pacemaker is a complex process, involving many diverse cognitive and emotional processes.

### **Psychosocial Impact of Congenital Heart Disease on Children and Their Parents**

Research into the impact of congenital heart disease is a growing area, but one that is still under researched compared to some other childhood illnesses such as diabetes, asthma and cystic fibrosis. Bowen (1985) found the school-aged children with congenital heart disease demonstrated poor self-esteem, anxiety and problems relating to their peers. The adolescents in the study also had problems in relating to their peers, but this was accompanied by changes in body image and problems developing independence from their parents. Other studies have reported higher rates of behaviour and emotional problems

(as measured by the Child Behaviour Checklist; Achenbach, 1988) in children and adolescents with congenital heart disease compared with both the age-matched norms of the questionnaire (Hövels-Gürich, et al., 2002) and control groups of healthy peers (Utens, et al., 1993; Oates, Turnbull, Simpson & Cartmill, 1994). In addition Utens et al., (1993) found 27% of the children and adolescents with congenital heart disease that they examined obtained scores indicating the need for referral onto specialist psychological services.

Despite many studies identifying difficulties associated with congenital heart disease, some studies have found positive psychosocial outcomes (Linde, Rasof & Dunn, 1966; Pelkovits, DeMaso & Russo, 1984). Other studies examining the incidence of behaviour problems (as measured by the Child Behaviour Checklist) found no significant differences between children and adolescents with congenital heart disease and norms (Utens, et al., 2001), or healthy control groups (Karl, et al., 2004).

An important mediator of child adjustment appears to be parental factors. McCusker et al. (2007) considered behavioural outcome in a systemic context. The authors looked at behavioural adjustment in 90 children. They found the biggest risk factors for poor adjustment were poor parental control, lone parent status, high maternal worry and maternal mental health difficulties. These variables made a greater contribution to behavioural outcomes than illness or surgical variables.

A number of studies have found that parents of infants with congenital heart disease are exposed to a wide variety of stressors, and they are at risk of suffering emotional problems (e.g., Cohn, 1996). Cohn (1996) found that parents of children with congenital heart disease reported higher levels of stress than those of healthy children. In her review of the impact of congenital heart disease on children and their families, Bowen (1985) found parents were generally more likely to experience problems in administering appropriate discipline, and to be overprotective and overindulgent towards their children with heart disease. In addition, she established that congenital heart disease diagnosed in infancy could lead to parents having difficulty in bonding with their baby. She reported that parents felt frustrated, guilty and as though they had failed in some way. In contrast however, DeMaso et al. (1991) and Visconti, Saudin, Rappaport, Newburger and Bellinger (2002) did not find higher stress levels in parents of children with congenital heart disease. In addition Carey, Nicholson and Fox (2002) found no significant differences in stress levels



and parenting practices (as measured by quantitative self-report questionnaires) between mothers of children with congenital heart disease and mothers of 'healthy' children. However the qualitative data did reveal mothers of children with congenital heart disease reported higher levels of vigilance in their parenting style.

A recent study by Doherty et al. (2009) investigated psychological functioning and coping styles in both mothers and fathers of 70 infants born with congenital heart disease. With regard to coping styles (as measured by the COPE; Carver, Scheier & Weintraub, 1989), the study found that mothers were more likely to 'vent' about their situation than fathers and were more likely to make use of social and religious or spiritual support. Fathers, on the other hand, were more likely to use alcohol as a coping strategy. Overall, the study found that mothers showed significantly higher levels of mental health problems (as measured by the Brief Symptom Inventory; Derogatis, 1993) than fathers; a third of all mothers and a fifth of all the fathers examined experienced clinically elevated levels of psychological distress.

The authors investigated how well medical and surgical variables, coping styles and various psychosocial variables predicted parent mental health. The psychosocial variables included measures of socioeconomic status, knowledge and understanding of the child's condition, subjective worry, social support and family functioning. Disease severity, socioeconomic status and social support did not predict the level of psychological functioning in mothers or fathers. For mothers the coping style of behavioural disengagement, poor understanding and knowledge of their child's condition and poor family cohesiveness were associated with greater levels psychological distress (as measured by the Brief Symptom Inventory). For fathers, high levels of worry and use of alcohol as a coping strategy were associated with greater levels of psychological distress.

To summarise, studies in this area paint a mixed picture of psychosocial adjustment in both children and their parents. Some research suggests children with congenital heart disease are more likely to demonstrate behavioural and emotional difficulties, whereas other studies have failed to find any differences between them and healthy controls. In addition some studies have found increased stress and mental health problems in parents, whereas others have not. This is consistent with findings across research into chronic illness that demonstrate that some children and families show good adjustment, while others find adjustment more difficult. Some of the research examined

here suggests parental factors such as mental health and psychological functioning, parenting style and marital status as possible mediators of child outcome in congenital heart disease. Coping strategies, levels of worry, knowledge of the condition and family functioning appear to be mediators of parent outcome.

### **Summary of Theoretical Frameworks Relevant to this Study**

During the process of carrying out this study I looked at a wide range of literature, a detailed summary of which is beyond the scope of this thesis. The extensive nature of literature examined was in part due to the lack of previous research in the field. My aim in this study was to begin from a position of “not knowing” in an attempt to let a group of people who had not been previously heard tell their story in the way that was most important to them. I did not want to introduce bias into the analysis by basing my research questions on any particular framework. However the academic requirements of a doctoral thesis meant it was necessary to use some theoretical frameworks to inform the study. In turn, some of the theory I examined went on to inform the questions in the interview schedule used in this study

Systemic family theory informed both my general thinking and the interview schedule. Family context has a huge influence on family members and on the way they see the world (see Dallos & Draper, 2005). Health beliefs are shaped by the context inhabited by the individual and by their interactions with others, particularly members of their own family (McCubbin, McCubbin & Thompson, 1993). Other literatures examined included those on the impact of diagnosis and medical procedures (see Roberts, 2003). The stress and coping model outlined previously (Lazarus & Folkman, 1984) also informed the interview schedule. In addition, other literatures that informed my thinking were those in the field of positive psychology (see Snyder & Lopez, 2002), in particular resilience (Masten & Reed, 2002) and benefit finding (Tennen & Affleck, 2002). This was in an attempt move away from a purely deficit-led view and to discover what helped people manage their situation and what, if any, positive aspects there were to chronic illness.

## Rationale for This Study

Children with pacemakers are an under-researched population. The few studies that have been carried out in this field are poorly designed, out of date and their results are contradictory. Therefore little is known about the impact pacemaker implantation has on a child and their parents. However, discussions with the Consultant Paediatric Cardiologist and senior nursing staff in the service where the research was carried out revealed some issues they identify with their pacemaker patients and their parents. Firstly, the team felt they did not know enough about what the experience is like for children and their parents, and have a sense that minor difficulties may go unnoticed by the team. Outpatient appointments are very brief and the main focus of the team is to check the technical function of the pacemaker. Staff feel there is insufficient time to ask families questions about adjustment or their psychological state. Instead, they rely on patients informing them of any significant problems in living with the pacemaker. However, despite the team's perceived lack of detailed knowledge about the experience, there is the general sense that pacemaker implantation is a relatively minor procedure and has little psychosocial impact compared to some of the other procedures the service carries out (such as open-heart surgery).

Despite the general perception of pacemakers as a benign intervention, the team are aware of some difficulties that emerge after the pacemaker is fitted. The consultant in the team has observed that both children and their parents become anxious every time pacemaker replacement surgery approaches. His sense is that this anxiety is in response to the fear that the battery may run out before the surgery, as well as anxiety about the surgery itself. The team have also noted that some children and their parents adjust well to the pacemaker, whereas others find this more difficult. For example the consultant explained that there are very few restrictions on what his patients can do, aside from the initial few weeks immediately post-surgery. His advice to children and young people is to 'go and get on with life' and his advice to their parents is to 'treat them normally and let them get on with things'. However, he feels they do not always do this because of their concerns regarding risk and the pacemaker. He believes the concerns come primarily from the parents, rather than the children and young people.

Despite giving parents the same information on risks and restrictions, the consultant has noted differences in the perception of risk between parents. Some have

very inaccurate perceptions, worrying excessively about pacemaker failure (a very small risk) or unnecessarily about the effect of environmental factors such as microwaves, electricity or mild magnetic fields. His view is that some parents are more prepared to take risks than others who become unnecessarily overprotective and restrictive. These observations are significant because the literature shows that transmission of anxieties and coping behaviour occurs between parents and children (Kliewer et al., 1994). In summary, the team is keen to develop a better, more responsive service for these children and their families. Gaining an understanding of their experiences should help services do this.

As so little is known about this area, an exploratory approach using qualitative methodology will be taken in this study. There are few examples of studies in the literature that talk directly to children and young people with chronic illness; the focus is usually on their parents. Even in the qualitative field much of the research relies on parental accounts of how children live with illness. More studies are now beginning to ask children and young people directly about their experiences, however very few speak directly to both. In fact only one study could be found (Gannoni & Shute, 2009). It is important to speak to both children and parents, not only in light of the local service observations, but also in light of the systemic nature of parent-child relationships and experiences.

Children and young people aged 11 to 16 were chosen to take part because it was important to identify a developmental stage when children were still dependent on and being cared for by their parents, but had reached an age where they had begun to develop a coherent sense of identity (Erikson, 1968) and could reasonably be assumed to have reached the formal operations stage of cognitive development (Piaget & Inhelder, 1969). This stage is defined by the capability of abstract thought and holding in mind contradictory information, something they will need to do when talking about and making sense of their situation.

### **Research Aims**

The aim of this study is to explore the experience of having a pacemaker as a child or young person and the experience of their parent in caring for them. This research also intends to examine how participants make sense of these experiences. Thus parent-child dyads will be interviewed separately about their pacemaker-related experiences.

Transcripts will be submitted to Interpretative Phenomenological Analysis. This was chosen as the most appropriate method of data analysis because its main concern is how people experience the world and how they make sense of those experiences. It is intended that the findings will inform relevant psychosocial support and interventions with this population.

### **Research Questions**

Due to the fact so little is known about what children with pacemakers today are experiencing, the research questions for this study have remained broad.

For the children and young people they are:

1. What are their experiences of having a pacemaker?
2. How do they make sense of their experiences?

For the parents they are:

1. What are the experiences of having a child with a pacemaker?
2. How do they make sense of their experiences?

## **METHODOLOGICAL CONSIDERATIONS**

### **Qualitative Research**

Qualitative research is concerned with the quality and texture of experience and how people create and negotiate meaning in their lives (Willig, 2008). It aims to explore the unknown and therefore, unlike quantitative research, does not attempt to make predictions. Instead it is inductive, working from a bottom-up perspective. It begins with the participant and allows them to lead the process of data collection. It is they who generate the data, upon which the researcher then imposes their own analysis (Willig 2008). This concern with the unknown makes a qualitative approach suitable for this study. There has been very little research in this area; therefore it seems appropriate to come from a position of 'not knowing'.

Qualitative psychology is not a homogenous discipline. There are many approaches, which differ from each other in methodological or epistemological stance. However despite this, to a greater or lesser extent, they share certain characteristics. These include the collection and analysis of data being based on language rather than numbers (Barker, Pistrang & Elliott, 1994). Data are collected in the form of verbal reports (such as interview transcripts), which are then analysed textually (Smith, 2008). This results in large quantities of rich, in-depth data. In addition, qualitative methodologies all seek to link the emerging themes to the raw data, and all recognise the importance of reflexivity.

### **Interpretive Phenomenological Analysis**

I shall analyse the data obtained in this study using interpretative phenomenological analysis (IPA). IPA is chiefly concerned with how people experience the world and how they make sense of those experiences. It is concerned with how individuals construct meaning in their personal and social worlds (Smith & Osborn, 2008). It is phenomenological in that it attempts to explore and understand experiences from the participant's point of view. That is, rather than trying to obtain an objective account of an event, it seeks to obtain the individual's idiosyncratic account of the event, from their perspective. It assumes that it is an individual's perception of the world that forms their personal reality.

IPA places particular emphasis on the role of the researcher, who plays an active role in analysis. The researcher seeks to gain an insider's point of view (Conrad, 1987) of the experience under investigation. However IPA acknowledges that this can never wholly be achieved, as the researcher can never completely share the participant's perspective. Therefore all that can be produced is an *interpretation* of the participant's experience. There are two stages of interpretation in IPA, which Smith (2004) describes as a 'double hermeneutic'. Firstly the participant tries to make sense of their lived experience. Secondly the researcher tries to make sense of the interpretation the participant has made. Thus, there is necessarily an interaction between the researcher and the participant. It is the fact that the participant's account must be filtered through the researcher's own view of the world that makes researcher reflexivity so important in IPA. They must be aware of how their previous experiences, and the position they are approaching the analysis from, can influence their interaction with the participant, as well as their interpretation of the account.

Finally, IPA is concerned with people's thoughts and beliefs. It assumes a direct link between language and cognition. The language people use reflects their thoughts and feelings, which in turn is linked to their understanding of their experiences. However IPA acknowledges that the language-cognition link is not a straightforward one. People do not always verbally express exactly how they are thinking or feeling, either because they are unable to, or because they are unwilling to do so. Therefore the researcher is required to make a critical interpretation of what the participant might be thinking or feeling from their verbal report.

I considered other methods of qualitative analysis as alternatives to IPA. I discounted discourse analysis, as this study is not concerned with the use of language, as such. Discourse analysis takes the position that language constructs social reality rather than describing it. This study is designed to help create understanding of the meanings of experiences for participants, rather than how they use language to construct that meaning.

The method of analysis I gave the most serious consideration was that of Grounded Theory. This approach was originally developed by sociologists Glaser & Strauss (1967) and shares some methodological similarities with IPA. They both use purposive sampling and carry out textual analysis of verbal accounts in an attempt to identify and link emerging themes from the data. However there are also key differences. Grounded theory

aims to collect data through theoretical sampling and use it to generate theory. Data collection continues until theoretical saturation is reached, that is until no novel categories emerge from the data. In addition, grounded theory's origins in sociology mean it is more concerned with social processes, rather than being specifically focussed on individual experience. This study aims to investigate the individual experience of young people with pacemakers and their parents, and the meaning this experience holds for them. Although not originally conceived as such, grounded theory can be used as a way to investigate meaning. However some have criticised its use for this purpose, as they feel it moves away from being a method of exploration and can become merely an exercise in categorisation (Hayes, 1997). Therefore I considered IPA a more appropriate method to answer the research questions in this study.

Other reasons for employing IPA include the fact that it has been used extensively in the field of health psychology. A large body of research has developed in this area and IPA has proved to be a very suitable method of investigation (see Brocki and Wearden (2006) for a review). In addition, the emphasis IPA places on reflexivity contributed to my decision to use it in this study. Reflective practice is essential in all aspects of being an effective psychologist. It is particularly necessary here, as I have already examined the literature behind the topic, which could introduce bias into my analysis of the data. Therefore it is important to try and become aware of any biases and acknowledge these. In this study I will maintain reflexivity by keeping a reflective diary throughout each phase of the study (development, data collection and interpretation).

IPA does have some limitations. These include its concern with cognition (the link between thoughts, language and self; Smith, 1996) and its alignment with the social cognition paradigm. Willig (2008) argues that cognition is not compatible with some aspects of phenomenology. Social cognition theory holds that people have internal beliefs and thoughts that help them interpret the external world. However phenomenology does not make a distinction between the observer and the observed, therefore a participant's world and their experiences operate on a continuum and are more difficult to separate.

Other limitations of IPA are linked to its assumption of the representational validity of language. IPA takes the position that language is a direct way of communicating thoughts and feelings and the verbal accounts of participants accurately represent their personal lived experience. One criticism of this stance is that IPA therefore relies on the



ability of participants to articulate their thoughts and feelings well enough to express what they are thinking and feeling. This could be a particular issue in the case of children and young people, who may not be as articulate as some adults. However other studies have successfully used IPA with adolescent participants aged 13 and over (Jelbert, Stedmon & Stephens, 2010; Shaw, Dallos & Shoebridge, 2009). Other arguments are that language is not merely the way in which we express thoughts and feelings but that in fact, language actually constructs those thoughts and feelings (Willig, 2008). Thus language can be said to effectively shape an individual's experience by constructing his or her perception of it. However IPA does not ignore language or indeed necessarily take it at face value. Smith and Osborn (2008) encourage researchers to take a critical stance in regard to interpreting questions about implied as well as explicit meaning. Analysis also takes into account tone and other non-verbal aspects of communication.

### **Method of Data Collection**

I selected semi-structured interviews as the method of data collection for this study. The proposed interview schedules can be found in appendices 3 and 4. I also considered other methods of data collection, including diaries and focus groups. I discounted diaries due to the high demand this method places on participants. Keeping such a detailed record of experiences requires a large amount of commitment and motivation and therefore dropout rates are high (Willig, 2008). In addition, I had concerns on ethical grounds about whether keeping the diary might unduly increase the pressure participants feel at particularly busy or stressful times. I considered focus groups to be more appropriate than diaries. However potential complications arising from group dynamics meant I discounted this idea. I thought there was a risk of a group consensus developing or one or two dominant voices and perspectives emerging within the group, both of which would constitute a threat to the richness of each individual account.

Smith and Osborn (2008) describe semi-structured interviews as the "exemplary" method for IPA. I chose this method because it facilitates rapport between the researcher and participant and it provides a flexible way of collecting data. Semi-structured interviews allow the interviewer to shape the process according to the participant's responses (or alternatively the participant shapes the interview by the responses they give). The

interviewer can follow the participant down interesting avenues into areas they may not have thought of prior to the interview. One benefit of this is that the account is more likely to contain the details that are most important to the individual participant, rather than what is most important to the researcher. However a note of caution is the fact that any questions being asked will shape the responses in terms of what the researcher wants to know, and their agenda. Therefore the account obtained can never be entirely from the participant's point of view.

## **METHOD**

### **Ethics**

This study received ethical approval from the Leeds (East) Research Ethics Committee on 13th July 2009 (see appendix 1) following a request for minor amendments to the participant information sheet and consent form. Research and Development approval was obtained from Leeds Teaching Hospitals Trust on 9th October 2009. I adhered to the research guidelines of the British Psychological Society (BPS) throughout the research process. These included the Good Practice Guidelines for the Conduct of Psychological Research Within the NHS (2005) and the Division of Clinical Psychology's (DCP) Professional Practice Guidelines (1995).

### **Design**

I employed a qualitative research design using a semi-structured interview schedule in order to generate data (see appendices 2 and 3). I carried out eight interviews with four parent-child dyads. All the children and young people taking part had a cardiac pacemaker implanted. In the interviews with the children I aimed to explore the experience of having a pacemaker, whereas in the interviews with their parents I aimed to explore the experience of caring for a child with a pacemaker. I analysed the transcripts of the interviews using interpretative phenomenological analysis.

## **Setting**

All the families who took part in the study were recruited through the Children's Heart Unit, part of the Yorkshire Heart Centre based at the Leeds General Infirmary. This is a regional centre for the diagnosis and treatment of congenital heart disease, arrhythmias and acquired heart disease.

## **Participants**

Eight participants (four parent-child dyads) took part in this study. Smith and Osborn (2003) recommend a sample size of five to ten in IPA studies, as this is sufficient to allow the necessary depth of analysis on a case-by-case basis.

## **Inclusion Criteria**

Children and young people aged 11-16 years who had been fitted with a pacemaker were included in the study, along with one of their parents (to create a child-parent dyad). Only participants who were fluent English speakers were included because the process of analysis relied on individual subtleties of expression that may have been lost if the participant was not fluent in English. Similarly if an interpreter were used this would introduce another level of interpretation, the extent of which the researcher could not be fully aware of.

## **Exclusion Criteria**

Children and young people who had had, or who were currently on the waiting list for, a heart transplant were excluded from this study. In addition, children and young people with any non-cardiac co-morbidity or any other physical and/or intellectual disabilities were also excluded. The rationale for this was that the presence of any of these factors may mean a family is facing different challenges to those posed specifically by having a pacemaker fitted.

## Procedure

Families who were eligible to take part in the study were identified from the service's database. This was done by the team psychologist and one of the specialist nurses, according to the inclusion and exclusion criteria outlined above. Twenty families were identified and sent a letter from the Consultant Paediatric Cardiologist, inviting them to take part (see appendix 4), along with an information sheet explaining the study (see appendices 5 and 6). They were encouraged to contact either me, or the specialist nurse if they required further information or explanation of what the study involved. Those who were interested in taking part were then asked to either complete a tear off slip, and return it in the stamped addressed envelope provided, or to email me. I contacted all those who expressed a desire to take part in their preferred way and arranged an interview at a place and time convenient to them. Of the twenty who were contacted, five replied. Their reasons for non-participation were unknown.

I carried out all the interviews in participants' homes. A buddy system was implemented to ensure my safety. I interviewed parents alone. I gave children and young people the option of having a friend or parent present; one participant chose to have his friend present during the interview. I obtained written consent from parent participants and young people aged sixteen just prior to the interview; I obtained written assent for those children and young people aged fifteen and under (a copy of the parent consent form can be found in appendix 7). Participants were aware that they could stop the interview at any time. They were also aware they could be referred to a specialist nurse or the psychologist from the team if they required further support if the interview raised any difficult issues for them.

Each interview took approximately one hour. They were all digitally recorded. After each interview I made notes on any pertinent body language or non-verbal communication. In addition I made notes on my initial impressions immediately after the interview, which were then used to aid analysis at a later date. All information was kept confidential, stored securely and used solely for research and publication purposes.

## **Interview Schedule**

I used two interview schedules, one for parents (see appendix 3) and one for children and young people (see appendix 2). The two were similar, however the one designed for use with children and young people used slightly simpler language, more appropriate to the developmental level of the participants. Each interview schedule consisted of nine open ended questions, each with several prompts designed to elicit the fullest response possible from the participant. In the case of children and young people the interview aimed to elicit a description of the experience of having a pacemaker. In the case of parents, the interview was designed to elicit a description of the experience of caring for a child with a pacemaker.

I piloted the interview schedules on a fellow trainee. Also, the initial participant interview was used to refine the schedule. Following the initial interview, I removed the first question requesting a full account of the participant's family, as I felt it detracted from the participant's account of their own experience. I used the schedule to guide the interview process rather than as a prescriptive tool. I changed the order of questions on an individual basis depending on the idiosyncrasies of each interview.

## **Analysis**

### ***Transcription***

I transcribed the first two interviews myself to enable me to reflect on the process of interviewing and on the interview schedule. Due to time constraints the other six interviews were transcribed by a secretary with prior experience of transcribing interviews for qualitative research. She was aware of confidentiality issues and signed a confidentiality agreement. She also anonymised all transcripts. On receipt of the transcripts I carefully checked each one and corrected any omissions and inaccuracies.

### ***The Process of Analysis***

Smith, Flowers and Larkin (2009) provide a thorough account of the conventional process of IPA. However they also state that there is no definitive method and each

researcher must find their own path. I used the recommendations outlined by Smith et al. (2009) to guide my analysis, along with additional notes I had made at the annual IPA conference in Birmingham, 2009, which I attended for training purposes.

I began the process of analysis with the child group. The rationale for this was that their accounts might be less rich and detailed and thus be an easier place to start as a novice researcher. I began by reading through each transcript while listening to the audio recording of the interview. This was intended as a way of immersing myself further in the data and providing an opportunity to observe the vocal tone and emotional content. Immediately afterwards I made notes of my first impressions in my reflective log. I then re-read the transcripts several times, underlining phrases I believed to be significant and making descriptive notes in the left hand margin. As I became excited about what I was seeing in the data, I found it difficult not to launch straight into interpretations at this point. However I was aware that moving too far from the data at this stage would risk subsequent interpretations not being fully grounded in the original data (Smith et al., 2009). In the initial stages of the analysis I worried that I was somehow 'not doing it right', however after meetings with my research supervisor my confidence in my ability to generate a meaningful set of analyses grew.

After the initial descriptive comments, I then began to make higher-level interpretations and began noting emergent themes in the right hand margin. I also started to take note of patterns and contradictions in the account. As I moved on to higher level interpretations I felt apprehensive about not remaining sufficiently grounded in the data and worried about 'going too far' with my interpretations. However I kept notes on how I developed interpretations, and revisited these throughout the process. This process, along with discussions in supervision, put these fears to rest.

The next stage in my analysis consisted of copying the emerging themes from the right hand margin onto numbered index cards. This enabled me to group the themes by positioning and re-positioning the cards. This felt more intuitive than "eyeballing" a list of themes in an attempt to find connections, as suggested by Smith et al. (2009) and it assisted in my visual processing of the data. This grouping and re-grouping was a long process and one that I revisited again and again over a period of days, until I felt satisfied the groupings reflected the essence of the participant's account. Eventually each account comprised various super-ordinate themes, subsumed under which were various

subordinate themes. The groupings were then transferred to a summary table with the transcript line numbers in which they occurred next to each theme, along with illustrative quotes. Several themes that did not appear to be part of the core experience were discarded at this stage.

After completing the analysis of the first transcript I then went on to analyse each child transcript in turn. I attempted to keep all the analyses separate and judge them on their own merits. After completing all the individual child analyses I then went onto carry out a group analysis. I did this by re-grouping all the original themes that emerged from the individual accounts to create a set of super-ordinate and subthemes that reflected the shared experience of the group. This part of the process took a great deal of time and effort, as I attempted to refine my groupings and make higher-level interpretations. I revisited this stage of the analysis repeatedly over several days until I was satisfied that I had reached a coherent and 'truthful' representation of the participants' experience. Finally, I repeated the same process with the parent group transcripts.

### **Checking the Quality of the Analysis**

I used a series of processes in order to check the quality and validity of my analysis based on recommendations by Yardley (2000), Elliott, Fischer and Rennie (1999) and Smith et al., (2009). Firstly I attempted to 'own my own perspective' throughout the research, as advocated by Elliott et al. (1999). I did this by using supervision and keeping a reflective journal throughout. I recorded my thoughts after each interview and during various stages of the analysis. I have also attempted to demonstrate some of my reflections throughout this thesis, including illustrating my own perspective on the research at the end of this chapter.

### ***Paper Trail***

It is essential that a researcher using qualitative methods should be able to demonstrate links from the raw data to the final report (Smith et al., 2009). One way of doing this is by creating a 'paper trail' through the analysis (Yin, 1989). This then creates the possibility of carrying out an independent audit of the analysis process to check the credibility of the account presented in the final report. I and a fellow colleague, who was

also using IPA for her doctoral research, audited each other's paper trails. We read an example of each other's coded transcript alongside the emerging themes and accompanying process notes. We discussed how well the themes were grounded in the data and asked each other to make further justifications of certain interpretations. This process increased my confidence in the rigour and trustworthiness of my analysis, especially in light of my novice status.

### ***Triangulation of Perspectives***

I met regularly with my research supervisor throughout the analysis process. We reflected upon the interview transcripts and emerging themes, which helped reveal themes I had not apprehended initially. In addition we discussed the grouping of themes in all the individual and group analyses. This assisted me in seeing alternative ways of grouping themes and elucidated some instances where I had been inconsistent in my coding or grouping of themes. I also made use of peer auditing processes (Stiles, 1993). I gave one of my transcripts to a fellow IPA researcher, along with the emergent themes. We then had a reflective and critical discussion of how well the themes reflected the data. The outcome of this reflective discussion was a level of agreement between us that gave me confidence in the reliability of my analytic process.

### **Introducing the Researcher**

'Owning one's own perspective' is an essential part of the qualitative research process, according to the guidelines set out by Elliott et al. (1999). Here I attempt to outline my own perspective and provide the reader with some context to help them understand the researcher, the relationship between the researcher and the participants and the process of interpreting the data.

I am not aware of any of my own experiences impacting directly on my choice of research topic. For example no one intimately connected with me has any experience of having a pacemaker or other cardiac problems. Rather, my interest in this topic emerged from my existing interest in the psychology of health (first developed as an assistant psychologist) and my developing interest in work with children and families. The decision



to pursue this area of research in particular was due to my field supervisor's observations that very little was known about the impact of having a pacemaker on children and their parents, both in the service in which she was based and the wider literature generally. She thought it would be an interesting area with important clinical relevance.

In my final year of training I have expanded and enriched my interest in the systemic approach to working with children and families. Firstly my elective placement has been based in a Child and Adolescent Mental Health Service. In addition, I opted to study a specialist option on Systemic Theory and Practice as part of my Doctorate in Clinical Psychology, which allowed me to gain a deeper knowledge of systemic theory. I have found both these experiences have helped me enormously during this project.

## RESULTS

### Sample

Eight participants (four parent-child pairs) took part in this study. The children and young people taking part were aged between 11 and 16. The parents taking part in this study were all mothers. This was not by design, rather that only mothers responded to the invitation to take part. The table outlines the characteristics of the child-parent pairs making up the sample. The pseudonyms used were chosen by the participants at interview.

**Table 1. Participant demographic information**

Participant *	Gender	Age at interview	Age at first pacemaker implantation (years)	Number of pacemakers received
Josh	Male	11	7	1
Lisa	Female	31	-	-
Gurdesh	Male	16	14	1
Noor	Female	39	-	-
Lucy	Female	11	2	3
Nicola	Female	36	-	-
Zack	Male	14	5	3
Angela	Female	45	-	-

Note. \*Names changed to protect confidentiality

Participants were broadly typical of the children with pacemakers seen in the Children's Heart Unit. They, like all the others seen in the service, had to attend routine

appointments for pacemaker function tests every six months. In addition, participants were typical in terms of psychological functioning and adjustment. None of the children or mothers had been seen for problems with adjustment, either by the team Psychologist or by local Child and Adolescent Mental Health Services. In terms of age at first implantation and number of pacemakers received, the children seen in the Children's Heart Unit can vary significantly. The age at which the first pacemaker is implanted varies depending on the patient's individual condition. In addition, the number of pacemakers received is directly related to the age of first implantation. A child who has had their first pacemaker at a young age will have had a greater number of pacemakers fitted than a child of a similar age, but who had their first pacemaker fitted when they were older. In light of this, although the children in the sample differed somewhat with regard to this characteristic, they can still be said to be broadly typical of children with pacemakers seen by the Children's Heart Unit.

### **Pen Portraits**

Each pen portrait draws together information gathered about each participant to form a clinical formulation. This includes some demographic information and, for the children, a brief history of their pacemaker. It also includes my initial clinical impressions formed during and immediately after the interview, which I recorded in my reflective journal. These included non-verbal aspects of the interview and reflections on the participant's style of interaction and the quality or richness of their account. In addition, the pen portraits include a summary of the main individual themes that emerged for each participant from the analysis of their interview transcript. Finally, for each dyad I also included some reflections on the relationship between mother and child and their separate accounts.

### ***Josh and Lisa***

#### ***Josh***

Josh was aged 11 at the time of the interview and was in his first year at high school. He was first diagnosed with congenital heart disease aged five. He immediately

underwent corrective surgery to correct the structural defects in his heart. His current pacemaker is his first, which he had implanted age seven when he received an additional diagnosis of heart block (a problem with the electrical conduction system of the heart) after several fainting spells. He is due for further surgery to replace his pacemaker battery in the next one to two years.

Josh did not say a great deal in the interview compared to the other children and young people and the data obtained from him were relatively 'thin'. He seemed reluctant to talk and not sure of what to say, although he was pleasant and his eye contact was good throughout. He also had a friend present throughout the interview, at his request, which suggests he found the idea of speaking to me alone uncomfortable. His friend's presence may have affected the quality and content of the interview. My initial impressions of Josh were that he felt very different and afraid because of the pacemaker. At the same time he was very keen to be seen as normal by others and was at great pains to portray himself as such. In addition, I interpreted his reluctant talk in much detail about his pacemaker as a form of avoidance.

He began the interview by saying that he felt no different from anyone else because of the pacemaker and that having one was just normal. He also insisted that the pacemaker did not place any restrictions on him. However, he went on to describe not being able to do the things his peers could and it became clear he did feel different. I interpreted this as him combating his feelings of difference by portraying himself as unchanged by the pacemaker, in an attempt to convince both himself and others that this was how he really felt. Finally, his description of how he and his family communicate about the pacemaker mirrored his communication style with me. He said he 'never' talks about it.

### *Lisa*

Lisa is a 31-year-old mother of four, of whom Josh is the eldest. She lives with her partner, the children's father. Lisa had a lot to say in her interview. She spoke very quickly and animatedly and was keen to take part and get her point across. My initial impressions were that Lisa experienced a lot of anxiety regarding what the future holds and is desperate to allow, or almost compel her son to feel 'normal'. The need for her to be in control was also striking.

These initial feelings were confirmed in the analysis of the transcripts. The analysis also revealed a huge underlying theme of guilt. She explained that heart defects run in her family and therefore she felt responsible for the fact Josh has a pacemaker. She felt a desperate need to atone for the 'damage' she feels she has caused and spends a lot of energy trying to prevent her son from feeling different due to his pacemaker. She has a fear of him blaming her for this at some point. Her guilt also leads to her violent rejection of the sympathy of others. She described worrying a great deal about Josh's safety and the function of the pacemaker. She also worried about what the future would hold in terms of Josh demanding more freedom, which she feared would lead to an increase in her anxiety. There is a sense that she feels there is no choice but to cope and she does this by retaining control at all costs, this involves using avoidance and rejection of emotion.

When comparing the accounts of Josh and Lisa I found that lack of communication between them regarding the pacemaker was a common theme. A systemic interpretation of this is that it is a result of both Lisa colluding with Josh's desire to avoid all thoughts of the pacemaker, and the fact that that Josh senses his mother's reluctance to discuss it and responds accordingly. Despite their lack of direct verbal communication, Lisa has still picked up on Josh's feelings of difference and has acted accordingly to minimise this. There is a sense of her trying to convince him that he is not different and a sense of him trying to convince himself. Finally, they both worry a lot about the pacemaker and use similar coping strategies of avoidance.

### ***Gurdesh and Noor***

#### *Gurdesh*

Gurdesh was aged 16 at the time of the interview and in Year 11 of high school. He was diagnosed with congenital heart disease at birth. He has had three operations to correct the structural defects in his heart, the first taking place at three years old. The last of these was two years ago, when his first pacemaker was implanted at the same time (aged 14). He also had an arrhythmia since he was a baby and it was known from that time that he would have to have a pacemaker implanted eventually.

This interview was the most difficult of all those I carried out. I experienced Gurdesh as very angry and defensive, making me question why he had chosen to take part. He wanted to control the questions I asked and had difficulty in articulating his thoughts and feelings about the pacemaker. My initial impressions were that he was attempting to control the interview as a way combating his feelings of powerlessness. In addition he portrayed himself as unaffected by the pacemaker and minimised its impact (both positive and negative) on his life. However, I found myself wondering if this was how he really felt or just what he wanted me to see.

My first impressions were supported by the analysis of the transcript. The main coping strategies he used were denial of the significance, or even the existence of the pacemaker. It is possible his anger with me stemmed from me preventing him using these strategies by asking him to think about it. I was struck by how little Gurdesh knew about his condition. He had a poor understanding of what happened at check-ups and what the purpose of surgery was, and he found this very anxiety provoking. It would appear that his coping strategies of denial and avoidance might not be very adaptive, as they have led to his lack of knowledge and the associated feeling of anxiety and anger. They have also contributed the pacemaker being poorly integrated into his sense of identity.

### *Noor*

Noor was a 39-year-old single mother with one other child at the time of the interview. She was happy to discuss her life with the pacemaker and talked at length. My first impressions after the interview were that she portrayed herself as strong and unworried by the pacemaker, yet she did have anxieties. In addition, I was struck by her denial of the pacemaker's impact (positive or negative) on their life as a family. Finally, I was left feeling faith was an important aspect of her ability to cope with this experience.

The subsequent analysis revealed an experience of feeling of powerlessness and wanting to be in control. For example she expressed a desire to have gone to medical school, so she could perform the medical procedures herself instead of handing Gurdesh over to others and relying on them to help him. In addition, there was an important theme of positive psychology; she found faith, gratitude, positivity and acceptance were all important to her ability to cope with her son having a pacemaker.

Finally, there was also a theme of her ideal situation versus the actual situation in many aspects of her experience. This was reminiscent of Gurdesh's account. Like Gurdesh, Noor denied that the pacemaker had any impact on their lives at all. She was keen to portray their lives as unchanged by the pacemaker, for either good or bad. However she then went on to describe occasions when she is restricted by Gurdesh's pacemaker and times when they have to do things differently because of it. She also portrayed herself as someone who had no worries about the pacemaker at all. Then she went on to describe the belief that she could never leave him alone, and her worries about pacemaker malfunction. Finally she told me how she believed Gurdesh had a very good understanding of his pacemaker and the purpose of surgery and check-up appointments. However the analysis of Gurdesh's transcript revealed he actually has a poor understanding of all this. This again suggests a disparity between her desired state of affairs and the actual situation.

### ***Lucy and Nicola***

#### *Lucy*

Lucy was aged 11 at the time of the interview and was in her final year at primary school. She was two years old when first diagnosed with congenital heart block and had her first pacemaker fitted at this time. It was inserted under her stomach muscle due to her small size, leaving a large vertical scar. Lucy had no additional structural defects requiring corrective surgery. At age four one of her pacemaker leads broke and she had to have a whole new pacemaker system fitted. Her third and most recent pacemaker was implanted last year, when she was aged ten due to the battery on the previous one running out. As she was much bigger, the pacemaker was moved to her shoulder, creating a new scar there.

Lucy was very articulate and spoke at length about her experiences. After the interview she showed me her previous pacemaker. She had kept it when they removed it and it was obviously special to her. My first impressions were that her mother and grandmother were valued and reliable sources of support. In addition, I felt she had accepted the pacemaker as part of herself and was actually quite fond of it. This was

confirmed by the analysis; although she felt different because of the pacemaker, it appeared to be well integrated into her sense of identity. As well as feeling different in a negative way Lucy also felt special some of the time. She also described how her friends were kind to her because of the pacemaker. Finally Lucy was the only one of the children who mentioned body image issues relating to the pacemaker. This could be due to the fact she is a girl and is just entering the stage of development when she is beginning to be more aware of her body, and perhaps is influenced more by society's expectations of women and their appearance.

### *Nicola*

At the time of the interview Nicola was a 36-year old working mother of three. Lucy is the eldest of her children. Nicola spoke very calmly, but articulately about her experiences of having a child with a pacemaker. My immediate impressions of her experience included the devastating impact of diagnosis and her sense of gratitude for her daughter's current state of health due to the pacemaker. The analysis of the interview transcript supported this initial impression regarding the impact of diagnosis. She experienced powerful feelings of shock and emotional trauma and was left wondering why this had happened. She was pregnant with her second child at the time and therefore these feelings were accompanied by worries for her unborn baby. There was a fear the condition could have a genetic cause and that the unborn child might have the same problem. There was a sense that Nicola had moved from having no ill children to potentially two ill children in the space of one doctor's appointment. However, despite these early experiences, she also described a feeling of having adjusted to the presence of the pacemaker in her life. She described seeing it as a normal part of life.

Nicola was very grateful to the pacemaker for keeping Lucy alive and described feeling that things could be much worse for them, especially when she compared Lucy to other children with heart conditions. When examining Nicola's coping strategies there was an interesting absence of any avoidance-based strategies. This was in contrast to all the other mothers who were interviewed. Instead, she uses a more approach-based set of strategies, seeking information and 'just getting on with things'. Finally, Nicola expressed some dissatisfaction with the service. However, all her complaints were about systemic



aspects of the service, such as those associated with it being a regional service. These included travelling distance and the recent removal of parental accommodation. She was keen to point out she was satisfied with the service as a whole and her complaints were not related to any of the members of staff, the relationships with whom she values enormously.

### ***Zack and Angela***

#### ***Zack***

Zack was 14 at the time of the interview and in Year 9 of high school. He was diagnosed with congenital heart block aged 18 months old and his parents were told he would eventually need a pacemaker. However, he did not have his first one implanted until he was five years old. Zack had no additional structural defects requiring corrective surgery. At 12 years old he had a routine pacemaker box replacement, due to the battery running out. More recently, he experienced a pacemaker lead malfunction just six weeks prior to the interview, and had surgery at that time to fix the problem. Therefore, at interview, he was still a little sore and restricted in what he could do physically until he had properly healed.

Zack was friendly and keen to discuss his life with a pacemaker. He spoke quickly and animatedly throughout. My first impressions were that procedural anxiety relating to surgery and pacemaker check-up appointments was a huge part of his experience. This was confirmed by the analysis of the transcript, which revealed the huge power the pacemaker has in his life. On a day-to-day basis the pacemaker has the power to keep him alive and allows him to live a full, active life. Being good at sport is core to Zack's sense of identity and the pacemaker allows him to realise this, thus exercising a protective effect. However Zack's relationship with his pacemaker appears to change when it is time to visit the hospital for routine check-ups or for surgery. On these occasions the pacemaker has the power to frighten him due to his considerable procedural anxiety. Also, surgery has a temporary but significant negative impact on his identity; immediately post surgery he cannot play sport, which leads to feelings of difference and exclusion.

It appears Zack has split the pacemaker into two parts; one of these is a welcome guest who keeps him alive and improves the quality of his life enormously. The other part is an unwelcome guest, who make his life very difficult periodically and requires a lot of medical and technical support, which is costly in terms of how much anxiety it provokes in him. He finds it easy to accept the positive aspects, which are equivalent to having a working heart. However he finds it more difficult to incorporate the part of the device that requires so much technical support, in other words the part that makes it a mechanical pacemaker, rather than a natural, working heart. Unfortunately the two are inextricably linked and he cannot invite one in without the other.

### *Angela*

Angela is a 45-year-old working single mum and has one other child aside from Zack. Despite being divorced from Zack's dad she receives practical and emotional support from him both on a day-to-day basis and when Zack has to have any procedures relating to his pacemaker. Angela was very friendly and happy to discuss her experiences. My impressions immediately after the interview were that Angela takes a very practical approach to managing the situation she finds herself in; I felt she avoided discussing the emotions of the experience in any depth. Finally, like Zack, procedural anxiety was also a strikingly significant aspect of her experience.

The analysis revealed that she uses denial, and avoidance of worry and upset, a great deal. However she does let this mask slip from time to time and reveals her underlying anxiety about the physical vulnerability of her son. Overall there is a feeling of her soldiering on and holding the more anxiety-provoking cognitions regarding Zack's safety at bay as much as she can, as they are too awful to even entertain. Angela felt a lot of gratitude for aspects of their situation. She was grateful that the problem was found and that the pacemaker now keeps him safe and improves the quality of his life. Guilt is also a significant part of her experience. This includes the feeling she may have caused this somehow, either via genetics or something she did in pregnancy. However, in addition to this, even her feelings of gratitude that things could be much worse for Zack cause her some degree of guilt. She appears to feel guilt that she is glad that Zack is not as unwell as

some other children. There is a sense of her thinking 'better than me'. However, it may be that she has beliefs that this sentiment is somehow wishing bad things on others.

There are some striking similarities in the descriptions provided by Zack and Angela, particularly those relating to avoidance of affect and procedural anxiety. This led me to think that the former may be an example of generational transmission of coping styles and the latter generational transmission of anxiety. Angela has modelled a practical, unemotional approach for Zack and described being very proud of him when he coped with procedures without becoming too upset. However she has also demonstrated to him her fear in response to medical procedures. Angela has had her own experiences of surgery as a young woman; both she and Zack described strikingly similar fear imagery relating to looking up at the fluorescent lighting flicking past on the journey down to theatre.

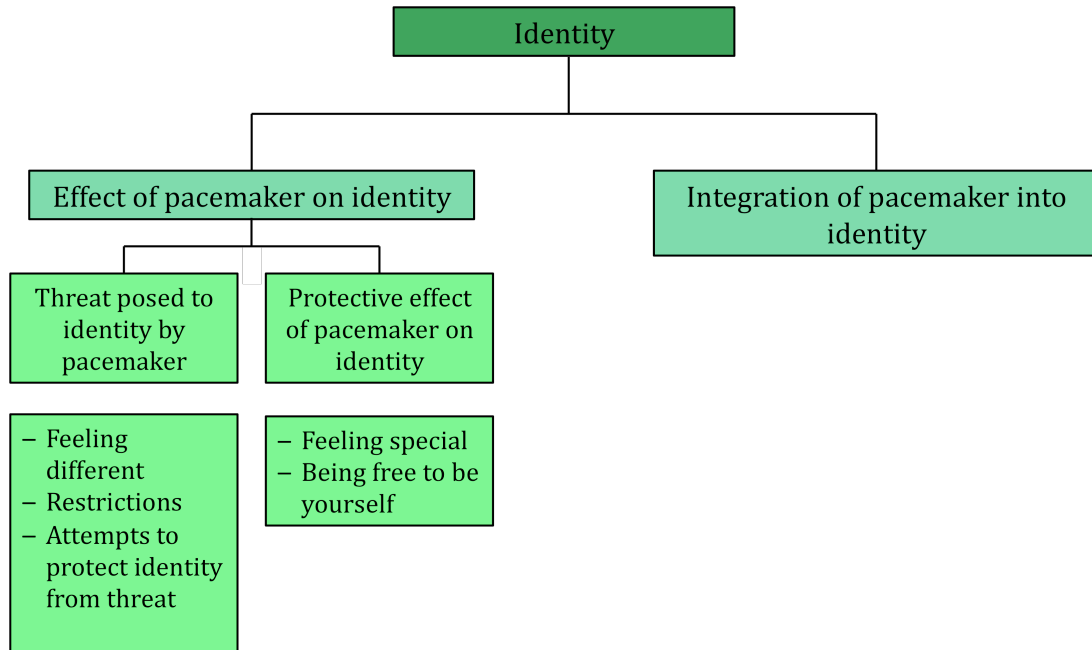
### **Child Group Analysis**

The analysis of the data provided by the child group revealed three main themes: 'identity', 'coping with having a pacemaker' and 'medicalisation of life'.

#### **Identity**

Interviewees described the relationship between their pacemaker and their identity. They told of the effect of the pacemaker on their identity, both positive and negative. They also described the experience of the pacemaker becoming integrated into their sense of selves. Figure 1 illustrates the relationship between subthemes for the main theme of 'identity'. Table 2 illustrates which themes applied to each participant.

**Figure 1. Relationship between subthemes for 'Identity'**



**Table 2. Subthemes relevant to participants for the main theme of 'Identity'**

	Josh	Gurdesb	Lucy	Zack
<b>Effect of pacemaker on identity</b>				
<i>Threat posed to identity by pacemaker</i>				
Feeling different	X	X	X	X
Restrictions	X	X	X	X
Attempts to protect identity from threat	X	X	X	X
<i>Protective effect of pacemaker on identity</i>				
Feeling special	X	-	X	X
Being free to be yourself	-	X	-	X
<b>Integration of the pacemaker into identity</b>	X	X	X	X

### ***Effect of Having a Pacemaker on Identity***

Participants described experiencing their pacemaker as having both a threatening and protective effect on their identity. The pacemaker makes life harder sometimes and they have to put a lot of effort into ameliorating its negative effect on their sense of self. However at the same time the pacemaker allows them to be themselves and live the life they want and be the person they want to be.

#### *Threat Posed to Identity by the Pacemaker*

*Feeling Different.* All the children and young people described feeling different from their peers due to their pacemaker. Some felt judged and misunderstood by others because of it; others had less overtly negative experiences, but still ended up feeling different. Lucy described her friends' attempts to tiptoe around what they saw as the sensitive issue, so as not to upset her. However this 'special consideration' simply served to show Lucy that her friends perceived her as different to them.

*"They don't mention much about it 'cause they think it might up...upset me; but um, they mentioned it once or twice". (Lucy)*

*Restrictions.* Adding to the interviewees' feelings of difference were the restrictions the pacemaker placed upon them and their lifestyle. All of them described their inability to take part in certain leisure activities due to risk of harm to their pacemaker. Often these were activities they wanted to do and that that their peers *were* able to do.

*"You can't like... do certain things as some people; like you can't do quasar and stuff" (Josh)*

Lucy described her inability to go on certain fairground rides such as roller coasters or 'bumper cars' (due to high velocities and strong magnetic fields respectively). This led to her feeling she was a disappointment to her younger brother, who wanted to share these experiences with her.

*“And he sometimes... he goes on rides and says, ‘Oh, can’t you come on?’ And I say, ‘No, it’s like made of mag...got magnets and ...’ ‘Oh’ And I think he gets a bit bored sometimes that I can’t go some places, rides like bumper cars.” (Lucy)*

*Attempts to Protect Identity from Threat.* Participants responded to these threats to their identity with various protective strategies. These included denying having any restrictions placed upon them that were important to their sense of self and doing things for other people in return for their kindness in relation to the pacemaker. Gurdesh made attempts to separate his identity from the pacemaker and its negative impact by making it clear to me his friendships were in no way related to the pacemaker. In fact he became quite irritated by my questions about his friends:

*“I just don’t like the questions about the friends and stuff like that. I think that’s useless towards your...if you’re finding out about a pacemaker, I don’t think that’s got anything to do with it.” (Gurdesh)*

Some of the participants experienced a difference between their actual and ideal selves. Their actual self was often one that felt different due to the pacemaker, whereas their ideal self felt normal, just the same as everyone else. Therefore other attempts to protect their identity from the threat of the pacemaker included portrayal of this ideal, normal self. When asked about the pacemaker by her friends Lucy described the following:

*“They’ve said, ‘How does it feel having one?’ I say, ‘Oh, it feels...it feels normal really.’ Um, and um, but I have to be careful um, because um, th...at playtimes um, at school balls: they play tennis and throw tennis balls at each other. And once, one nearly hit me so it hit my arm instead; and football and um, once a boy in my class, he didn’t mean to but, he...he hit my arm.” (Lucy)*

This suggests she wanted to be perceived by her friends as normal, despite then going on to describe the precautions she feels she needs to take that others are not required to.

As well as this desire to be seen as normal, participants also had a strong desire to *feel* normal themselves. Some described feeling the same as everyone else despite having already admitted to feeling different to their peers. For instance, despite having already told me what he cannot do that his peers can, Josh went on to say of his pacemaker:

*"It don't stop me doing ought. It's just... it's just like being same as a regular person. I just feel same as everyone else" (Josh)*

These professions of normality from interviewees felt like some sort of self-soothing strategy, an attempt to reassure themselves that, although they felt different, they are just like everyone else really.

#### *Protective Effect of the Pacemaker on Identity*

As well as posing a threat to participants' identity, the pacemaker was also experienced as serving a protective function; it made them feel special and freed them to be themselves.

*Feeling Special.* At times two of the young people experienced a feeling of being special due to having a pacemaker. This feeling of being different, in a good way, was illustrated by Lucy.

*"I get to miss school sometimes because I go to the checkups...and sometimes I go for operations...for an operation er, too. And um out of me...the whole school, I'm basically the only one who's got a reason to be off." (Lucy)*

In addition Zack told of receiving special treatment in P.E. lessons because of his temporary inability to play cricket due to recent pacemaker surgery. He was able to access an opportunity that none of his class mates could.

*“Umm.. ‘cause I can’t do much of the sports now my teacher is like teaching me how to umpire a game.” (Zack)*

*Being Free to Be Yourself.* The other protective role the pacemaker played with respect to the identities of the children and young people was that of freeing them to be themselves. Being good at sport was central to Zack’s identity:

*“Yeah I’m proper like athletic sport like playing football for my team and PE, I’m not allowed to do that for like two months ...which is end of May. At school they’re doing softball and cricket. Two of my favourite sports. I love them both.” (Zack)*

He went on to explain how his pacemaker enabled him to keep that as part of his sense of self, as without it he:

*“Wouldn’t be able to do sport and I wouldn’t be able to do lots of other stuff I like”. (Zack)*

The pacemaker also enables them to be the sort of person they aspire to be. Gurdes’h experiences of having a pacemaker enabled him to provide help and comfort to a friend going through the same thing, which was good for his self-esteem.

*“Yeah, but I’ve got...had my operation; but he’s going to have his soon. So, I like tell him there’s nothing to be worried about; it makes you better; stuff like that.” (Gurdes’h).*



### ***Integration of the Pacemaker into Identity***

Integration of the pacemaker into one's identity was an issue for all the children and young people. The three who have had their pacemakers longest (Josh, Zack and Lucy) described accepting the pacemaker as having become part of them; it has become a normal part of life:

*"It's alright. I never notice it. I always forget about, lots of times." (Lucy)*

Despite this, Lucy's scar also acts as a visible reminder of the fact she has a pacemaker, meaning she can never completely forget. However, the feeling of discomfort appears short-lived.

*"I look at where one scar is um, it...it sort of looks funny 'cause um, it's been open three times now. Um, look at it and think, 'Urgh!' And then you remember everything and then after a while you forget." (Lucy)*

Zack explained that having a pacemaker from a young age has helped with the process of integration into his sense of self.

*"It doesn't not feel ok because it's just a natural thing I've grown up with. So I've got used to having it." (Zack)*

However not all of the children and young people experienced the pacemaker becoming a well-integrated part of their identity. Gurdesh had had his pacemaker for the shortest amount of time. He called into question the very fact that he even had a pacemaker:

*"Well they say I've got one but I don't know if I actually have so..." (Gurdesh)*

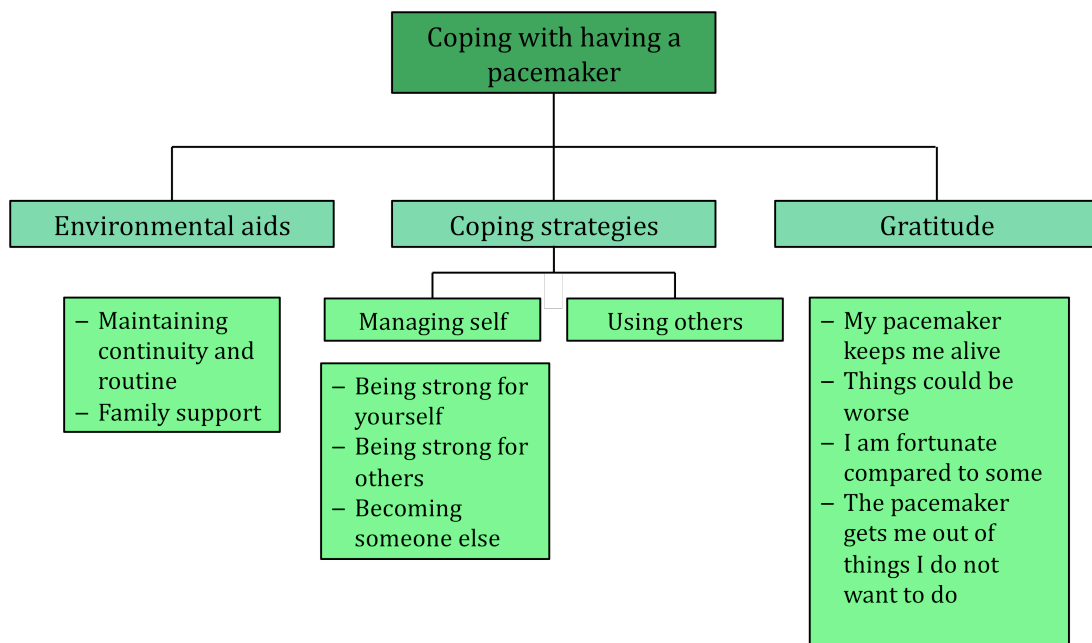
This doubting the existence of his pacemaker indicates a lack of acceptance of the pacemaker into his sense of self. This could be partly due to the relatively short length of

time since implantation. However, it could also be due to him having difficulty differentiating between the impact of his pacemaker implantation and the impact of his corrective cardiac surgery, as they were both carried out in the same surgical episode.

### Coping with Having a Pacemaker

For the child group, coping with having a pacemaker incorporated environmental aids, coping strategies and gratitude. Figure 2 illustrates the relationship between subthemes for the main theme of 'Coping with Having a Pacemaker'. Table 3 illustrates which themes applied to each participant.

**Figure 2. Relationship between subthemes for 'Coping with Having a Pacemaker'**



**Table 3. Subthemes relevant to participants for the main theme of 'Coping with Having a Pacemaker'**

	Josh	Gurdesh	Lucy	Zack
<b>Environmental aids</b>				
<i>Maintaining continuity and routine</i>	-	-	X	X
<i>Family Support</i>	-	X	X	X
<b>Coping strategies</b>				
<i>Managing self</i>				
Avoidance	X	X	-	X
Distraction	-	-	X	X
<i>Using others</i>	-	X	X	-
<b>Gratitude</b>				
<i>My pacemaker keeps me alive</i>	X	X	-	X
<i>Things could be worse</i>	-	-	X	X
<i>I am fortunate compared to some</i>	-	-	X	X
<i>My pacemaker gets me out of things</i>	X	-	X	X
<i>I do not want to do</i>				

### ***Environmental Aids***

It emerged that there were things surrounding the children that they experienced as helpful in making coping with the pacemaker easier. These included maintaining continuity and routine and family support.

#### ***Maintaining Continuity and Routine***

Participants found maintaining continuity and routine helpful in living with a pacemaker and in particular when going into hospital for surgery. For example when asked if there was anything that made being in hospital for her second pacemaker implantation easier, Lucy replied:

*“Yeah, ‘cause I was in the same bed. I kept being in the same bed. I’ve a lot of memories where the cards were and I saw where the string were, where you put your cards up.” (Lucy)*

### *Family Support*

Many of the children and young people said that the support they received from their families, especially their parents, was a key aspect of making coping easier. The following participants explained how important their mum just being there is to them when they have surgery.

*“Well, um, she stays in hospital with me all the time. And even when she has to go out, she leaves me um, um, the...a little TV on and she says, ‘I won’t be long! I promise.’ And she makes me happy and after my operations she says, ‘Are you alright?’ And she says...she looks after me and she stays with me.” (Lucy)*

*“You just feel like more comfortable, you know if your mum’s with ya...it’s not that bad”. (Gurdesh)*

Interviewees also talked about the special ways in which family members demonstrated their love and support. In particular, one way of demonstrating this love was through the use of food and drink. Zack’s parents made him his breakfast and his mum brought in a special drink of Lucozade as a treat when he was in hospital:

*“I remember like them bringing in toast for me to eat and then my mum gave me some Lucozade. You know, energy drink.” (Zack)*

In addition, Lucy recalled her grandmother’s special treatment on days when she has to travel to Leeds for her pacemaker check-ups:

*“Sometimes my Nan sometimes, erm, gets some food for me and pack it up in a lunch box so I can eat it on the way there”. (Lucy)*

### ***Coping Strategies***

The children and young people revealed strategies they used to help them cope with living with a pacemaker. Two main types of strategy emerged, those that help them manage themselves and their reactions and those that involve using others to help them cope.

#### ***Managing Self***

Again two main strategies of managing the self emerged, those of avoidance and distraction.

*Avoidance.* Some of the participants managed their anxiety about the pacemaker by avoiding talking about it with their family or anyone else:

*“I never talk about it.” (Josh)*

Other participants described attempts to avoid having memories of surgical procedures as a long term coping strategy, in the hope it would make future procedures less anxiety provoking.

*“ ‘Cause they didn’t give a pre-med and I didn’t want to remember going into the theatre because it makes me feel, like nervous. So I wanted the pre-med so I didn’t remember it. I don’t like remembering going into the theatre because then I remember knives, anaesthetic and all that blood and stuff. I don’t like remembering that.” (Zack)*

*Distraction.* The children and young people used distraction to take their mind of things when they were feeling “fed up” about having a pacemaker:

*"I watch TV sometimes just to make me forget about the whole thing or I play on games or I play with my brother sometimes". (Lucy)*

They also employed this strategy to distract themselves from worrying about impending medical procedures:

*"While I was waiting I had my Nintendo DS. I had two games. One of them was the... one of the Pokemon Ranger games. I kept going on that, like going round trying to complete that. Yeah because when I play Pokemon games it always, like, relaxes me". (Zack)*

#### *Using Others*

Several of the participants actively used other people to help them cope. In particular they found it helpful to know someone in a similar position:

*"Well I have a friend who has a heart problem as well...he's one of my good friends, yeah. So, it's not like different... so I've got someone I can relate to". (Gurdesh)*

Gurdesh also found that when someone faces similar challenges, they could help each other get through difficult times:

*"It's better having someone who understands what you're going through. 'Cause then we can talk about things; and if he's got a problem, I'll be able to help him and he can help me." (Gurdesh)*

#### **Gratitude**

Gratitude emerged as an important facet of coping with a pacemaker for many of the children and young people.

### *My Pacemaker Keeps Me Alive*

Many of the participants expressed gratitude for the fact that ultimately their pacemaker keeps them alive. This fact seemed to help stop them thinking about the negative aspects of having a pacemaker. When asked if he ever got “fed up” of having a pacemaker, Josh replied”

*“No, ‘cause it keeps me alive.” (Josh)*

### *Things Could be Worse*

In addition many of them described the feeling that things could be much worse than they are. For instance life could be much more restrictive without a pacemaker.

*“So if I didn’t have one then I’d be in and out of hospital quite a lot. Wouldn’t be able to do sport and I wouldn’t be able to do lots of other stuff I like”. (Zack)*

### *I’m Fortunate Compared to Some*

Some of the children and young people compared themselves favourably to other children with heart conditions. They saw themselves as fortunate in their situation compared to other children they had met during their times in hospital.

Downward comparisons, comparing themselves with those worse off than themselves, allowed them to evaluate their situation more positively.

Lucy did not feel ill in comparison to others and felt able to do more in terms of physical activity:

*“I can still do a lot of things I-i-k-e play on trampolines. And play...play a lot of games and most people might not be able to do tha... ‘cause they’re pretty ill so um...” (Lucy)*

### *My Pacemaker Gets Me out of Things I do not Want to Do*

Another aspect of having a pacemaker to be grateful for was the fact that it sometimes meant they did not have to do things they didn't want to. Josh appreciated the fact that his pacemaker meant he could escape the inconvenience of passing through the metal detectors at the airport.

*"Mm. And when I go on holiday, I'm not allowed to go through machines I don't really like going through the machines... 'cause you have to take your shoes off." (Josh)*

In addition several of the interviewees cited time off school as an advantage of having a pacemaker:

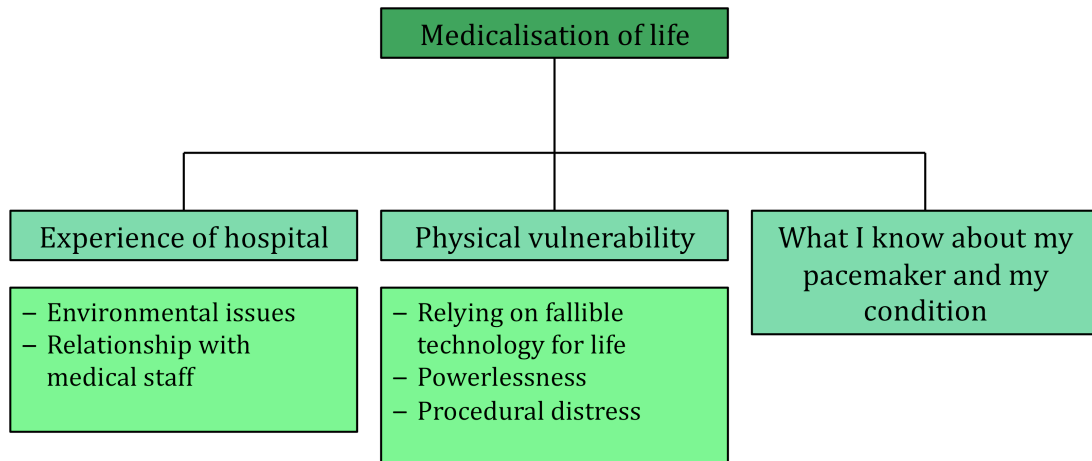
*"Well, I get to miss school sometimes because I go to the check-ups." (Lucy)*

### **Medicalisation of Life**

For many of the participants having a pacemaker meant many aspects of their life had become medicalised. This included having to make regular visits to the hospital, feelings of physical vulnerability and the significance of knowledge about their condition and pacemaker function. Figure 3 illustrates the relationship between subthemes for the main theme of 'Medicalisation of Life'. Table 3 illustrates which themes applied to each participant.



**Figure 3. Relationship between subthemes for 'Medicalisation of Life'**



**Table 4. Subthemes relevant to participants for the main theme of 'Medicalisation of Life'**

	Josh	Gurdes	Lucy	Zack
<b>Experience of hospital</b>				
<i>Environmental issues</i>	X	X	X	-
<i>Relationship with medical staff</i>	X	X	X	-
<b>Physical Vulnerability</b>				
<i>Relying on fallible technology for life</i>	X	-	X	X
<i>Powerlessness</i>	-	X	X	X
<i>Procedural Distress</i>	-	X	X	X
<b>What I know about my pacemaker and condition</b>	X	X	X	-

## ***Experience of Hospital***

### *Environmental Issues*

Some children described negative experiences of attending check-up appointments in hospital. Josh felt that appointments often take too long when he would prefer to be doing something else

*“Like, if your appointment’s at like half past 2 you don’t get seen until about half past 3. Wasted half your day sitting in hospital.” (Josh)*

However, as long as they felt well enough after surgery, some of the children experienced hospital as a fun place to play:

*“I also liked it because I liked...when I got a little bit better, I liked going to play”.*  
*(Lucy)*

However, some of the children found the experience of hospital harder as they got older and outgrew playing with the toys in the playroom. As adolescents they found themselves needing to find new coping strategies more appropriate to their stage of development. When asked what hospital visits were like Gurdesh replied:

*“I used to like going...” (Gurdesh)*

When asked when this changed, he explained:

*“When you stop going in playrooms!” (Gurdesh)*

It seems the usual methods used to help children cope with attending hospital, such as distraction with toys, are less relevant as they become adolescents. The challenge adolescents face is to find new coping strategies that are more appropriate to their developmental stage.

### *Relationship with Medical Staff*

Interviewees described nursing staff as kind. Lucy in particular found they tried to cheer her up however they could and described several such instances:

*“One of my dogs dropped on the floor so a nurse put like a bandage round its ear”.*  
(Lucy)

*“A nurse asked me which sticker would I like. And I just asked for a blue one and then they gave me a certificate as well”.* (Lucy)

However, some of the participants had less straightforward relationships with staff at the hospital. Gurdesh described relationships with staff that were sometimes difficult for him due to sometimes feeling misunderstood and at times, ignored. When asked if he would change anything about hospital visits he replied of the staff:

*“Well, like make them talk a bit more; be a bit more like understanding. They just like do stuff and they don’t even tell you what they’re doing. Well, I think that’s quite rude; they just stand there talking. I don’t like that.”* (Gurdesh)

Nevertheless, he then went on to deny being bothered by these experiences and said it did not stop him wanting to go to the hospital for check-ups.

*“It’s alright. It’s not that bad. It’s not like I don’t want to go to the hospital... I don’t mind it’s just I don’t think...I think it can be a lot more polite than they are.”*  
(Gurdesh)

I interpreted this contradiction as confusion about his feelings towards medical staff. He appeared to be angry with them for hurting him and interfering with him, but at the same time he values the fact that they contribute to making him better and keeping him alive.

### ***Physical Vulnerability***

Common to all the children and young people interviewed, was the experience of feeling physically vulnerable due to having a pacemaker.

#### *Relying on Fallible Technology for Life*

Three of the children described feeling reliant on a battery-powered device for life, in the knowledge that batteries run out. There was a sense of there being a 'countdown' to pacemaker replacement:

*"They kept monitoring me every like...from 6 months to 3 months. Saying, "Right, the battery's running low, we need to, like, replace it"". (Zack)*

This caused me to speculate on how they view their battery and whether they compare it to the less sophisticated and shorter-lived batteries powering their toys and games consoles.

In addition, two of the children had experienced pacemaker malfunction and described relying on fallible technology to keep them alive. Their response to this was shock and an overwhelming fear of death:

*"I was surprised then they kept saying, like, we need to get it done, "Have you got any questions?" The only two I could think of was, "Am I going to die?" and "Am I gonna to be Ok?" I couldn't think of any other questions". (Zack)*

As part of relying on fallible technology for life, participants experienced check-ups as providing reassurance that the pacemaker was working well. This reduced the anxiety around relying on a device with a history of going wrong to stay alive.

*"It makes me like feel more OK 'cause if I didn't go to see the people who tell me I'm ok it might make me feel worried, knowing that something might be wrong".*  
(Zack)

### *Powerlessness*

Several participants described experiences of being powerless and not in control in relation to having a pacemaker. Gurdesh alluded to the lack of control associated with being a passive recipient of technology. He found explanations of medical staff too complex to understand; he found it easier to just allow them to do it.

*"Yeah, well they did try and explain it but it was just a bit too complex so I thought, 'well, it's alright then.'" (Gurdesh)*

### *Procedural Distress*

Three of the children experienced procedural distress around pacemaker surgery and check-up appointments. They expressed a strong fear of surgery. When asked what the worst thing about having surgery was Lucy explained about the shock of waking up to a painful and unsightly scar:

*"Well...um...basically, waking up to it really...waking up and having like a scar on ya." (Lucy)*

Zack was the child who experienced most extensive procedural anxiety, which made every visit to hospital and medical procedure anxiety provoking.

*"I was worried because I don't like really the operation side of things." (Zack)*

### ***What I Know About My Pacemaker and Condition***

The medicalisation of these children's lives extended to knowledge of the heart and pacemaker function. Many had knowledge of how their heart works that other children their age would not ordinarily have. Lucy had good knowledge of her condition and why she needed a pacemaker.

*"Well, I think the first time my heart was going pretty slow and so they needed to sort it out really and...and then the second time, my heart was going fast because it didn't...um, that's why I was getting warm because it were going pretty fast." (Lucy)*

Not all the children and young people had such knowledge, with some knowing relatively little. This lack of understanding led to increased anxiety and a feeling of lack of control around surgical procedures.

*"Well, everyone's scared when they have an operation like you don't know what it's about; but you know you've got to have it and get better and that's it really." (Gurdesh)*

### **Parent Group Analysis**

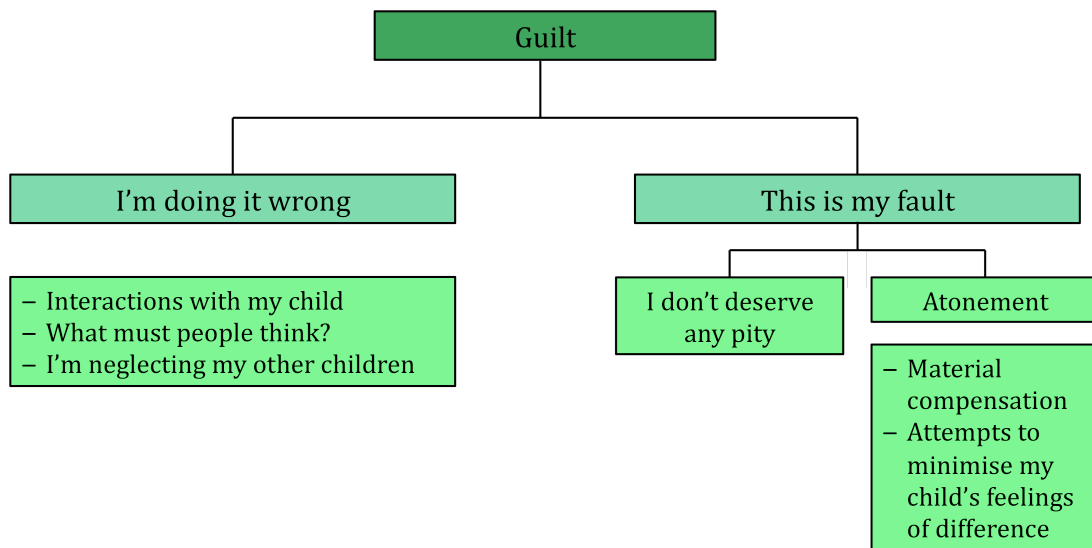
The analysis of the data provided by the parent group revealed five main themes: guilt, adjustment as a process over time, coping with having a child with a pacemaker, the battle for control and my perception of my child.

#### **Guilt**

Mothers described feelings of guilt as part of their experience of parenting a child with a pacemaker. These included the feeling that they were doing it 'wrong' much of the time and that the very fact their child had a pacemaker at all was their fault. Stemming from this sense of responsibility came the belief that this meant they did not deserve any pity and that they had to try and atone for it in some way. Figure 4 illustrates the

relationship between subthemes for the main theme of 'Guilt. Table 5 illustrates which themes applied to each participant.

**Figure 4. Relationship between subthemes for 'Guilt'**



**Table 5. Subthemes relevant to participants for the main theme of 'Guilt'**

	Lisa	Noor	Nicola	Angela
<b>I'm doing it wrong</b>				
<i>Interactions with my child</i>	X	-	X	-
<i>What must people think?</i>	X			X
<i>I'm neglecting my other children</i>	-	X	-	X
<b>This is my fault</b>	X	-	-	X
<i>I don't deserve any pity</i>	X	-	-	-
<b>Atonement</b>				
Material compensation	X	X	X	-
Attempts to minimise my child's feelings of difference	X	-	-	X

## ***I'm Doing it Wrong***

### *Interactions with my Child*

Several of the mothers felt they were making mistakes in their interactions with their child. Lisa felt that she should talk to Josh more about his pacemaker, but found this difficult due to her fear of upsetting him. This created an internal conflict between being open and honest, and protecting her son and herself from difficult emotions. The outcome was that she chose protection and avoided difficult discussions, which then led to feelings of guilt

*"I don't tend to talk about it with him. And I should really, but when I do he really does get upset." (Lisa)*

### *What Must People Think?*

Participants were also concerned about how they were perceived by others and in particular how their emotional reactions were perceived and appraised. They worried about not living up to their imagined expectations of other people. For example Angela was of the opinion that taking a matter of fact approach to Zack's surgery was the best way of dealing with it and communicated as much to others. However, this led to worries that they would think she did not care enough.

*"Whenever I've had time off work cause he's gone in - they've said 'How's he doing?' and I've said, 'Oh he's great, thanks.' And I've thought, is that a bit shallow? Do they want me to say, 'Well, you know, it's quite serious?'" (Angela)*

### *I'm Neglecting My Other Children*

All the interviewees had other children aside from the one with a pacemaker. At times they felt guilty that they were unable to give their other children the attention they either needed or desired due to having to look after the child with a pacemaker. Noor explained how her daughter feels sometimes:



*"She complains that she's a neglected child. 'We don't do things. Gurdesh gets priority.' When she was younger she came out with a line, 'D'ya know what I'm gonna do when I get older? I'm gonna assassinate Gurdesh' (Laughs). As silly as I found it and um, you know but there's a serious side to it because that's how she feels." (Noor)*

Although Noor makes light of it somewhat I believe this quote reflects a genuine concern that her parenting of her daughter is not adequate at times.

### ***This is My Fault***

Many of the mothers felt that they were responsible for the fact that their child had to have a pacemaker, either because the heart defect was found to be genetic or because it occurred in utero. Some wondered if they could have done anything differently during pregnancy to change things. Lisa knew the problem was genetic, as other members of her family had more minor heart defects. So there was nothing she could have done during pregnancy to change things, but this did not assuage her feelings of guilt that her genes had caused Josh to need a pacemaker.

*"Sometimes I thought to myself, 'Is it my fault he's got that heart?' Because it were all my family; do you know what I mean? It were all my family that's got somat wrong." (Lisa)*

### ***I Don't Deserve Any Pity***

As a result of this self-blame Lisa would not allow herself to feel sorry for herself. She also felt she did not deserve any pity from others. She became angry at people for pitying her and violently rejected their sympathy.

*"Everybody around me is going, 'I'm so sorry!' and crying and like that. 'Why are you telling me you're sorry? It's not me!'...You know, it's him." (Lisa)*

## *Atonement*

Another result of participants' feelings of responsibility for their child's heart condition was that they experienced a need to somehow atone for it.

*Material compensation.* Many interviewees attempted to make up for their child having a pacemaker by showering them with material possessions.

*"From the day I found out, he were ruined, you know what I mean? When I found he needed a pacemaker, got took into hospital, when I left me mum I went to Argos and bought him a Game Boy. There were no need for me to do that but I went and bought him a Game Boy. And I went home and got his pyjamas and stuff, come back down and went like that, 'Mummy's bought you a present.' Like...like I were trying to compensate for it. (Lisa)*

*Attempts to minimise my child's feelings of being different.* Further attempts at atonement involved trying to minimise their child's feelings of difference, feelings of difference that they felt responsible for. Participants sometimes employed seemingly opposing strategies. However they were all directed at the same outcome, trying to reduce their child's feeling of being different.

Some mothers took the approach of not treating their child any differently at all. In particular they tried to avoid being overprotective.

*"I don't think there's any point wrapping her up in cotton wool. Um, she gets on with doing whatever." (Nicola)*

However although they tried not to treat their child differently on a day-to-day basis, many were of the opinion that surgery was different and that they *did* need special treatment on these occasions. Angela described taking all Zack's favourite foods into hospital to make it feel more like home.

*"I took his favourite stuff in. I took marmite for his toast, I took Jelly tots, and I took biscuits and juice and stuff like that. Everything, you know, that they haven't got in hospital that he wants to make his coming round a bit better I suppose." (Angela)*

She had also forgone breakfast in a show of solidarity with her son, who was nil by mouth prior to his operation. She explained this lack of food as a cause for her feeling faint in the hospital.

*"They started fussing round me, I said, 'It's because I hadn't had any breakfast'. He didn't have any - I wasn't going to have anything." (Angela)*

A contrasting approach was to give them extra freedom that their other children did not have. Lisa believed her parental boundaries would be firmer if Josh did not have a pacemaker. This seemingly paradoxical approach of treating them differently in an attempt to stop them feeling different felt like a form of positive discrimination.

*"I don't want him to go to town, you know what I mean? I don't want him to go to the skate park. But if I say, 'No,' to him I don't want him to think, 'Oh God, I am definitely different aren't I now? Cos she won't let me go anywhere.' And he will say, 'It's cos I've got a pacemaker you won't let me go.' 'It's not! It's cos you're 11!" (Lisa)*

Another popular strategy was to make great efforts to prevent the pacemaker from placing any restrictions on the children. Mothers were proactive in getting their child included in someway in anything they wanted to do. Angela was particularly proud of her efforts:

*"I don't let it stop him doing anything he wants to do. If there's a way round it." (Angela)*

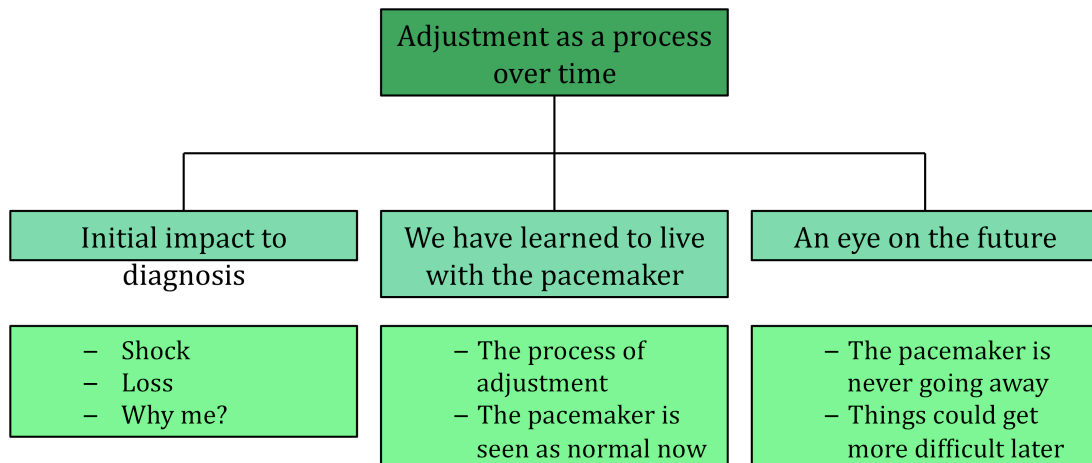
Finally they attempted to prevent others from treating their son or daughter differently. Lisa explained what she told school in response to their anxiety about him going on a residential holiday.

*“I don’t wrap him in cotton wool and I’m his mother. So don’t I don’t expect you to, you’re his teacher.” (Lisa)*

### Adjustment as a Process Over Time

All mothers described adjustment to their child having a pacemaker as a process over time. They began with the initial impact of diagnosis and their reaction. They then went on to describe how they have learned to live with the pacemaker in the present day. Finally they explained their thoughts of the future with regard to the pacemaker. Figure 5 illustrates the relationship between subthemes for the main theme of ‘Adjustment as a Process Over Time’. Table 6 illustrates which themes applied to each participant.

**Figure 5. Relationship between subthemes for 'Adjustment as a Process Over Time '**



**Table 6. Subthemes relevant to participants for the main theme of 'Adjustment as a Process Over Time'**

	Lisa	Noor	Nicola	Angela
<b>Initial impact of diagnosis</b>				
<i>Shock</i>	X	-	X	-
<i>Loss</i>	X	-	-	-
<i>Why me?</i>	X	-	X	-
<b>We've learned to live with the pacemaker</b>				
<i>The process of adjustment</i>	X	X	-	-
<i>The pacemaker is seen as normal now</i>	X	X	X	-
<b>An eye on the future</b>				
<i>The pacemaker is never going away</i>	-	-	X	X
<i>Things could get more difficult later on</i>	X	-	X	-

### ***Initial Impact of Diagnosis***

#### ***Shock***

Interviewees reported feeling shocked and stunned when they first discovered their child would need a pacemaker. Often the diagnosis was experienced as very sudden, with little time to process the news before surgery was required to take place. Nicola had a poor memory of the events immediately after the event due to the shock she experienced.

*"I drove to my mum's house and I just got out the car and just was devastated to think that there was something wrong with her. Basically fell out of the car, I think! That's the only bit I remember! Pulling up, my mum coming into door and then just...that were it." (Nicola)*

## *Loss*

For some, their child having a pacemaker implanted meant the loss of their old doctor. Josh had a pre-existing congenital heart problem that he had received previous surgery for. However having a pacemaker automatically meant being transferred to the care of the doctor who cares for all the congenital heart disease patients requiring pacemakers.

*“ ‘We’re admitting ya.’ He says um, ‘And now you won’t have me as consultant no more, you’ll be transferred to Dr Blackburn’, he said.” (Lisa)*

## *Why Me?*

Parents responded to the news their child would need a pacemaker with thoughts of ‘why has this happened to me?’ There was a sense of injustice and needing to find answers.

*“Why’s my boy got that? Why my boy? Why’s he got a heart problem and why’s he got a pacemaker?” (Lisa)*

## ***We’ve Learned to Live with the Pacemaker***

### *The Process of Adjustment*

Parents described adjusting to the fact the pacemaker is part of their lives as a process over time.

*“It’s...it’s not...it’s sort of a part of his life and we’ve just learnt to live with it.”  
(Noor)*

### *The Pacemaker is Seen as Normal Now*

Many reported that the pacemaker was normal to them now and that they could not imagine life without it.

*“I look at it now, it’s kinda...it’s just everyday life now. It’s the norm.” (Lisa)*

### **An Eye on the Future**

#### *The Pacemaker is Never Going Away*

However despite feeling they had adjusted to the presence of the pacemaker and find it manageable now, there is also the knowledge that it is never going away. There is no relief from this and their child will never be free from medical interference as long as they live.

*“You just think she’s got a lifetime of this. When someone actually explains to you...Dr Blackburn explained to us what she’d have to have done and...you just think it’s...it’s a lifetime commitment with it really. She’s got to go for regular checkups. She’s got to, you know endure operations every – I know it’s only every so many years, but it’s something that she’ll never be able to...At the moment it’s not gonna change.” (Nicola)*

#### *Things Could Get More Difficult Later On*

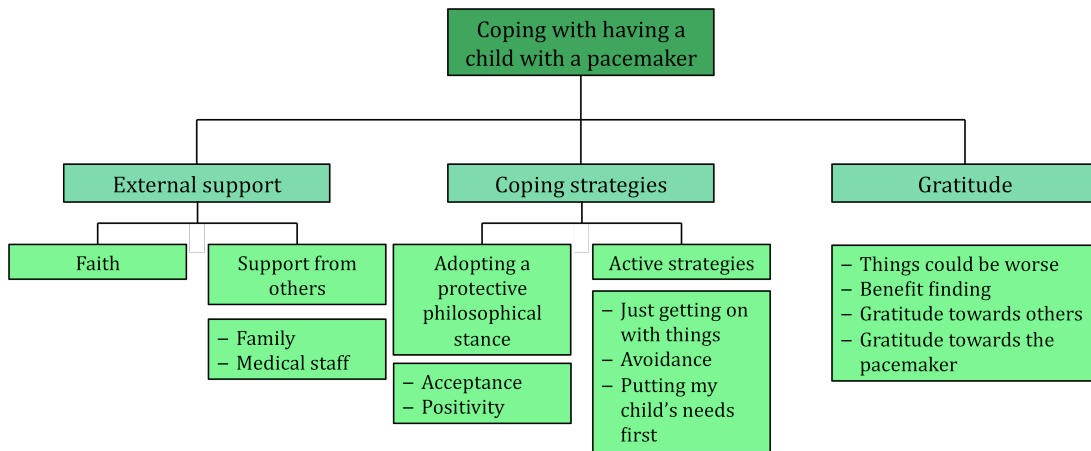
In addition mothers felt an uncertainty as to whether this well adjusted state would endure into adulthood. Some anticipated things might get more difficult to manage as their child got older, as the pacemaker may affect their life to a greater extent, as they become an adult.

*“I suppose maybe as he grows older I don’t know how much of an inconvenience it’ll be.” (Angela)*

## Coping with Having a Child with a Pacemaker

Participants described different aspects of coping with having a child with a pacemaker. This included the significance of external support, their own coping strategies and finally, the importance of gratitude to coping. Figure 6 illustrates the relationship between subthemes for the main theme of 'Coping with Having a Child with a Pacemaker'. Table 7 illustrates which themes applied to each participant.

**Figure 6. Relationship between subthemes for 'Coping with Having a Child with a Pacemaker'**



### **External Support**

#### **Faith**

Only one of the mothers cited religious faith as an external support which helped her cope, and this was Noor. However, it felt very significant to her and it was a recurring theme throughout her interview.

*"I do have a religious belief, right um, which I've developed. I didn't have any belief to start off with. Um, I have picked up, you know my religion on the...on the...on this whole of trial or whatever you want to call it through Gurdes's illness." (Noor)*



**Table 7. Subthemes relevant to participants for the main theme of 'Coping with Having a Child with a Pacemaker'**

	Lisa	Noor	Nicola	Angela
<b>External support</b>				
<i>Faith</i>	-	X	-	-
<i>Support from others</i>				
Family	X	-	X	X
Medical staff	X	X	X	X
<b>Coping strategies</b>				
<i>Adopting a protective philosophical stance</i>				
Acceptance	X	X	-	X
Positivity	-	X	X	-
<i>Active strategies</i>				
Just getting on with things	X	-	X	X
Avoidance	X	X	-	X
Putting my child's needs first	-	X	X	X
<b>Gratitude</b>				
<i>Things could be worse</i>	-	X	X	X
<i>Benefit finding</i>	-	-	X	X
<i>Gratitude towards others</i>	X	-	X	-
<i>Gratitude towards the pacemaker</i>				
The pacemaker keeps my child alive	X	X	X	-
The pacemaker allows my child to live their life	-	X	-	X
The pacemaker makes my job as a parent easier	-	X	X	X

*Support From Others*

*Family.* Most of the interviewees described how family support had made things easier for them. When asked what got her through Lucy's first operation Nicola explained:

*“We’ve both had really strong families as well like support – support from our families so, um people ringing and asking how she was and um, you know that was...that was the biggest help really.” (Nicola)*

As well as showing concern for Lucy, Nicola found the practical help with everyday tasks her mother provided allowed her to focus on Lucy’s needs at that time.

*“My mum would take a lot of um, my mum would come round and remove the stress off me shoulders like, you know. My washing; my ironing; just knowing that Bobby [younger son] was taken care of as well; obviously I’ve got him and I need to know he’s okay, so my mum had Bobby. Um, that’s a massive weight off your mind.” (Nicola)*

*Medical staff.* All the mothers cited medical staff as a huge part of coping with their experience of living with the pacemaker.

*“Staff were great at the hospital. Without a doubt, they were brilliant. They were absolutely fantastic. Erm, I mean it’s such a difficult time.” (Noor)*

Lisa went as far as to describe the medical team as an extended family, a reflection of the high status she bestows upon them.

*“He’s as much a as an important part of Josh’s life as what...as what we are, I think. And so are them down there. They’re like a bit of an extended family.” (Lisa)*

One of the most significant aspects of interviewee’s relationships with staff was consistency. They all valued the level of familiarity they had been able to develop due to seeing the same people every time they attend hospital.

*“I suppose if you had to have a (I’m not going to call it a second home), but a place where you have to visit regularly it’s always nice to see the same faces. Um, know*

*that they're still there and nothing's changed. It could be six months or a year since you were last there but that little band of people that always see to you, that are always there, make everything right." (Angela)*

### **Coping Strategies**

#### *Adopting a Protective Philosophical Stance*

Many mothers coped with this experience by adopting the protective philosophical stance of either acceptance or positivity.

*Acceptance.* Accepting what they felt they could not change and thus avoiding wasting valuable energy was a part of coping for many of the mothers. Noor found there was no point wishing things were different, but simply accepted things as they actually were.

*"You can't sort of think, 'Oh, can we be without it or can we be with it?' Because it's what...it's...it's part of his condition." (Noor)*

*Positivity.* Maintaining a positive outlook was also helpful for some, with some going as far as the belief that hope and positivity would affect their child's health outcome in a positive direction.

*"That's what I've taught my son: to be very positive and if he's positive, then things are gonna be positive; there's gonna be a positive outcome." (Noor)*

#### *Active Strategies*

Participants also adopted more active coping strategies including just getting on with things, avoidance, handing over parental responsibility to the doctor and putting their child's needs before their own.

*Just getting on with things.* Many participants adopted the pragmatic approach of just getting on with things and ‘holding it together’. They often felt there was no choice other than to cope.

*“Then I’d to sort of snap out of it (snaps fingers) and deal with what was in front of us. You just...you get on with it, don’t ya?” (Nicola)*

Lisa illustrated her response to people who expressed surprise at her ability to cope with her situation:

*“ ‘I don’t know how you can cope with him having a pacemaker.’ Well, why not? If I didn’t I’d be stuck, and I’d sit in my own, I’d sit in me own pee.” (Lisa)*

Participants coped out of necessity because they feared the alternative would be catastrophic (in Lisa’s case complete physical and mental breakdown).

*Avoidance.* Many employed avoidance as a coping strategy; some avoided difficult emotions or cognitions. Lisa described a feeling of being numb in response to Josh’s surgery. For her, this avoidance of psychological processing prevented her from falling apart:

*“I can’t explain how I felt ‘cause I don’t think I felt owt...Do you know what I mean? My brain kinda told me not to feel owt...don’t feel it ‘cause if you do you’re gonna...I’ll crack.” (Lisa)*

Others attempted to manage by minimising the extent of the trauma or distress they experienced.

*“I’m always pleased it’s not my son, because the trauma you have – well not the trauma – but the upset and the worry that you have as small as it is...” (Angela)*

Angela let her mask slip by mentioning the word trauma, but she quickly corrected herself and played down her own distress.

*Putting my child's needs before my own.* It was important to mothers that their child was coping well with the experience.

*"As long as she's alright, I'm alright." (Nicola)*

Therefore, a way of improving their ability to cope was to focus on their son or daughter's needs, often to the detriment of their own. Some described an inability to think about themselves unless they knew their child no longer needed them.

*"You don't really think about you: you're not... that important...How you're feeling is not important. You just deal with your child, yeah...you just deal with... with how she's feeling. And there's time for you later." (Nicola)*

However, mothers did not always find it easy to constantly put their child's needs before their own. Sometimes this involved making sacrifices and led to feelings of frustration, as Noor explained:

*"Well, it was really frustrating because um, when Gurdesh had his operation last Easter, we went to um, Florida. And um, I had to take somebody else along with me so that my daughter could enjoy all the Disney parks. I've always wanted to go, you know. I'm into my rides and things but then I had to sacrifice that for my son because all we did was sit around, and we walked round and we enjoyed everything else but we couldn't...well, I couldn't go onto any of the rides because my son; because I couldn't leave him out. And it is... you change your lifestyle to meet with theirs." (Noor)*

## **Gratitude**

Gratitude was an important facet of coping for all the interviewees.

### *Things Could be Worse*

Many expressed a feeling that things could be much worse for them and their child. Many made favourable comparisons with other children with much more serious conditions and more disrupted lives.

*"We are just pleased that it's a manageable problem that he's got and he still has a full good quality life." (Angela)*

Nicola explained how she felt having a son with a pacemaker would be more difficult than a daughter, due to her beliefs about the gender differences in lifestyle.

*"I don't think there's anything difficult with having a girl...I think it could be more...harder if it was a boy. Because they can't do high-contact sports or anything like that." (Nicola)*

### *Benefit Finding*

Some described the benefits of their child having a pacemaker. Two of the mothers viewed the diagnosis as a positive event. There was a sense that it was better to know about it than not and they felt fortunate that the problem was found instead of lying undiscovered. They both alluded to the phenomenon of sudden death in adolescents and felt reassured that the diagnosis would prevent this from happening to their child.

*"I'm just thankful that someone found it and now the initial problem and that it's been treated in that she's thriving now. So it's positive that she's...it's positive that she's it's been found and she's sorted. I know she's not going to be one of them*

*statistics of young adolescent dying...dying somewhere. I know that...I know that she's safe! (Nicola)"*

Mothers also found benefits in the effect their experiences had on strengthening interpersonal relationships. Nicola explained how her relationship with Lucy had been strengthened by their shared experience.

*"We've got quite a close relationship, me and Lucy, probably because we've spent so much time together in hospital. Um, and I think I have a closer relationship with her dad's mum, her grandma, because of it..." (Nicola)*

#### *Gratitude Towards Others*

Participants expressed gratitude towards others including family members for all the support they provided, and medical staff for keeping their child alive. Lisa explained her feelings towards Consultant:

*"He's as much to do with Josh's life as I am. D'ya know what I mean? He...he keeps Josh alive in my opinion." (Lisa)*

#### *Gratitude towards the pacemaker*

Most of the gratitude that mothers felt was directed towards the pacemaker itself.

*The pacemaker keeps my child alive.* Mothers expressed their gratitude to the device that keeps their child's heart beating.

*"The pacemaker is keeping him functioning, his heart, which really keeps him alive." (Noor)*

*The pacemaker allows my child to live their life.* As well as keeping them alive the pacemaker also improved quality of life for the children. Mothers explained that without it their child would have much less freedom and be unable to do the things they enjoyed and that made them who they were.

*“Without his pacemaker, I suppose he wouldn’t have such a long leash. He certainly wouldn’t be playing football.” (Angela)*

*The pacemaker makes my job as a parent easier.* Finally interviewees were grateful to the pacemaker for making their job as a parent easier. It allowed their children to do more, so parents were required to say ‘no’ less and thus had fewer arguments about boundaries. In addition, knowing they were safe provided them with a sense of security, allowing them to worry less.

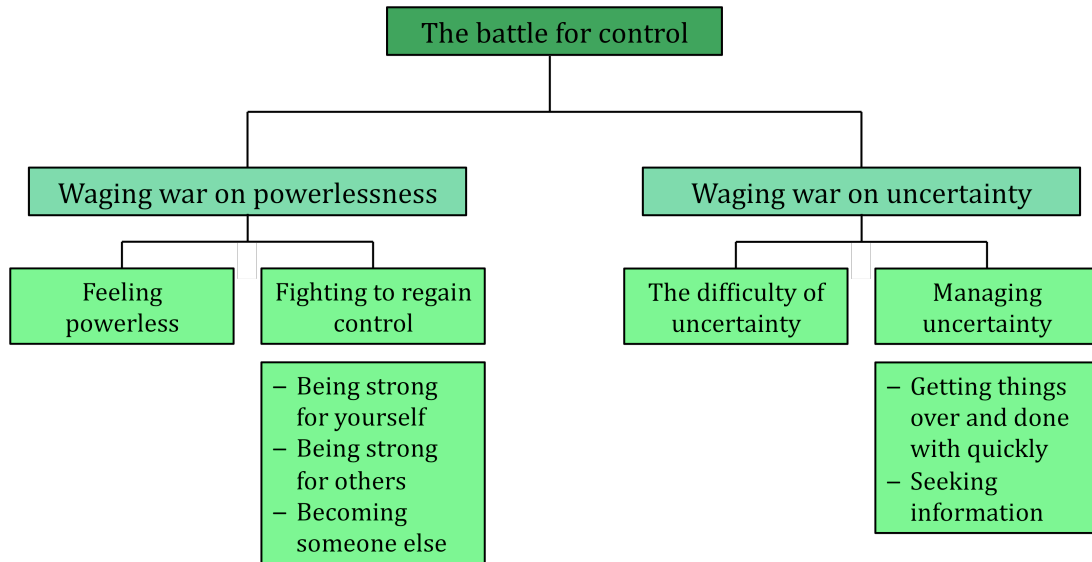
*“ ‘Cause he’s more...more...well you feel more sec...secure psychologically because you know something...he’s not going to be collapsing or fainting.” (Noor)*

### **The Battle for Control**

Much of the language used by the mothers in their interviews was reminiscent of the language of war and conflict. This inspired the metaphors used to describe the experience of the battle for control with regard to the pacemaker. This battle involved waging war on both feelings of powerlessness and uncertainty in order to gain a sense of mastery of the experience. Figure 7 illustrates the relationship between subthemes for the main theme of ‘Battle for Control’. Table 8 illustrates which themes applied to each participant.



**Figure 7. Relationship between subthemes for 'Battle for Control'**



**Table 8. Subthemes relevant to participants for the main theme of 'Battle for Control'**

	Lisa	Noor	Nicola	Angela
<b>Waging war on powerlessness</b>				
<i>Feeling powerless</i>	X	X	X	X
<i>Fighting to regain control</i>	X	X	-	-
Being strong	X	X	-	X
Being strong for others	X	X	-	X
Becoming someone else	X	-	-	-
<b>Waging war on uncertainty</b>				
<i>The difficulty of uncertainty</i>	X	-	X	X
<i>Managing uncertainty</i>				
Getting things over and done with quickly	X	-	X	-
Seeking information	-	X	X	-

## **Waging War on Powerlessness**

### *Feeling Powerless*

All the participants reported feeling powerless with regard to the pacemaker and their child's condition. This lack of control was difficult to accept.

*"When you've got an ill child... because you're helpless, you're not in control...any...you're not in control of any circumstances." (Noor)*

Following a pacemaker malfunction, one mother described the frustration of being forced to stay in hospital until an operating slot for her daughter became available. This frustration was compounded by the fact that outwardly there did not appear to be anything wrong with her daughter, yet she was still compelled to remain in hospital. There was a feeling of being kept there against her will, almost as a hostage, or prisoner of war.

*"So, we had to stay that weekend and she was um... she was done first thing on the Monday morning. All that time you're waiting for them to say, 'There's nothing wrong with her! She was in a hospital bed! And there was nothing wrong with her. And he said, 'We can't guarantee that she'll get that slot but if you go home she'll not get it.'" (Nicola)*

Angela described an alternative experience of powerlessness, that of having a lack of control over her own body. She experiences fainting in a response to her fear of hospitals and medical procedures. She described her long and unsuccessful battle to suppress this response.

*"I wish I didn't but it's an automatic bodily reaction for me. It's something I've tried to master all my 45 years. But, erm, no, I'm not too good with it." (Angela)*

### *Fighting to Regain Control*

Participants responded to their feelings of powerlessness by fighting to regain control of the situation. Lisa felt the need to control this aspect of her life as she did every other.

*"It were kind of like, I had to control it all. Do you know what I mean? I am the one that, not in a bad way, but kinda like because in my house, I'm the one who runs my house." (Lisa)*

*Being strong for yourself.* One of the strategies used to regain control was trying to stay mentally strong. Noor portrayed herself outwardly as strong. At times it felt like she was trying to convince herself of the truth of her assertion as much as she was trying to convince others.

*"I am an extremely, extremely strong person." (Noor)*

Some mothers felt they did not have permission to be afraid. For Lisa, crying represented a loss of control and a failure to be strong, therefore was not allowed. However maintaining this tough persona was costly, resulting in a dramatic flood of emotion when she could no longer hold it at bay. Here she describes how hard she was on herself when, in her eyes, she failed to maintain her façade:

*"When he goes down for surgery and if I...when I walk away. I cry, I do. I blubber. I end up falling on floor and blubbing. Like you see on telly, that's what I do. But in my head I'm thinking, 'You dick-head! Get up! Stop doing that.'" (Lisa)*

The final part of the quote is reminiscent of a sergeant major shouting orders to a soldier.

*Being strong for others.* As well as being strong for themselves, interviewees felt they had to be strong for others in their life. This was particularly true with regard to their children and the rest of their family. Often it felt like there was a sense of isolation, of

ultimately having to fight a single-handed battle. Lisa explained her need to protect her family. She was afraid that if she did not cope, then no one would cope.

*“I didn’t want to upset me mum, you know what I mean? And everyone else, I didn’t want them to see me crying. Because, like if I cried...if I break, they’d break.”*  
(Lisa)

It felt like her reasons for protecting her family were both complex and circular. She needed to prevent them falling apart because if they did, then so would she. She could not manage without them either; the supportive relationship was actually entirely reciprocal.

*Becoming someone else.* Sometimes to regain control and remain strong, participants felt they almost needed to become someone else. Lisa described crying uncontrollably to a friend on the phone outside the hospital but then automatically switching to someone else (someone calm and unemotional) as she re-entered the building. She had to become like a soldier in order to be brave enough to get through this difficult experience.

*“Then I’d walk back into hospital doors and, whoompf, I’m someone else. It were so weird; ‘cause I didn’t want to upset him; I didn’t want to upset me mum, you know what I mean? And everyone else. It’s like I go into soldier mode...I just get on with it.”* (Lisa)

### ***Waging War on Uncertainty***

#### *The Difficulty of Uncertainty*

Mothers experienced the many uncertainties of having a child with a pacemaker as very challenging. This was illustrated by Lisa, who did not mind the doctor being blunt about her son’s diagnosis, as this made the situation easier to deal with by removing any ambiguities.

*“He were quite blunt, but I liked him being like that because there was none of this messing around saying, ‘We think it’s this...we think it’s that.’ He told me what...what were wrong.” (Lisa)*

Many also experienced the fear of the unknown as the worst thing about the first time their child had surgery. Uncertainty as to what would happen and what it would be like increased their anxiety levels. When asked what Zack’s first surgery was like, Angela replied:

*“Umm. Nerve racking I will admit, nerve racking. It’s the fear of the unknown. And you’re not sure what is going on.” (Angela)*

### *Managing Uncertainty*

Interviewees employed different methods of managing the inherent uncertainty and thus regaining a feeling of control over the situation.

*Getting things over and done with quickly*. Participants tried to get things such as surgery or check-ups over and done with as quickly as possible in order to reduce their anxiety around the uncertainty of the outcome. Nicola explained how she and her partner communicated this to the doctor once they knew Lucy would need surgery:

*“We said to him at the time, you know, ‘Everyone’s really anxious. We just want to get it over for her’”. (Nicola)*

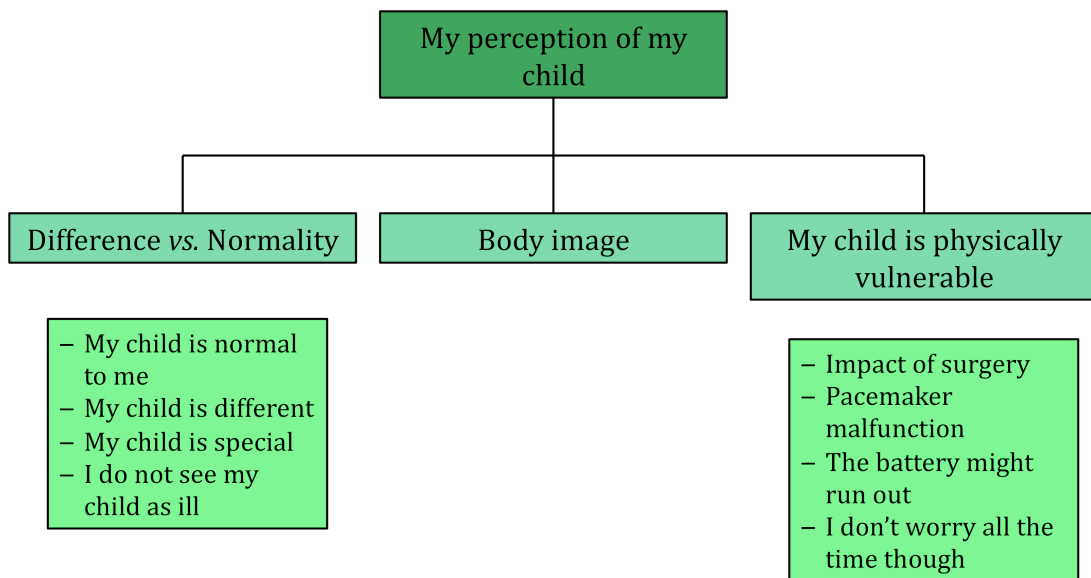
*Seeking information*. Another way of managing uncertainty, including fear of the unknown, was to seek out further information and knowledge.

*“We did a lot of jumping on the internet and reading things in America. ‘Cause you do, you feel better when you know more, don’t you?” (Nicola)*

## My Perception of My Child

Mothers explained how the pacemaker affected their perception of their son or daughter. The themes that emerged were: difference versus normality, body image and my child is physically vulnerable. Figure 8 illustrates the relationship between subthemes for the main theme of 'My Perception of My Child'. Table 9 illustrates which themes applied to each participant.

**Figure 8. Relationship between subthemes for 'My Perception of My Child'**



**Table 9. Subthemes relating to participants for the main theme of 'My Perception of My Child'**

	Lisa	Noor	Nicola	Angela
<b>Difference versus normality</b>				
<i>My child is normal to me</i>	-	-	X	X
<i>My child is different</i>	X	-	X	-
<i>I do not see my child as ill</i>	-	-	X	X
<b>Body image</b>	X	-	X	-
<b>My child is physically vulnerable</b>				
<i>Impact of surgery</i>	X	-	X	X
<i>Pacemaker malfunction</i>	X	X	X	X
<i>The battery might run out</i>	X	X	X	-
<i>I don't worry all the time though</i>	X	-	X	X

### ***Difference Versus Normality***

#### *My Child is Normal to Me*

Two of the mothers expressed how, despite the fact that their child had a pacemaker, they still perceived their child as normal.

*"To me, he's just a lad." (Angela)*

*"She's normal really in my eyes." (Nicola)*

However participants were also conscious of the fact that, although their son or daughter was normal to them, they were not perceived as normal by others. Angela illustrated how the experience of others being shocked by Zack having a pacemaker served to make her feel abnormal.

*“That somebody so young would have that condition. It’s like, “Oh, oh right!” I think they expected it for old people. Yes, yes they look at you – not gone out but double takes maybe. ‘Cause we’re out the norm.” (Angela)*

### *My Child is Different*

At other times mothers did perceive their child as being different to their other children and to the child’s peers. In admitting she sees Josh as different, Lisa was also admitting that her desire for him not to feel different was futile.

*“I don’t want him to feel like he’s different. ‘Cause he is different; he is different to his friends. There’s no two ways about it. He is different.” (Lisa)*

### *My Child is Special*

However Lisa also saw Josh as different in a positive way. She believed the pacemaker made him special and set him apart from his siblings and his peers.

*“I see him as being that little bit more...I know I shouldn’t say it, I see him as being that little bit more special.” (Lisa)*

### *I Do Not See My Child as Ill*

Two mothers had children who did not have any additional diagnoses aside from heart block and had not any form of corrective cardiac surgery (Nicola and Angela). These interviewees experienced a disparity between the knowledge that their child had a life threatening arrhythmia that required correction by a pacemaker, and the child’s outward appearance of health and vigour.

This was particularly so when the child was initially diagnosed, when interviewees experienced a sense of disbelief. However this feeling of incongruity also persisted to the



present day due to the treatment being effective in maintaining their vitality. The pacemaker is invisible and does its important work privately, beneath the surface. The fact their child does not require any overt symbols of illness such as medications added to the feeling of incongruence felt by mothers. Angela goes as far as to say she sees Zack as the healthiest of her two children.

*“Well he’s never been a sickly child. When people talk about children they expect them to be on medication and they expect them to be poorly. Zack has never been poorly. Out of the two boys, he’s the healthiest one of the two even though he has you know... He’s got his pacemaker in.” (Angela)*

### **Body Image**

Despite the internal nature of pacemaker, there are some outward signs when a child has one. There is the scar on the shoulder and the pacemaker box can sometimes be seen to protrude under the skin if a child is slightly built. Some mothers commented on the scarring and visible presence of the pacemaker. There was a sense that the pacemaker had changed their child’s body from the perfect, unmarked one they gave them at birth. Lisa admitted to experiencing disgust at having to look at or touch Josh’s scar and so avoided doing so whenever possible. It felt like it was visible and tactile reminder of his condition.

*“I don’t like seeing his... when he gets in bath and stuff like that. I kinda tend not to look at...look at there; ‘cause I don’t like that...I can see it poking out and that scares me. And like when we go on holiday, and I’m putting sun cream on him and get me mum to do it and that’s an awful thing to say, but I don’t want to touch it. Because it sticks...because it’s so thin, it sticks out; it’s like a little box here on him. And I don’t like to.” (Lisa)*

### ***My Child is Physically Vulnerable***

All participants perceived their children as physically vulnerable at times due to the pacemaker.

#### *Impact of Surgery*

Many saw their son or daughter as too small and vulnerable to undergo surgery. Many described a huge sense of relief when the surgery was all over and their child had come round from the anaesthetic. The fear that their child might never wake up was prevalent.

*“That’s obviously a fear: That they’re gonna be put to sleep and never wake up again.” (Nicola)*

#### *Pacemaker Malfunction*

This was a source of worry regardless of whether the scenario was real or imagined. Two of the participants had actually experienced their child’s pacemaker malfunctioning. In Nicola’s case, one of her daughter’s pacemaker leads partially fractured. Her quote conjures up an image of the fragility of her daughter’s life, which she felt was hanging by a thread.

*“I can remember looking at the notes and it saying, ‘Possible lead failure,’ on her notes. She was basically being kept alive by a finest of wires.” (Nicola)*

The other two mothers who had not experienced any form of malfunction, still worried about the fact that it was a possibility. Noor illustrated how her perception of Gurdesb’s vulnerability was increased by worries that things in the environment may cause the pacemaker to malfunction. These worries persisted despite information provided by medical staff, which failed to reassure her.

*“My personal worries are things like um, you know broadband, which Gurdesh says no, no, but I think it does affect...I don’t...I don’t know if it affects the pacemaker like microwaves and, you know all this what we’ve got in our environment as a general...but I mean, you know they say, ‘Oh, it doesn’t.’ But I personally believe that there are effects; and that’s all around us and it’s not something we can control. So I always have that in the back of my mind.” (Noor)*

### *The Battery Might Run Out*

All but one of the mothers expressed a fear that the pacemaker battery might run out. This was despite repeated reassurances from the doctor that this would not happen due to regular check-ups and a large back-up reserve.

*“They still say he’s got like a year and a half to two years left of battery on it. ‘Cause that scares me, what if the battery runs out? But Dr Blackburn said to me, ‘Lisa we know when it’s going down. It’s also got three months reserve on it as well.’” (Lisa)*

Participants may be comparing the pacemaker to other battery-powered devices in their lives such as mobile phones, remote controls and laptops. Although these batteries function in a very different way, it is the only frame of reference they have. In addition, none of the other battery-powered devices in their lives are as indispensable or emotionally salient as the one keeping their child alive.

### *I Don’t Worry All the Time Though*

Despite these feelings that their child is physically vulnerable, mothers reported that they did not worry about this all the time. Many of the participants described trusting their children to know their own limits with regard to the pacemaker, which provided some relief from worry.

*“She’s sensible enough to know if there’s something wrong.” (Nicola)*

In addition when discussing Zack's pacemaker failure, Angela explained that her lack of hyper-vigilance to signs of pacemaker problems meant that, although with hindsight she recognised the signs, pacemaker malfunction was not her initial conclusion.

*"Thinking about it backwards the signs were there but that was the last thing we thought of, that it wasn't working." (Angela)*

## DISCUSSION

### Summary of Main Findings

#### *Child Group*

All of the children and young people commented on the relationship between their identity and the pacemaker. This relationship consisted of the direct effect of the pacemaker on their identity and the process of integrating the pacemaker into their sense of self. They all experienced the pacemaker as simultaneously exerting a threatening and a protective influence on their identity. The threat posed by the pacemaker included making them feel different to others and placing restrictions on their lifestyle, adding to their feelings of difference. The children and young people also went on to describe ways in which they attempted to protect themselves from this threat. These included portrayal of their ideal self and attempts to reassure themselves they are just like everyone else. The positive effects of the pacemaker on identity incorporated the fact it made them feel special and freed them to be themselves.

Finally integration of the pacemaker into their identity was an issue for all the children and young people. Three of them appeared to have achieved this fairly successfully, describing the pacemaker as part of them. However the other young person had not accepted the pacemaker in the same way, calling into question its very existence and denying its impact on his life.

All the children and young people discussed coping with having a pacemaker as a significant part of their experience. Three main aspects of coping emerged from the analysis, environmental aids to coping, coping strategies and gratitude. Environmental aids to coping included maintaining continuity and routine and family support. The coping strategies described by the participants fell into two types, strategies involving managing the self (consisting of avoidance and distraction) and strategies that made use of others to facilitate coping. Finally the children and young people experienced gratitude as a key aspect of coping. They were grateful that the pacemaker kept them alive and that it allowed them to avoid things they do not want to do. They also felt things could be worse

for them and they saw themselves as fortunate compared to some other children with heart conditions. This allowed them to evaluate their situation more positively.

All the children and young people experienced the medicalisation of their lives due to the pacemaker. This encompassed experiences of hospital, feelings of physical vulnerability and knowledge of their pacemaker. The experience of hospital included environmental issues, such as hospital being a fun place to play, check-up appointments taking too long and the changing experience of hospital with age. It also incorporated relationships with medical staff, some of which were positive and others of which were more complicated. All the children and young people experienced feelings of physical vulnerability as a result of having a pacemaker. They described relying on fallible technology for life and feelings of powerlessness. They also described experiencing procedural distress before surgery and during check-up appointments. The final aspect of the medicalisation of their lives was their knowledge of their pacemaker and condition. Some of them had good knowledge that exceeded what would be expected from the average child. Conversely others had very poor knowledge, leading to feelings of anxiety and lack of control.

### ***Parent Group***

All the mothers experienced feelings of guilt as part of being the parent of a child with a pacemaker. They felt as though they were doing things wrong. For instance, some felt they were not getting things right when it came to interactions with their child with regard to the pacemaker. In addition, they worried what other people thought of them and about their reactions to their child's condition. They experienced feelings of guilt for not living up to their perceived expectations of other people. Mothers also worried about not doing a good enough job of parenting their other children at times due to focussing on the child with pacemaker.

Participants also felt that it was their fault their child had to have a pacemaker. From this belief emerged the view that they did not deserve any pity from others regarding their situation. They also felt the need to atone for the damage they felt they had caused. There were a number of ways in which they attempted to do this. Some mothers attempted to compensate their child with material possessions, whereas others made strenuous and dedicated efforts to minimise their child's feelings of being different.

All participants experienced adjustment to the pacemaker as a process that took place over time. The experience began with the initial impact of the diagnosis; mothers experienced feelings of shock, loss and were left asking the question, "Why me?" However all participants reported that they had now learned to live with the pacemaker. They described the process involved in getting to this point and the current feeling that the pacemaker was a normal, everyday part of their lives. Some parents also had an eye on the future; they acknowledged that the pacemaker would always be there and their child would never be free from medical interference. They also felt uncertainty as to whether life with the pacemaker might become more difficult to manage as their child grew into adulthood.

As with the child group, coping was a central part of the parental experience for all participants. The three main aspects of their experience of coping with having a child with a pacemaker were the importance of external support, the coping strategies they used and gratitude. External support encompassed faith and support from others. Faith was only cited by one mother as an aid to helping her cope, however it seemed to be a highly significant feature of her experience. Mothers also found support from family, and in particular the medical staff, essential to their ability to manage the experience.

All the mothers described various coping strategies. These included adopting a protective philosophical stance, something done by all the mothers. As part of this they found both acceptance and positivity helped them cope with the experience. Other coping strategies were more active and involved just getting on with things, avoidance and putting their child's needs before their own. In addition, all the mothers interviewed experienced gratitude as an important facet of coping. Gratitude encompassed the feeling that things could be worse and being grateful that they were not, seeing the diagnosis as a positive event and finding benefits of their child having a pacemaker. Also mothers were grateful to others, such as their family, friends and the medical team for their care and support. Finally participants expressed gratitude to the pacemaker itself for keeping their child alive, allowing their child to live their life and making their job as a parent easier.

All mothers experienced having a child with a pacemaker as a battle for control at times. This battle involved waging war on both powerlessness and uncertainty. All participants experienced feelings of powerlessness. They responded to this by fighting to regain control. Some did this by trying to be strong for themselves, something that was not

always easy. Others felt they could regain control by being strong for others or becoming someone else (someone tough and capable). The mothers' war on uncertainty emerged from experiencing the inherent uncertainties of having a child with a pacemaker as difficult and anxiety provoking. Their attempts to manage this uncertainty involved trying to get things such as surgery and check-up appointments over and done with as quickly as possible and seeking as much information and knowledge as possible.

All the mothers found the pacemaker influenced their perception of their child. A theme of difference versus normality emerged. Some considered their child as normal and others considered them as different because of the pacemaker, with one mother seeing their child as both normal and different. Some parents did not see their child as ill, despite knowing they had an arrhythmia requiring correction by a mechanical device. Finally some mothers described how the pacemaker had changed their child's body and described how this made them feel. They commented on the scarring and the visibility of the pacemaker under the skin and some admitted feelings of disgust.

All participants perceived their child as physically vulnerable. They described the impact of surgery and pacemaker malfunction on this perception. Some worried about the danger of environmental influences on the pacemaker and the possibility of the battery running out, despite reassurances provided by medical staff. Despite these worries mothers also reported that they experienced relief from worry about physical vulnerability at times. Some trusted their children to know their own limits and others reported not being hyper-vigilant to signs of problems with the pacemaker.

## **Placing the Findings in the Context of the Existing Literature**

### ***Child Group***

All the children and young people involved in this study discussed the pacemaker in relation to their identity. Every child, including those who have an illness, has to go through the same developmental challenges. One such challenge is that of identity formation. Erikson (1968) proposed a psychosocial model of identity development with many different stages across the whole life span; he stated each stage was characterised by a developmental task to be met and usually involved a conflict of some kind. The children



and young people in this study were aged between 11 and 16 years. They therefore spanned two stages of Erikson's model (1968), *industry versus inferiority* (age 7 – puberty) and *identity versus role confusion* (adolescence). In the *industry versus inferiority* stage the developmental task to be achieved is learning to be competent and effective at activities valued by adults and peers, otherwise facing feelings of inferiority. The *identity versus role confusion* stage is when adolescents attempt to establish a sense of identity as part of their social group; if they do not succeed they become confused about who they are. Erikson considered this to be the most decisive period in identity formation, where most turmoil could be expected. Although these stages are separated by age for clarity in the model, it may be assumed there is some degree of overlap in tasks between ages. Erikson merely considered these conflicts to be the most characteristic of each stage, not the only ones. Therefore in this study the two 11 year olds may already be attempting some of the tasks in the *identity versus role confusion* stage and the two adolescents may still be contending with aspects of the *industry versus inferiority* stage.

All the children and young people in this study described feeling different to their peers. This was sometimes as a result of restrictions on their activities, meaning they could not always do the same things as their peers. According to Erikson this could compromise their ability to be competent and effective at activities valued by their peers, and thus lead to feelings of inferiority (*industry versus inferiority*). However on the other hand some of the children reported the pacemaker allowing them to do more, so in some cases it would help with meeting this challenge and prevent feelings of inadequacy. The feelings of being different reported by all the participants makes establishing a sense of identity as part of their social group (the main challenge of adolescence in the *identity versus role confusion* stage) difficult. Thus overall, the pacemaker may pose a threat to the ability of children and young people to achieve the normal developmental tasks of identity formation. Finally these feelings of difference are at odds with the findings by Alpern et al. (1989). They found that children with pacemakers did not feel different, but, like the children and young people in this study, they worried about being perceived as different by their peers.

With regard to integration of the pacemaker, there are some similarities between the findings here and the adult pacemaker literature. Three of the four children and young people had accepted the pacemaker as having become part of them. This echoes the work by Dlin (1966) Blacher and Bach (1970), who described the process of adjustment to having

a pacemaker. Dlin (1966) characterised the final stage as a feeling of “oneness” between the pacemaker and the self. Blacher and Bach (1970) described the final phase as acceptance and adjustment, where the pacemaker had become incorporated into daily life and was often forgotten or ignored (a state of affairs, described by three of the children).

Finally the children and young people found the pacemaker allowed them to be themselves and live their lives how they wanted. In the adult literature Beery et al., (2002) found similar themes, with their participants expressing relief at having a device that allowed them to live their lives the way they wished. Another similarity between the findings was participants expressing how normal they felt despite describing experiences outside the norm, such as restriction of activities and risk to life from pacemaker malfunction.

This study revealed that the children found family support important in coping with having a pacemaker. Supportive family relationships predict better adjustment of children to illness, including fewer behaviour problems, better psychological functioning, higher self esteem and better social functioning (Drotar, 1997; Wallander et al., 1989). Participants also cited the importance of their parents being present with them in hospital before and during and after medical or surgical procedures. There is good evidence for the positive influence of parental presence during a period of hospitalisation (Petersen et al., 1985). However parental presence during specific medical procedures does not always have a positive effect. Frank et al. (1995) found that during medical procedures 53% of the variance in child distress behaviour was predicted by parent behaviour. Children whose parents are anxious are more likely to be more distressed than those whose parents are not (Jacobson et al., 1990). Parental behaviours such as talking to the children about subjects unrelated to the procedure, humour and other forms of distraction are most likely to facilitate child coping. Providing reassurance, making empathic statements and becoming agitated are likely to increase levels of child distress (Manimala, Blount & Cohen, 2000).

Gratitude was an important facet of coping with having a pacemaker. There is little research on the effect of gratitude in children, however in adults it has been linked with increased feeling of subjective wellbeing (Watkins, 2004). Research has also shown that people who demonstrate gratitude also use more positive coping strategies (Wood, Joseph & Linley, 2007). Children and young people expressed gratitude towards their pacemaker

for keeping them alive, but also for preventing a worse health outcome. Morse (1997) cited recognising “it could be worse” as an important part of learning to live with the consequences of illness. Finally, in order to make sense of their experiences the children and young people compared themselves with children who were worse off than them and judged themselves to be fortunate in comparison. Similar processes to this have been observed in the oncology literature (van der Zee, Buunk, Botke & van den Bergh, 2000).

The most common fear expressed by the children with pacemakers studied by Alpern et al. (1989) was pacemaker malfunction. This was a fear also experienced by the children and young people in this study and emerged as part of the theme of physical vulnerability and relying on fallible technology for life. One young person explicitly expressed his fear of dying as a consequence of pacemaker failure. This was at odds with the findings of Alpern et al. (1989), who found none of the 30 children they interviewed expressed a fear of dying. However, the authors attributed this finding to denial rather than the actual absence of such fears. The participants in the current study also reported feelings of powerlessness and not being in control due to having a pacemaker. This finding is similar to one made by the Alpern et al. (1989) study, which found pacemaker patients were significantly more external in their locus of control than those in the control groups. These authors suggested this feeling of lack of control could have an effect on the children’s ability to develop autonomy in the transition to young adulthood. In addition, patients with an external locus of control have been found to be more compliant with treatment and less active in seeking knowledge about their condition (Oberle, 1991).

Some of the children and young people interviewed had accurate, detailed knowledge of their condition and the function of their pacemaker. However, others knew very little, which led to them feeling more anxious and powerless during check-ups and before surgery. This variance in knowledge is reflected by findings in the congenital heart disease literature. Veldtman et al. (2000) found that only 30% of the 63 children with congenital heart disease questioned had what the researchers considered to be a good understanding of their illness. In addition 36% had inaccurate or very poor understanding and 33% only had partial understanding. Illness understanding has serious implications for adjustment and wellbeing. Children with better understanding have been found to experience less emotional distress and better compliance with treatment regimes (McGrath & Kolwaite, 2006). This is supported by the findings in this study, that children

and young people with less knowledge appeared to experience increased anxiety and feelings of powerlessness.

### ***Parent Group***

Some mothers felt as though they were not doing things as they should with regard to parenting their child, that they were doing things 'wrong'. This is mirrored in the findings of an early study by Bowen (1985) with parents of children with congenital heart disease. She found parents felt frustrated, guilty and had a sense of failure. The guilt that some parents in this study felt for their child having a pacemaker also altered their parenting style. It led to them becoming more permissive and to a loosening of boundaries. They allowed their child freedoms that they would not have otherwise enjoyed were it not for the pacemaker. Again, similar findings were made by Bowen (1985). She found that parents were more likely to be overindulgent and experience problems in administering appropriate discipline than parents of 'healthy' children. However Carey et al. (2002) found no difference in parenting styles between parents of children with congenital heart disease and parents of children with no health problems. Research has shown parenting style influences child outcome; McCusker et al. (2007) found that parenting style was an important predictor of adjustment in children with congenital heart disease. They found poor parental control of the child was a risk factor for increased behaviour and emotional problems as measured by the Child Behaviour Checklist (Achenbach, 1988).

A theme of adjustment being a process over time emerged from the analysis. This is reflected in the literature on adaptation to negative events, which generally conceptualises this as a gradual process happening over a period of time (Tennen & Affleck, 2002; Horowitz, 1986). Mothers in this study reported initial feelings of shock in response to the news their child needed a pacemaker. Other qualitative studies on adaptation to childhood illness have found similar reactions to diagnosis, with responses of parents encompassing shock, worry and numbness (Gannoni & Shute, 2009). In addition Eiser (1990) cited the shock of diagnosis as a considerable stressor of childhood illness.

Mothers also described having reached a point where they had learned to live with the pacemaker, seeing it a normal aspect of their life. A search for meaning may facilitate adjustment within the context of chronic or life threatening illness (Sharpe & Curran, 2006). This began at diagnosis with mothers asking themselves the question, "why me?".

The literature suggests that questions of “why me?” and feelings of self-blame (something felt by several of the mothers) may result from a belief that negative outcomes are a result of bad deeds (Sharpe & Curran, 2006). Park and Folkman (1997) suggest meaningfulness is arrived at when the new event is incorporated into one’s “life scheme”. Ways of doing this include changing pre-existing beliefs to accommodate the event, or changing the meaning of the event to match helpful pre-existing beliefs.

At the point of diagnosis all the mothers interviewed were faced with a situation that they appraised as threatening and stressful (Lazarus & Folkman, 1984). Therefore the task they were then faced with was coping with this threat by attempting to reduce the associated stress and distressing emotions. Threatening situations produce attempts to reassert control and this in turn can lead to more effective coping and the development of a sense of meaning (Thompson, 1981). All the mothers interviewed described the experience as involving a battle for control. Part of this battle was about having a feeling of uncertainty and the challenge this posed to their sense of wellbeing. Jessop and Stein (1985) have remarked upon the fact that uncertainty with regard to illness course and outcome is psychologically unsettling for both children and parents. They also found that it is associated with greater maternal psychological problems and a greater perceived impact on the family.

Mothers reported family support as being important to their ability to cope with the experience of having a child with a pacemaker. The benefits of a supportive family have been seen elsewhere in the literature. For example in a recent study Doherty et al. (2009) found that a high level of family cohesiveness was associated with low levels of psychological distress in mothers of children with congenital heart disease.

Another form of external support was religious faith, with one mother citing this as something that helped her cope. She explained how she felt that her faith had developed as a direct result of her son’s condition. This is seen in other parents of ill children. A study by Spilka (1989) found that two thirds of the parents of children diagnosed with cancer became more religious as a result of the diagnosis. It has been hypothesised that faith and religion help because they provide an outlet for emotional expression and offer social support (Pargament et al., 1988). A recent study with parents of children with congenital heart disease found mothers made use of religious or spiritual support to help them cope and were more likely to this strategy than fathers (Doherty et al., 2009).

One of the coping strategies used by some mothers in this study was that of adopting a positive philosophical stance. One mother described believing that having optimism would improve her son's health outcome. Optimism is the expectation that good things will happen (Scheier & Carver, 1985), or the maintenance of hope. It is associated with an active, problem focussed coping style, which in turn may prevent unproductive immersion in distressing emotions (Scheier & Carver, 1987). In this study many mothers reported an active style of 'just getting on with things' or avoiding difficult emotions and cognitions, the aim of which may have been to avoid becoming 'lost' in their own distress. Optimism has also been associated with acceptance in circumstances that are perceived as uncontrollable (Scheier, Weintraub & Carver, 1986). Many of the mothers experienced the situation as out of their control and some used acceptance as a way of managing those things they felt they had no control over.

Kliewer et al. (1994) proposed that parents influence their children's coping styles by coaching them to use particular strategies and modelling their own strategies for their child. Although there was insufficient time to analyse the parent-child dyads in any detail, it was apparent from initial comparisons that Josh and Lisa used similar coping strategies of avoidance, particularly when it came to communicating with each other about the pacemaker. It is possible Lisa had transmitted these coping strategies to her son via the process of modelling.

As with the children and young people, gratitude appeared to be an important aspect of coping for the mothers. As stated previously, gratitude has been linked with increased feeling of subjective wellbeing (Watkins, 2004) and more positive coping strategies (Wood et al., 2007). Mothers felt gratitude towards both medical staff and the pacemaker itself. Part of their gratitude towards the pacemaker was that it improved their child's quality of life. There are similar findings in the adult pacemaker literature, which suggests pacemaker patients experience an improvement in health-related quality of life after implantation (Lamas et al, 1998; Catipovic-Veselica et al., 1990).

A theme of benefit finding also emerged from the analysis, with parents finding positive consequences of their difficult experiences. Benefit finding in threatening circumstances has been interpreted as a coping strategy by researchers in the field (e.g. Tedeschi, Park & Calhoun, 1998). Folkman & Lazarus (1988) included benefit finding as an item in their Ways of Coping Scale. One of the benefits reported by participants included

the strengthening of interpersonal relationships; one mother described both being closer to her daughter and her daughter's paternal grandmother because of the pacemaker. Similar findings have been made elsewhere in the childhood illness literature. In their study of mothers whose newborns had been treated in a neonatal intensive care unit, Affleck, Tennen and Gershman (1985) found that 60% of the mothers perceived some benefit to the experience. In addition 20% of the mothers cited benefits involving closer family relationships. Finally, research has suggested that benefit finding emerges towards the end of the adjustment process (Janoff-Bulman & Frantz, 1997; Tedeschi & Calhoun, 1995).

Some mothers did not perceive their child as ill much of the time, partly due to the pacemaker's efficacy. In studies of congenital heart disease maternal perception of the severity of their child's condition has been found to be a much more significant predictor of child adjustment (DeMaso et al, 1991) than the actual severity (as defined by their doctor). They found that lower perceived severity was associated with better psychosocial outcomes. Therefore this may have a positive influence on the child.

Despite some of the mothers not perceiving their child as ill much of the time, all the mothers interviewed perceived their children as physically vulnerable at times. A great deal of stress and worry for their child's safety accompanied this perception and this could have a negative influence on their child. In the chronic illness literature research has found that maternal adjustment predicts child adjustment (Thompson, 1985; Wallander et al., 1989). Mothers showing high levels of distress and poor adjustment have children who are more distressed and poorly adjusted (Drotar, 1997). In addition, O'Dougherty et al. (1993) found higher levels of parental stress are associated with poorer psychosocial outcome in children with congenital heart disease. Finally McCusker et al. (2007) found raised levels of maternal psychological symptoms and high levels of maternal worry were associated with worse behavioural outcome in children with congenital heart disease.

Kliewer et al. (1994) suggested that one way in which parents influence their child's appraisal of threat and emotional reactions to stress is through modelling. Therefore if the child observes their parent appraising a certain situation as threatening, then they too are likely to appraise the same situation as threatening and have a similar emotional reaction. It was apparent from initial comparisons that Angela had transmitted her procedural anxiety and fear of hospitals to her son, Zack. It is possible that this occurred through her

modelling her appraisal of medical procedures as highly stressful and her anxious response to being in hospital.

### **What Does This Research Add to the Existing Literature?**

This study adds to the existing literature on childhood illness by drawing attention to the experiences of children with pacemakers (and their parents), who are a virtually un-researched population. There are some findings in this study that are similar to previous studies into congenital heart disease and childhood illness in general. These include the finding that the illness has an impact on the child's identity and on their mother's parenting style. Other common themes are coping, procedural distress and the importance of family support and knowledge of the condition.

However, the findings of this study do add something new to the childhood chronic illness literature. There is still little regarding gratitude in the extant literature, particularly with regard to children. This study highlights that gratitude was an important part of coping with the situation. In addition, this study has drawn attention to the importance of control for parents. It highlighted how easily parents of children with a chronic illness feel a lack of control and how unsettling uncertainty is for them. It also highlighted the importance of regaining and maintaining some degree of control and the great efforts parents go to in order to do this. Also, what appears to be different about the experience of having an arrhythmia requiring a pacemaker, compared to most other chronic illnesses, is the fact that the treatment requires the implantation of a 'foreign' device in the body. Further difference comes from the fact that recipients rely on this fallible technology to keep them alive. Thus, there is the anxiety associated with the possibility of device malfunction and the potentially catastrophic consequences of this.

Finally this study draws attention to differences between child and adult pacemaker recipients. For adults, and particularly older adults, having a pacemaker has become more commonplace in the years since they were first introduced. In addition, advances in technology have meant pacemakers have become less conspicuous and more reliable. However, this research highlights that in the case of children, having a pacemaker is not commonplace and still creates a feeling of shock and difference. There is the perception that pacemakers are for older people and that a child having a pacemaker is at



odds with the norms associated with their developmental stage. Another difference between having a pacemaker as a child and as an adult is the knowledge that a child will have to live with the pacemaker for a much greater length of time. They will have to undergo more procedures and live with it for a greater proportion of their life.

### **Strengths, Limitations and Future Research.**

The main strength of this study is that it allowed participants the opportunity to talk freely about their experiences of both having a pacemaker (in the case of the children and young people) and having a child with a pacemaker (in the case of the parents). This allowed the exploration of an area in which the limited extant research was poorly designed or somewhat dated.

The size of the sample could be regarded as a limitation. Smith and Osborn (2003) recommend a sample size of five to ten in IPA studies, therefore overall the sample size of eight was consistent with their recommendation. However, as the participants were made up of parent-child dyads, this translated into a group of four children and young people and four parents, rather than a larger, homogenous group. It is possible that this small sample size reduced the scope for group analysis and that further themes might have emerged with larger sample sizes of both children and parents. The small sample size makes the themes somewhat tentative and they would benefit from further corroboration by further studies.

Nevertheless, Smith et al. (2009) assert that quality is the primary concern of IPA studies rather than quantity. They are of the opinion that given the complexity of human experience, IPA studies usually benefit from a more detailed focus on fewer cases. Smith et al. (2009) also went on to say many published studies by experienced IPA researchers now have sample sizes ranging from three to six, which avoids the danger of becoming overwhelmed by the amount of data generated. Despite this, future research may benefit from having slightly larger numbers of both children and parents to maximise the richness of the group data.

The homogeneity of both the child and parent groups was also an issue. The children and young people differed to some extent in terms of time since first pacemaker implantation, number of pacemakers received and additional diagnoses. Time since

pacemaker implantation ranged from two to nine years. Two of the participants had received only one pacemaker so far, whereas two had already received three to date. Perhaps the most significant difference between participants was in diagnoses. Two of the children had diagnoses of congenital heart block (causing an arrhythmia requiring a pacemaker) with no accompanying structural defects requiring surgical correction. However, the other two had diagnoses of structural defects as a result of their congenital heart disease in addition to having an arrhythmia requiring the fitting of a pacemaker. They had both had several surgical procedures aimed at repairing these defects. This fact created increased heterogeneity in both the child group and the parent group, as it could be said parents were dealing with slightly different issues, as well as the children.

During the design of the study I considered making additional structural defects and subsequent surgical correction an exclusion criterion. Unfortunately the number of children and young people in the desired age range meant this would have made the eligible population prohibitively small. Further research could be done over several regional centres to increase the numbers and enable children to be separated on these terms. With sufficient participants, comparisons could then be made between the experiences of the two groups.

The fact that the parent group was only made up of mothers could be considered to be both a strength and a weakness. It added to the homogeneity of the sample, but could also have created a bias towards maternal accounts and resulted in the neglect of the experience of fathers. The exclusion of fathers was an accident of sampling. It would appear mothers are more likely to put themselves forward to take part in research than fathers. Further research could use more purposive sampling to recruit fathers in order to access their experiences. Given a large enough sample, both mothers and fathers could be interviewed and comparisons made between the two.

Aside from not examining the experiences of fathers, the study also did not address other gender differences or cultural differences directly. The study's exploratory nature meant its focus was too broad to address such specific areas. However with more purposive sampling this would be an interesting aspect to investigate in further research in this area.

A strength of the study is that it involved interviewing both children and their parents. I could only find one example of this being done in the field of childhood illness.

However a limitation is that unfortunately, due to time limitations and the restricted length of my doctoral thesis, I was unable to analyse each dyad in any detail. Ideally, I would have like to have compared the parent-child accounts in detail to reveal any significant similarities or differences in the emerging individual themes. I feel I have missed an interesting opportunity that might have significantly added to the findings. Further qualitative research could involve detailed analysis of parent-child dyads, comparing experiences and exploring areas of divergence and convergence.

My analysis of the data may be a final source of limitation. I am a novice in IPA research and as such I experienced fears of not remaining grounded in the data. This led to a rather conservative interpretation of the data, a common criticism of researchers new to IPA (Smith, 2004). A more experienced researcher may have achieved a more penetrating analysis of the data, and it is possible I may return to my data and reach a deeper level of analysis at a later date. Despite this, however, I believe I was able to achieve some level of abstraction in my current analysis.

It is interesting to note that there was a slightly different quality to the written account of the group analysis, compared to the individual pen portraits. I believe that I conducted and reported the group analysis 'by the book'. I attempted to stay as close as possible to the method of IPA laid out by Smith et al. (2009). This was due to anxiety about not getting it 'right' as a novice researcher. However in contrast to this, when composing the pen portraits I gave my intuitive clinical instincts more of a free rein. I feel I made slightly more incisive interpretations in order to form what was, essentially, a clinical formulation.

It is possible that this addition of more of my own clinical impressions could have introduced some bias into the accounts of the experience of the participant. However, I do not believe this was the case. Although the pen portraits perhaps contained slightly more of my interpretations of the participants' interpretation of their experience than the presented results of the group analysis, this still remains true to the methodology of IPA. I believe the addition of more clinical opinion and development of a clinical formulation was a strength of the pen portraits. This allowed me to add a further dimension to the analysis, including some comment on family dynamics between members of dyads. I believe the pen portraits were able to capture the sense of the individual to a greater extent, which is more difficult in the process of group analysis. When reporting the group analysis it can

sometimes feel like the individual voice is not as clear and the quality of the individual experiences can sometime appear less vibrant. Also, in terms of clinical utility, it is these types of clinical formulations that inform the interventions carried out with young people and their families.

### **Clinical Implications**

It is apparent from the findings of this study that having a pacemaker has a significant impact on the lives of children and their parents. All the mothers and the children appraised the pacemaker as threatening in some way. This is at odds with the perceptions of professionals in the regional service where the research was carried out. From conversations with these professionals prior to the research, it emerged that generally, they believe having a pacemaker implanted is a relatively minor procedure. The view is that it has little psychosocial impact, particular in comparison with other procedures carried out in the service, such as open-heart surgery. As such, it appears the specific needs of children with pacemakers and their families are not fully understood by the team. The fact there has been so little research in this area suggests that this is a widespread perception and not restricted to this particular service.

As a result of the perception of pacemakers as fairly benign, pacemaker clinics do not routinely have a liaison nurse assigned to them, unlike other paediatric cardiac clinics. Also, clinical psychologists in the paediatric cardiology team typically receive very few referrals from the pacemaker clinic. In light of how stressful some children and parents find pacemaker clinic appointments, it would seem appropriate to have a liaison nurse assigned to pacemaker clinics as a matter of routine. This would enable families to speak to someone aside from the consultant (who has a limited amount of time in clinic to see each patient) about their concerns. In addition, if any malfunction were uncovered at the appointments (something revealed to be a very traumatic experience), a dedicated nurse would mean greater availability of immediate emotional and practical support for families. Finally, attempts should be made to raise awareness in families of the psychological support provided by clinical psychologists and the counsellor as part of the service.

It appears that the initial stages of diagnosis are particularly stressful. Diagnosis itself has a significant impact, followed by anxiety and uncertainty surrounding the surgery

for the initial pacemaker implantation. Children and families may benefit from more psychosocial support immediately after diagnosis and more preparation before the initial procedure. Offering every family a routine assessment session with a clinical psychologist immediately after diagnosis may be of benefit. This is an achievable goal considering the relatively small numbers involved. As having a pacemaker is life-long, continuing access to psychosocial support after implantation and into adulthood is essential to cope with the challenges posed by different developmental stages.

Good understanding and knowledge of the condition is important for both children and young people and their parents, as it is associated with greater psychological well-being and higher levels of satisfaction with services (McGrath & Kolwaite, 2006). Some of the children demonstrated poor knowledge of their condition. Also, parents often had worries based on inaccurate beliefs regarding pacemaker function. In addition some parents find knowledge and information seeking an effective way of coping with their distress. A way of improving understanding, and satisfying the need for information immediately after diagnosis, is provision of more leaflets and internet-based information at the time of diagnosis. The benefit of this is that children and families may find it difficult to absorb and retain information provided by the consultant in face-to-face meetings. Leaflets and online resources would enable them to access this information between clinic appointments. Materials provided could include information on common worries and misconceptions and should also include information on how to access psychosocial support. Separate leaflets should be designed for children, young people and parents, with information appropriately tailored to the intended audience. Finally, efforts should be made to check the understanding of both children and parents at a later date to allow misunderstandings or gaps in knowledge to be addressed.

The findings of this study suggest children and young people in particular use others as a source of support. In particular, they found it helpful to know other people going through similar situations, as they could provide each other with support. Therefore peer support groups would be of benefit. These could be web-based in order to address the problem caused by the widespread nature of the population served by a regional service. A chat forum could be added to the online resources suggested previously. This would provide a place to discuss experiences and concerns and provide a source of peer support and interaction. This is a support strategy that has been found to be successful in

adolescents diagnosed with cancer and is being used increasingly in this field (Suzuki & Beale, 2006). In addition to age appropriate peer support, other developmental issues presented themselves. The children and young people explained the changing experience of hospital visits as they got older. They found they had grown out of many of the facilities aimed at making things easier for them; the playroom no longer held the same attraction as it once did. Therefore increased provision of facilities and activities aimed specifically at this age group are required.

Continuity of care emerged as an important theme for the children and young people and the mothers. They particularly valued the continuity provided by the professionals in the service. They appreciated seeing the same small team, consisting of the consultant, nurses and technical support staff, at each appointment. This enabled them to get to know and trust the professionals and allowed the professionals to get to know them. This provided participants with reassurance and a feeling of security, making what can be a difficult experience easier to manage.

### **Personal Reflections and Conclusions**

I feel have learned a great deal from carrying out this research, both as a researcher and as a clinician. I have valued the opportunity to meet children and their parents and to find out first hand about their experiences of living with a pacemaker. I was surprised by how moving I found some of the accounts. I was struck by the huge emotional impact both during and immediately after the interviews. On one occasion I even found empathic tears springing to my eyes. In everyday clinical work I find myself prepared for the possibility of having an emotional reaction to the content of sessions. However in the context of being a researcher I was taken by surprise by this, as it was not something I had anticipated. An even stronger emotional reaction often came from analysing the accounts at a deeper level, as I made more sense of their experience. I was particularly struck by the feelings of maternal guilt and the desperate attempts made to atone for this. Despite some very difficult experiences for mothers and children, it has felt positive to hear to that some families have coped well. I was struck by the power of human resilience and left wondering if I would cope equally well with such traumatic events.

I significantly underestimated the richness of the accounts that participants would provide me with, particularly the children and young people. I was impressed with how eloquently some of them spoke about their experiences, despite their tender years. Although I am grateful for these detailed, carefully considered accounts, analysing all the data to form a coherent account was a huge challenge and one that I had not fully apprehended. It has caused me to reflect on the complexity of human experience, which in my experience can sometimes be over simplified by professionals working with children and families. For example in the current context of my clinical practice, a Child and Adolescent Mental Health Team, children are sometimes defined by their diagnoses and the importance of the quality of the experience associated with this is discounted.

The aim of this thesis was to explore the experiences of children and young people with pacemakers, and their parents. As such I feel the study has answered the research questions I set out to address. I hope the findings will be helpful in guiding service provision for this population.

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**APPENDIX 1**

**Ethical Approval Letter**

**Leeds (East) Research Ethics Committee**  
Room 5.2, Clinical Sciences Building  
St James's University Hospital  
Beckett Street  
Leeds  
LS9 7TF

Telephone: 0113 2065652  
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13 July 2009

Ms Katherine Wilkinson  
Psychologist in Clinical Training  
Leeds Teaching Hospitals NHS Trust  
Leeds Institute of Health Sciences  
Charles Thackrah Building,  
101 Clarendon Road  
Leeds  
LS2 9LJ

Dear Ms Wilkinson

**Study Title:**                               **The experience of having cardiac pacemakers among adolescents and their parents: A qualitative study**  
**REC reference number:**               **09/H1306/37**  
**Protocol number:**                       **1**

Thank you for your letter of 16 June 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research (“R&D approval”) should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

***It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).***

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>	
Covering Letter			
Application		07 April 2009	
Protocol	1	06 April 2009	
Investigator CV		12 April 2009	
CV of Sylvie Collins			
Letter of invitation to participant	1	06 April 2009	
Interview Topic Guide: Parent/Carer	1	06 April 2009	
Interview Topic Guide: Young Person	1	06 April 2009	
Training Clinical Psychology Research Information Sheet			
Peer Review		18 March 2009	
Letter from Sponsor		07 April 2009	
Compensation Arrangements		02 October 2008	
Response to Request for Further Information		16 June 2009	
Participant Consent Form: Assent Form	2	16 June 2006	
Participant Consent Form: Young Person	2	16 June 2009	

Participant Consent Form: Parent/Guardians	2	16 June 2009	
Participant Information Sheet: Young Person	2	16 June 2009	
Participant Information Sheet: Parent/Guardian	2	16 June 2009	

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>09/H1306/37</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

**Dr John Holmes**  
Chair

Email: [Amy.Beckitt@leedsth.nhs.uk](mailto:Amy.Beckitt@leedsth.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"  
Copy to: Clare Skinner, University of Leeds

R&D Department, Leeds Teaching Hospitals NHS Trust



## APPENDIX 2

### Child/Young Person Interview Schedule

The precise wording, the emphasis and the order of the following questions, may vary in response to individual participants. Prompts only used if necessary to elicit more detail.

- Can you tell me the story of you and your pacemaker from the beginning?
  - Do you remember finding out you had a problem with your heart? (if yes:)
  - What was that like for you?
  - Can you explain what the problem is to me?
  
- Do you remember finding out you needed a pacemaker? (if yes:)
  - What was that like for you?
  - Can you explain to me why you need a pacemaker?
  - Some people tell me there's a difference between having a heart problem and having a pacemaker and some people say there isn't. What do you think?
  - Which is worse?
  
- Do you remember having surgery? What was/is it like for you when you have surgery?
  - How many times have you had surgery to do with the pacemaker?
  - (If more than one procedure then) What was it like the first time?
  - (If more than one surgical then) Were the next times any different?
  - What's the worst thing about having surgery?
  - Are there any good things about it?
  - Does anything/anyone help/make it easier?
  
- What is it like for you having a pacemaker? Everyday life
  - What's bad about having a pacemaker?
  - What's good about having a pacemaker?
  - Do you have any worries about the pacemaker?
  
- How do you manage with having a pacemaker?
  - Do you ever get fed up of having a pacemaker? When? Why?
  - What do you do when you're fed up?
  - What/who helps you when you're fed up? How? (friends/family/pets)
  - Are there times when having a pacemaker feels ok?

- What would your life be like if you didn't have a pacemaker?
  - Would you be different?
  - Do you think the way you and your (parent/carer) are with each other would be different?
  - Do you think the way you and other members of your family are with each other would be different?
  - Are there things you can't do or can't do as well as you used to since getting it?
  - Are there things you can do better since getting it?
  
- What would your life be like if you didn't have a problem with your heart?
  - Would you be different?
  - Do you think the way you and your (parent/carer) are with each other would be different?
  - Do you think the way you and other members of your family are with each other would be different?
  - Would there be things you could do better?
  - Would anything be worse?
  
- What do you think of the people you come to see at the hospital?
  - What's good about coming to hospital?
  - What's bad about coming to hospital?
  - Could people at the hospital do anything to make things better for young people your age who have pacemakers?

## APPENDIX 3

### Parent Interview Schedule

The precise wording, the emphasis and the order of the following questions, may vary in response to individual participants. Prompts only used if necessary to elicit more detail.

- Can you tell me the story of (child) and his/her pacemaker from the beginning?
  - When did you first notice/find out something wasn't right with (young person)?
  - What did the news mean to you?
  - What's your understanding of their heart condition?
- What was it like finding out (young person) needed a pacemaker? (ask if this happened at a later date after discovering the heart condition).
  - What did the news mean to you?
  - What is your understanding of why (child) needs a pacemaker?
  - What difference did learning about the pacemaker make, what did it add?
  - Is there a difference between having a child with a heart condition and having a child with a pacemaker?
- What was it like for you when (child) had surgery to fit their pacemaker?
  - How many times have they had surgery to do with the pacemaker?
  - (If more than one surgical procedure then) What was it like the first time?
  - (If more than one surgical procedure then) Were the next times any different?
  - What was most difficult about it?
  - Did anything/anyone help? What got you through?
- What's everyday life been like for you since (child) got a pacemaker?
  - What is difficult about having a child with a pacemaker?
  - Are there any positive aspects?
  - Do you have any worries about the pacemaker?
- How do you cope with your child having a pacemaker?
  - What do you draw on to help you cope? (e.g. people, services)
  - Are there times/circumstances when things feel more difficult?
  - Are there times/circumstances when things feel easier?
  - What/who makes things easier?

- What would your life be like if (child) did not have a pacemaker?
  - Would (child) be different?
  - Would you be different?
  - Do you think your relationship with (child) would be different?
  - Do you think any other relationships in the family would be different?
  
- What has been your experience of the care you have received from the service here at the hospital?
  - What have you found helpful?
  - What have you found less helpful?
  - Could they have done anything different?

**APPENDIX 4**

**Letter of Invitation**

**The Yorkshire Heart Centre  
Paediatric Cardiac Unit  
Leeds General Infirmary (E Floor)  
Calverley Street, LS1 3EX**

Tel: 01132 432799 Direct line: 0113 392 5783 Fax: 0113 392 8101

**Participant Invitation Letter – Version 1 (06.04.09)**

Dear (name of young person) and their parent/guardian (delete as appropriate),

You are being invited to take part in a research study being carried out with the Paediatric Cardiology Service here at Leeds General Infirmary. We are interested in looking at the psychological impact of having a pacemaker on young people aged 11-16, and their parents (or guardians). This study will be conducted by Kate Wilkinson (who is a Trainee Clinical Psychologist) as part of her doctoral research.

If you were to take part in the research it would involve you each (young person and parent/guardian) having a separate, informal interview with Kate, in which she would ask you some questions about how the pacemaker affects your lives.

Enclosed are two different information sheets, one for each of you, explaining the study in more detail. If after reading these, you are interested in taking part or would like more information, please complete the tear-off slip below and return it in the stamped addressed envelope provided. Alternatively you can email Kate at the address below.

The decision you make about whether or not to take part in the study will have absolutely no impact on the care you received within this service.

Yours sincerely

**Dr M E C Blackburn  
Consultant Paediatric & Adult Congenital Cardiologist**

-----  
Name of young person (please print).....

Name of parent or guardian (please print).....

We would like to take part in the study. We would like to arrange a time to meet with Kate. We would like her to contact us by:

Phone (parent/guardian's number is.....)

Email (parent/guardian's email address is.....)

Alternatively Kate's email address is [umkw@leeds.ac.uk](mailto:umkw@leeds.ac.uk) (please include the same information as on the tear off slip).

**APPENDIX 5**

**Child/Young Person Information Sheet**

-

**The Yorkshire Heart Centre  
Paediatric Cardiac Unit  
Leeds General Infirmary (E Floor)  
Calverley Street, LS1 3EX**

**Young person's information about the research - Version 2 (16/06/09)**

**Study title:** "The experiences of adolescents who have cardiac pacemakers and their parents: A qualitative study"

I am a trainee clinical psychologist and I would like to invite you to take part in a research study that I am conducting as part of my doctorate at university. Before you decide whether or not you want to take part you need to carefully read the following information about why the research is being done and what it would involve for you. You can take as much time as you need to decide. You can also talk to other people like your family, friends, doctor or nurse about it if you want to.

**What is the purpose of this study?**

To date there haven't been many studies that have looked at the impact of having a pacemaker on young people and their families. However the team has noticed that some young people and their families manage quite well, but others find it more difficult. If we knew more about the impact of having a pacemaker and what makes things easier for you, then we could improve services even more.

**Why have we been invited?**

You were chosen to take part because you have a pacemaker and you are aged 11-16. We also want to talk to one of your parents or the person who looks after you.

**Do we have to take part?**

You do not have to take part in this study; it is up to you to decide. If you decide to take part you will be asked to sign a form to show you agree to take part. If you are under 16 your parent or guardian will also need to sign a consent form to show they agree you can take part.

You can stop taking part at any time if you change your mind, without having to say why. If you decide not to take part or to stop part way through this will have no effect on the care you get from the team at the hospital.

**What will happen to us if we take part?**

If you decide you want to take part, I will arrange a time to come and meet both you and your mum, dad or the person who looks after you. I will interview you both on your own, separate from each other. I will ask you about what it is like having a pacemaker and I will ask your mum, dad or the person who looks after you about what it is like looking after a young person with a pacemaker. Each interview should last around 60-90 minutes at the most, depending on how much you have to say. We can meet in the best place for you; this could either be at home or in a quiet room on the ward at the hospital.



You can do the interview on your own or with someone sitting with you. This might be a parent, or a friend. Remember you can also stop the interview and withdraw from the study at any time, without giving a reason.

I will tape record both conversations. This is because afterwards I will be looking at what you have both said, and trying to find the main issues that you talked about.

After I have looked at all the interviews, I will write to everyone who has taken part with a summary of what I thought the main issues were.

I will also look at your medical records to check details of your heart condition and pacemaker. I will not look at any other parts of your records.

**What are the advantages or disadvantages of taking part?**

If you decide to take part I cannot promise that this study will have any direct benefit for you. However some people find talking to someone about their experiences can be helpful, and any information you give me might help improve treatment for other young people with pacemakers.

It is possible you might get upset in the interview. If you do feel upset either during or after the interview I can let your parents know, if you say that's okay. If you want me to, I can also tell the psychologist or one of the specialist nurses in the team. You will be able to talk to them about the way you are feeling.

**Will our taking part in the study be kept confidential?**

After the interview everything you say will be written down. Any information that identifies who you are will be kept separately from this written version, and they will both be kept in a secure place, until they are got rid of in 7 years time.

I will not tell anyone else what you have said unless I am worried about you or someone else getting hurt in some way. If I am worried about this happening I will have to tell someone.

**What will happen to the results of this study?**

I will write up the results of this study for my doctorate. I will include some of the exact things people have said. It is also possible that I will present the results at a conference, or publish them in a journal article. At all times your privacy will be protected. I will do this by calling you a different name, which you can choose yourself if you want.

When I write up this research I will try my best to protect your privacy. But because you and your parent/carer know each other so well, if you read my report, you might think that you recognise each other from what is being said. However, it is very unlikely that anyone else reading it will be able to tell who either of you are.

**Who has reviewed this study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure the research is fair. This study has been checked by the Leeds East Research Ethics Committee. It has also been checked by people at the University of Leeds.

**Contact details**

If you would like further information, or have any worries about the study you can contact me (Kate Wilkinson), Judith Huntley (specialist nurse), or Dr Sylvie Collins (my project supervisor) on the contact details below.

**Kate Wilkinson**

Trainee Clinical Psychologist  
Leeds Institute of Health Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ  
0113 3430815  
Email: [umkw@leeds.ac.uk](mailto:umkw@leeds.ac.uk)

**Judith Huntley**

Children's Cardiac Specialist Nurse  
Children's Heart Unit  
Leeds General Infirmary (E Floor)  
Calverley Street,  
Leeds  
LS1 3EX  
0113 392 5467  
Email: [Judith.Huntley@leedsth.nhs.uk](mailto:Judith.Huntley@leedsth.nhs.uk)

**Dr. Sylvie Collins**

Clinical Psychologist  
Leeds Institute of Health  
Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ  
0113 3430815  
Email: [s.c.collins@leeds.ac.uk](mailto:s.c.collins@leeds.ac.uk)

If you would like to seek independent advice regarding taking part in this study, you can contact the Leeds Teaching Hospitals PALS (Patient Advice and Liaison Service) on 0113 2067168.

**APPENDIX 6**

**Parent Information Sheet**

**The Yorkshire Heart Centre**  
**Paediatric Cardiac Unit**  
**Leeds General Infirmary (E Floor)**  
**Calverley Street, LS1 3EX**

**Parent/guardian's information about the research - Version 2 (16/06/09)**

**Study title:** "The experiences of adolescents who have cardiac pacemakers and their parents: A qualitative study"

I am a trainee clinical psychologist and I would like to invite you and your child to take part in a research study that I am conducting as part of my doctorate. Before you decide whether or not you want to take part you need to carefully read the following information about why the research is being done and what it would involve for you both. You can take as much time as you need to decide and you can talk to others about it if you wish.

**What is the purpose of this study?**

To date there haven't been many studies that have looked at the impact of having a pacemaker on young people and their families. However the team has noticed that some young people and their families manage quite well, but others find it more difficult. If we knew more about the impact of having a pacemaker and what makes things easier for you, then we could improve services even more.

**Why have we been invited?**

Your child or the child you look after was chosen to take part because they have a pacemaker and are aged 11-16. You were chosen to take part as their parent or primary care giver.

**Do we have to take part?**

You do not have to take part in this study; it is up to you to decide. If you decide to take part you will be asked to sign a consent form to show you agree to take part and that you agree for your child to take part.

Both you and your child are free to withdraw at any time, without giving a reason. Not taking part or withdrawing will have no effect on the standard of care you or your child receives.

**What will happen to us if we take part?**

If you decide you want to take part, I will arrange a time to come and meet both you and your child to carry out an interview. I will interview you both, separately from each other. I will ask your child what it is like having a pacemaker and I will ask you about what it is like looking after a child with a pacemaker. Each interview should last around 60-90 minutes at the most, depending on how much you have to say. We can meet in the best place for you; this could either be at home or in a quiet room on the ward at the hospital.

If your child wishes, it is fine for them to have someone sit with them while they take part in the interview. This can be either a parent or a friend, depending on who they prefer. Remember you or your child can also stop the interview and withdraw from the study at any time, without giving a reason.

I will tape record both conversations. This is because afterwards I will be looking at what you (and your child) have said, and I will try to identify the main issues that you raised.

After I have analysed all the interviews, I will write to everyone who has taken part with a summary of what I thought the main issues were.

I will also look at your child's medical records to check details of their heart condition and pacemaker. I will not look at any other parts of your child's records that are not relevant.

### **What are the advantages or disadvantages of taking part?**

If you decide to take part I cannot promise that this study will have any direct benefit for you or your child. However some people find talking to someone about their experiences can be helpful, and any information you give me might help improve treatment for other young people and parents in a similar situation.

It is possible you or your child might get upset in the interview. If this happens either during or after the interview, I can (with your permission) refer either of you to the psychologist or one of the specialist nurses in the team. You can talk to them about the way you are feeling and they will be able to offer you further support and advice.

### **Will our taking part in the study be kept confidential?**

After the interview everything you say will be transcribed. Any information that identifies who you are will be kept separately from these interview transcripts, and both sets of information will be kept in a secure location, until they are destroyed in 7 years time.

I will not tell anyone else what you or child says in the interview unless I am worried about the safety of you, your child or anyone else. If I am worried, I will have to talk to my supervisors and seek further advice.

### **What will happen to the results of this study?**

The results of this study will be written up for my doctorate. I will include some direct quotes of what people have said. It is also possible that I will present the results at a conference, or publish them in a journal article. At all stages I will protect your anonymity, and that of your child, by using pseudonyms. That is I shall refer to you both by other names than your own - you and your child may choose these alternative names if you wish.

When I write up this research I will make every effort to protect your anonymity by withholding identifying information and using pseudonyms. Because you and your child know each other so well, you may, should you read any of my reports, think that you recognise the other from what is being quoted. However, it is highly unlikely that anyone else reading the work will be able to identify either of you.

**Who has reviewed this study?**

All research in the NHS has to be looked at by an independent group of people called a Research Ethics Committee to protect your rights, dignity and well-being. This study has been reviewed and approved by the Leeds East Research Ethics Committee. It has also been reviewed by two academic panels at the University of Leeds.

**Contact details**

If you would like further information, or have any concerns about the study you can contact me (Kate Wilkinson), Judith Huntley (specialist nurse), or Dr Sylvie Collins (my project supervisor) on the contact details below.

**Kate Wilkinson**

Trainee Clinical Psychologist  
Leeds Institute of Health Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ  
0113 3430815  
Email: [umkw@leeds.ac.uk](mailto:umkw@leeds.ac.uk)

**Judith Huntley**

Children's Cardiac Nurse Specialist  
Children's Heart Unit  
Leeds General Infirmary (E Floor)  
Calverley Street,  
Leeds  
LS1 3EX  
0113 392 5467  
Email: [Judith.Huntley@leedsth.nhs.uk](mailto:Judith.Huntley@leedsth.nhs.uk)

**Dr. Sylvie Collins**

Clinical Psychologist  
Leeds Institute of Health  
Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ  
0113 3430815  
Email: [s.c.collins@leeds.ac.uk](mailto:s.c.collins@leeds.ac.uk)

If you would like to seek independent advice regarding taking part in this study, you can contact the Leeds Teaching Hospitals PALS (Patient Advice and Liaison Service) on 0113 2067168.

**APPENDIX 7**

**Parent Consent Form**

**The Yorkshire Heart Centre  
Paediatric Cardiac Unit  
Leeds General Infirmary (E Floor)  
Calverley Street, LS1 3EX**

**Consent Form for Parent/Guardian– Version 2 (16.06.09)**

Title of Project: “The experience of having cardiac pacemakers among adolescents and their parents: A qualitative study”

Name of Researcher: Kate Wilkinson

Please tick the boxes if you agree

1. I confirm that I have read and understand the information sheet dated 16.06.09 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation and that of my child is voluntary and that we are free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I give permission for the interview to be tape-recorded.
4. I understand and agree that the researcher and their supervisors may look at relevant sections of my child’s medical notes and the data collected during this study. If the results of this study are presented or written up for publication in a journal, I understand my details and those of my child, along with any data collected will be anonymised. I give permission for this to happen.
5. I agree to take part in the above study.
6. I agree to my child taking part in the above study.

\_\_\_\_\_  
Name of child/young person

\_\_\_\_\_  
Name of parent participating

Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent

Date

\_\_\_\_\_  
Signature

**Thank you for your help**